

“My Bones Become like Old Trees”: Coping and
resilience building with people living with chronic
pain in Sindhupalchok, Nepal.

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This thesis is submitted in the fulfilment of the requirements for the
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I, Paula Bronson, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

A black rectangular box redacting the signature of Paula Bronson.

Paula Bronson

Abstract

This research investigates how villagers living with chronic pain navigated and coped within the setting of a Nepali farming community recovering from the earthquakes of 2015. The work examines these strategies within the emergent milieu of the multifaceted social landscape within the rapid changes of emigration, natural disaster, recent political events, the local spirit world and Indigenous medical practices, and the hardship of physical accessibility. Anthropology of pain is under-investigated in medical anthropology in recent years, and this research has brought new insights to the foreground. Chronic pain is complex, often confounding biomedical professionals since organic causes and biomarkers are rarely apparent. Many pain professionals agree that the standard, most widely practiced model of diagnosis and care, the biopsychosocial model (BPSM), although originally conceived as a useful approach, has not shown to be deployed as was intended. Practice has tended to remain biomedically reductionist and psychosocial factors have not been adequately integrated.

To develop a less fragmented application of the BPSM, with less emphasis on the biomedical, this research applies Coninx and Stilwell's (2021) conception of a hybrid enactivist/ecological framework within the field of chronic pain studies, which has the view that an understanding of the complexities of chronic pain would benefit from more developed models of the interrelatedness of the three domains, through the addition of the concept of 'fields of affordances'. This ethnographic research in Nepal contributes to the argument that a more "holistic, integrative, and dynamic" (Coninx and Stilwell 2021, 7844) understanding of pain is crucial for care.

My research has as its central aim to introduce the experience of people living with pain within the construct of 'idioms of resilience' (Kim et al. 2019), as supplementing and filling the spaces where the BPSM does not stretch. The participants' primary coping strategy was that their resilience was not a show of strength or grit, but a transformative process as seen through these approaches.

Impact statement

The direct impact of my research will be seen in several domains inside and outside of academia. Firstly, in academia, the anthropology of pain has not been widely investigated in recent decades. As demonstrated in my work, biomedical pain professionals have laid some exciting groundwork to further the much-needed integration of the sociocultural into research and clinical care with chronic pain. My study extends this work and analysis to contribute to the anthropology of chronic pain. To achieve this aim, I utilize the anthropological construct of 'idioms of resilience' to analyze, discuss, and implement coping strategies and resilience building for my research participants. This view extends beyond the social to include the sociocultural as a vital domain for a more holistic understanding of pain.

My methodology used clinical ethnography, where findings were gathered and framed in a narrative approach (Mattingly 1998) to learn from the participants directly how they developed resilience. This produced 'research on the ground,' in real time, which was then integrated with Indigenous knowledge practices and sense-making particular to the participant's social worlds. From this generative methodology, significant findings emerged. These findings were available to apply directly to knowledge production and evidence-based care during the study but will also be directly applicable to anthropologists interested in further study of chronic pain and community health in the Himalayan region.

In terms of impacts outside of academia, medical anthropology is well positioned to inform patient care through its vigorous ethnographic methods and emic accounts of the needs of patients and people living with chronic pain. Often health institutions and health professionals have sparse literature or evidence on patient experience to translate to their care practices. As an applied medical anthropology project, my research is well situated through its methodology, theoretical perspectives and results to provide immediate beneficial data for provision of care in the clinic or patient's home for individual health practitioners, such as general practitioners, musculoskeletal

physiotherapists, pain specialist physiotherapists, community-based rehabilitation workers, in non- governmental organizations, private and government institutions. Regarding service development in and for pain services, professional multidisciplinary teams and commissioning bodies will find invaluable data for planning and decision-making. The literature in pain science reveals a lack of integration of biomedical factors with the vital psychosocial aspects as contributors to the complexities of chronic pain, and this research can assist to fill those gaps.

In terms of conducting research in the aforementioned facilities, this research provides an important resource on which to base further investigation and will be indispensable for future work within minority communities internationally, and also locally in Nepal. This future work can then be directly applied again into the new clinical contexts, self-generating more applied research and improvements in care in clinics and communities for those living with pain.

Impact can be brought about and disseminated by further collaboration with larger research projects internationally in the healthcare sector and in academia. Disseminating outputs can take the form of collaborative publications, workshops and clinical teaching opportunities, and other public engagement with international non-government organizations.

Research Paper Declaration Form

Signed document available on request. Unable to upload/embed pdf file.

Acknowledgments

I would like to firstly acknowledge and thank Dr. Joseph Calabrese, my primary supervisor, for his consistent guidance. His insights have always been invaluable and his attention to detail has been indispensable throughout. Our discussions surrounding the psychological aspects of my work have provided me with new and interesting perspectives that have aided me to see different sides to the many stories I heard in the field. His clarity with words I can only aspire to emulate. I have appreciated his direct approach to finding the holes in an argument and his no-nonsense approach to standing one's ground, all with a sense of humor in the end. This has helped me see all sides in debate, a much-needed skill to learn.

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List of Abbreviations

ACT: Acceptance and Commitment Therapy

APA: American Psychological Association

BPS: British Pain Society

BPSM: Biopsychosocial Model

CBR: Community-Based Rehabilitation

CBT: Cognitive Behavioral Therapy

FAM: Fear Avoidant Model

IASP: International Association for the Study of Pain

INGO: International Non-Governmental Organizations

NICE: National Institute for Clinical Excellence

NHS: National Health Service

Credits/Statements

Paula Bronson took all the photos. Informed consent was given in verbal and written form through a native Tamang and Nepali speaker. These consent forms went through ethical clearance with UCL Ethics Committee, the Nepal Health Research Council, Kathmandu Medical School and Dhulikhel Hospital research and ethics' boards. The photos chosen that show participants and their faces are used to contribute to the thesis, in a manner such that the exercise positions, and facial expression aid in understanding the context of their chronic pain experience. Other photos of people's faces are not only for aesthetic purposes but to further provide and enhance the ethnographic descriptions given.

All participants were given pseudonyms to protect their anonymity with the exception of John, the retired British nurse, who asked me to use his real name.

Introduction

1. A painful shoulder, a frayed rope, and missed opportunities.

The dark clouds began to gather in the late afternoon sky as Maila, my Tamang research assistant, and I quickened our pace down the uneven dirt path to avoid the sudden monsoon downpour. To our left, a line of four women bent over from the waist, calf-deep in the muddy paddies, their brightly colored cotton trousers hiked up below the knee, stood up slowly from their rice planting, wiping the sweat from their foreheads and batting flies away to squint through the remaining sun rays, looking curiously at us as we passed. I slowed and steadied my feet on the bumpy road, careful not to slip in the mud from yesterday's rain.

The men were making their way home in the opposite direction, six-foot-long wooden plows balanced on one shoulder and held steady with one arm. After hours in the afternoon sun tugging and coaxing their oxen through the thick flooded paddies, their work was done for the day. Some stopped to chat, again inquisitive as to what a fair-skinned, redheaded middle-aged woman could be doing, and without family, in the village. Others had a vague sense, as word traveled quickly, although I had been in the small Tamang village for just two weeks. That some people knew I was collaborating with people living with chronic pain became more apparent when we saw a man, dry mud caked to his knees from the fields, standing outside his house waving both of his arms to get our attention. We walked slowly down the short, slippery slope, arms stretched out like wings for balance, leaning our upper bodies back at just the right angle to prevent our feet from shooting forward under us to be greeted by the man and his wife at his house next to the paddies.

The man introduced himself as Ashik and asked directly, "Can you help me? My shoulder has been hurting for a long time, and it is still very painful when I plow the fields." Maila translated from the local Tamang language, and his wife, Riya, invited us into their one-story cement house. We introduced ourselves and said we could have a chat. I kicked my plastic sandals off before entering and walked behind all three through the narrow,

musty-smelling, darkened hallway filled with haphazard sacks of animal feed into a back room where we sat on woven stools. It was pleasant to be away from the outdoor heat and humidity. I looked behind me to the half-painted wall, where various long rusty hooks were nailed, holding empty sacks and tools. Among the various farming implements was a medium-sized old, frayed rope, probably used to lead a goat, which hung just next to my head and swayed from the jostling for seats seconds earlier, scattering light dust particles. It brushed slightly against my neck as I sat waiting for Maila to finish explaining that I was not directly working with the clinic but doing a study about people with pain.

“So, how can you help?” Ashik asked, looking at me anxiously. “The local hospital’s medicine did not help. Can you give me some other medicine that will make the pain go away?”

I did think that it was necessary to tell people up front that I did not give pain medication. Nevertheless, I would lead into that by first explaining what I did and why I was there. This brief introduction was followed by the fact that I did not provide medications but a different approach involving working through self-management and toward resilience. I phrased it as ‘ways to make day-to-day things easier.’ I told Ashik I was interested in learning his story about the pain. I do not often do examinations as a specialist pain physiotherapist, but I said I would look at his painful area, if it was localized pain instead of widespread, whole-body pain, to see if it could be helped in a way that was different from what he was already doing. Alternatively, I could advise on how to do more of the same coping strategies or chat about making some changes. Ashik clearly had localized pain, and I was curious how he coped with it, if he kept up his work in the fields, how he went about his day-to-day life, how his sleep was, and how the long-standing pain made him feel. So, we had a preliminary chat, initially with me determining if he was suitable for my research and, of course, if he was amenable. Ashik agreed, and Maila read the consent forms before he signed them.

Ashik shifted his weight on the stool, pulling his thin, worn trouser legs down over bony knees, and began to tell me how he did not have one particular incident where he injured his shoulder but that it gradually came on when he plowed the fields. He described how he pushed and pulled on the two oxen, adjusting the heavy wooden plow and directing it to turn the brownish-black soil over, both before and after the water was let into the paddy to flood in preparation for the women to plant the bunches of rice seedlings. Ashik said it became more difficult to handle the oxen each year due to his pain.

I asked him if his shoulder was painful doing other chores. "Yes, my wife has to carry heavy loads of grass and vegetables, which is hard for her," Ashik explained. "Does it hurt when you sleep on that side?" I asked as I began to paint a picture in my mind regarding the chronic overuse injury. Ashik looked surprised that I might know that and answered, "Yes, and I toss and turn trying to get to sleep."

Ashik agreed to have me take a look. When I asked him to raise both arms overhead, he winced as his painful right shoulder neared his ear.

"OK, I will try to avoid making it hurt more, but I just want to check out a couple more things. Is that okay?" I asked as I stood beside Ashik by his stool. He said it was fine, and I completed a few simple passive movements of his right shoulder and compared it to his left. "Thank you, Ashik. Is it all right if we chat about what I think might be going on? And then, if you have time and are comfortable talking, I am curious about how you may have changed things to help you work and sleep and how this pain makes you feel inside." Rubbing his right shoulder, Ashik nodded in agreement but, by this time, had begun to look perplexed.

I was reasonably sure Ashik had not wholly torn or ruptured a tendon in his shoulder, but the one responsible for lifting his arm from his side up to his ear and for most overhead movements above ninety degrees was the primary cause of his problems. In my mind's eye, I pictured a partially torn rotator cuff tendon, frayed, and scarred. I knew that my explanation would need to differ from the biomedical ones I gave in the UK pain

management service, although, with the Bengali patients in London who may not have a concept of tendons, I usually used metaphors, as they did, to describe their pain and functional challenges. So, I thought this was the best approach to take. I returned my gaze to the old rope on the wall hanging near my head when I was sitting down. I quickly formulated that the rope's function, to hang and pull things, that is, to move things, could be likened to a tendon, as it was connected to bone and served to move the bone. This rope's appearance, resulting from years of pushing and pulling, was tattered, not unlike Ashik's tendon. This metaphor made sense to me, and the visual aid accompanying it was readily available, so I asked if I could pick up the rope.

"Your shoulder has done much work over the years," I began, "And there is a section of it that is like this rope that helps your arm to move, and like this rope, to pull other things. But also like this rope, it has been used a lot, and the little threads are unwinding with lots of little mini breaks, but the whole rope is still there and works. But it is under strain, and it is painful." As I spoke and lightly touched the tiny, unraveled threads of the rope, I saw that Ashik was looking beyond me, and I felt I had lost him.

"My shoulder is NOT an old rope!" Ashik said in disbelief that I was comparing the two. "Are you going to give me some medicine or not?"

The vignette above introduces some core challenges and insights that developed into themes of this thesis, which related to my central research questions: How did the villagers see their pain? How did they cope? How could I develop a way to communicate, as a clinical ethnographer, with their way of seeing and living with their pain and then expand that to help them make sense of it for them? How would I integrate their knowledge with mine to assist them in better accepting the pain and building coping strategies toward resilience? As the thesis will show, these questions developed and directed the research, which drew a thread around resiliency that weaves through the participant's stories and experiences living with pain.



Figure 1. Villager returning from ploughing

2. Thesis rationale

The people with pain with whom I worked came from three ethnic groups, the Tamang and the Hyolmo, who are Buddhists, and the Newar Hindu group. They live in three small villages in the northwestern region of Sindhupalchok District, Bagmati Province, Nepal. It is a low-income, hilly region where transport, access to health care, and food production are challenging, mainly due to the rugged landscape. My participants were subsistence farmers, most not earning outside wages. My fieldwork began four years after the two devastating earthquakes that hit the region in 2015, and all of my participants were still recovering physically, emotionally, and financially. The already green, lush area is deluged from July through September with persistent heavy rains from the monsoon, making these struggles all the more challenging. Given the challenges, and hardships I have explained, I felt that Nepal was the ideal place to study the resiliency of people living with chronic pain.

The research was an applied medical anthropology project employing a clinical ethnography methodology. Applying an enactivist/ecological framework inspired by Coninx and Stilwell (2021) within the field of chronic pain studies, my analysis and treatment approach extend beyond and fill the gaps where the well-established multi-disciplinary biopsychosocial treatment methods (based on the Biopsychosocial Model - BPSM) commonly used for pain patients in the Global North remains the preferred standard of care. By implementing the construct termed 'idioms of resilience', conceived by Kim and colleagues (2019), and described as, "... some social factors and cultural contexts that facilitate positive outcomes amidst a range of adversities..." (722), the gaps within the BPSM are more fully integrated in terms of the three domains of the biological, psychological and social aspects of the lives of those living with chronic pain. This application of these cultural "modes of expression" (Kim et al. 2019, 721) resonates well with the enactivist/ecological approach. My research, as influenced by Kim and colleagues, adds the cultural contexts of coping and resilience in rural Nepal to better understand these processes toward acceptance of chronic pain as transformative.

To ground this approach, I will introduce the constructs of Coninx and Stilwell (2021) briefly here. The authors' focus is on the experience of pain and its conceptualization primarily through the field of affordances as conceptualized within ecological psychology, that is, the possibilities for action or choices as described by Gibson (2014). To people with chronic pain, these affordances are often in terms of physical accessibility, for example, obstacles encountered due to physical challenges such as walking. They may look up from the bottom of a long staircase to see the potential for increased pain, or the possibility of tripping for instance. People who do not live with daily persistent pain view the stairs as a means to an end; stairs may be an aid to access the second floor of their house to reach a destination. Their thoughts would focus on such questions as "is my sweater in the bottom drawer upstairs?", for example. However, these affordances or possibilities may also be in the form of how the person in pain may view the impact of chronic pain on their lives; they may understand the cause of their pain to be wrongly diagnosed, for example, therefore they may feel a lack of agency to accept the changes in their life or gain a thorough understanding of their

pain. Through the person living in pain and their choices made based on what may be available to them, their relation to pain and to the world can change. To Coninx and Stilwell, pain is transformative because it alters the field of affordances, narrowing the range of potential actions. As clinicians, we can expand the possibilities for action. This construct is useful for my research since this change in the field of affordances being transformative and garnering potential often leads to resilience, which is the central theme in this thesis.

Moreover, Coninx and Stilwell conceive of a hybrid approach as the authors integrate their work in enactivism with core aspects of the ecological tradition (Gibson 2014). The authors see the process of acute and subacute pain leading to chronic pain as enactive, “in terms of the alteration in the dynamic, interactive, and embodied relation between subjects and their environments” (2021,7837). However, they significantly part ways with Varela et al. who first described enaction “to emphasize the growing conviction that cognition is not the representation of a pre-given world by a pre-given mind but is rather the enactment of a world and a mind on the basis of a history of the variety of actions that a being in the world performs” (1991,9). Instead, Coninx and Stilwell place affordances as their central tenet. To clarify, this thesis does not engage in the philosophical or those aspects of enactivism that discuss cognition relating to representation but instead aligns with the emphasis enactivism places on sensorimotor learning as does Coninx and Stilwell’s work. Their work is also ecological in the sense that they describe an interrelatedness with the person in pain with their environment which, through embodied action, shapes how they perceive pain and how it is experienced, as with the example above with stairs. This is a bidirectional relationship, but a complex one clarified by the statement, “While enactive theories focus on the perspective of the subjects acting on the world, ecological approaches often select the opposite starting point describing how the structure of the world shapes the subject’s possibility to act” (Baggs and Chemero 2018 quoted in Coninx and Stilwell 2021, 7838). They then elaborate that Merleau-Ponty completes this view within the phenomenological perspective, that we act and relate through the lived body within the world to complete this dynamic (1962).

Coninx and Stilwell summarize this hybrid approach, as it centers on “(i) a subject’s active engagement with the world and their perceived possibilities to act, (ii) the dynamic bi-directional relation between subjects and their environment mediated by the body, and (iii) the lived experience of subjects and their transformative potential” (2021, 7838).

These developments will be expanded in more detail in the next section on Theoretical Background and will be described as the natural course beginning with the biopsychosocial model.

Differing from the biopsychosocial approach, in framing the interviews, treatment sessions, and time spent with my participants, my analysis is based on investigating the emergent aspects of the pain as lived experience, as the nexus of the lives of the villagers, extending and embedded in and to their sociabilities, within their families and communities. Moreover, their sociability extends beyond humans and into the spirit world of ancestors and other forms. Their social dynamics extend to their challenges with accessing and receiving healthcare, and emotions are embedded in living with pain, and their challenging Himalayan landscape. Crucial areas of study to complete Coninx and Stilwell’s “holistic, integrative, and dynamic” construct include the consideration of the sociocultural and the experiential domains (2021, 2842), both of which underlie my ethnographic contribution to the understanding of chronic pain.

Within an enactivist/ecological theory, pain is embodied, and as emergent, pain becomes something new in itself; it is not the sum of its parts, as is my understanding and experience of the manner in which the standard biopsychosocial model can be employed and misrepresented (Cormack et al.2023) Coping, acceptance, and resiliencies are also demonstrated to be emergent, as they are co-created through the social dynamics of the person living in pain. Indeed, the biopsychosocial model, initially conceived by Engel (1977), enables clinicians to integrate the three components - biological, psychological, and social - in some manner. Most pain clinic teams have

specialist psychologists, physiotherapists, doctors, and nurses, each providing vital input to the multi-disciplinary team. However, I agree that this approach in practice, not so much so in theory, continues to compartmentalize and provide a reductionist lens to the person living in pain with a dominant biological lens, for which chronic pain does not fit. Chronic pain, by its nature, involves not only the painful body part but the whole person.

There have been more recent developments in work with people with pain to broaden this scope and integrate the fragmented biopsychosocial model with newer frameworks, however Coninx and Stilwell remain major contributors (Stilwell and Harman 2019; Coninx and Stilwell 2021; Stilwell and Coninx 2021; Coninx and Stilwell 2023; Cormack et al. 2023; Vaz et al. 2023) The “enactivist biopsychosocial model” conceived by Cormack and colleagues (2023) added dimension and is an important contribution and proved to be an essential theoretical development, however this construction is still better developed by Coninx and Stilwell. By introducing the hybrid concept, Coninx and Stilwell’s framework utilizing the field of affordances is a better fit for this research. Furthermore, this thesis will address questions such as: how will the enactivist biopsychosocial model and the enactivist/ecological constructs be further researched, developed, and implemented?

In reading the introductory narrative about Ashik, upon arrival in the field, I knew about the shoulder and the rope; by bringing an anthropological lens to this project, I aim to learn about the person.

Anthropological perspectives demonstrate and enrich this approach through ethnography. Significantly, under the lens of the enactivist/ecological framing of living with chronic pain, this thesis examines how the participants developed coping strategies and their idioms of resilience as a continuing thread (Kim et al. 2019 ; Mendenhall and Kim 2021).

What follows in the Introduction is the background to the research; that is, how I formulated my ideas for the theoretical frameworks, which are the foundation of the analysis of how people living in pain cope with their lives and how they work toward

resilience. To provide some context, I begin by describing the foundation of how chronic pain is understood, primarily from the biomedical perspective, since, as I discuss, this remains the dominant view. Reviewing the basics and background of pain science and the development of the theories surrounding pain provides the process under which the biopsychosocial approach became the standard model of care. I will follow this by explaining the self-management model used to deliver this care. The next section analyzes the concepts of coping and resilience as the central thread of the thesis, followed by a review of the theory of the enactivist/ecological approach and its application to my work. I then review my methodology in conducting clinical ethnography. Finally, I present a brief synopsis describing the content of each chapter and its major themes.

3. Thesis background

3.1 Synopsis of chronic pain

Chronic pain is a prevalent health concern worldwide. According to the National Pain Audit compiled by the British Pain Society, from 2010 through 2012, 7.8 million people in the UK lived with chronic pain (British Pain Society 2012). According to the National Institute for Health and Care Excellence guidelines on their website, “Chronic pain persists for more than three months. Chronic primary pain has no apparent underlying condition or is out of proportion to any observable injury or disease. Chronic secondary pain is a symptom of an underlying condition. Chronic secondary pain and chronic primary pain can coexist” (National Institute for Health and Care Excellence (NICE) 2021). Numbers in developing countries range from 5% upwards to 33% of the population suffering from chronic pain, whereas in more economically advantaged countries, figures range from 18% to 20% (Bond 2011).

Furthermore, the treatment gap in developing countries is due to difficulties accessing education for professionals, pain service facilities, and the availability of medications. Some initiatives, such as The International Association for the Study of Pain’s (IASP) Developing Countries Working Group, have begun developing successful programs to

address pain education training and clinical improvements. However, more work is needed to develop frontline care in underserved areas (Bond 2011).

Persistent pain or chronic pain is a multifaceted and complex phenomenon. In general terms, a chronic illness is one where there is no medical cure, however symptoms can be managed to a greater or lesser extent. To the individual, it is a long-term condition that has taken on a life of its own, affecting every aspect of their world¹. There may have been an initial injury, but in addition to pain in that region lingering and increasing, the physical pain has 'spread' to other areas of the body. Logically, these individuals think, often emphatically, that their injury has become more severe, has not healed, and again, logically, has now worsened to the point that other areas are now involved. This trajectory is commonsensical from a Cartesian analysis (Descartes 1633/1972), which is a perspective that there is a one-to-one correlation between the painful region and tissue damage. Unbeknownst to the individual as their 'way of knowing,' it is often incorrect from a physiological and environmental standpoint (Moseley and Flor, 2012; Moseley and Vlaeyen, 2015). Thus begins the pain experience of many people whose lives involve numerous specialist medical appointments on a never-ending quest for answers, resulting in lost employment, subsequent financial difficulties, family stresses, loss of mobility, and a myriad of comorbidities such as depression, obesity, diabetes, and hypertension (Main and Spanswick 2000). This combination of life-changing events has as its foundation a misconception regarding the physiological mechanism of persistent pain and 'how it works' (Thacker and Moseley 2012). What follows describes how the scientific community developed theories and frameworks to answer this question.

A continual search for reasons and meaning dominates the lived experience of persistent pain patients. Loss of agency and lack of independence have become the norm for many. The question this research poses is essentially, 'How is that different in

¹ Read *Under the Medical Gaze: Facts and fictions of Chronic Pain*, a thought-provoking autoethnography by anthropologist Susan Greenhalgh, who writes of her challenges with navigating the US healthcare system while seeking care for the chronic pain condition, fibromyalgia syndrome (2001).

Nepal?’ Some individuals live with persistent pain throughout the world and do not experience this burden of suffering; that is, people who cope. How did they learn this? Did they learn this from family or clinicians through their medical knowledge base? How does one become resilient and self-reliant in Nepal, or does one?

The one-to-one Cartesian paradigm which assumes that pain equates to damage, was disputed beginning with Melzack and Wall’s (1965) description of their new concept known as the gate control theory. This theory was in opposition to the specificity model accepted previously, which was taken to be the most ‘logical’ to the science and medical community, as well as those experiencing acute pain. The specificity model assumed chronic pain functioned in much the same way as other senses. Information processing was a one-to-one correlation with the stimulus and response. What the gate control theory brought was the perspective that central mechanisms originating from the brain had an impact on centers lower down. Moreover, thoughts and feelings originating in the brain could also affect pain from the descending pathway, which again opens or closes the gate. Therefore, now opening or closing the gate, a series of physiological actions within the spinal cord, could modulate pain. How one thinks and feels could directly affect one’s pain. This was groundbreaking from a biomedical perspective and opened the way for the biopsychosocial model of care.

Often, a search for a ‘reason’ for the pain that originates in the painful area of the body is ongoing for both clinician and patient, distancing the pain patient from their experience and sense of agency. Melzack further developed a more nuanced understanding of pain mechanisms with his Neuromatrix Theory (1999). Though still primarily situated within a brain-based framework, Melzack’s model integrated more aspects of sensory modification. Most importantly, however, Melzack outlined the importance of how an injury could induce stress responses that would cascade to activate homeostatic regulation, affecting neural, hormonal, and immune responses. The system, in turn, produced loops that aimed to restore homeostasis driven and perpetuated by behavior. My reasoning for a brief history of pain science is to

demonstrate how this translates and continues to carry over into the dominant mode of understanding chronic pain in the biomedical arena.

Nonetheless, the culture of biological reductionism persists in the consultation room despite the well-researched newer models considering the environment, emotions, and context². The patient living with long-term pain nearly always brings in their understanding of 'how pain works' as the mechanism of acute or subacute pain, which is as the result of an injury or trauma. The role of behavior as a perpetuating factor meant, logically, that changes in behavior could somewhat alter the cascading system (Melzack 2002). As a consequence, the biopsychosocial approach to the treatment of pain was developed (Engel 1977). In 2020, The IASP defined pain as "An unpleasant sensory and emotional experience associated with, or resembling that associated with actual or potential tissue damage" (Raja et al. 2020,1976). This definition accounts for the multifactorial nature of pain and includes the emotional experience and the subjectivity of the person living with pain.

Moreover, included in the newer models in pain science, such as the Neuromatrix Theory implemented through the BPSM of care, would be the new neuroscience of plasticity, which referred to the adaptability of the nervous system to grow and change, whereas it was once seen as fixed. The terms central and peripheral sensitization describe the changeability of the central nervous system and its outer branches, which could become 'wound up' and hypersensitive to pain. This process accounted for patients' experiences of the pain worsening or spreading as correlated with further 'damage' or injury being inflicted. However, this 'wind up' was physiological and occurred in a small percentage of people after four to six months. Unfortunately, these were those who went on to develop chronic or persistent pain based on the factors mentioned above.

² For a comprehensive historical perspective of the medical and social development of the concept of pain , see *The Story of Pain: From prayers to painkillers* (Bourke 2014).

Lorimer Moseley's and others more recent developments carried Melzack's further, and these are the most widely accepted in modern pain science and pain management centers in the UK and in the physiotherapy department with which I collaborated in Nepal (Moseley and Flor 2012; Butler and Moseley 2013; Moseley and Vlaeyen 2015). I also saw that these concepts are instructed in the physiotherapy training in Nepal (Cocks 2015). Patients are taught that 'pain does not equate to damage' and are gradually exposed to more movement to dispel fear-avoidant behaviors and threats to their safety. Moseley and Butler (2013) describe pain as a response to a real or perceived threat to the body. The slightest movement due to the 'wind-up' and hypersensitivity often elicits pain. These theories and the teaching and treatment strategies based on them regard 'pain as being in the brain' to paraphrase and are not accepted as the whole picture by some, this researcher included. Nevertheless, general practitioners, musculoskeletal physiotherapists, and the general public often view chronic pain as 'an issue with the tissues.' They may not be aware that the pain is from multifactorial systems and influences, as described in the theories covered above.

3.2 A natural development to and from the biopsychosocial model (BPSM)

In a UK pain clinic, treatment now takes a biopsychosocial treatment approach to the holistic care of the individual patient. This treatment is recommended as the most effective in increasing patient function and well-being in the UK and the Global North (International Association for the Study of Pain 2009; British Pain Society 2019; National Institute for Health and Care Excellence (NICE) 2021). With this method, the physiotherapist instructs and facilitates the patient to learn to self-manage their persistent pain to increase their activity levels despite the pain rather than providing overall pain relief. However, decreases in pain have often been seen as well, but this is not the aim. Topics covered are: pain education, that is, understanding how pain 'works' in the body and the impact of environment and activity; patient-centered goal setting; gentle graded exercise/mindful movement to increase function and decrease fear-avoidant behavior; activity management and pacing to avoid 'winding up' the pain; sleep hygiene; acceptance of pain and solution-focused approaches to goal setting; and flare-

up management (Harland and Lavalley 2003).

Sessions in any pain clinic always involve various disciplines other than physiotherapists. Underlying the basic principles is a psychologically informed approach, and pain specialist clinical psychologists generally lead the services (Harland and Lavalley 2003). The 'gold standard' in the National Health Service (NHS) has been Cognitive Behavioral Therapy (CBT) as the guiding framework (NICE 2021). Beck is considered the father of CBT, and his theories, along with others, significantly influenced the development and implementation of most treatments for people with chronic pain (Rush, Khatami, and Beck 1975; Winterowd, Beck, and Gruener 2003). Initially implemented as a treatment method for depression, Winterowd, Beck, and Gruener (2003) applied CBT more specifically to chronic pain patients. Essentially, those with chronic pain can develop automatic thoughts that are 'unhelpful.' These take the form of distorted thinking or thinking errors, according to CBT theory. Examples are 'catastrophizing,' which would suggest that one would internally say to oneself, "My back really hurts; I must have cancer." Using a CBT approach, the patient would then be taught to identify and reflect on the automatic thinking errors, the subsequent emotion, and the resultant behavior. They are taught to 'challenge' unhelpful thinking with various techniques. One strategy may be to 'weigh' the evidence for or against that thought, listing the supporting evidence in one column and the disproving evidence in another. Patient workbooks such as *Mind over Mood* became part of the programs (Greenberger and Padesky 2015). Weighing evidence and challenging thinking errors were recommended by all the disciplines in the pain clinic to assist patients in improving their activity levels and quality of life, either while doing exercise or doing the housework. CBT was efficient and pragmatic. However, given that chronic pain manifests primarily as physical pain rather than 'thinking errors,' CBT proved not to be as effective. Thus, newer cognitive-based approaches began to gain momentum.

Following the development of the various methods and theories that underlie the reasoning behind assessment and treatment serves to ground what is known as self-management principles in biomedicine and BPSM today for those living with pain. Most

widely seen now are psychologically based approaches within the multidisciplinary team, based on Acceptance and Commitment Therapy (ACT) and mindfulness-based approaches, a recent widespread development stemming from CBT (Hayes, Strosahl, and Wilson 1999). The reason for my descriptions of these developments is to frame them within my research and mode of treatment niche, which utilizes resilience building through self-management techniques.

McCracken and Vowles (2014) summarize that ACT relates pain and suffering as an everyday part of the typical human experience. This approach strays from CBT's analytical and problem-solving-based approaches, which state that thoughts or behaviors must be 'fixed.' Rather than taking a direct approach to changing thinking, as with CBT, ACT aims to adapt responses to symptoms more experientially, described as developing psychological flexibility. It can, however, reduce the frequency or intensity of feelings of sadness or pain. According to Hayes, Strosahl, and Wilson (1999), psychological flexibility, like resilience, comprises the following concepts and processes: acceptance, cognitive diffusion, flexible attention to the here and now, the self as the observer, and value-based and committed action. It is not common sense, as were the older, more CBT-based approaches to coping and self-efficacy within self-management. If one experiences something we do not like, we want it to disappear; that is common sense. Mindfulness-based meditation type practice can assist in bringing the person to 'defuse' and avoid getting carried away with the overwhelming aspects of pain, reducing the burden and impact of it on the person's life. McCracken & Vowles suggest, "A difference may be as small as a shift from seeking to understand the reality of the world to seeking ways to act successfully in the world", in describing small changes in the processes in ACT (2014, 185).

Thacker and Moseley (2012), both physiotherapists initially trained in the medical model, describe in "First-person Neuroscience and the Understanding of Pain" how physiotherapists and doctors traditionally have not viewed the whole person in pain. The basis of today's multidisciplinary pain service is person-centered and does not utilize a medical model, per se. However, this thesis will develop to show how pain

management delivery continues to be a predominantly (bio) medical model. The mediation of pain as being in the brain with specific pain centers that ‘light up’ on functional MRI is not based on recent research but remains a current understanding. The experience of pain is far more integrated physiologically and is reflected in functional MRIs demonstrating the involvement of various centers throughout the brain. Thus the impact of social, psychological, and cultural experience is becoming more established, as this thesis will demonstrate (Iannetti et al. 2013).

Further developments in understanding chronic pain are influenced by enactivist theoretical approaches originating from cognitive science, aiming to escape theoretical and practiced reductionist and fragmented approaches as described previously (Stilwell and Harman 2019; Coninx and Stilwell 2021; Stilwell and Coninx 2021; Coninx and Stilwell 2023; Cormack et al. 2023; Vaz et al. 2023). The basis of enactivism and its application to chronic pain and its relevance to this thesis’ theoretical framework will be explored in the next section of the Introduction in more detail. As demonstrated in this section, the trajectory of the theoretical foundations of research and applied clinical practice followed first (in modern times in the Global North), from the neuro-centrism to the development and implementation of the biopsychosocial model. Essentially, in bringing in some aspects of the theories of enactivism, the newer models extend beyond. “In the context of healthcare, a patient’s experience (e.g., pain) and their interactions in their physical and social environment can shape disability and actions afforded, for better or worse”, as explained by Cormack, Stilwell, Coninx, Gibson (2023, 2280) regarding their views on the perception of pain. This approach places the person with pain as having agency to make decisions and interact with those affordances in the environment. This approach is meaningful for this study as, in this framing, the biological aspects of pain are no more relevant than the social. As stated previously, however, I believe more dimensions can be added to the enactivist BPSM and enactivist/ecological models through an anthropological inquiry, as shown in this research.

3.3 Self-management as a treatment approach for chronic pain

My research is situated in a care delivery model termed 'self-management.' What does this mean, and why has this been the gold standard treatment and recommendation for chronic pain, as well as many chronic illnesses in the UK (and globally) by the BPS (2019) and NICE (2021)? A brief introduction to these concepts follows and why they may be utilized to assist people living with chronic pain.

In general terms, self-management treatment approaches recommend improvements in quality of life based on knowledge, guidance, and information primarily gained through a biomedical clinician (they are usually part of a multi-disciplinary team using a BPSM) that the individual follows on their own accord at home and away from the medical center of care. Components have traditionally included individual goal setting and lifestyle modification within a framework of a cognitive behavioral model leading to change (Kamper et al. 2015). This model has been adapted from the medical community's perspective for people with chronic pain as their condition does not fit a medical model of disease; that is, it cannot simply be cured or fixed (Butler and Moseley 2013). More implicitly, however, the main symptom, pain, often cannot be traced to a structural source in the body compared to a chronic disease such as diabetes that lifestyle changes can manage in addition to insulin administration (Moseley and Vlaeyen 2015). For chronic pain, there is often no biological marker, nor do patients reduce their pain with passive treatments other than short, temporary relief with assistance from medications, manual therapies, or even surgeries (Main and Spanswick 2000).

These approaches are based on the notion that individuals do or will possess the requisite motivation and problem-solving skills to help themselves once given guidance. The clinician's challenge is assessing each individual's 'readiness.' Some advice given, such as smoking cessation, is not so readily adhered to, although the patient will know this behavior is not healthy. Hence, newer approaches have included behavior change models, and steps to readiness to change have been incorporated widely (Harland and Lavalley 2003; Winterowd, Beck, and Gruener 2003). Readiness to change and self-

efficacy became guiding litmus tests for predicting and maneuvering patients through changes that they made, taking on more personal responsibility for their well-being. This reasoning can be applied to self-managing chronic pain. However, this may not apply to those who are in significant pain and fear that more activity will 'damage' their back, for instance. Vlaeyen and Linto (2000) describe this concept through the fear-avoidant model of disability. Individuals are taught through a series of graded exposures to gradually explore movement and activity while listening to their thoughts and feelings. By slowly engaging in safe, non-threatening movement, they learn to accept that nothing overly threatening will happen, and they can participate more in life.

A very useful approach for the defusing of threat is ACT, which promotes 'psychological flexibility' and acceptance of oneself and solving problems, which have served to keep one in an isolated and disabled and painful lifestyle. Again, this is a nuanced difference between coping and getting on with it. Again, the aim is not to 'push' the problem or pain away but to have it result in less suffering (Hayes, Strosahl, and Wilson 1999; McCracken and Vowles, 2014).

The following section will develop the theoretical frameworks that informed my position and approach to understanding how my participants learned to see the role of pain in their lives. Within the enactivist/ecological approach to chronic pain, resilience became a dominant thread. Within this dynamic framework, resilience, like pain, was emergent; it was built and constructed around and between aspects of their lives and became a new perspective for the participants.

3.4 Theoretical frameworks

3.4.1 Resilience

The main research focus of this thesis is how the participants living in pain learned to cope and work toward resilience. This question concerned me throughout my career as a pain specialist physiotherapist each day. Why did some people struggle, and others did not? The physiology and science of pain were briefly outlined in the beginning section

of this introduction, and further neurobiological description is beyond the remit of this research. Regardless, these physiological mechanisms are not entirely known through science, and those theorized do not provide a clear path to explain why some people develop chronic pain and why some struggle less. However, through the added anthropological lens, the coming chapters will discuss how my participants learned to adapt and make changes through the village and their cultural, relational, and environmental context.

In this section, I will review some background and theories surrounding coping, acceptance, and resilience that informed my analysis provided in each chapter. Firstly, I review the definitions on which I draw the components and attributes and how I adapted them for my work. These definitions then expand and further clarify the importance of context and meaning to how people can work toward resiliency. To further this view, I discuss the entanglements between examining the individual traits seen in the Global North of resiliency as strength and grit and the more complex understanding of acceptance and emergent properties leading to transformation. Lastly, the construct of idioms of resilience is explained, and how its application is used to further my method and framework with the analysis of resilience.

Each chapter introduces a person or people living with pain with whom I spent much time as a clinical ethnographer, in semi-structured interviews, open-ended interviews, at family celebrations, and as a neighbor in the village. The chapters will focus on specific components and attributes of resilience, and by providing thick ethnographic descriptions of their lives, they will examine what individual qualities and characteristics within the events, contexts, affordances, and opportunities led to their coping with pain.

The definitions of resilience are introduced further in Chapter Four – The Copers. Preceding chapters lay the groundwork for the contextual challenges put forth in Chapter Four. One definition of resilience I support is psychologist Michael Rutter's (2006), which is, due to his thoroughness and direct application to this work, "some form of successful coping with the challenge or stress or hazard. This is likely to involve

physiological adaptation, psychological habituation, a sense of self-efficacy, the acquisition of effective coping strategies, and/or a cognitive redefinition of the experience “ (2). I feel all of the traits are significant. However, the inclusion and wording of “cognitive redefinition of the experience” is most helpful in my analysis. According to the American Psychological Association (APA) (2023), resilience is “the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioral flexibility and adjustment to external and internal demands.” This definition is also useful. However, it does not describe the process of change as transformative as with Rutter. A “redefinition” appears more internally, emotionally, and cognitively altered. Through an enactivist/ecological approach, this process is emergent because it is new and generative and leads to more potential, relating to fields of affordances. It may be my reading of the APA’s framing of the term “adjustment,” which may not be as descriptive but may be a similar process of change. The term psychological flexibility is discussed further in Chapter Four and would include, as the APA definition mentions the “mental, emotional, and behavioral.” To stress the point, this path toward resiliency is not linear or fixed and requires psychological flexibility or openness to change - and I see this as an essential step. I am not suggesting that resiliency and acceptance are endpoints and goalposts that are passed. However, there does appear to be a point at which acceptance can be applied in most situations with those living in pain as if a destination has been achieved. This level of acceptance, which affords resilience, will be tested repeatedly and made more challenging when under added emotional and physical stress.

Kim and colleagues (2019) state that “One area of theoretical concern that we pose to future research of resilience is the conceptual difference between coping and resilience” (738). These two terms can be seen as interchangeable. However, I agree with Karoly and Ruehlman (2006) that resilience is a wider term, and in this thesis, I take coping as a step and perhaps a set of strategies that can lead to resilience. As will be developed through this Introduction and thesis, resilience in my context is seen as not a show of strength and ‘grit’ but a change and a transformation, an emergent state of acceptance.

In reviewing the paper “Resilience definitions, theory, and challenges: interdisciplinary perspectives,” which resulted from a plenary panel at the 2013 meeting of the International Society for Traumatic Stress Studies (Southwick et al. 2014), the authors do state that as individuals, they would define resiliency in different ways. However, they agree that resilience is a multifaceted concept in which cultural, family, and community dynamics impact outcomes and resources. The following analysis will look beyond the aspects of these definitions. It is agreed that the attributes may differ in different contexts, including Nepal. More directly, how does one develop these traits when becoming resilient in Nepal?

Therefore, what constitutes resilience can be debated; however, what brings one to develop the traits and components of resilience? I have discussed what traits one needs. This section will focus on the *who* and *how*. Bonanno and Burton (2013) examined individual differences in emotional regulation³, which can predispose or lead one toward better coping. Their paper reviewed the current literature and concluded that many researchers and theorists, despite having the data that people respond to stress in various ways, dependent on the context and event, and the strategies they have chosen, use models focused on the practice or regulatory strategy that the individual may have incorporated as being a ‘good’ or a maladaptive practice (Baker and Berenbaum 2007). Bonanno and Burton termed this the fallacy of uniform efficacy, essentially, that ‘one size fits all.’ The paper compares other work that proposes more dynamic inclusive models. However, it concludes that these frameworks are poorly structured, for example, pointing to Kashdan and Rottenberg (2010), although they are more applicable to my research on the efficacy of psychological flexibility, which is developed more in the following chapters.

³ Example of a specific emotional regulation strategy: “Reappraisal: A specific regulatory strategy that changes the way a stimulus or situation is perceived, typically to decrease emotional impact. One instantiation is to reinterpret an emotional event in more objective terms”(Bonanno and Burton 2013, 606).

The conclusion for Bonanno and Burton was the identification of three processes that described the process of emotional regulation strategies toward coping and resilience building: “sensitivity to the situational context, the ability to utilize a diverse repertoire of regulatory strategies, and the ability to monitor feedback about the relative efficacy of a chosen regulatory strategy and maintain or adjust regulation as needed”(2013, 605). For my purposes, these data reinforce the essential need to provide a person-centered approach within the context of my participant’s experiences, which are quite different from my personal and professional experiences in the past.

The following work brings the individual back into the relational sphere. Betselot Wondimu (2023) discusses the formation of resilient subjects with the theme of moral injuries in public health and psychiatric settings. By suggesting a shift away from the person who may be the self-reliant subject and focusing on the adverse conditions that may have created the context, event, or circumstance, she argues for further examination of treatment approaches toward building resilience as perpetuating a victim positionality. Drawing on Margaret Urban Walker’s (2009) work on justice in reparations, Wondimu describes a second injury resulting from the resilient subject’s attempts to adjust to adverse conditions. Resilience is viewed as courage if achieved by the subject ⁴; however, the institution or structures are not held accountable for the injustices that may have initiated the need for the challenges faced.

Relating this dynamic to the villagers in Nepal, they talked openly about the challenges they faced, as seen in my ethnographic descriptions; however, in my opinion, they did not see how they could change the institutions and structures, so they saw the value of making the change in themselves. This theme also relates to the care delivery model of self-management described in section 3.3 of this chapter. My reasons for taking this approach are many; however, in this context, with the lack of available health care and, more importantly, the nonavailability of options for effective care for chronic pain, was

⁴ The term resilience when applied to people, is likened to physical properties not unlike the strength of a metal for example (Kirmayer et al. 2009).

that chronic pain does not respond well to standard biomedical musculoskeletal physiotherapy therapeutic approaches which are better suited to acute and subacute pain. These treatments could include medication and employ passive techniques such as tissue/joint manipulation, strengthening, stretching techniques and other methods to directly impact and improve motor function.

In her work entitled “Resilience, agency, and everyday *Lojong* in the Tibetan diaspora” (2018), as well as in her volume, *Spacious Minds* (2020), anthropologist Sarah Lewis follows similar themes of resilience not having to be a show of strength, and bearing the pain, as may be the assumption in the Global North. Lewis argues that this approach to adversity is also culturally shaped within the Tibetan diaspora in Northern India through a Buddhist practice called *Lojong* (Tibetan: mind training). Developing and cultivating compassion is a practice and an ethos (Rinpoche 2009).

Sara Lewis writes, as compared to being valorized, as may be the case in other cultural contexts,

Instead, those who are most resilient use their vulnerability as a way to deepen compassion. In this way, compassion is both the result of resilience and a method to train in resilience. Similar to what researchers call “post-traumatic growth,” Tibetans in their practice of resilience use suffering as a transformative opportunity. Because suffering is seen as an unavoidable aspect of everyday life, this approach is not limited to remarkable individuals. (2020, 19)

My participants would not have had the opportunity to be instructed in *Lojong*⁵, but the similar frameworks for understanding within this cultural context would have been an

⁵ *Lojong* is a Tibetan Buddhist practice and a view that is carried over into the everyday and refers to overcoming adversity by cultivating compassion. In the text, which was brought to Tibet by Atisha (982-1054 CE) and written down by Geshe Ckeckawa (12CE), there is a list of aphorisms or slogans which aid in thinking about others who are suffering as well as yourself and to send feelings of compassion to all sentient beings.

influence. Suffering as a part of life does not mean the aim is to tolerate pain, but to be transformed. Throughout this thesis, this is the thread of ‘moving beyond,’ which follows resilience building from the Nepali Buddhist villages parallel to the Western understanding of working with people living with pain with the development of the second wave of cognitive therapies, such as Acceptance and Commitment Therapy (ACT).

3.4.1.1 Idioms of Resilience

There is a resonance to Lewis’s (2018,2020) work in my research, in her subject matter, but more directly in her approach to her narratives as an everyday application of resilience building. Using the culturally Buddhist practice of *Lojong* as a commonplace embedded method of working toward resilience for the displaced Tibetans, Lewis’s approach is one Andrew Wooyoung Kim and colleagues termed ‘idioms of resilience’ as was introduced in the Thesis Rationale section of this Introduction (Kim et al. 2019; Mendenhall and Kim 2021)⁶. This heuristic is influenced by Mark Nichter’s⁷ (1981; 2010) construct ‘idioms of distress.’ By listening to the narratives and details surrounding the whole experience their participants provided in their research on cancer patients, Kim and colleagues extend beyond process-oriented and socioecological approaches to emphasize collective and cultural meanings behind the adversities and the paths toward resilience building. Liana Chase and colleagues’ (2013b) work investigated coping and

For a modern commentary refer to *The Path To Awakening: A Commentary on Ja Chekawa Yeshe Dorje’s Seven Points of Mind Training* by Shamar Rinpoche and edited and translated by Lara Braitstein (Rinpoche 2009).

⁶ Each chapter of the thesis will center on one or more themes as they relate to an idiom of resilience.

⁷Nichter (1981) defines idiom of distress as, “an adaptive response or attempt to resolve a pathological situation in a culturally meaningful way” (402). An example in Nepal is described by Brandon Kohrt and Daniel Hruschka (2010) in their research with the Bhutanese-Nepali refugees following the decade long Maoist civil war who suffered with what was diagnosed as PTSD. The work sought to identify the local idioms of distress to assist to ease communication to improve service users’ access to mental health services in an area where there is stigma regarding mental health concerns.

resilience among Bhutanese refugees in Nepal who experienced fractured social networks and high suicide rates as a result of displacement. For fifteen years over 100,000 refugees lived in camps in eastern Nepal before resettlement in 2013. This study utilized ethnographic data to assist in the analysis of results of a standardized measure called the Brief COPE which was modified for cultural context and language. Positive reframing and planning were seen to be the most common strategies followed by acceptance, religious practices, and seeking emotional and social support. In their paper, “Making Peace in the Heart-Mind: Toward an ethnopsychology of resilience among Bhutanese refugees”, Chase and Bhattarai (2013a) work with the same population. However, they looked more closely at local constructs of the self and personhood, such as heart-mind (Nepali: *man*) and brain-mind (Nepali: *dimag*) and their relation to conceptions of well-being among the refugees. Here they sought to ... “identify locally meaningful indicators of favourable responses to salient stressors, as well as lay beliefs and knowledge or ethnopsychology, surrounding the promotion of such favourable responses. Instead of mapping our findings onto existing psychological constructs, we sought to develop an emic model of resilience ...” (148). The interlocutors described a change in their heart-mind and a sense of a personal transformation using culturally specific religious (Buddhist and Hindu) strategies such as rituals and meditation. Another term used was “making one’s own heart-mind peaceful” (150) as an acceptance and adaptation based on the notion of *karma* (Sanskrit: Action and its consequences) found in both religions.

Chase and Bhattarai (2013a) described their study as developing an “emic model of resilience” (162) which aligns closely with the construct of idioms of resilience, although they did not use this term. Their work aligns with Lewis’ work (2018,2020) mentioned above, as these two studies conducted with Bhutanese refugees refer to the transformative nature of cultural practices primarily based on Hindu and Buddhist conceptions. Thus, religious practice can be seen as an idiom of resilience, and an example is developed in Chapter Six. Descriptions and conceptions of the self and centers of the ‘heart’ or ‘heart-mind,’ and ‘soul’ vary across cultural contexts, and the aim here is not to analyze or categorize. However, these notions of self, centers of emotion, and personhood do shape how people in pain relate to their place in the world

and their relationship to their environment, and humans and spirits among them. Pasang is a participant whose story is told from various perspectives through this thesis. The idiom of resilience surrounding the conception of what he terms his *hungsa* (Tamang), his soul, or life force, which was taken from him by a ghost and if not returned soon he would die, figures significantly in his story toward healing. Each chapter will detail instances and examples within the village sociocultural dynamic and environment which thread through the lens of idioms of resilience.

An example of analysis through the framework of idioms of resilience outside of the Himalaya region is Leith Mullings (2005), who researched African American women's access to reproductive health care and used an intersectional lens to reflect on their inequalities regarding class, race, and housing disparities. The women formed support groups as a form of resistance, building resilience together. Laurence Kirmayer and colleagues (2011), in their work among Indigenous people in Canada, called for a framing of the resiliency work done previously in the developmental psychology and psychiatric fields, which focused on specific individual traits to overcome adversity, with research based on inner-city children in the Global North. The work of Kirmayer and colleagues suggests reframing the thinking of researchers and health care providers within the specific cultural context, aligning with their patient's or participant's epistemologies of health and healing. Understanding the Indigenous Canadian people's collective attachment to land, place, and the environment was essential for Kirmayer and colleagues to establish an anthropological lens that looked at sociostructural barriers to forming resiliency in their communities. In this research, I have begun with the fundamental psychological definitions of resilience and its attributes; however, I have developed this to incorporate this thinking into an emergent framework that brings together the psychological components of cognitive redefinition of experience (Rutter 2006) with the Indigenous Buddhist constructs of my participants as does Lewis (Lewis 2020; 2018). Essentially, the practice of *Lojong*, in my experience, could be seen as a similar coping strategy or path to resilience. To my mind, this has formed an integrative approach in my work within the idioms of the resilience heuristic.

Kim and colleagues (2019) explain:

Attention to idioms of resilience can also enrich cross-cultural clinical practice and health promotion by identifying culturally salient resources that structure the process of healing. Idioms of resilience may index certain perspectives of disease or health practices that are individually and culturally understood to promote healing and well-being but that are not considered in biomedical models of disease or are viewed negatively (274).

As a final example of idioms of resilience as applied in the field, and as an example also of my approach in Nepal, in their work in Afghanistan in 2006, Mark Eggeman and Catherine Panter-Brick (2010) look at the collective understanding of fundamental cultural values amidst a war-torn community in Afghanistan. They spoke with children and their caregivers and developed constructs around how the communities work toward resilience based on the values of family, honor, faith, service, effort, and morals. The research highlighted these individual characteristics or attributes and values; however, given extreme poverty and structural inequalities, adherence to these values often led to entrapment, the inability to reach goals and aspirations based on cultural constructs, and not resiliency or transformation. This example points to the need to look beyond the individual components or values and to understand the collective meaning they may bring to the person impacted by adversity.

3.4.2 Enactivism as part of the enactivist/ecological approach

What follows is a brief section outlining the structure and detail of theories of enactivism as they apply to my work. To provide context, as argued throughout this thesis and mentioned previously in the Thesis Rationale section, the predominant model implemented therapeutically in pain services, and the view in which chronic pain is understood by biomedical pain clinicians in the UK and Nepal, is the biopsychosocial model (BPSM), which has been shown to have limitations, as demonstrated in practice, primarily due to the dominance of the biological and the lack of integration of the psychosocial aspects. As discussed previously, it is clear that Engel (1977) did not foresee

the lack of integration in practice, and his model did envision that it would be practiced as described. However, through decades of not seeing a clear path to application of all three domains equally, pain clinicians in particular have conceived and described newer approaches as an extension, not a replacement of the original BPSM.

In my personal professional experience, I conducted many workshops and teachings to GPs, musculoskeletal physiotherapist and medical students who also have considerable caseloads of chronic pain patients. During and following these lectures and discussions, as well as clinic supervisions, there was indeed a majority of musculoskeletal non specialist pain clinicians who did not see the role of the psychosocial or sociocultural as a domain of interest to them in their clinic work. Often the physiotherapists would tell me that they would 'lose' their clinical skills if they incorporated the biopsychosocial model. There was an open view that their patients had 'real' problems and pain, and that people with chronic pain did not have the same concerns.

Furthermore, for some pain clinicians using the BPSM, and as mentioned above with more musculoskeletal focused physiotherapy, there is no clear sense of how these disparate processes interact (De Haan 2021). BPSM was conceived by Engel (1977) as a response to the perpetuating Cartesian model (Descartes 1633/1972), which saw the body fundamentally as biomechanical and distinct from the mind. This thinking continues to inform most biomedical practice as the literature cited confirms. As I argue, drawing on the literature as well as my professional experience, despite the adoption of the BPSM, the biological view of pain (as pathology, something that need to be fixed) underlies much clinical reasoning in physiotherapy and biomedicine in relation to chronic pain today. In addition, people living with pain are challenged by the 'pain in the brain' explanations that many pain physiotherapists and musculoskeletal physiotherapists will discuss with them. Those with pain feel that there are structural 'damages' such as a 'slipped disc' or signs and natural aging that cause a one-to-one cause for their pain. GPs may continue to look for structural changes after more sinister reasons have been ruled out. Thus, in my research theory, approach, methods, and analyses, I felt it prudent to provide a broader, more integrative model to describe

chronic pain, based on the newer models of Coninx and Stilwell with the addition of an anthropological lens, as an emergent lived experience, and in terms of what I saw my participants build as an emergent resilience. To summarize, musculoskeletal physiotherapists often see flaws in the BPSM as they do not always appreciate the need to include psychosocial domains. The pain specialist physiotherapists see the need for a more integrated extension of the BPSM, because of its limitations of integration in application but also due to the lack of engagement with other non-specialist physiotherapists working with chronic pain, as well as the challenges the patients may have with taking the neurocentric explanations for pain on board.

By succinct historical synopsis leading to the embodied enactivist theories which Coninx and Stilwell apply within a sensorimotor interpretation rather than cognitive, understanding the body from a phenomenological perspective starts with philosopher Edmund Husserl (2012). This notion of the subjective body is further developed by Merleau-Ponty (1962), where the body is seen as an object and as a subject with the added abstruseness; however, that one can see one's body as an object. Thus, it is the subject who is perceiving and is/has the body. The body experiences, acts, and moves in an embodied way in the world, as both body-object and body-subject (Merleau-Ponty 1962). Our interaction with an object is then an inevitable part of our body's relationship with movement and the environment (Gallagher 2012). This construct was taken further in the publication (now revised in 2017), *The Embodied Mind: Cognitive Science and Human Experience*, where Francisco Varela and colleagues (1991) are credited with introducing enactivism as a theory of cognitive science that posits that cognition is a process that is created through and by the interaction between an organism and its environment, both biologically and socially. However, the enactivist/ecological model and the enactivist biopsychosocial model extend beyond this and move away from the original conception of enactivism with its cognitive focus, emphasizing the sensorimotor learning process through embodied concepts. The isolated brain alone is not the sole center of chronic pain, but the brain relies on the sensorimotor pathways, the peripheral

pathways, and other complex systems that process experiences that eventually emerge through this view of enactivism. The brain is part of this system for chronic pain. Pain is in the body (of which the brain is a part) and dynamically co-creates meaning through these relationships and the experience of the person with pain. Thus, this process of pain is emergent as the body moves in the world (Moseley and Thacker 2012).

What follows are the core principles of enactivism that inform this thesis, described in terms of how they relate to chronic pain, shifting focus from physiological and cognitive processes and toward an emphasis on the person living with pain and their interactions with their body and how they move, their understanding of why they have pain and their past experiences with it, social relationships, environment, and landscape (Thacker and Moseley 2012; Lehman, David, and Gruber 2017; Low 2017; Stilwell and Harman 2019; Bolton and Gillett 2019; De Haan 2020a; Aftab and Nielsen 2021; Buetow 2021; Coninx and Stilwell 2021; De Haan 2021; Maiese 2021; Cormack et al. 2023).

Pain as Embodied Experience: The theories of enactivism see perception as generative and dynamic processes, which is a solid framework for viewing and understanding chronic pain physiologically, but more importantly, as an embodied integrated approach that includes the body and the mind in such a way that applied and proactive treatment can be facilitated.

Embeddedness: Refers to people in pain becoming part of a support system and finding meaningful activities, where they become active participants, giving them confidence, agency, and resilience. This construct also includes finding coping strategies and therapies aligned with ACT or culturally embedded practices.

Extended mind: Pain as experience extends beyond the individual and their body; it includes communities, family, and the context of culture. For someone living with pain and disability, their landscape and environment become part of their experience, whether negotiating stairs, using a wheelchair for mobility, or a cane for balance.

Emergence through interaction: Chronic pain becomes something ‘more’ than a Cartesian in-processing – out-processing producer of the well-known Cartesian figure of the boy with his foot in a fire, the result of which is a straight pathway which goes to the brain which signals pain (Descartes 1633/1972). Pain representations go through the continuous feedback and interactions within the organism and the environment.

Enactment: Pain is perceived and lived differently once viewed through acceptance; there is a transformation. Perception and action are entangled; the organism creates cognitive/experiential worlds based on actions.

How enactivism translates into an applied approach:

Enactivism translates into an applied approach by encouraging active participation in pain management programs through an enacted BPSM - an integrated program that provides psychological, social, and physical support. By using integrated techniques to include ACT, mindfulness, and gentle movement activities to improve activities of daily living and help to change how pain is perceived, a holistic approach can be achieved (Cormack et al. 2023).

As suggested in this thesis, I go beyond the above statement. I will argue for a more culturally embedded approach to chronic pain as a lived experience, as evidenced by the anthropological methods, data, and analysis. This approach should include more transdisciplinary integration, including Indigenous healing or medicine, if applicable. Emphasis should not be placed on the biomedical, but rather, all aspects of the lives of the people for whom pain impacts their well-being.

In the physiotherapist literature, Gunn Kristin Oberg and colleagues (2015, 245) describe embodied cognition as “A theory or approach in cognitive science that emphasizes the role of embodiment (i.e., a wide range of bodily processes, including sensory-motor and affective processes) in cognition”. They continue with the definition of enaction: “A dynamic process (or coupling) between a cognitive organism/agent and its environment. The agent actively participates in the generation of meaning through

entering an active embodied engagement with the environment or process of interaction with other people” (245). In response to this, and in my opinion, with enactivism as utilized in the field of physiotherapy in the literature I cite thus far, the profession feels it is important to embrace the construct of embodiment as a central means of description and bridge to understand the manner in which bodies interact within their environments. This is not a new notion to physiotherapy, but many are trained (as I was in the 1980s) in the purely physiological/biological framework. However, they know of course that there is a person in front of them experiencing the pain, and again the BPSM available to them had gaps in the realm of causality. In searching for concepts such as embodiment to fill these gaps, the profession looked toward cognitive science as a progression but did not conceive of some of the misapplications and limitations when mapping onto chronic pain, as was discussed previously regarding cognitive representation.

In considering anthropologists writing about chronic pain patients, Jean Jackson (1994, 2011a 2011b, 1994), Byron Good, and Arthur Kleinman (M.-J. D. Good, Brodwin, and Good Byron 1994) first come to mind. However, their work is not directed to enactivist/ecological central tenets. Although the themes of embodiment are evident, these essential writings instead elegantly focus on people living with pain and their need to be legitimized, form identities and social roles, the cultural context of mental health, and the use of narrative medicine in mental health and patient experience.

As an example of the culturally embedded analysis regarding pain, in the edited volume *Embodiment, Enaction, and Culture: Investigating the constitution of the shared world*, Peter Henningsen and Heribet Sattel’s (2017) work is on chronic pain in the workplace. In this chapter, they discuss the cultural embeddedness of work practices and how individual responses and experiences differ. They describe a syndrome called *katakori*, which in Japanese translates as congealed or stiff shoulders and implies a lack of energy flow. *Kori* also relates to the ‘stiffness’ that old friends may feel following a falling out, a sort of awkwardness in which they will never resume their closeness. This syndrome is

seen in circumstances of social stress in a workplace where hierarchal organizational support is lacking.

This section briefly provided the foundations of the theories to assist the reader with the context to follow the ethnography and analysis in the body of the thesis. This description was deliberately kept brief as the application and its development will become more evident.

4. Methodology

“Nothing is stranger than this business of humans observing other humans in order to write about them.”

The Vulnerable Observer: Anthropology that breaks your heart (Ruth Behar 1996).

4.1 Pre-fieldwork planning

I am grateful to people too numerous to name and to events as my fieldwork in Nepal unfolded. Many experiences and circumstances were serendipitous and frankly fell in my lap. I left for the field in March 2019, taking a year sabbatical from my position as a lead senior pain physiotherapist in an east London NHS Trust pain service, and returned at the end of January 2020 to my full-time job that was hit full force two weeks later with the first lockdown of the Covid -19 pandemic. I worked in my usual role, often via Zoom, and as many did, I took on new and higher-level positions to meet the challenge of that time, restructuring the service and keeping waiting lists in check for the next two and half years until I retired. My doctoral research and fieldwork are self-funded except for a small grant from the Chartered Society of Physiotherapy UK to hire a research assistant/translator in Nepal. My UCL ethical approval gained clearance. What follows is a brief overview of the processes, reflections, and methods I undertook before and during my fieldwork.

In 2011, I spent several weeks in Nepal at a nunnery for my MSc in Medical Anthropology, living with the nuns and listening to their illness narratives about their

pain experiences. I wanted to continue along these lines but initially thought of research in Bhutan for my PhD. However, Nepal drew me back.

I made one trip there before my MSc, first in 2010, doing physiotherapy work with a Germany-based NGO with Buddhist monks and nuns, which provided an inroad to work at the nunnery in 2011. Following that, like many who visit Nepal, I yearned to return and eventually made it back for many subsequent trips for trekking, Buddhist teachings, and to visit my new nun friend, Dolma, whom I met during my Masters. Dolma and I had been discussing starting a UK-based charity to help aging nuns, but when I visited in February 2015, plans changed as her neighbors asked for her help with children from her village and to send them to school in Kathmandu. So, we hired a jeep for the long journey. Three months later, in May 2015, the earthquakes hit, and the children and Dolma found themselves homeless in Kathmandu. They slept outside under tarps for four months since there were sometimes hundreds of aftershocks daily. We organized the charity in time for them to receive some help and pay for rent in the house where they stayed once it was safe to return to sleeping inside. I recount these events as they laid much groundwork regarding fieldwork preparation, such as navigating the transport system, sourcing places to stay, exposure to the health care system, and other small nuances of day-to-day life, as well as meeting many wonderful Nepali people. In terms of considering a place to conduct research, Nepal was becoming increasingly practical. At this point, I had begun my PhD and contacted a Nepali pain specialist physiotherapist, Saurab Sharma, whom I followed on Twitter. I had planned a trip back in December 2015 to see how Dolma and the kids were getting on, and I set up a meeting with Saurab. In the meantime, he had put me in contact with the Department Head of the Hospital, where he was affiliated, to begin ethics clearances and research visa applications. This process was long and completed in Nepal, and I met with many learning experiences my Nepali colleagues confirmed as what they usually faced. Common with most applications, as they had warned me, were long response times. However, most studies seeking clearance were quantitative random control trials and since my research used a qualitative methodology, there were many delays since I had to clarify this in several different versions. Suffice it to say that it required several trips back to Kathmandu from

my field site. I was successful and gained clearance through The Nepal Research Council (NHRC) registration number is 297/2019. Ethics Boards for Kathmandu Medical School and Dhulikhel Hospital in addition to the UCL Ethics Board.

Fortunately, Nepali language classes were available at SOAS, so I managed two terms of basic Nepali in my first year. Again, as much as you plan, fieldwork can throw curve balls at every turn, and the language spoken in the village where I lived was Tamang, and the other non-mutually intelligible language was Hyolmo. Everyone did speak Nepali, and I attempted to practice as much as possible. However, people understandably spoke their ethnic language amongst themselves, so I did not progress to fluency, which I regret. I had plans to hire a translator regardless.

Before I departed for Nepal, I spent two weeks in London, going through a long list of supplies to bring. From my conversations with Saurab, I knew I would be going to a remote village in Sindhupalchok with a nonprofit/nongovernment satellite clinic/small hospital attached to the main hospital in Kathmandu. A homestay in the village was arranged. One of my primary concerns was my data collection and storage. I bought two laptops, one for myself and one for my research assistant. The issue of confidentiality and data protection was clear, and I followed the EU GDPR and UK Data Protection Act of 2018 in line with UCL guidelines. For voice recording interviews, I brought an SD card hand-held Dictaphone audio recorder with DSS file software and later switched to my phone for recording with MP3 despite using more data. However, I had seen from my previous visits to Nepal that electricity was unreliable and frequently went out, sometimes for hours, sometimes for days. For good measure, I lugged a small foldable solar panel in my backpack, which I found out the hard way, never worked. Numerous attempts were made to find a reliable power bank for my phone in Kathmandu, but they always broke within days, so I relied on a wall socket (few and far between) to recharge my phone, on which I depended on for photos and recordings. Other practicalities, such as access to cash, were a concern. This transaction was not so simple, as the closest cash machine to the villages was a six-hour walk away or, if brave enough, a bus ride of about three to four hours, with the route only passable outside of monsoon season.

For some context regarding timelines, several major life events have occurred since the start of the research, which delayed my fieldwork and post-fieldwork writing up.

4.2 Arrival in Nepal

Since I had made previous trips, I had a place to stay to set about in-country tasks. I planned to interview the research assistant/translator, meet the team from the nonprofit/nongovernment Kathmandu hospital, begin my ethical approvals, and arrange more language training.

Monsoon rains were on their way, and I was aware of the long trip to Sindhupalchok, but I still wanted to spend a month with more intensive Nepali language training. Through Dolma, I was welcomed to stay at a monastery in Pokhara for a month, and one of the lay teachers there agreed to instruct me.

Back in Kathmandu, a young cook I had met on a retreat was happy to accompany me to my field site. We planned to take the four-hour bus from Kathmandu up to Melamchi and hire a local porter and guide to walk the last leg of about six hours through the jungle and small villages with us. Here, I learned, too late then to impact this initial journey, to pay a guide *after* the trip and not before, as his wages were consumed by local alcohol along the way. I noticed we had been walking in circles at one point as the same flooded rice paddies appeared repeatedly. Ten hours later, we were lost in a cannabis field, and red-faced and exhausted, I laid down, the plants poking into my sweaty back, to elevate my swollen feet on a granite rock while the cook went off to convince local farmers to bring us some food from their home kitchen. The spicy noodles arrived in a plastic bag and energized us enough to push us through a few more hours of steep walking. We eventually stumbled into the Hyolmo village six hours late and were greeted by the smiling hospital staff.

For three days, I observed the clinic staff and their patient encounters. If I could meet some potential chronic pain patients, I would ask them to participate in my work, start with that base, and expand my contacts and networks as I went. After a busy three days

of observing and chatting through predominantly sub-acute cases, lots of lacerations from farming mishaps, dehydration, and probable food poisoning, I saw that the villagers would not be accessing this facility necessarily with complaints of chronic pain. Much more on this later. I did meet a delightful eighty-four-year-old woman with chronic back pain, whose story I tell in Chapter Four.

Nonetheless, according to the plan of spending time in the clinic for a few days to get my feet wet, I observed how the hospital workflow went, including who came for what and how far they had come, and other nuances of watching the comings and goings of any institution central to life in a village anywhere, as well as the work patterns and ethos of the staff. I decided again, according to plan, to see the first participant whom I had met at the clinic in her home, the reasons for which will be developed in the next section, and she agreed. Relying on the snowball effect of expanding my contacts, I completed my time at the clinic and returned only for social calls.

4.3 Why do a clinical ethnography?

The principal methodology framing my work was what is termed clinical ethnography. Calabrese (2013) defines this method as “Culturally and clinically-informed self-reflective immersion in local worlds of suffering, healing, and well-being to produce data that is of clinical as well as anthropological value” (17). Why was this approach chosen? Much of my private physiotherapy work had always been domiciliary or conducted in the patient's home. Chatting with a person living with pain in the confines of a clinic room, regardless of how cozy we make it with plants and soft, relaxing hues of blue, the chair they sit upon is not theirs. If I ask them to stand up and move about the room or extend their movement to the clinic hallway and stairs, it is an unfamiliar environment. We can assist people in negotiating stairs between floors in health facilities or venture out to the physiotherapy gym and request that they lay down on a mat to assess their functional movement transitions while chatting about how it challenged and made them feel. However, this process would not transfer to their own environment. There is little carry-over.

I brought many of my pain physiotherapy methods to each session, the foundation of which is facilitating movement, with overall intentions to help improve function and well-being. Unlike standard musculoskeletal physiotherapists, we employ psychologically informed dialogue to encourage purposeful and functional movement within their environment, and do not employ hands on techniques. For example, I ask, after assisting with the movement, how it felt to take the first few steps after being in bed for many months or years with a chronic illness, and then to explore that feeling more. In a session, there will be discussions about problems with sleep, and how that impacts pain, mood and overall function and offering practical evidenced based steps to facilitate change. The next section entitled Typical Sessions will detail more approaches.

While seeing them in their home, my starting point may be to have the person in pain lie down in their bed, mobilize themselves to get up and go to the living room or kitchen, or perhaps to the toilet, and climb the stairs if they are en route. This process is not a simulation but the real thing, albeit with me observing only, at least for the first visit. Therefore, I have always felt that seeing someone in their environment creates a more functional, integrated and interactive process of exploring and assisting them in negotiating their landscape.

Furthermore, family and carer relationships can be observed in a way that may aid in understanding the dynamics, which may help assist, and they can be invited into the process. Many people in pain may also feel anxious in a clinical setting and more comfortable at home. Traveling to a facility is often financially and physically prohibitive for many worldwide. Consequently, a central reason for my motivation to pursue a PhD in applied medical anthropology undertaking a clinical ethnography was to extend this process further and deeper.

Equally, I was interested in integrative and collaborative therapies. I often felt that I was somewhat imposing a process in presenting current biomedical biopsychosocial approaches to pain management treatment and thought it might be done differently in other parts of the world. In some regions where I worked, the biomedical approach may

have been different from the Bengali system, the dominant patient group with whom I worked in East London; for example, however, for many regions that had exposure to a Global North biomedical system, pain management, as delivered in a Global North pain service, was still not adequate and was challenging to take on board for most. Having worked with people in pain for decades, as with many clinicians, I wanted to know what could help. I was interested in integrating biopsychosocial and Indigenous medicine, and I was curious how this was practiced in rural Nepal and if there was a collaboration with both systems or overlaps in care provision (Read, Jilka, and Singh 2023). I felt I could provide valuable answers by conducting a clinical ethnography and immersing myself as a working clinician-researcher.

4.4 Typical sessions

Clinical ethnography is an iterative, emergent process. To illustrate this approach, the thesis is detailed with examples and narratives of sessions, and these instances bring the thesis arguments and analysis to the foreground. Here, I will relate a typical session to emphasize the ideas beyond the method.

Before arranging a first visit, my Tamang research assistant, Maila, and I would have either met the person in the community and got to chatting, or someone, usually a relative, would have suggested that we meet, or sometimes the person in pain would approach us to request a visit. It was a tiny village, and everyone seemed to know about me. Most people thought I was a doctor. The first visit always began with an informal but polite chat, and then I turned it naturally to why I was there and that I was not a doctor. Explaining what an anthropologist was did not seem practical, so I framed it usually as I was studying and came to Nepal to learn more about how people living with pain coped. I would come to their house or accompany them in the community and offer to chat about what things were working and were not so helpful. I explained that I was also a physiotherapist who specialized in working with people with long-term pain (I explained what that was), and perhaps I could offer some advice in line with their choices and goals. I explained that as a pain physiotherapist, I did hands-off therapy; in

other words, it mainly was psychologically informed chatting about challenges and observing and demonstrating activities or, in some cases, gentle stretches. Importantly, sessions also involved discussing what was happening in the body from a fundamental biomedical lens and finally discussing some value-based goals they would identify.



Figure 2. Researcher instructing participant in home exercise

The approach was always an iterative, flexible process that changed and emerged depending on the participants' motivations and abilities. I engaged Cheryl Mattingly's (1998) conception of therapeutic emplacement to encourage and understand their narratives. My intentions were then to assist in developing change as and if they wanted. The premise was self-management, not because I was not there for the long term, or as is often thought in the NHS that this approach is taken to 'save money,' it is more efficacious if it comes from the individual. The villagers were empowered when they were more actively involved rather than receiving passive treatment such as massage (Ashburn and Staats 1999). This dynamic will be discussed further in the thesis. A few people wanted only medication, to which I said I could not provide that, and they decided not to participate.

All the conversations were conducted in Tamang and translated to me in English or Nepali (for the Hyolmo speakers since Maila did not speak Hyolmo). They were also translated back to me in English. They were recorded, as mentioned before, and Maila

later transcribed both the English and the Tamang and Nepali conversations. We had a consent form in Nepali that Maila read aloud, which outlined the basic information about the study and stated that all was confidential and that we would use pseudonyms. It also allowed them to agree or not to be photographed, and it was explained that they would be used only for research publications or instruction. I sent these pictures to them on their phones so they could access them. I often took photos of the participants for them to refer to when doing gentle stretches. We took pictures of them walking, for example, so they could check back and gauge their progress with mobility. Lastly, the form said they could leave the study anytime.



Figure 3. Participant demonstrating home exercise taught the week before

I usually started the conversation with open-ended questions such as "Tell me about your pain from beginning to end." I borrowed this from Mattingly (2010), where she framed her initial question with her time spent with parents of young children with disabilities in an African American community, encouraging open and heartfelt interviews. I would never have done this in a biomedical clinic; I would have been there for hours. However, this was precisely the point of my research. For each participant, I also had a piece of paper with a loosely structured format with open-ended question prompts. I took many notes and began formulating ideas surrounding their circumstances and coping strategies. Usually, their answers were long and detailed; however, we did have to artificially pause for the translation, so I knew where to take the conversation. I often interspersed their answers with prompts such as "How did that

make you feel?" and other prompts to gain insight into their subjective experiences. Sometimes, on the first visit, I would ask them if they were comfortable getting up and moving around so that I could look at their function. More importantly, I would get a glimpse into how they approached movement. For example, was it with anxiety? Were they trying to push themselves to show me they were capable? We ended with me asking them how they thought I might be able to assist them in coping with their pain or doing things easier. It was always important to remind them that the main point was not to cure them or rid them of their pain but to make things more adaptable. Often, when things did become more manageable, they were not as aware of their pain, and its impact was not so significant, so in effect, it may lessen its control in their lives and provide them with more choices. All the above aligns with what I would have done on a home visit in the UK. However, many of the chats in Nepal opened to broader underlying issues such as relations with family and their obligations, concerns about children's marriage prospects, and other challenges particular to rural Nepal that may have contributed to the perpetuation of chronic pain. These particulars are what this thesis is about and what a clinical ethnography can bring.



Figure 4. In a session chatting with participant and Tamang translator.

We tried to make as many visits as was feasible, and the range was between six and fourteen visits, usually lasting at least two hours and sometimes longer. I started with field notes but stopped this practice once I began the visits, mainly relying on my notes during visits (a kind of field note), many photographs to jog my memory (especially of participant observation in community events), and the recorded conversations.

Sometimes, people would ask why I did not give lots of exercises with them written on sheets of paper, as they may have encountered it in a city hospital therapy department. I responded that exercise was tedious; most people did not do it, and I focused on breaking down their daily activities and homing in on those. In the villages, everyone walked everywhere, not only to the fields but also to shop and visit friends and family. So frequently, the physical activity was increased walking. I was not concerned with their posture or how they walked, only that they did. If a participant spent much time in bed, we discussed more accessible strategies to get up, breaking down the movement into manageable chunks. If they depended on family to get them out of bed or walk, the focus was to work toward independent activity since most families worked in the fields during the day.

What can be said to someone who may ask, "Where is the anthropology?" or "This approach is physiotherapy!" My response has usually been that, with respect, they may not be familiar *with* home-based physiotherapy to know when it is not. The immersive embedded role a clinical ethnographer finds themselves in differs, as is seen throughout this thesis, although it builds on the basic premise of using clinical skills when needed. Alternatively, as posed in Chapter Four, what if it is needed and declined? Moreover, who decides what 'needed' means in the clinic or in the field? The expressed intention is to facilitate acceptance of pain as an outcome of self-motivated change, hopefully, as resilience through coping strategies, as is this thesis's central focus. As clinical ethnographers, we are concerned with these outcomes, but on a much slower scale. This space to allow *and* observe this change and see why and how it may happen is the privilege of the clinical ethnographer.

4.5 Participant observation: Weddings, pilgrimages, rice planting, cremations, and everything in between.

Covering the primary methods above leads to other ways of learning how the villagers with pain and their families and communities lived. Participant observation is fundamental to anthropological ethnography, both a means of data collection and a research style and attitude. Musante (2015) describes this long-term commitment as where the ethnographer “takes part in the daily activities, rituals, interactions, and events of a group of people as one of the means of learning both the explicit and tacit aspects of their life routines and culture” (251). Pierre Bourdieu (1990) conceives of the term participant objectivation in response to the contradictory nature of participant observation, which holds the problem of the researcher as the object observed (they will analyze and write the ethnography, with a degree of reflexivity as discussed below) but also as the informed and knowledgeable subject. In this mode, they are never embedded or absorbed in the participant observation milieu. This significant rewording of the hallmark of anthropology’s research method presupposes that the knowledge held by the researcher is learned by sociological means.

The most pleasurable aspect of doing anthropological fieldwork is the opportunity to muck in with the activities; others may disagree, but I think the most enjoyable place to participate is in a farming community. As fun as it was to sling mud at each other during the rice planting, I entered this task with the underlying (maybe thinly disguised) intention of observing how the women worked. How did they pace themselves if in pain? How did they delegate the work between the age groups? Did the older women take breaks guilt-free? These issues form how people in pain work together and how people without pain show compassion toward others who cannot, to name a few significant observations.



Figure 5. Drama performance after a Tamang cremation

4.6 Reflexivity and positionality

Reflexivity for the ethnographer is an integral part of the analysis. Whitaker and Atkinson (2019) consider reflexivity as follows: “Central to reflexivity is an awareness that the researcher and the object of study exist in a mutual relationship with one another. Thus, reflexivity calls for attention to how thinking comes to be, how it is shaped by preexisting knowledge, and how research claims are made” (2019,2). It would

be misguided to think that activity is conceived only as 'self-reflection.:' it does not circle around personal identity as such. Bourdieu (1990) refers to an 'intellectual field'; inquiries may be formulated according to the ethnographer's background and area of study or intellectual orientation. In my research, this may refer to the intertwining of clinical science and anthropology.

In writing about Nepali villagers in pain, I was aware of the propensity to 'other' those as different (by definition separate) from myself. To do otherwise is a physical and existential impossibility, and the distance between 'self' and other' cannot be closed, but it can be connected. In her suggestion for writing ethnography, I took on board Abu-Lughod's (1991) term, 'ethnographies of the particular,' which worked well and came naturally with my focus on person-centered analysis and ethnography. By avoiding generalizations in writing that describe participants as stuck in time, instead writing can be expansive and dynamic. The 'differences' are never removed entirely but can be respected and appreciated. I tended to be viewed by research participants through my nationality, gender, and age, as was suggested by their comments and questions. My position as a researcher was not discussed as much as my role as a clinician. However, an exceptional curiosity did appear to be placed on my single status. This view showed me the importance of marriage and family to them. Being a Buddhist practitioner was not a significant topic; some people picked this up based on my knowledge of prayers. Often, as is the case, the positionality of the ethnographer may be identified and determined through the perspectives of the participants and their community. They determine your standing and place based on what is important to them (Halstead 2001). Nonetheless, as ethnographers, we continually question *ourselves* and our place. What are we doing there? (Cohen 1992). In her engaging collection of essays, *The Vulnerable Observer, Anthropology that Breaks your Heart*, Ruth Behar (1996) likens fieldwork to a voyage where you do not know your way and how you will get there. We wholeheartedly want to be part of the places we study, but it can be fearful at every turn," ...the rage of cowardice, the insight that is always arriving late, the defiant hindsight, a sense of the utter uselessness of writing anything and yet the burning desire to write something, are

the stopping places along the way. At the end of the voyage, if you are lucky, you catch a glimpse of a lighthouse, and you are grateful” (3).

As anthropologists, we attempt to represent our participants as they see themselves and have taken their time to tell us (or, more importantly, show us) as dynamic and complex. The ethnographer's role in writing that complexity may result in what James Clifford (1986) calls all ethnography: ‘true fiction.’ However, I agree that I can never fully represent another’s thoughts. Some ethnographies may have a specific purpose - to be emancipatory, for example, for people with disabilities. Alternatively, to inform public policy (Hammersley and Atkinson 2010).

Current studies within a decolonizing framework may involve various methods, such as participatory action research aimed to collaborate equally with participants who design the structure (Andrews 2021). The approach within clinical ethnography is very much engaged with the participants, as it would be in an enactivist biopsychosocial model of care and an enactivist/ecological approach, which would be driven by the participants and person-centered, as I aimed to accomplish.

5. Overview of Chapter Contents

Chapter 1 provides an overview of the field site in rural Nepal and then sets the scene within the context of specific challenges to my participants negotiating to live with chronic pain and finding strategies to cope. The challenges varied; however, as my conversations with people living in pain described to me, particular themes and idioms of resilience within these emerged that contributed significantly to their life experiences and entanglements in working toward acceptance and resilience in their lives, namely: 1) local marriage/social practices, 2) the harsh nature of subsistence farming due to the natural environment, 3) low income/high emigration, 4) the earthquakes in 2015, and 5) available health care. As a segue to these factors, the chapter recounts significant recent historical and political occurrences of the last several decades related to these developments and

the emergence of a resurgence of ethnic identity, which has empowered Nepalis politically to some degree.

Chapter 2 describes my personal account of Indigenous healing for a recalcitrant gastrointestinal illness in the field and how this provided a glimpse into understanding my participants' processes toward their awareness of their illness and pain, the fear and anxieties surrounding it, and healing and work to cope with living within the complexities of chronic pain. The ethnography recounts my illness narrative and the story of a middle-aged man I call Pasang, who undergoes a healing ritual for soul loss. I detail the ritual for Pasang with the *Bombo* (Tamang: shaman) as a living embodied presence who communicates with his deceased ancestor to seek guidance to confront the ghost who took Pasang's soul or life force (*hungsa* in Tamang) and the sociality and relations and his place in the village. Pasang's sense of vulnerability is explored, as he explained that he felt that he was weak and the ghost who came for his *hungsa* primarily due to his physical disability, chronic pain, and mental anguish, which prevented him from working in the fields. In a small agricultural community, this stigmatized both him and his family. Further in this chapter, I recount two pilgrimages I took with the *Bombos*, where I discuss experiences of fear and anxiety and link these to attempts to comprehend some similar circumstances with Pasang and my participants.

Chapter 3 continues from the previous chapter to explore emotions more explicitly and how the complexities of situated experiences around their sociality for three villagers, whom I call Asmita, Tenzin, and the third is Pasang (whom the reader will know from Chapter Two), can contribute to, and often perpetuate pain. The concern of one's social standing in the community is queried, and how the feelings of mistrust and vulnerability can impact pain. Both Asmita and Pasang explained that their pain was from supernatural causes and that they felt isolation and victimization, and a subsequent lack of self-efficacy required to cope. Tenzin, whose disability and pain also prevented social engagement in the community due to challenges with mobility, felt a profound sense of hopelessness and purpose. There was a fundamental doubt in the biomedical staff's decision-making for all three. My treatment involvement with Tenzin and Pasang (Asmita was not a patient per se) consisted of working and reworking improvements in strength and mobility through

functional activities and exercise to increase walking skills and other activities of daily living. Integrated into this was a psychologically informed conversation to increase awareness of thoughts surrounding pain and its control in their lives. This chapter explores how the three people navigate this extension of pain into their social worlds and how they seek to shift their underlying challenging emotional states to find meaning in their lives. The processes of change were subtle but tangible. Pasang and Asmita benefitted from the *Bombo's* rituals, increasing their feelings of safety and acceptance in themselves and the community. Tenzin's hopelessness turned to feelings of accomplishment and self-acceptance.

[Chapter 4](#) tells the stories of two villagers who have coped relatively well, Bharat and Tashi. Following the first three chapters, where the focus centered on adversity and internal states of emotions as a bidirectional process within the community, this chapter develops aspects and circumstances that can lead to acceptance of living with chronic pain. By following individualistic and contextual coping strategies, which the villagers were ready to initiate, they moved to a place of resilience. This was not a final state of acceptance and resilience but one that was constantly negotiated and renegotiated within changes that were inevitably presented. When first meeting Bharat and Tashi, they had already developed many resilience attributes; this chapter will explore those components and how the villagers brought them into their everyday lives to cope. The title 'Looking Outside' refers to Bharat and Tashi's style of looking *beyond* their immediate internal emotional states, which may have hindered the participants mentioned above. This chapter examines how two people have developed some core skills that they could then extend to the community. From an enactivist/ecological perspective, these dynamics emerged from integrating the many layers of challenges and opportunities afforded to Tashi and Bharat to bring contentment despite living with chronic pain. Within this approach, their perceptions of their pain, and hence their resilience was deeply connected and integrated with their environment. Treatment sessions had a basis in the foundational exercises to stretch and strengthen, emphasizing having the participants look at how movement 'made them feel' in terms of empowering toward improved resilience and function.

Chapter 5 describes one man's experiences, called Ram, who is living with pain and paraplegia following a traumatic accident. Following the previous chapter, wherein attributes of resiliency have been explored, this chapter further advances this theme by emphasizing the difficulties and frustrations of trying to 'make things better.' Through the focus on Ram's feelings of anger and isolation, his family involvement and availability regarding his multiple care needs as a person using a wheelchair and non-ambulatory, and the frustrations of attempting to access healthcare and the embeddedness of motivations to help (or not), this chapter illustrates how the choices available to people with disabilities are often limited. Our conversations and treatment sessions are described in detail as we work together to improve his personal activities of daily living skills. Contingent to the practical tasks, the chapter discusses Ram's feelings of hopelessness and lack of self-worth. An underlying theme is my positionality as a clinical ethnographer regarding assisting a person living with pain, as demonstrated in this exigent case, which brings to light some of the ethical issues in this study.

Chapter 6 tells the story of a young woman living in a Buddhist community who has converted to Christianity and continues to build on how the participants explored various ways of finding support and acceptance in themselves and within themselves in the social structures surrounding them. Janeesha developed paraplegia from spinal cord inflammation several years before, and in addition to her being unable to walk and mobilize, she experienced pervasive pain. Her church community and her close family, who were also converts, were a place of unconditional acceptance and support. This chapter illustrates Janeesha's journey through coming to terms with her conditions and understanding their symptoms. I detail our conversations regarding her prognosis from a biomedical perspective and work with her to develop value-based goals. The chapter's theme is the question of what forms acceptance and resiliency can take and who is in the position to decide. Questions posed include: Is acceptance legitimate if one does not make the changes toward resilience independently but, as in Janeesha's case, relies on others to tell them they have been accepted? That is, can acceptance of own's pain be a form of passive rather than active coping?

Chapter 7 brings the thesis to a close and examines the pivotal role and place of the local Indigenous healers, the *Bombos*. The central theme in this chapter is trust, trust in the healers primarily. However, confidence issues around the biomedical staff are added for comparison as several conversations surrounding their relationships with the participants are explored. Again, we revisit Pasang and his journey. Here, our work together is described, and we follow his healing rituals when he is prepared to take on some of his difficulties with improving his mood, as seen in previous chapters. As with most participants, the focus of treatment was improved mobility to regain social contacts, a sense of purpose and community, and an understanding of their relationship with their pain and its acceptance. Complex issues concerning continued obstacles for him are discussed, involving his self-care and family dynamics as a means of much-needed emotional support. Trust in the *Bombos* is analyzed as a component of efficacious healing toward acceptance of pain and, thus, resilience. The *Bombos* had to earn the villagers' trust, a perpetual state of earning and re-earning, always in fluctuation. The multilayered world of the healers is explained as a constant negotiation between three places of the realm of existence of the ancestors, the spirits, and the world of the living, including the social aspects of maintaining a sterling reputation in which to provide their work.

Chapter 1 The Villages: Lives of work in the foothills

“A wise mother’s daughter rises with the chickens; a cowardly mother’s daughter keeps on sleeping until the sun is high.” Tamang song, The Chicken Song from *If Each Comes Halfway: Meeting Tamang women in Nepal*. Kathryn S. Marsh (2002)

1. Introduction

This chapter will contextualize my field site’s background in rural Nepal through ethnographic data. I aim to ‘set the scene’ and branch out to develop the concerns and obstacles surrounding the people living with pain in the villages where I worked and how these factors may or may not have come to develop their coping skills and resilience as they face living with chronic pain within their environment. Subsequent chapters will expand on these themes as they weave through village life and relate them to ‘idioms of resilience,’ particular to the person and context. Many situations may have preceded my participant’s challenges of chronic pain. However, to attempt to cover all, for instance, the impact of childhood experiences growing up in a household in which alcohol misuse was common, is outside the purview of this chapter (Maté 2022). By contextualizing Nepal’s recent history and social arrangements, including 1) local marriage/social practices, 2) the challenging nature of subsistence farming due to the natural environment, 3) low income/high emigration, 4) the earthquakes in 2015, and 5) available health care, I will discuss the possible links, as my participants explained to me.

The social structures and past events were and continue to be difficult for many Nepalis. Long-term exposure to stressors, both psychological and physical, such as these factors discussed often can contribute to pain and chronic illness. Living with the pain may then become cyclical as the distress from pain compounds the difficulties (Hassett and Clauw 2011). Lacking agency and experiencing oppression, perceived or not, people cope in diverse ways. The villagers with whom I worked lived within ways of navigating and coping with their struggles with pain. Though not always direct contributing factors, life situations and opportunities or lack thereof, as well as issues of validation and legitimization of the pain experience, can predispose one to illness and pain or, indeed, perpetuate it, impacting chronicity (Honkasalo 2001; Skuladottir and Halldorsdottir 2008).

Drawing on theories of hybrid enactivist/ecological theory with chronic pain as described by Sabrina Coninx and Peter Stilwell (2021; 2023), first discussed in the Introduction to the thesis, I see that the experience of chronic pain is perceived and lived, and perpetuated in multifaceted ways. Chronic pain is not, as once understood and treated, only a sensory or emotional experience. This approach further develops and expands the longstanding biopsychosocial model within biomedical pain management (Coninx and Stilwell 2021; Stilwell and Harman 2019). This framework does not rely on the biological or physiological mechanisms of pain; it places people living with pain, as with all, in an embodied interaction with the environment (social and physical) grounded in their perceptions and their experiences, past and present, and also future predictions (expectations). This framework maps well with anthropology and biological science, as explained elegantly by Guilio Ongaro and Ted J. Kaptchuk (2019)⁸. In the anthropology literature, Elisabeth Hsu's (2008) term medical landscapes also bridges the gap between the social and the biological explanations of chronic pain. "The notion of medical landscapes implies social processes, relatedness, and movements between foregrounds and backgrounds, and across boundaries" (320). In these 'places,' the five factors I describe in this chapter 'live.' I feel that coping and resiliency can occur within and as part of this medical landscape. Therefore, there is no one reason or theory for longstanding pain. These theories become necessary in understanding the treatment and perhaps how some of these interactions may be accepted or changed by the person living with pain. Some influences may be more obvious, such as several of my participants who sustained life-threatening injuries during the earthquakes. However, circumstances can be more complex and subtle, for instance, the pervasive loneliness felt by those in my study whose children have emigrated to Dubai only to return every few years for brief holidays.

The concept of resilience and idioms of resilience, as developed by Kim and Mendenhall (2019; 2021) and others, will be developed and demonstrated throughout the thesis by

⁸ Guilio Ongaro is the first anthropologist I came across in my reading to address these topics which are more widely discussed in cognitive science and pain neuroscience, which is beyond the scope of this thesis. My approach will look more closely at the social and relational aspects.

looking through a framework of the emerging themes of the villagers' coping strategies and their mechanisms of overcoming hardships within the medical landscape. I saw that the means of coping led to facets and stages of resilience, and by further building on these strategies, this learned fortitude and level of acceptance of the hardship and stress, in turn, led to a further level of coping. This process is often described as post-traumatic growth in the psychology literature (Tedeschi and Calhoun 2004). The psychological and cognitive processes of coping and becoming resilient will not be addressed as much as the social and relational spaces and landscapes surrounding the villagers. The overarching themes drawn relate to the stressors described here as experienced by the villagers.

For the sake of brevity in this first chapter, these noteworthy events, such as The People's War of the 1990s, will be succinctly recounted when discussing the historical context of Nepal; however, with the knowledge that this, as any country-wide civil armed conflict, was a significant event. The concerns of low incomes resulting in extensive emigration, the physical strains of farming, the 2015 earthquakes, and social changes such as marriage practices will be revisited throughout the thesis as these occurrences and social structures are central to life in the village and here, they are introduced to provide an understanding of their profound significance. These dynamics contribute to strain and stress and were a daily topic of conversation in my research. For example, today, young people often elope to escape an arranged marriage. The stigma and shame this may cause often lead to new stressors and new instances of lack of agency for the couple and their family. Despite a change in practice and context, attitudes remain unchanged, and the result is the same. By contextualizing these experiences, I lay the foundation for the thesis' central questions: how did the people living with chronic pain cope? What had made them resilient (or not) in the first place? How did they develop that resiliency?

Lastly, this chapter briefly describes Nepal's healthcare system and the region where the research was done will be introduced. Access to biomedical care early in my participant's struggles with injury, pain, or stroke was and is essential. For people with chronic pain in the villages where I worked, following perhaps an initial episode of care or visits to a medical clinic, long-term care was usually sought through the local shamans or *Bombos*. Navigating care in order to seek a diagnosis, either from a biomedical clinic or from the

Bombos, brought considerable anxiety. This uncertainty is seen with all types of chronic pain and is not region-specific, and I found this journey to access answers and help not to be different from Nepal and the UK or the US. Due to the nature of chronic pain, in that there is often no biomarker or imaging tests that can demonstrate a source or cause, the person in pain will live with uncertainty and worry that can result in chronic states of anxiety and depression. These mental health concerns often demonstrate a bidirectional relationship with the pain exacerbated by low mood, fear, and anxiety (Garnæs et al. 2022).

This state of unknowing impacts the family and all aspects of the person in pain's life. A study conducted across multiple centers demonstrated that anxiety, fatigue, and insomnia scores on standardized testing were significantly higher, interestingly more so than depression scores, with people with chronic musculoskeletal pain (Zarean et al. 2021). There can be thoughts of dread, the feeling that the constant pain must be a signal of a sinister or life-threatening illness. Why else would the pain not dissipate? Accepting that a previous injury has healed (if there indeed was one) and that the pain has persisted is usually met with skepticism, understandably. The person in pain feels that if they experience this level of discomfort, *something* that can be removed or cured must be there. Trust in the health care worker or healer is a central issue in this journey and will be covered later in the thesis in more detail. Here, access to care is introduced to frame some of these complexities and how navigating help is often precarious and stressful.

Reviewing methodology, explained more thoroughly in the thesis Introduction, I conducted a clinical ethnography as a medical anthropologist doctoral researcher and a chronic pain specialist physiotherapist. I developed/utilized notions of therapeutic emplotment, as described by Cheryl Mattingly (1998), in the field to learn my participants' stories. This method was layered within an iterative process to build on treatment. This process did not replace their stories but helped to make (interpret) the narratives meaningful to them. My intentions were then to assist in developing change as they wanted. This treatment started as an integrative embodied cognitive approach based on the person living with pain's local and subjective epistemologies. The villagers' goals were to change/improve practical and functional activities, such as walking and working in the

fields. Their emotions, primarily fear, appeared to be the lens through which they navigated their change. The relationship with fear and the multifaceted nature of other emotions and how this impacted their perception of pain and their relationship with pain will be discussed in more detail in the subsequent chapters.

However, to situate the landscape of the complexities mentioned earlier and the vicissitudes in my participants' lives and family members, I will begin with a concise history of modern Nepal, as there have been sweeping changes since the 1990s.

2. A brief overview of the country of Nepal

In recounting some points about Nepal's past, I aim to highlight the instability that the country has faced.

The high-altitude Himalaya Range forms Nepal's northern border with the Tibet Autonomous Region of China. This geography is noteworthy, as northern Nepal and Tibet inhabitants share long-held traditions and ancestry, including the dominant religion, Buddhism. The two ethnic groups with which I worked, the Tamang and the Hyolmo, speak languages from the Tibeto-Burman family; however, they are not mutually intelligible. These two groups also speak Nepali, the official national language (from the Indo-Aryan language family), between each other. The northernmost region of Nepal is also populated by various groups who speak languages in the Tibeto-Burman family and share some similarities. Tamang and Hyolmo share similar healing, social, and religious practices, and I had the privilege of attending a marriage between a Tamang and Hyolmo couple. Nonetheless, from my interviews, the 'reputation' and stereotypes of the Tamang differed from the Hyolmo in the eyes of the wider Nepali public and will be developed through ethnography.

The country's southeast is low-lying and tropical, bordering on the Indian state of Bihar. The Indian state of Sikkim forms the eastern border and geographically resembles the hills of the country's central region. Uttar Pradesh, a state of India, lies southwest. The geopolitical and cultural relationships between Nepal and India are meaningful but unrelated to my research.

The modern political history of the country of Nepal is complex⁹. Relevant events will be recounted which relate to the field site and the lives of the villagers. I will summarize significant political changes since the 1990s to provide further context. These events affected the country dramatically, seeing the transition from a monarchy to a democratic republic. One development that impacted the locals in the region was the new recognition of their ethnic identities, giving them a voice. This significant sequence of outcomes ultimately led to a new constitution for Nepal promulgated in 2015. Some people I worked with in the village were directly involved in the armed conflict that preceded these transitions. However, the predominant influence I saw was the lack of trust held for the government and political leaders, again perhaps holding a view that they lack agency in affecting change. Nevertheless, there was an active group of local political involvement and leadership.

Regarding recent history in Nepal, I thought it most helpful to chat with a Tamang friend, Binod, who grew up in the village where I lived. He had had the opportunity to study to be a lawyer in India. Binod had come back to Nepal and had his law practice in Kathmandu. He has a keen interest in local and national politics and feels a genuine commitment to his country's development, so I felt he was an excellent person to chat with about the past and, more importantly, current relevant challenges facing the region in a changing world. I was interested in learning from his perspective about the current political climate and its impact on the village. To provide some background, Binod briefly outlined events of the last few decades that saw the end of a monarchy and the establishment of a democratic republic. He told me that until the 1990s, the area known as Nepal had been under autocratic rule or a system of monarchies. He explained, however, that as more people traveled overseas to study and became exposed to other regions, the notions of democracy began to develop. "When they have a system where people will be elected, then people make the laws for themselves; it means people will have rights on particular issues," he said. He told me that political parties were formed and that many people were

⁹ See *History of Nepal* (Whelpton 2005) and *Nepal* (Adhikari and Lawoti 2024) for further reading for this section.

drawn to the Communist party because they had previously felt exploited and discriminated against, especially as ethnic minorities such as the Tamang and the Hyolmo living in a majority Hindu country (Whelpton 2005; Adhikari and Lawoti 2024).

In summation, in the late 1940s, the Nepali Congress Party (social democrats) overthrew the Rana dynasty's autocratic regime, resulting in a parliamentary democracy in 1951. Nevertheless, King Mahendra (who ruled from 1955 to 1972) ended this system in 1960, and the Panchayat system began (1960-1990), effectively giving sole power to the king. The People's Movement influenced King Birendra (who ruled from 1972 to 2001) in 1990 to set up a multi-party democracy. In 1996, led by the Maoists, there was an armed conflict until 2006 to remove the royal parliamentary rule. This civil conflict resulted in 16,000 dead. King Birendra and his brother, the crown prince, were killed in a massacre in the royal palace in 2001, and King Gyanendra took the throne in 2001. The monarchy again suspended the parliamentary democracy in 2005. In 2006, the Maoist Party joined mainstream politics with a democratic revolution and established a secular republic. 2008 saw Nepal declare a federal republic. In 2015, the constitution was promulgated after years of deliberation, with Nepal becoming a secular federal parliamentary republic (Whelpton 2005; Adhikari and Lawoti 2024). I recount these events mainly to situate the lives of the villagers and paint a picture of decades of uncertainty, including the precarity of resources, including financial resources and access to education and health care. As previously mentioned, I felt that the political past impacted the lack of trust in government institutions across the generations. Living with insecurity overall can contribute to increased stressors and directly and indirectly affect health (Marmot and Wilkinson 2011).

3. Ethnic identity with the Tamang & Hyolmo - marriage, morality, and religion

The two ethnic groups with whom I worked, the Tamang and the Hyolmo, are marginalized and subaltern in their own country. This section will highlight some areas where those Tamang and Hyolmo people living with pain may have been placed and lived within intersectionalities and added challenges of ethnic identity and rapid changes in family structures and dynamics, rendering it all the more difficult to cope.

This research was conducted over eleven months in Sindhupalchok, a district northeast of Kathmandu, the capital city. The field site spanned over three remote farming villages; however, I spent most of my time in the Tamang village where I lived, which was scattered between rice paddies and jagged boulders. One of the other villages was also inhabited predominately by Tamang people and was reached by crossing a riverbank on foot over a rickety steel bridge. The third was thirty minutes on foot and sat at the base of a hill, which shot up at a near vertical incline to nearly one thousand feet and was populated mainly by the Hyolmo ethnic group. There are many similarities between the Tamang and Hyolmo; both originated centuries before in Tibet, and Tibetan Buddhism is practiced in the Nyingma tradition alongside Bon shamanism, having various levels of influence (D. H. Holmberg 1996). In Nepal, over one hundred different ethnic groups speak a similar number of different languages (Adhikari and Lawoti 2024).

The region of my field site was in the Melamchi Valley and was approximately eight hours by bus from the capital, mostly over unpaved, narrow roads through vertiginous drops comprising the foothills of the Himalayas. The precarious bus road had recently been built, and prior to this new construction, the area was reachable only on foot. My choice of means of travel to Kathmandu was typically to walk for two days, followed by a four to six-hour bus ride, especially during monsoon when the bus would frequently get stuck or blocked due to landslides. The locals often traveled by the same means, but many young people had access to motorbikes and bumped down the rocky unpaved roads carrying friends and family. Much of northern Nepal is dominated by the steep and scarped foothills, and the landscape makes many sections of the region difficult to farm, if not impossible. Facing the challenging terrain is the only way Nepalis know. Nonetheless, with age and disability, even the most experienced find walking and traveling taxing.

The three small villages where I worked had a population of 2,786 in 1991 (Government of Nepal National Statistics Office). More recent stats were not available. It was estimated that 46% were 'educated,' although to what level was not stated. Nepal's Buddhist population is considered to be 8.21% as of 2021.

The colorful origin story of the Tamang in Nepal centers on a monk in Tibet in the year 911 AD who fled Buddhist persecution perpetrated by a king called Gyalbo Lungdar. The monk disguised himself in lay clothing, painted his white horse black, shot the king with a bow and arrow, and fled south. As he crossed a river, the black washed off the horse to reveal his white coat. More horse riders followed and settled in Nepal. They were called Tamang; the *ta* refers to a horse in the Tamang language. Although more than likely a legend, this tale lives on and continues to have a place in ethnic identity (March 2002).

In the 1990s, an ethnic resurgence movement began across Nepal, which was termed The Janajati Movement. The Tamang people are the fifth largest ethnic group in Nepal, numbering more than 1.6 million or 5.62 percent of the population as compiled in 2021 (Government of Nepal National Statistics Office). The statistics for the Hyolmo group were not available. Both groups continue to be denied rights and are discriminated against in the job market ¹⁰. There are various groups of Tamang, namely Western, Central, and Eastern, who speak varied dialects; therefore, there may not be a solid singular notion of what it means to be Tamang (Kukuczka 2011). However, it appeared that my participants felt a sense of belonging.

The literature on ethnic identity is beyond the scope of this chapter, but it is included to introduce the place the Tamang hold in Nepali society as marginalized people. This social inequity situates many families and individuals outside the usual, albeit scarce, opportunities and prospects within the country. As this pertains to this thesis, social determinants of health are well-researched and documented and impact comorbidities such as hypertension and obesity with resultant increases in arthritis and cardiovascular disease (Marmot and Wilkinson 2011). Post-COVID-19 pandemic research through the Brookings Institute reported a significant 3.5 times death rate amongst African Americans compared to the white US population based on Centers of Disease Control (CDC) data. These statistics were mainly attributed to many social inequalities, including access to

¹⁰ For further reading on minorities in Nepal refer to (Gellner, Pfaff-Czarnecka, and Whelpton 1997) and (Toffin 2009), for the Tamang in particular, (Kukuczka 2011) and (Samuels 2018).

health care and limited job opportunities resulting in employment in the service sector, which prevented social distancing. A higher incidence of stress-related comorbidities such as hypertension was also described, which increased infection rates (Graham, Chun, Grinstein-Weiss, and Roll 2020). This chapter presents some of the many social concerns facing people who are denied choices that impact health directly and indirectly. This marginalization pertains to the Tamang and the Hyolmo.

Binod talked openly about how the Tamang people were often ostracized. To him and the Tamang people in the village, I sensed mixed feelings surrounding their identity. The new constitution explicitly stated that all ethnicities should be treated fairly (Government of Nepal). However, this was not the experience of many. “We will not be chosen for government jobs,” Binod related. There were grassroots political forums in the villages, and although I did not visit them in person, I saw they were well attended. Other people who were Hindus from Kathmandu told me that the Tamang people were known for drinking a lot, being loud in their speech, being emotional, and gambling. These stereotypes reinforced the Tamang’s marginalized place.

The villages were essentially small hamlets with houses at the periphery of their rice and millet fields. A dirt road ran through all three, lined by various shops. Where I lived, this ‘Main Street’ was approximately seventy-five feet long, had a tailor shop where one could be measured standing by the road, a furniture shop selling premade wardrobes, a café which also sold replacement mobile phone parts and animal feed, another sold expired crackers and potato chips from India as well as internet data cards, and at the end was a family run restaurant with beer and packaged ramen noodle combinations which were cooked up upon request. There was not much in the way of fresh vegetables. During the day, these establishments were usually empty of customers since everyone was in the fields. Sometimes, there was no shopkeeper until a teenage daughter came home from school. Apart from the shopkeepers, the minority lower caste Hindus, the majority of the others received no wage earnings and relied on subsistence farming and remittance sent home from family working abroad.

Robert Desjarlais (2016) comments on the extreme changes over the recent decades seen in the Hyolmo communities in Helambu, similar to my field site across the Melamchi Valley. One of my Hyolmo participants pointed to Helambu and said, “That is where we are from.” Like many rural farming communities, young people have emigrated, and portions of the remaining families have moved to Kathmandu. Davide Torri (2016) sees changes through the influence of Buddhist principles of nonviolence impacting *Bombos* traditions of animal sacrifice as placing Hyolmo shamanic practices outside of their regional culture. I disagree with blood sacrifice; however, this is an example of changes that have been seen, probably for the better. As an aside, I did witness animal sacrifices during shamanic rituals at my field site despite the practice being made illegal, as I was told; however, its practice is pervasive throughout the country. Change can create uncertainty and a sense of loss; the central point is that this disruption and rupture with the past can diminish a sense of security, especially for older villagers. Difficulty coping with change and not showing the flexibility to accept it can be linked to perpetuating pervasive or chronic pain (McCracken and Morley 2014). Fighting against change may be a way of coping, although it may be clinging to modes of thinking that could be morally objectionable to some.¹¹

3.1 Marriage

The village Tamang community centers around their social and family dynamics, focusing on marriage first (Fricke 1988). Binod talked at length about marriage in the communities. He is Tamang, but I did see similarities with the Hyolmo people. While there, I attended several weddings and an engagement party where a Hyolmo woman was to marry a Tamang man. It was a big topic of conversation. From my perspective, I saw that the villagers approached unions as reasonable, practical, and functional. My interest lay in how

¹¹ For further anthropological reading on the Hyolmo communities, including ethnic identity movements, see (Clarke 1980b; Desjarlais 1989; Bishop 1998; Desjarlais 1992; Desjarlais 2016; Gawne 2016; Sato 2016; Torri 2019).

marriage established, expanded, and solidified social relations, and it circled back to who cares for people who live long (long-lifers) and family members with disabilities.

Additionally, changing roles through marriage can elevate a person's sense of purpose and role in a family or, as often is the case, take it away, leaving the woman to feel a loss of agency and social support, and I witnessed this with my participants (Franqueiro et al. 2023). In my clinical work in East London with the NHS, we saw that in traditional Bengali households, when aging women lost their roles in caring for the family due to changes in family structures, they felt increases in low mood and experiences of pain. Other questions: Who would bring in the money needed to care for them? Does one's agency in the negotiated sphere of arranged marriage contribute to stressors that can impact chronic pain? Are changes in marriage practices providing families with less stress and illness?

As marriage was a common topic, I asked about it many times. For any young person with whom I had contact, there was always a liminal stage related to pressure from parents to marry the person of their choosing and worries and dilemmas if they dared marry their current love interest by 'eloping.' In the past, people married young; most of my research participants married as young teenagers, some as young as age twelve. This practice was now illegal, and it states in the new constitution that the legal age for men and women to marry is twenty (Government of Nepal). The education system encouraged young people to 'wait' until they were at least twenty-five to marry. I was aware of this as I attended a young people's symposium during my first week in the village. I was asked to speak in an impromptu way about the benefits of finishing school and marrying later. Eloping meant running away to another village or town and getting married (a 'love marriage'). The couple would usually return to live with the husband's family. I was told about a neighbor, a young man in his twenties who had "brought home" a fifteen-year-old woman. "If he brings her to his house to stay, the family has to accept her as his wife," Binod described. I knew that this had happened in the past, but I was surprised that a family would accept a young bride nowadays. In this case, the couple had a previous love relationship. Often, I would sit on the front porch watching the clouds gather over the mountains across the river while eating breakfast and see the young wife swing her school bag over her shoulders as she left her husband's family house to walk to her 10th-grade class. Once a Tamang or Hyolmo

couple lived together, they were considered married, although there was typically a traditional ceremony within that first year.



Figure 6. Tamang couple at their wedding ceremony

Before the Hyolmo woman and Tamang man's wedding, as mentioned previously, I was invited to their engagement party since I lived with his extended family. Liters of home-distilled *rakshi* (Nepali millet distilled alcohol) were prepared, and the young male friends of the groom carried them on their backs to the soon-to-be bride's family home as we women negotiated the slippery path, pulling up our skirts to avoid tripping. In my naivete, I thought there would be food, music, and dancing. Instead, the women sat in one room, and the men from both families entered another. I was invited into the men's room, and someone roughly translated the conversation to me: they were negotiating the inheritance and where the couple would live. The husband-to-be sat quietly; the bride was called in and sat away from him, not looking in his direction.

On the wedding ceremony day, a pick-up truck usually used for hauling rocks stopped outside my house. Neighbors came running out, and we piled into the open back and

bumped our way up to the bride's house. Here, the ceremony began with the groom pulling out money to 'buy' the bride from her father at the entrance to the house. The mock haggling continued amidst the laughter and jeers. Several moments later, the father returned with his daughter on his back, a long red cloth covering her body and head. She cried as she clung to her father. Slowly, she was pulled away to join the groom in the procession. It was my impression that this was a performance. However, a 'bride price' was discussed at the engagement ceremony, as described above: "What came with the bride." This union was a "love marriage"; they had chosen each other; however, my thoughts were concerned with what choices they may have in the future. The negotiators included the father of the bride and his brothers, and since the groom's father had been killed in the earthquake, his older brother spoke for him. The 'agreement' was that the couple would live with the older brother, his wife, and two children. The older brother's wife, Asmita (who owned the separate house where I stayed), was not consulted, but she told me that she had welcomed someone to help with the chores since she was in the late stages of pregnancy. She was also responsible for arranging and cooking for the wedding. Asmita was one of my participants who described her back and associated radiating leg pain as coming from a ghost sent by the village witch ¹². This event coincided with the wedding preparations and family marriage consultations, as she was very anxious about the changes imposed in the household. In future conversations with Asmita, she described animosity and eventually moved her family out after I left my field site when that house became available. The stressors of the need to comply with a convention beyond one's control, again despite the newer modern 'love marriages', were visible in my research.

Once married, the Tamang and Hyolmo I met had a child soon after. The pressure was on the wife to have boys, Binod explained. In the past, a man would take a second wife or more for several reasons, often because he formed a new relationship, but sometimes because the first wife did not 'give him sons.' I ask, what is the relation between this pressure and psychosomatic illness and pain since it is beyond a woman's control what gender her children will be? I knew a young woman whose mother had seven girls, and her

¹² Asmita's story is described in more detail in Chapter Three.

father then brought home a new wife. There was hope that the second wife would have a boy. The new wife had several more girls before she gave birth to a boy. In the case of this family, the father was a *Bombo* and hoped to have a boy to carry on the tradition. The inherited role of the shaman is discussed in more detail in later chapters.

Binod said the first wife had to accept the second wife in the Tamang community. I was curious if the two wives got along, and he told me that often they did, but they usually did insist on having their personal kitchen. The kitchens were separate from the main house with a corrugated metal covering and may or may not have thin makeshift walls. The woman's reputation once married did not appear to be of consequence; she was not looked down on if she was the first or second wife. In the past, if a man had an affair and it was made public, he had to marry the woman to preserve his reputation. However, today, if a man does marry a second wife, their reputation is negatively impacted. Binod told me that polygamy does not happen often and was made illegal in 2018.

Binod explained that the data from before 2015 showed Nepali men had two and often three wives. However, this has been prevalent in villages with my research participants since they married decades ago. With society still being male dominated, often a woman will not leave as she has no means of support. If the woman does leave, they will only separate, not divorce, and remarriage for the woman is rare. She is usually given some land from her husband and his family, and the children often live with her.

I asked what things the family looks for when they arrange a marriage,

First is financial security, the second is the property owned by the boy's family, and the third is the boy's background. They want to see their daughter listen to her husband since he will make the decisions. The boy will have social prestige; the boy will have social pressure, which means he is bound to respect the community.
(Binod)

Traditionally, the male inherits the land, and the daughter stays with her husband's family. Binod told me that he had family members who had no sons and who had a large gambling debt (he said as an aside that Tamang men were known for gambling). To pay off his debt, he sold the land, knowing that the land may go to his brother's family and not stay in his.

He added that a woman might inherit the land more recently, or it was broken up between the children. Binod said Nepal was traditionally “a patriarchy,” the father always made significant decisions regarding jobs, studying money, and inheritance. Binod then described a horrific situation that mainly occurred between 1985 to 2000. He recounted how family members, usually the uncles, would be convinced by brokers to send their young school-aged nieces to Kathmandu to work because they could send money back. These were often young girls. Sending girls to school was considered “meaningless,” and many were not educated past year two or three in the past, if at all (this has changed now; however, many do not attend more than year 10). The broker would then traffic them into prostitution in India. The statistics showed that about 50,000 young girls were trafficked, Binod said. He explained that it was the village’s primary source of income during that time. Migration in recent times and its impact on family dynamics will be discussed in another section of this chapter.

Since 2018, having more than one wife has been illegal, so few do. In earlier times, his reputation was good if a man had more than one wife, but it also depended on the second wife’s family’s reputation. Nowadays, if a man has a second wife, it is not looked on favorably; Binod said,

Now they get divorced. There is a high divorce rate among couples who work overseas. Now men and women have equal responsibility legally for divorce- some women working overseas do not have anyone to support them, so they will leave their Nepali husbands to be supported overseas. (Binod)

The complex social dynamics are briefly introduced here to illustrate how complex it can be to delineate care responsibilities for those with disabilities and chronic pain, as well as the lack of a voice many women have within arranged marriages, but also paradoxically within a ‘love marriage.’ Binod recounted instances in the village where there were conflicts among family members related to who would serve the husband his meals when he was in pain, the first wife or the second. Where and how can they gain agency?

3.2 The role of women's morality

Women's roles as carers, wives, and mothers were central to judging their morality in the village. In the past, it appeared through my interviews, and I also saw in the present day that women did not seem to mind a second wife; however, was this the result of fear of speaking up? Binod explained that the first wife did not leave in the past, as she would not have any means of support. I also did not see any instances of remarrying. Again, this circles back to morality and being respected in the community ¹³. It must also be remembered that these decisions, particularly those of the women, were discussed and agreed upon among the men in the family regarding the woman's welfare. The significant point here is that lacking agency and choice for some can lead to increased anxiety aligned with chronic pain and psychosomatic illness.

The custom of 'kidnapping a wife' was another practice, and I heard of a few instances where a man would abduct a woman against her will and bring her to his family's home, knowing that both families had to accept this once she was 'brought home.' This practice took away a woman's choice in the extreme, but conversely, it was also used as a method where the couple regained some of the power lost when the family engineered the marriage. In this instance, the man may stage a fake abduction to take the woman he had a previous sincere relationship with away from her arranged marriage. If he was in an arranged marriage, he may abduct his true love and bring her back to live with the first wife.

Henrike Donner (2016) looks at similar frameworks around modern marriage practices in Kolkata. It is unrelated in some ways, as the context is middle-class families in the article and does not involve the extremes of abduction. However, many of the dynamics align. Here, the notions of individual choice are not a central driving theme; as in my field site in Nepal, young people continue to make 'choices' that are entangled with implications related to the extended family. They attempt to break away from their family and lead

¹³ Refer to Chapter Seven, "My Reputation Means Everything", for an ethnographic example of a Bombo who negotiates his reputation through his daughter's conduct.

their own lives. Leading to the next section in this chapter regarding emigration, parents are anxious about this independence and may not develop the resilience to adjust to their adult children abroad, always hoping they will return. This 'abandonment' may create an eventual loneliness and hopelessness, which could perpetuate chronic pain. Conversely, on a more positive note, some people living with pain may develop new forms of resilience, knowing they must take responsibility for their health and lifestyle. These notions are expanded more in the subsequent chapters and lead to the next section on emigration.



Figure 7. Typical Tamang kitchen

This section has drawn together the multifaceted, and entangled layers of social relations in the villages which may predispose and perpetuate a person's experience with chronic pain. Underlying the pressures of living as a stigmatized ethnic group, the strains of the traditional arranged marriage, and the thinly disguised ways out through elopement and

even consensual abduction remain the unstoppable rapid changes in village life. Of interest throughout this thesis is how the villagers cope with these challenges. Some positioned themselves at a crossroads of needing to change themselves to adapt and accept; for others, the expectations were that the commensurate change needed to come from outside.

4. Emigration

In my research area, lack of available income was a pervasive source of anxiety, driving many aspects of the villager's experiences with pain. Due to inadequate opportunities for young people, many emigrated and sent remittances home. Their absence added a needed supplement to income; however, they left previously held caregiving roles vacant, thus creating an added strain on some of my research participants' coping abilities. The older adults had expected their children to always be there to care for them, and the disruption was a common theme in my conversations with my participants.

The population of Nepal in 2022 was 30 million, with a GDP per capita of \$ 1,293, ranking Nepal 167th in the world out of 190 countries (International Monetary Fund 2023).

"My father wants me to go to Dubai and work as a waiter," Gopal told me as we sat in his Aunt's kitchen in front of the open fire. "My older brother says I have to finish school before I go work abroad," a neighbor girl of thirteen pitched in. I heard these stories about plans to leave and work abroad, usually in Dubai, from nearly every young person in the village. What surprised me was that it was not their choice alone regarding where they would go and when.

Emigration was not the individual's decision, much like the marriage arrangements discussed previously – it was the whole family's and led by the father. The mother was not involved in the cases I saw in Tamang and Hyolmo families. I understood that the added income was a central incentive; however, the family's social status was also raised considerably with a son or daughter working abroad. The elevated social standing also brought 'better' marriage prospects.

I saw the quiet suffering of my participants while their children lived abroad. Especially with the women who had no say in this but resigned themselves to the situation, feeling it was inevitable. They worried about who would care for them and who would farm their land. They worried about their children's welfare, the harsh working conditions, and the poor treatment they frequently endured. Some families 'sent' one adult child abroad (they were often sent as children in the past; see Chapter Six for a recounting of one of my participants who went to India to work as a cleaner when a preteen) while another remained at home to help with elder care or care for the family member in pain. In October, during the religious festival of Dashain ¹⁴, the buses sputtered through the villages, speakers blaring popular Nepali songs, bringing family members home who had returned from foreign jobs to visit for the month. It became apparent how many young adults had left when they returned.

¹⁴ Binod explained Dashain as a Hindu festival although many others celebrate, including the Tamang. It commemorates the win of 'good' over 'evil' by the goddess Parvati who defeated the demon Mahishasura.



Figure 8. Swing (ping in Tamang) erected for festival of Dashain.

I chatted with Binod about the significant numbers of young people emigrating from the villages:

We do not have trafficking now, but it is taking a new form, like a domestic worker in a foreign country; previously, we had a structure of trafficking of girls from Nepal to India, but recently, the dimension is wholly changed now, they do not talk about going to India for work, they are just convinced to go to Dubai. They do not talk about your skills, they do not ask, they just show the dreams. (Binod)

He continued adding more specifics about daily working life in Dubai:

Previously, they were sold to the brothel house, but recently, they go to Dubai or other countries, but they are not paid for a long time. They are paid little, and they

are not allowed to use the mobile even though they have to work more than twelve hours. They do not get any holidays. They cannot raise their voice if they get raped by their male or their owners (Binod's words). They cannot even tell, and even if they have to send money to Nepal, they have to take support from other relatives who take more commission to send money to Nepal. There is no certainty of getting money to Nepal even though they have to stay and cannot even come here as they want. If they went to Dubai for two years, it is not sure that they will return in two years. (Binod)

According to the World Bank, foreign remittance is reported to account for about 26.9% of the GDP (World Bank 2023). In my time there, it did seem that more of the younger men, aged eighteen and through their twenties, were most likely to emigrate. I learned that Karma, Nima's father (introduced in the next section), was twenty-five and had been to Dubai to work, probably in a manual labor role. I was told the family would typically pool money for the trip. This sum involved travel and fees toward an agency that secured work and a work visa. The work visa was tied to that one job, and if the job ceased, the visa expired, and the worker would return. Salaries were higher than in Nepal. There was little paid work in the village and environs, and a day laborer, for example, assisting with harvest or house building, would earn about 1000-1800 NPR per day (£7-£12). I was unclear how much a laborer made in Dubai, but a hotel worker I spoke to made 30,000 NPR a month with one day off a week. This amount may be equivalent; however, steady work was available in Dubai and not in the village or Kathmandu.

Binod was well-placed to talk about emigration and disputed family issues surrounding it as he manages these cases in his law practice. He also told me about emigration's impact on his family. As with any family, the dynamics are altered back home when one leaves to work abroad or for various other reasons. He recounted how, in the past and with his family, children left to work and never finished their education. Additionally, when an older sibling left to work, the younger ones had to labor in the fields or care for other siblings in their place. On both sides, children often did not study past year 2 or 3 as they were then old enough to help the family. Those children are now adults and have limited options in Nepal, so they may go overseas now to work in low-paid, unskilled roles. More than likely that children now finishing school through secondary will have more options; however,

Binod explained that those girls with secondary educations are sent overseas to work as cleaners to send remittances back.

How does this upheaval in family structure influence those living with chronic pain? Those villagers with pain or psychosomatic illness may have been the young girl who was sent to work in a brothel or as a domestic, as was the case with many of my female participants. A history of childhood adversity or trauma predisposing to chronic pain has been demonstrated (Dalechek et al. 2024). They may be the parent whose young child left decades ago or an adult child who can now not gain skilled employment due to limited education and qualifications. I saw that all of these scenarios played out with my research. With more than one of my participants, the caring duties (traditionally a female role) were left to the husband, who may also have a disability. Emigration results in significant changes and ruptures and creates a cycle of challenges despite bringing in much-needed cash. For a person living with pain, these intersections become more poignant.

5. Realities of day-to-day challenges as shaped by the landscape

Nima is two years old with a round face and a button nose. She has her father Karma's big eyes and is often seen in his arms. Being two, Nima carries herself in a confident, broad-based toddler's stance. She lives with her extended family next door to me. I first glimpsed her standing outside while her grandmother bathed her, hearing shrieks and cries as I sat in the sun to comb my hair. There is no indoor plumbing in the area, so water for bathing is collected by women, usually carrying big brass vases known as *gagri* (Nepali) strapped to their backs with a cord, a *namlo* (Nepali) which then crosses their foreheads taking on much of the weight. Day-to-day life is physically demanding in the village. A small black polyethylene pipe snakes down from a groundwater source several kilometers away from atop a hill, another five hundred meters or so higher, bringing the water down to the village. This community water source received no waste-water treatment or purification and served as drinking water. The water was collected at three to four public areas scattered deep through the rice paddies. A fifteen-minute walk down a more slippery slope courses the local river, a water source sometimes used for washing clothes. I preferred to bathe here, but the villagers were often wary of the river spirits (Sanskrit: *nagas* or

Tamang: *lu*), so they avoided it, especially in the late afternoon when they usually appeared.

Walking out through the rice paddies, a path levels off for about five meters as I approach the first terrace. The tall grass thins to an overgrown clearing partially covered by loose bundles of dark green heavily leafed branches. I quickly see for whom they were intended. I bend down, place my hands on my thighs to support my shaky legs, and see three smiling faces: two white kids and their mother goat standing under a corrugated metal roof. All three have identical small half smiles, sleepy eyes, and long, floppy ears. After a few seconds of amazement at my intrusion, they let out loud bleats of different pitches in protest. Inside the low shelter were more bundles of the leafy fodder. The clinic nurse, Yangchen, accompanied me, telling me that most households kept goats for slaughter for meat consumption. They remained tethered under the small, wobbly shelters, which were three-sided and open in the front. Families often walked up the steep hills to 'cut grass' for their goats.

Throughout the coming days, I would notice the *hanasiya* (Nepali for small grass-cutting sickle) secured into the plain white cotton waist wrap, called a *patuka* (Nepali) which was sometimes two meters long when stretched out, at least for the women. This wrap was worn by men and women during the day and was wrapped tightly, serving as a convenient corset to ease a sore back. It was also handy for tucking in other items, such as lighters and strong cigarettes, which the Tamang frequently smoked. The *namlo* head strap secured the load around the large conical basket termed a *doko* (Nepali). The basket was often so big that it seemed that only a massive bundle of cut vegetation was walking down the tracks. I asked Yangchen why the goats were not free to roam and forage, as that seemed a much more manageable, practical alternative to the exhausting work. She says that in the recent past, leopards roamed, which would snatch goats, so the habit probably remained. She makes a fleeting reference to the worry that other people may also do the snatching. I was not surprised that the local Buddhist communities, both Tamang and, to a lesser degree, the Hyolmo, were not vegetarian, but I was surprised that the goats were not milked for dairy. I asked someone later and was told, "That is for their babies."

With this short walk up a hillside, I witnessed a cycle of duty of care for a family of goats. It made sense that the labor involved would be intensive. What impressed me the most was how a grazing animal was kept tethered, and the fodder was brought to them. As Yangchen described, this was done in the past for fear of theft or natural predators. I wondered how social conventions of care for livestock, which have been done in this manner for centuries most likely, could be perpetuated when these practices directly or indirectly lead to chronic pain. There was available grazing land; each village had a common land area.

The next terrace led to a broad set of worn stone steps. I am somewhat relieved to have some stability underfoot, and standing there in the brilliant sun, I look down and then up at the never-ending vertical structure. A sudden dizziness overcomes me from the humidity and the thought that my days would be spent negotiating this steepness if I ever wanted to get anywhere. Now, however, we turn to the right and head upwards. My *kurta* cotton top sticks to me in the heat, and I billow it to bring in some cool air. Scurrying up the steps were groups of school children rushing to make the start of the day at 10 am. I am pleased to catch my breath when Yangchen stops to chat with one or two young women whose parents she had known for years. She explains the school's class structure and that these children were mostly coming up to year ten end-of-year exams and would gain what was equivalent to a high school diploma. Many children would not go on to what was termed 'plus 2' or 'college' despite the facility in a nearby village. I was pleased that these young women were attending school but equally concerned for the aging parents working in the fields, knowing that these students would be sent overseas to work in the coming years. There were no easy answers.



Figure 9. Steep hill paths

The above vignettes help to illustrate how challenging and physically demanding living in this region can be on a day-to-day basis. In this section, I look at the landscape as the physical geography, the people and wildlife, that is, what can ‘be seen.’ Throughout this thesis, however, there is mention of other realms where spirits inhabit, which are part of what villagers include in their landscape: the ‘unseen,’ which Davide Torri terms ‘the animated landscape’ of the Himalayas (Torri 2015; 2021). The villagers were subsistence farmers, and few had jobs that paid wages. The terrain was rocky and precipitous, and farmers would walk up and down the hills with the livestock forage on their backs until they could no longer physically endure. The plowing was done with oxen, a yoke, and a plow, which had been unchanged for centuries if not thousands of years. Although some of my research participants had suffered accidents, most developed chronic pain related

to this challenging work. In many settings, people would leave the hard manual labor to the more non-disabled family members; however, with the low income from farming and lack of local opportunities, most had to carry on. As described in the following chapters, the inaccessible terrain prevented most of my study participants from leading the lives they wished for due to mobility concerns, as they struggled to negotiate the uneven paths laid with mismatched and sharp rocks and stones. A good deal of my time spent with them was providing solution-focused and problem-solving strategies to begin to walk, albeit sometimes just short distances. Many of my research participants would stay in bed or remain in one spot in the house and avoid moving, thus increasing their pain due to fear of falling or tripping, and rightly so.



Figure 10. Plowing the rice paddies before planting

Many people endure physical hardship and severe injury but do not develop chronic pain. If one returns to the integrated framework, pain is neither a singular event nor a singular cause-and-effect sensorial output in the body resulting from painful physical stimuli. As will be described in length through the thesis, chronic pain can be part of a system developed from and contributing to unhelpful coping with hardship and adversity. A question I aim to approach is what contributed to making some of my participants more flexible in their thinking about their challenges and, therefore, more resilient. Through this section detailing the arduous farming life and challenging landscape, the complex nuance of hardships and the limited options available, whether from a practical stance or societal pressures, becomes more apparent. The following section introduces the catastrophic events of the earthquakes of 2015, which shook the already precarious lives of the villagers living with pain.

6. Earthquakes of 2015

Images from Nepal dominated the international news on 25th April (and then again on 12th May 2015), airing the devastation of the 7.8 Richter scale earthquake. Scenes in Kathmandu showed buildings leaning at precarious angles atop piles of rubble while local citizens frantically dug with their hands, following the cries of children buried. Main roads through Kathmandu erupted from the ground up, leaving wide crevices and cars crumpled. Not seen were the remote villages, like my field site, where 85% of the structures lay in heaps of rock. Coming to terms with the aftermath of this devastation was not foremost on the villagers' minds several years afterward. However, the impact on their lives and those changes towards resilience were everywhere, spoken, or unspoken.

When I arrived at my field site in May 2019, it was nearly four years to the day since the first earthquake. There was little mentioned about that time unless I directly asked. I

traveled to Nepal six weeks before the first earthquake and again in December 2016. In 2016, much of the rebuilding in and around Kathmandu was still underway. I had never been to Sindhupalchok on the six trips to Nepal before my fieldwork, so I had no comparison. I had seen the photo above of the Hyolmo village a year before I arrived, so I knew that the entire village had slid down the hill except for the *stupa* (Buddhist shrine) as displayed in the image. There was one house, however, which was spared, and I learned this when I visited my participant, Tashi, a Hyolmo woman in her eighties ¹⁵. She told me that her daughter was working in Kuwait, and because of this, she could send money back to build a solidly constructed concrete house, much more earthquake-resistant than the traditional local houses made of stone with heavy rooves.

Interestingly, her house was substantial and built well and withstood the quakes, which was not that different from her fortitude in living with pain, as I came to learn as I worked with her. Paday et al. describe the role of social support within the communities for search and rescue and other emergency tasks immediately following the earthquakes before the international aid arrived. However, it was salient that once the relief did arrive, it did not extend to the less accessible marginalized groups (2021).

¹⁵ Tashi's story is expanded in Chapter 4.



Figure 11. Local Hyolmo Buddhist temple after earthquakes

The factors in this chapter that predispose to and maintain chronic pain in the villages are interrelated, all are part of a system, resonating with the Coninx/Stilwell model of pain as shaped by multiple interacting levels. Nevertheless, the earthquakes did have a profound and probably a more immediate effect on the villages. All three withstood severe damage. Most fortunately, the earthquakes came during the day when most people were in the fields. The destruction caused an increase in emigration, as well as the changes mentioned previously. Foreign aid was outpouring, but as many villagers told me, the government only allocated funds for rebuilding under strict earthquake resistance guidelines, understandably. However, the stipends were woefully short to finish the rebuilds, necessitating young people working abroad ¹⁶. Though not a central framework of the

¹⁶ For a thorough and in-depth analysis of the impact of the 2015 earthquakes from a multi-disciplinary and multi-faceted framework, edited by anthropologists, Refer to

analysis of this project, one cannot avoid the notion of impermanence, that is, everything is changeable, and how those perpetual ruptures, 'good' and 'bad,' weaved through the lives of the villagers more strongly felt in the aftermath of the 2015 earthquakes.



Figure 12. Houses rebuilt after the earthquakes had blue roofs, temple in the background

Impermanence is a central Buddhist tenet, and with my participants, it was difficult to gauge its application to their daily lives as a philosophy of understanding and acceptance of perpetual change. No one spoke of it directly, as was the case with monastics I met. In the anthropology literature, editors Haidy Geismar, Ton Otto, and Cameron David Warner (2022), in the volume *Impermanence*, have collected ethnographies of lives in flux and understandings of its impact. Geismar writes in the Introduction, "In short, impermanence

Epicentre to Aftermath: Rebuilding and remembering in the wake of Nepal's earthquakes (Hutt, Liechty, and Lotter 2021). Also the website ("Sway - After the Earth's Violent") <https://sway.soscbaha.org/> accesses a major project undertaken between School of African and Oriental Studies (SOAS) South Asia Institute and various other stakeholders including Social Science Baha, Kathmandu.

opens up a range of timely questions and discussions that speak to our shared experience of transformation – local and global, cultural and natural” (2022, 2).

The theme of this thesis is resilience. As mentioned, I was not in the villages post-earthquake, and with what I witnessed four years later, I feel I need to give credit where it is due. I can only show immense respect for the extreme bravery and capacity to endure the hardship the villagers called upon during the rebuilding phase.

7. Health care in the villages

John sat cross-legged in a plastic chair with a glass of cold water, obviously enjoying the respite from the hot sun outside. He had a rumpled cloth hat that provided little protection to his already sun-damaged skin and a long-sleeved cotton shirt and cotton trousers. I had just woken up to my first morning in Nepal by shouts from the children in the house, “English, English!” I went bleary-eyed into the family’s living room and saw a fair-skinned man seated there. “Hello, I am John, and I used to work at the clinic here.” He went on to detail for over an hour his forty-year-plus career, when which began in the Boudhanath neighborhood of Kathmandu as a nurse for a charity to his current, retired life living full-time in Nepal. As a new graduate nurse, he left England and drove overland to Nepal following ‘The Hippie Trail’ as many young adventurers did in the late 1960s. He had returned to the UK for years but spent most of his career in Nepal. John seemed to know everyone and about everyone spanning decades. My head reeled with the richness of the details. I explained to him that I was a doctoral student researching chronic pain and affiliated with the clinic. John was an excellent resource. He began to tell me about the basics of Nepal’s healthcare system, the clinic’s history of local healthcare provision, and some changes over the years regarding the villages. We agreed to meet the next day, and he would take me around.

As structured with the preceding sections of this chapter, I introduce the last variable of the structure and accessibility of the health care system that has affected change directly or indirectly, bearing on the lives of those living with long-term pain. Covered first was the overview of the historical and political changes. This move towards democracy led to a

large degree of uncertainty; however, it also created a nationwide movement towards a renewed sense of ethnic identity, empowering the Tamang and Hyolmo people. Their identity is entwined in the current challenge of negotiating traditional marriage practices and social relations. As the traditions changed, the young people sought opportunities far away, leaving caregiving responsibilities at home. Further building on these vicissitudes is the background of the unforgiving landscape of the Himalayan foothills. What follows are stories, recollections, and descriptions of the people living with pain and their relationships with and around the biomedical and traditional health care available to them.

In the late 1960s, there were some considerably basic healthcare facilities, and charities ran others. John explained that he was part of the development team for a birth control clinic in the Boudhanath neighborhood of Kathmandu when he first arrived.¹⁷ His work as a family practice nurse brought him to my field site region, where he was based in one government clinic but traveled to even smaller, less equipped facilities across the river near the village where I lived. He recounted that when he was in his twenties, some fifty years ago, he would travel down and traverse the river using ropes. He added, very amused with himself, that he crossed carrying his dog on the ropes to gain access to the villages set in the equally jagged hills across the valley.

Today, many small government basic health units continue to provide care. In the Tamang village where I lived, there was one government clinic about twenty minutes away by foot, on the gravel and rock bus road. It was usually empty of patients.¹⁸ As detailed previously, these facilities, usually staffed by a nurse and health assistant, generally treat acute and subacute conditions. The people with chronic musculoskeletal pain, like my participants, tended to see the *Bombos* or not seek biomedical care after their initial visits to the local fee-paying nonprofit/nongovernment hospital (supported by international grants) or

¹⁷ charitable organizations continue to contribute a significant proportion to Nepal's health care, further reading on the history of health care system ("Health System in Nepal | Nepal's Health System Structure" 2023)
<https://publichealthupdate.com/healthsystem/>

¹⁸ Refer to Chapter Six for a detailed account of one of my participant's experiences with the local government clinic.

government clinic or to larger facilities in Kathmandu to seek diagnoses. One of my participants, Tashi, would occasionally visit the fee-paying nonprofit/nongovernment hospital in the Hyolmo village where she lived when her back pain was severe during a flare-up. This facility provided me with my research visa, and I spent my first three days observing their patient visits. It was staffed with a young doctor and five ancillary staff. They were equipped with X-ray and ultrasound machines and a newly expanded maternity unit.

Regarding the provision of physiotherapists, most of them were employed in the Kathmandu hospitals, but a new graduate physiotherapist began work at the village fee-paying nonprofit/nongovernment hospital several months before I left. I was unclear about access to care in Kathmandu. A nun friend told me she had to pay when visiting a government hospital there.

Nepal has seen drastic improvements in overall health care, most significantly in infant mortality and infectious disease. Nevertheless, as in many lower-middle-income countries (LMIC) like Nepal, there has been a rise in noncommunicable diseases (NCD), such as heart disease and diabetes Type 2, due to lifestyle changes. Sagar Chawla et al. (2016) state that there are approximately 2.35 million people in Nepal with chronic musculoskeletal disorders, and went on to qualify that non-availability of care together with a lack of trust in the care that was available, in addition to low financial resources accounted for most significant challenges.

For the few chronic pain patients who did visit the clinic during their episodic short-lived flare-ups, I was not surprised that the staff approached their care within the biomedical model. Treating with paracetamol and restricting lifting or movement (though not so much ordering of imaging) was done and is also generally seen in the Global North. The biopsychosocial model still tends to be the remit of mostly pain specialist physiotherapists in comparison to musculoskeletal physiotherapists who may work with people with acute or subacute conditions. As mentioned previously, some pain specialists are taking more of an enactivist/ecological approach in addition to considering the bi-directionality of mental health with chronic pain. (Mansfield et al. 2023) (Vaz et al. 2023).

7.1 Traditional notions of pain and healing

Witches were living among them, the villagers told me. Some were poison givers. Asmita talked about witches in the village: “*Bigar* (Nepali: poison) is like something given by the witch (*Boksi* in Nepali). *Bigar* will be the food they give you. And also, in coconuts.”

Other witches sent ghosts who could inflict pain. For some, the ghosts came on their own. When I asked the villagers how they knew who or what brought their pain, they always told me they had to go to the *Bombos* to find out.

My participants did not all receive visits from witches or ghosts who were the harbingers of their illness or pain. Two had visited the *Bombos* and were told that their long-term back pain was from lifting the heavy loads and was called *chaalaak* (Nepali word for something tearing apart). My participant Tashi’s back pain was described to her this way by the *Bombos*, and she received many sessions of ‘blowing’ (*ngaba* ritual in Nepali) with them but without any relief. Tashi logically thought that her pain did not result from *chaalaak*, and she sought the care of the small local nonprofit/nongovernment hospital where a probable stress fracture was seen on X-ray, essentially the same as the reasoning behind the *Bombo*’s approach ¹⁹.

This section introduces various experiences with health care that may relate to underlying or entangled sources of chronic pain, and these villagers’ experiences will be elaborated on throughout the thesis. The descriptions of the local milieu of care are necessary. Essential to the villagers’ journey was who told them about the reasons for their condition, what it was, and how it was explained. The literature in biomedicine and physiotherapy on this topic is extensive and is the focus of the Australian pain specialist physiotherapists and neuroscientists Lorimer Moseley and David Butler’s (2013) book for the patient called *Explain Pain*. Sharma et al. (2019) describe chronic pain research in Nepal, and their

¹⁹ There are many sources on Nepali traditional healing through the *Bombos*. The anthropology literature includes the following authors, Desjarlais, Holmberg, Peters, Tautscher, and Torri .

systematic scoping review of the literature showed an overwhelming biomedical approach to diagnosis and treatment. If a person with pain is told their back is ‘crumbling,’ ‘degenerating,’ or has their X-ray or MRI explained in terms of pathology when they display typical signs of aging, this understandably leads to fear. Some people with pain at my field site were given other explanations by the *Bombos* about fearful forms that cannot be seen. Any fear can lead to avoidance of movement, avoidance of other people, and avoidance of full participation in life.

8. Conclusion

This chapter’s sections introduce some of the many influences, stressors, and changes relevant to initiating and sustaining long-term pain for my research participants. Acute or subacute pain may diminish when the injury heals. In these cases, the long-term suffering impacted most aspects of their lives and continued to be experienced. Additionally, rapid changes in the villagers’ lives were unsettling and, taken together, significantly affected their overall well-being. Often, these transformations became normalized, for instance, a father knowing that his sons would leave to work overseas. However, are they aware of the consequences of these events on their families and their communities, and as a central concern in this research, on their health and development and perpetuation of chronic pain? No one I have encountered wants to be in pain or feels that they should be in pain. In *Moral Laboratories: Family peril and the struggle for the good life*, Mattingly (2014) describes ‘the good life’ as something related to these expectations; we want what is best for our family’s well-being. How does the individual, within the connectedness of the Nepali family, navigate the structural inequalities and challenges of living in pain?

For a variety of complex reasons, some of the people I encountered became resilient despite their hardships, but others did not. I am interested in how this occurs. What follows in the thesis are stories of what happened to my participants, how they met these challenges and others, and how they coped.

Chapter 2 “Try feeding the ghost more”: Illness Experience and Understanding the Unseen in a Tamang Village, Nepal²⁰.

1. Introduction

The July monsoon rains had come and gone, leaving a soft humidity in the air as I crossed the swaying steel footbridge with Maila, my Tamang Nepali doctoral research assistant²¹. We often enjoyed stopping midway to view the river below. That day, it was swift and coursed over the large boulders, covering most of what had been visible just days before. We traversed slowly, holding onto the fraying metal threaded railing, and stepped into a clearing where more large rocks lay. I pointed and said, “*aram dungha*” (my Nepali term for “rest rocks”), signaling it was time for a break before we pushed up the steep riverbank through the thick forest.

Maila found a dry spot, took out a pack of biscuits, broke off a piece, and quietly said “*shoota*” (Tamang expression of offering to the ghost) as she scattered the crumbs. She noticed my expression and explained, “My grandfather, the *Bombo* [Tamang: shaman], would always do this to feed the ghosts.”²² This was the first I had heard directly about the ghosts (Tamang: *Mung*) in the region. She continued to describe the practice. “He always said it if he ate outside, but not inside the house. *Bombos* also say it when they eat at other people’s homes. We can do it too. There are ghosts that are near the rivers, and

²⁰ An earlier version of this chapter was originally published by the author as Bronson, Paula. 2023. “Try Feeding the Ghost More”: Illness Experience and Understanding the Unseen in a Tamang Village, Nepal" In *Other Worlds, Other Bodies: Embodied Epistemologies and Ethnographies of Healing* edited by Emily Pierini, Alberto Groisman and Diana Espirito Santo, 115-132. New York, Oxford: Berghahn Books. <https://doi.org/10.1515/9781800738478-008>

²¹ See *Himalayan Mountain Cults: Sailung, Kalingchok, Gosainkund territorial rituals and Tamang histories* (Tautscher 2007) for a brief history of the Tamang people and description of their pilgrimages discussed in this chapter.

²² Refer to Angela Sumegi’s (2008) work which describes the blending of *Bombo* and Buddhist practices as a third place.

they like to come out at dusk and through the night. They are the spirits of the dead. Most people will not come down here in the evenings.”

This chapter is an ethnographic description detailing personal experiences of healing practices with the local Tamang *Bombo* for a recalcitrant common gastrointestinal illness²³. The aims are to demonstrate how my insights developed and informed my understanding of my own healing, as well as others in the community, through the shared spaces of Tamang spirit realms and the everyday. This epistemological embodiment (how these sensory/bodily experiences impacted ways of knowing and how this knowledge was produced) created by mutable perspectives and direct experience opened boundaries that may have been otherwise closed or inaccessible during my fieldwork. Ethnographic data discussed in this chapter informed my emerging understanding of how my participants may feel when ill and how they negotiate seeking and receiving help from the Indigenous healers. Moving toward building resilience for the villagers living in pain began with their awareness of their illness and their embodied experiences with healing. This quote from Desjarlais regarding his work with the Hyolmo in Nepal resonated with me and is a theme of this chapter, “I felt that my body developed a partial, experiential understanding of their world, from the ways in which they held their bodies to how they felt, hurt, and healed” (1992, 13).

I recount an experience of one of my participants, a man living with chronic pain. Through our in-depth conversations, I learned that he felt that the pain caused him to be vulnerable to haunting by a ghost²⁴. I detail his journey as he initially lived with persistent bodily pain and how this created a physical and mental “weakness” that allowed a ghost to torment

²³ My illness was giardiasis, common in Nepal, caused by a protozoan infection, usually from contaminated water. Maire Casey Stapleton’s (1989) study categorized beliefs surrounding the etiology of diarrhea in Nepal. Results showed that rather than supernatural causes, beliefs from natural causes prevailed. Babies teething was the most common; 38 percent of respondents listed dirty water.

²⁴ Asha Lal Tamang and Alex Broom (2010) researched the health-seeking behavior of rural Eastern Nepal. My field site was in another district, but I found similar views. Their interviews with villagers and spiritual healers found that the majority seek traditional medicine and carry beliefs that their illnesses originate from the spirit realm.

him, deepening and perpetuating his suffering. Through this chapter, I follow the progression of my way of knowing gained through my senses, my discomfort and anxiety, and their resolution, brought to life through time spent with the *Bombos*. When I became ill, I sought the care of the local shamans, and through this participation, my impressions and perceptions evolved to inform my research. Through this unfolding of trust, acceptance, and bodily participation, I became more aware of my participants' personal struggles with illness and fear. The International Association for the Study of Pain's definition of pain states: "An unpleasant sensory and emotional experience associated with, or resembling that associated with actual or potential tissue damage." (International Association for the Study of Pain 2021). The meaning given to those experiences is essential to the individual pain experience, emotions, and expression (Ahmed 2014). As suggested by Kim Knibbe and Peter Veerstag (2008, 60), I attempted to avoid my personal overrepresentation of the villagers' spirit worlds. However, I aimed to remain mindful that this chapter is, and can only be, my interpretation of others' experiences as well as my own. In framing my journey, I draw on Robert Desjarlais (1992), who, in his long-term fieldwork with the Hyolmo Sherpa in a nearby region to my field site, describes embodied values that weave through Nepali village life and asks how these emotions impose on the body and illness. From *Body and Emotion*, Desjarlais further defines this concept of intertwining as aesthetics:

I use the term 'aesthetics' . . . to grasp (and tie together) leitmotifs that shape cultural constructions of bodily and social interactions . . . which include for the Yolmo wa values of harmony, purity, and wholeness—as embodied through the visceral experience of cultural actors rather than articulated through concrete artistic or philosophic tenets. Desjarlais (1992, 65)

Maila's sister, with whom I was living, had told me in passing several weeks before that their grandfather had been a prominent shaman healer and that he had died the previous year. At the time, I was not aware of just how much the *Bombos* and their healing practices would feature in my research and time spent in the community. When a neighbor whom I had met very briefly previously invited a local *Bombo* to conduct a *puja* (Sanskrit: homage, worship; in this context, used for a healing ritual; Tamang: *Yalmo Kyonda*), my host

suggested to me that I might be interested in observing. My host family knew I sought out villagers living with long-standing pain to talk to them and get to know their stories. Earlier that week, I walked out onto the family's front porch, a loose gravel-covered strip of earth shielded by a lightweight corrugated awning that had been widely distributed after the earthquakes in 2015. Sitting on a plastic chair, wearing a winter coat and wool beanie despite the humid July weather, was a middle-aged man named Pasang who quietly said "Namaste" (Nepali: hello) to me when Maila introduced us. She told me that Pasang had long-term neck pain. He sat looking very small, covered by his unseasonal heavy clothes, perhaps wearing them to cover the significant curvature of his spine. This man would go on to be one of my central research participants. I visited him every week until I departed from Nepal; his neck pain was only one of the many struggles he was experiencing.

Lawrence Kirmayer (2008) discusses body posture as metaphor and as suffering displayed and embodied. Sitting briefly with this man on the porch, I felt a drawing down, curling up in my upper body, my chest caving in on my heart. A type of postural mirroring, often unknown to the observer, may occur between people.

2. Scare the fright away

I had heard the drumming while sitting on a steep set of worn granite slab steps a short walk from my room. This spot was my favorite place to sit and view the handful of village homes surrounded by the newly sown rice paddies bordered by the much-less-ordered soybean crop planted to retain the soil. The tall trees could be seen in the distance, closely following the banks of the ever-expanding river. The drumming was loud and showed no signs of abating after about half an hour. My previous Buddhist *puja* experiences suggested to me that this was different in some way, but I was unclear about what the difference could be. Following the sound led me up an uneven path through two terraces of swollen rice paddies to a single room cement dwelling. I did not go in. Half an hour later, back home with the family, I asked about the drumming. Maila's sister told me there was a *puja* for their neighbor to "scare the fright away." She continued, "You can go up there now, but it will not be interesting until later tonight. Now the *Bombo* is just calling his *guru*" (Sanskrit: teacher; in this instance, "inner guru" or "spirit guide," usually from a deceased relative).



Figure 13. Local Tamang Bombo drumming to call his guru

I asked why it would become interesting; she looked at me and drew her index finger across her throat. “They kill the chicken.”

I spent the next nine hours sitting on a well-worn straw mat on the floor of the one-room house I had peeked into earlier in the afternoon, crouched among a changing group of ten villagers with the loud thudding of the *Bombo*’s ritual drum, the *dhyangro* (Nepali: flat ritual drum with a carved handle; *nga* in Tamang) beating continuously. The *Bombo* wore a set of heavy brass bells across his shoulders, and with a sudden jerk and twist at his waist, they sounded with the drums. Crossing his shoulder was also a chain of rudracche nuts. In

the corner of the room was the ill man. His eyes were wide, and he sat patiently, sometimes leaning his frail frame against the wall for support. Another elder *Bombo* was present, as was a younger man who appeared to be an apprentice. The drumming, interspersed with bells clanging, continued well into the early morning hours. As I was told by a villager sitting next to me, the *ngaa* (Tamang: chants, prayers) that accompanied the sounds were “calling the guru” in a unique language only known to the *Bombos*. Various white *torma* (Tibetan: cone-shaped figures twelve centimeters high made of rice dough used for offerings) were displayed on a flat basket typically used to separate rice husks. There was rice scattered on one side, with an egg and an object wrapped in cloth alongside it. A bowl fashioned by large leaves held hibiscus flowers and long white feathers, which stood upright with the quills poking through the bowl as a base. A teenager blew on the smoldering dry juniper incense, which burned in a small brass pot near his feet. There was a geometrical layered star pattern drawn with various light and dark grains and white flour on another flat basket. Placed atop this was a bent tripod of branches affixed together like a tent with thread at the apex. The white thread was wound around the propped leafy assemblage ²⁵. Beneath this branch canopy was a group of smaller brown *tormas* and another egg. A middle-aged man sitting next to me told me that the brown *tormas* were the ghosts situated in their “world.” The apprentice gently shook a twig dipped in a liquid in time with the drums over the bound tripod. The *Bombo* continued to follow instructions given to him during his trance state by his guru to scare away the ghost.

²⁵ Nicoletti (2008, 76) details the “geography” of the branch shrine, which represents the three realms where entities reside: the underworld: basket with rice and *tormas*; the earth: where humankind lives is shown by the vertical sticks as the four cardinal points; and the white thread: the celestial realm.



Figure 14. Branch shrine used in a puja

I watched as a succession of activities took place, a performance of the magical duels fought against the ghost (Nicoletti 2008, 34). The *Bombo* chanted over a clump of thick-bladed grass that he held tightly; later, he gripped a carved wooden dagger called a *phurba* (Tibetan), displaying a chopping movement, all while the singing continued.



Figure 15. Duel with a spirit

Outside, a chicken was sacrificed by hanging by its beak. Well after midnight, quite suddenly, the *Bombo* stood up and bolted from the door. Everyone scrambled to follow as he ran from the house down toward the village, still drumming and singing the *ngaa*. We kept close behind him through the darkness and the puddles along the paths, scrambling through the nearby trees, tripping over branches along the way to keep up. Again, quite abruptly, the *Bombo* moved quickly, and still in a trance, listening only to his guru for instructions, he stopped on a slippery path over a small stream. Someone placed the leaf bowl with the flowers and feathers on the ground. We gathered around, and some villagers held burning branches while the younger ones held their mobile phones toward the

offering bowl for illumination. Two men leaned forward with their lighters and set it alight. We watched the offerings burn. The *Bombo* stomped on the bowl to extinguish the flames, and we returned to the house. The frail man was still sitting on the floor when we returned. The elder *Bombo* beat his drum and danced with a skip step around him. Later, an egg was centered on the floor and spun, the resulting direction indicating whether the ghost had gone. It was nearly three in the morning when the puja ended, with the white torma passed around for us to eat.



Figure 16. *Bombo dancing during the puja*

Nicoletti understands the *Bombo*, as a living presence, to be the conduit to the ghost, “a living body that itself forms and imbues the entire spatial context of the séance . . . without a specific bodily dimension, shamanism has no other way of coming alive” (2008, 15). The *Bombo*’s shaking, twisting, and sudden jerking are controlled ²⁶. This physical demonstration is a means of communication to the possessed and audience that the *Bombo* meets with the spirit realm and has control and power over it (Miller 1997, 261). Nicoletti continues to describe the *Bombo* as the embodiment of the divine. This fully-fledged body results from the apprentice/neophyte process of successfully curing their initiate sickness, which was bestowed on the young man’s body by the gods’ realm. The healing identifies the source of power as from the divine. Accepting the calling and overcoming the somatic inflictions (both mental and physical) qualifies him for the vocation.

Four days later, the neighbor’s family arranged another *puja*. A different group of *Bombos* was there, starting much the same way as the previous one. The white *torma* figured prominently, as did the canopy of branches covering the brown *torma*, the white thread encircling the green tripod. However, that night, I recognized the frail man as the same one I had met on the porch. I had not connected the two previously. His name was Pasang, and he sat in the corner of the room with a man aged about forty years behind him. The man’s back was against the wall, and his outstretched legs encircled Pasang’s crossed legs while his arms were draped around his shoulders in a loose hug.

The expression on Pasang’s face showed fear, with his eyes wide and darting from side to side. The *Bombo* wore a woven grass hoodlike hat while he chanted over a live chicken. Pasang was handed one end of the white thread and held it close to him for what seemed like hours while the chanting and drumming continued. Later, another man was sitting

²⁶ The *Bombos* explained how they “were chosen.” It commonly runs along family lines. One said that a deceased relative’s (a *Bombo*) spirit began to visit him in his dreams at age eighteen. During the day, he experienced uncontrolled shaking and behaved erratically. See Peters (2007, 77). On the pilgrimages, I saw novices in this shaking phase; the entourage was patient and slowed down as they regained control of the involuntary movements.

behind Pasang and embraced him as, after several hours, he abruptly tightened and extended his legs and attempted to flail his arms. With his head bent back from across the room, I could see the whites of his eyes as he clenched his jaw, and froth gathered on his lips. Pasang jerked his body, and the man behind him closed his grip to prevent him from hurting himself. Pasang looked terrified. The *Bombo* stood up to dart out the door, as before, beating the drum as he left. The small room's entourage quickly followed, leaving Pasang behind. A local teenager carried the chicken as we went down another rocky path toward the river. Another teenager took the flat basket with the branches. We stopped on a trail behind a rice paddy in the darkness, mobile phones lighting the way. Without warning, the teenager killed the chicken with a swift pull to its neck; its decapitated head was placed on the flat basket with the branches and burned on a slanted slab of granite surrounded by tall grass.



Figure 17. Branch shrine left at the site where the ghost was found in the jungle

During the exorcism, Nicoletti (2008,36) describes the possessed person's body as, "a passive object in the shaman's hands, manipulated, struck, beaten, lifted, made to move and dance, according to the specific requirements of the therapy applied". Pasang had to entrust his body to the *Bombo* to permit the relationship between his and the *Bombo's* body. Again, the *Bombo's* physicality, his senses, and experiences form the interchange between his and his guru's souls. His dreams are also pathways from the spirit world to this embodied knowledge. Rather than the ritual objects and performances seen as symbols, they are part of the *Bombo's* visualization faculties (Miller 1997, 260). For Pasang, he felt that his dreams were also a means of communication, and that his dreams carried over into his waking life. He later told me that the evidence that he had a ghost was the recurring visitations haunting his nighttime world, plaguing his waking world with physical and mental symptoms.

The next day after the second puja, I paid a visit to Pasang. He described having widespread chronic pain for many years. He said that he had fallen from a tree about thirty meters high and broken his upper back. I wondered where a tree that tall would be in the Himalayan foothills, so I was confused by this story. I was later to hear elsewhere that he had been assaulted. Ten years later, his upper back was severely curved. Pasang then told me a harrowing story of how his roof collapsed on top of him during the 25 April 2015 earthquake. A beam fell on his thigh and fractured his femur, and the pain persisted although the bone had healed. He also described having nightmares for a long time in which a dead friend's ghost came to him. He had witnessed the man die suddenly in the middle of the road. I asked him why he thought the ghost had come to him, and he said that it was because he was in pain, weak, and vulnerable. He said that he continued to have the dreams after the first puja, so Pasang knew the ghost was not gone, and he requested the second ritual.

This account was the first I had heard of any subjective experience of ghosts. I was especially interested in how it had chosen Pasang due to his perceived vulnerability he experienced living with his chronic pain. Pasang's fear was especially palpable at the second puja. At the first puja, I focused on my acceptance as a researcher in the room. By the second puja I attended, I was more comfortable. However, looking back, my awareness was still mostly of which ritual objects were used and the procedural details. Nonetheless, naturally, I found myself looking for any evidence of the ghost's presence and how that may have affected me. But I was more drawn to Pasang and his visible distress, not feeling any of my own.

Two weeks after the second puja, I met with Pasang for a much longer interview at his home. He was visibly more relaxed, and I told him he looked ten years younger than when I saw him last. He divulged to me that the dreams had ceased and that the ghost was gone. He said his *hungsa* (Tamang: mind/life force) was back.

Belief in ghosts was pervasive in the Tamang community in which I worked. I knew from Nepali monastics that there were six realms, one of which was the realm of the hungry ghosts. The villagers did not speak of the various realms but did have a strong sense of the plane where ghosts prevailed. The monks and nuns also often "fed the hungry ghosts" by leaving a bit of food on their plates after a meal. The villagers understood that ghosts were everywhere but preferred certain spots near rivers, in forests, under bridges, to name a few, as well as in individual people, they told me. Pasang continued to describe what had happened to him since his last puja. He was optimistic about his life, and he confided that he felt that he could get better and that his pain would lessen. Pasang also spoke of his nightmares, which had since entirely disappeared: "The ghost, after taking my *hungsa*, he tried to take my whole body." He recounted that, although he still had the pain, his appetite and sleep were much better, and he felt like doing more everyday activities. He said the first puja did not change things, and the second was more effective. He was no longer shivering all the time. Previously, with his lost *hungsa*, "I was trapped . . . my nerves had shrunk." Pasang described it as his mind being gone, leading him to do things he would not normally do, such as having "a restless urge to run to the jungle . . . or eat dirt." He continued, "It is like getting scared if people are around." He further explained that if your

hungsa is completely gone, you will die; he said, “It is deep in your heart.” If you feel tense, it makes it worse as well, he elaborated. Everyone told him not to worry. If he did, he would not get better. In looking back, he thought he should not have worried, and he should have thought that it would resolve. Now that his *hungsa* was back, he could think more positively. The *Bombos* brought back the *hungsa* from the ghost, he explained further. “The ghost took it and played with it [his *hungsa*]. The ghost must be killed or tricked so that it [the *hungsa*] can be returned into my body... The *Bombos* gave the chicken’s body to the ghost instead of *me*, in exchange for my body.”

3. Blowing it away

My host family noticed that I was not eating as much, and I confided that I had some troublesome and recalcitrant gastrointestinal problems for the past week. They arranged that I meet with their uncle, a *Bombo*, for a healing ritual called *ngaba* in Tamang (chanting and blowing healing ritual). They did not explain further. This practice was very different from the two *pujas* I observed for Pasang. Here, I was the patient, and I thought it an excellent opportunity to learn more as a researcher, again focusing on the process.

Not knowing what to expect initially, I walked quickly down the muddy path, dodging the debris-filled streamlets of water runoff from the daily rains. The *Bombo*’s house was still under construction. The earthquakes of 2015 had decimated the village, and many of the buildings were only partially reconstructed. Entering the nearly completed ground floor, I was shown into a bedroom and sat on a small cushion on the cold floor. The *Bombo* came in, dressed in his very worn *daura* (Nepali: men’s shirt), fitted cotton trousers, and *dhaka topi* (Nepali: traditional men’s hat), and sat close to me. He smelled strongly of the local beer, and his bare feet tucked loosely under his crossed legs had deep cracks in the thick, calloused skin. As was typical, the electricity was off, and we sat in the semidarkness; I looked at his weathered face for clues as to what may happen next. He did not acknowledge me but closed his eyes.

I was shivering, and my abdominal pain from my illness wrenched through my body. The *Bombo* took his *mala* (Sanskrit: prayer beads) out from the folds of the two-meter-long

white cloth wrapped around his waist and began to chant *ngaa*. I listened to the words; I could not catch familiar words with my limited understanding of Nepali and Tibetan. What language was it? I felt detached, subject watching object, overthinking, the chanting just a din in my ears. Realizing the expectation for a cure was not here, I watched and listened more acutely as he blew quick puffs of air into my face and then toward my abdomen. Intrusive thoughts broke my observation, “How did he remember all of these words?” I felt a sense of responsibility to be there since he was a family member of my host family.

I remembered that Maila said I would go for a ritual “where they would blow” called a *ngaba*. I was going through the motions and was aware of it then, but I did not know how to change that. I sensed at the time, and in retrospect, that I was somehow judging the “quality” of the healing because I could smell alcohol on his breath. I was a Buddhist practitioner myself, and I was intensely aware that this was the first time I had allowed my previous expectations of familiar practices and rituals to impede my nonjudgmental observation in my fieldwork. For example, I was accustomed to a particular “decorum”, a sober *Lama*; (Tibetan: Highest principle, meant for a teacher of the *Dharma* (Sanskrit) or Buddhism principles in Tibetan Buddhism) and to “feel” a sense of equanimity and nonjudgment due to trust and familiarity. I had not witnessed a Buddhist healing practice in the past, so I was uncertain if the *Bombo*’s was similar. I felt skeptical. It was paradoxical that I expected to feel something but did not think I could be cured. Working with chronic pain patients in physiotherapy, we take a holistic approach according to the understanding of pain as “experience,” cited by the IASP 2021. This view aligns somewhat with the Buddhist tenets of accepting ever-present change and acknowledging pervasive suffering, which will be discussed in later chapters as a form of resilience building. However, how could chants and blowing fix giardiasis?

Was I sick enough to deserve this attention, ask that a busy, tired farmer take time from his day? I felt a bit of a fraud. Was I taking advantage of the situation to observe the ritual as a researcher? The issue of deserving care and how that informs our work crossed my mind. Our positionality is movable in this context. “Openness” to the healing process, the placebo effect came to mind. The relatively uneventful, in my estimation, ritual ended abruptly after about fifteen minutes of the same. The *Bombo* nodded his head and got up

slowly from his cross-legged position on the floor. Did I anticipate a change in my daily abdominal symptoms following this first ritual? This episode was the first bout of this illness that would persist for at least another eight months until I departed Nepal. In retrospect, perhaps I was not so invested simply because I thought it would be self-limiting after a few days. After five days without change, I did not want to admit to my hosts that this ritual did not work. My thoughts, assessing the situation from a scientific “rational” standpoint, most certainly turned to a type of food poisoning or contamination. However, I was the only one in the household who was ill, and I did not recall any overtly suspect food. Surprisingly, at this point, it did not occur to me that it may be the water, despite me boiling it for drinking...

The weekly visits to Pasang continued. My illness also continued. It was tedious and a nuisance, but I did not feel overwhelmed by it. Pasang remained optimistic and very confident that the ghost had gone. However, he struggled with the daily life that followed the unrelenting nightmares and fear and thirteen years of living with persistent pain.

4. Pilgrimages and more ngaba

With the full moon in the month of *Shrawan* (the fourth month in the Bikram Sambat, the Nepali calendar), it was *Janai Purnima* (Sanskrit: full moon sacred thread festival) ²⁷. My Nepali hosts had arranged that I travel to Panch Pokhari (Nepali: festival place name meaning “five lakes”) with a group of local *Bombos* and their friends and family. Their houses surrounded a pond twenty minutes’ walking distance from my house. Gabriele Tautscher (2007, 44) explains that the Tamang people choose to locate their homes around a ritual center, a mountain top, or a lake. The deities inhabit these spaces and protect the village. This trip would be the first of two pilgrimages I made as a guest of the *Bombos*. I felt I could gain more insight into their healing practices by accompanying them.

²⁷ Refer to Tautscher (2007) for a recount of *Janai Purnima* in a nearby district. Like Gosaikund, this Panch Pokhari pilgrimage is primarily a Hindu festival to sacred lakes of the deity Shiva. It is customary to exchange a red thread on the wrist, worn for protection (2007, 136) . My *Bombo* interlocutors explained their journey simply as a means to travel to “recharge their powers from the gods.”

Additionally, by traveling with them and embodying the physical and mental hardship expected on a pilgrimage, I hoped to have a fuller understanding of their approach to coping with these challenges. Before embarking, one of the group apprentices explained that the local *Bombos* made this pilgrimage every year to go to the holy lakes to “recharge their powers.” It was a Hindu festival; however, it also held significance as it was a sacred site for *Mahadev* (Sanskrit: Hindu deity also known as Shiva), whom the *Bombos* revered (Tautscher 2007, 47). At one edge of our local pond was a shrine to Mahadev and his consort, *Parvati*.

The trip would take two nights and three days of arduous walking to the sacred place. En route, the *Bombos* danced and spun, beating their drums as they walked up the steep paths. The clothing they wore was specific for the dancing. Their headdresses, made of red, white, and green two-meter-long swaths of cotton wrapped around their heads, trailed down the length of their backs with a pheasant feather on the top. They wore full white cotton skirts that flapped and billowed in a complete circle around their thighs during the dance.



Figure 18. Bambo dancing en route to a pilgrimage

Heavy bells hung across one shoulder and clanged with the constant movement and drumming. The Bombos jumped over small streams and through wet grass and rocky tracks as they danced. The entire journey was made barefoot.

We progressed slowly to the next village, stopping to make offerings along the way as the local families had requested.



Figure 19. Villagers make offerings for the Bombos to take up to the holy lake.

Mid-morning, I met the lead *Bombo* from the first puja, Karsang, who had joined the group. He intended to join the procession for the day, which included stops averaging about every ten minutes. This pilgrimage was several strenuous days long, often walking for hours at altitudes over 3,500 meters with heavy rains. However, I was able to form bonds with the *Bombos*, leading to many more discussions about their healing practices.

What followed for the next two months was a cycle of ten days of antibiotics obtained by the local health clinic, which relieved my symptoms for one week. I lost count after seven courses in total for my ten months of fieldwork. I sought out another *ngaba* healing ritual about two months after the first. I had told my host family that I was still ill, and at their suggestion, I decided to give it another try.

I returned to the house where I had received the first treatment. I returned to the same small bedroom and again sat on the floor. The *Bombo* who followed me looked very similar in stature and facial features to the previous one, but I had known beforehand that they were indeed brothers. It is common for families to have several *Bombos* in their ranks. He looked into my eyes, and I felt reassured immediately. Sitting cross-legged as everyone sat

on the floor, perched on a very thin cushion, he turned to face me directly and took out his mala. By this time, I had spent more time with the local *Bombos* and had a more broad-based understanding of what to expect. Rather than observing, I genuinely wished this ritual would help me, as the antibiotics had not. I was steadily losing weight. Overall, I was feeling much more defenseless and weaker than when I underwent the first ritual. My symptoms did subside for a few weeks, longer than they had following a course of antibiotics. My host family was anxious that I was improving under their father's care. Their open-ended trust was developing. As the *Bombo* chanted and blew on me, I experienced a tickling sensation in my stomach, unlike the first time when I did not feel anything. It was too easy to read into this as some sort of response; avoiding overanalyzing, I tried to stay in the present moment.

I accompanied the *Bombos* on another pilgrimage during the month of *Poush* (Nepali: December equivalent) leading up to the full moon at a site in the district of Nuwakot called Karejung, led by Karsang. This trek was longer and more challenging than Panch Pokhari. When Maila first told me about Pasang's *pūja*, she described it as where the *Bombos* would "scare the fright away." Following my second pilgrimage, I began to see much more clearly where fear was situated in Pasang's life, living with the ghost for so long, and how the *Bombos* had brought him back to safety, much as I experienced in my journey to Karejung. The following vignette recalls my own experience with fear and anxiety in traveling with the *Bombos* and the parallels I saw with the journey of Pasang's healing ²⁸.

I had developed a trust in the *Bombos'* healing knowledge and felt an overarching sense of security in their presence that was hard to describe. We walked all day through the forest for at least ten hours and well into the night. We finally reached even ground after the strenuous trek up through thick brush and winding, slippery tracks. It was misty and cold as we sat down in the open grass two nights before the full moon. The clouds dimmed its light. I was so relieved to be sitting. Initially, I did not realize the hushed tones were the *Bombos* saying we had taken a wrong turn. What I felt was a stillness and calmness, almost

²⁸ Refer to Desjarlais (1992) for a rich and extensive ethnography of "soul loss" within the Helambu region, across the valley from Pasang's village.

like the mist that enveloped the group. I believe what I experienced was the *Bombos'* strength and power. I stopped looking for signs and realized that this was it. This sense of serenity was as real and solid as the trees surrounding us.



Figure 20. Lost during the pilgrimage

I reflected on the Karejung pilgrimage and the notion of fear. Several times after the experience when we were lost, I checked in with myself to see whether I was afraid, as I thought I should have been, and I was not. I began to use the presence and context of fear in relating and understanding Pasang's experiences. His life was fraught with fear. This connection was central to my understanding of how his healing emerged and came into being as transformative. In Nepali society, there is the concept of *rta* (Sanskrit/Nepali: order). Casper Miller (1997) explains that this view extends to a healthy body and to a smooth-functioning society as a whole. The role of the *Bombo* is to restore order to the

body, whereas the *Lama* (Tibetan: honorific title for a monk, usually a teacher; one who has completed a three-year retreat) is concerned with the social order (1997, 260). The Lama bestows offerings to the spirit realm, but the *Bombo* meets them head-on.

I had been living with gastrointestinal symptoms for many months and was persistently weak and tired. It was winter, and the nights were cold despite the sun shining during the day. Boiling my drinking water had not made a difference. I contacted the lead *Bombo*, Karsang, who had performed Pasang's first *puja* and became a close interlocutor.

Karsang arrived at my door with his usual namaste greeting, placing his folded hands on his head, a display of high respect. We sat down on the cushions on my floor as I felt my sense of weariness sink into the ground beneath me. I told him that I was fearful that I might never recover from this illness, that it may have done something permanent to my system. My head mildly swirled while I spoke. There was an inner tremor through my core as I asked him hesitantly, believing and not believing what I was saying at the same time, "Do I have a ghost?" Without hesitation, he said, "Try feeding the ghost more; it is coming around you." I felt relief at that point that I had some direction, some reassurance that there was something I could do; I knew exactly what he meant—I had to leave a tiny pile of food on my plate at the end of a meal as my monastic friends did, and when outside feed them as Maila had shown me months before.

The ritual began with Karsang taking out his mala as the others had. The sonorous sounding of the chanting buzzed through my head and put me at ease. After about ten minutes, I settled into the rhythm. My breathing slowed down without anticipating the next steps. Karsang reached into his shirt, took out a yellow powder from a pouch, and mixed it into the small metal bowl filled with water I had been asked to bring. He took his *khukuri* (Nepali: curved knife), which he had tucked into his cotton waistband, and placed the tip into the base of the bowl as the chanting continued to resonate. He motioned for me to turn my palm upward. Taking the *khukuri* from the other water, he dripped a few drops on my hand. A sense of stillness pervaded. Karsang then took out a small, folded piece of worn paper and slowly unwrapped it. Inside were several tiny brown seeds, which he handed me to chew. I asked cautiously. "*Piro xa? Tito xa?*" (Nepali: Are they spicy? Are

they bitter?) The taste was bland, unlike what I had expected. The ritual came to an end as I drank some hot water from the flask I kept in my room.

5. Conclusion

In retrospect, the relief and dispelling of anxiety I experienced during the rituals may have arisen from a sense of validation, regardless of etiology to which it was linked – whether related to the Tamang world of the unseen *Amrang Ba* (Tamang) or to common intestinal parasites. There is fear and anxiety that come with a long-term condition, the future unknown and uncertain. Would I be cured? My vulnerability emerged and was co-created from my illness. It was from a place of bodily and emotional weakness; vulnerability was movable throughout the healing journey. Moreover, the levels and boundaries of the dichotomy of belief/experience were changeable and uncertain. This synchronous movement allowed the researcher to develop a greater awareness of the experiences and suffering of Pasang, as well as my other research participants.

Consequently, a level of knowledge through the notion of enskillment emerged in this way. What I maintained objectively as awareness of my cognitive process as the discerning researcher, my healing process, and then through Pasang's, melded with my embodied knowledge of both. Insofar as the culturally specific ritual process acted through my body as a conduit and through the *pujas* and pilgrimages' physicality and practice, I developed reassurance that healing could occur.

I was unaware of my fear until Karsang described it as a ghost, an invader. It was a parasite on both counts, microscopic protozoa, or an entity from another realm, both "unseen." Nonetheless, another body in one's own. Through my experiences with mine and Pasang's healing rituals and my travels with the *Bombos* on pilgrimage, I saw how the role of the *Bombo* was to identify and provide a form, a manifestation, that is, to embody fear—this fear Pasang carried with him every day, everywhere.

Michael Jackson (2017) recounts his post-fieldwork reflections on witnessing séances in West Africa by explaining that he felt a lifting of anxiety. In their desperate circumstance, the client's impasse in their lived experience surrounding it was also allowed to change

(2017, 193). My vulnerability felt from weakness with the persistent illness allowed me openness to expectations and trust from the healing. I searched for out-of-body and extrasensory experiences with the *ngaba*, during the *puja*, and on the pilgrimages. Instead, there was an overreaching sense of calm, stability, and security. The influence these experiences had on my work was tangible. Was this reassurance similar to what my participants felt, what Panter-Brick (2014) termed ‘a resource’ as required for acceptance and building resilience?

I will describe several observations on how my illness proved a rich source of embodied knowledge in the field. This interplay was complex and multilayered, and I pose several questions surrounding it. The most significant initial shift in my understanding was when I realized that the villagers understood my illness to be from the spirit world. I had the impression that they did not consider that I would not accept this explanation. This awareness garnered a sort of leveling of the playing field, so to speak, a commonality with my interlocutors, the community, and me. My research topic was chronic pain, commonly associated with ghosts, as Pasang had told me. It picked him because, in his words, he was disabled and vulnerable.

This illness experience showed me how I viewed my participants, my gaze in seeing their illness, and how that informed my epistemological embodiment. I felt at some point that I expected them to accept their pain, ghosts, and infestation because they lived surrounded by the “unseen.” It came to mind to question whether the villagers had more or less to overcome than I did, regardless of the etiology of their illnesses and pain. The associated omnipresent fear, that emotion which resulted as a response to a perceived threat, “real” or not, to those not Tamang, appeared to be the perpetrator of harm, both mentally and physically, with Pasang. The *Bombo*’s role was to name it, objectify the threat, make it tangible and real for him. With biomedical knowledge and treatment, such as antibiotics for giardiasis, my background would lend itself to trust in this treatment. However, my condition did not improve.

I often asked Karsang if he was afraid when he performed the rituals. He said he was not, and it was his role to confront the ghost and chase it away. He further explained that it did

not possess him; he lured it and chased it away or killed it. He embodied resoluteness; I clearly felt this in the jungle to Karejung.

Who or what is the body of a *Bombo*?

My sense of having my body infested/possessed translated to how I viewed their bodies. As infested or different from my infestation? I felt mine was different because I had not lived with ghosts. Having a spirit world that was living and tangible to them also meant that they were safe when ghosts were scared away by the *Bombo*.

I felt that working in tandem with the *Bombo*, him doing the puja and giving me the task of feeding the ghost, gave me the agency I needed. The act of 'doing something' assisted in my healing, a ritual I continue now, as the ghosts are sentient beings/actants who need to eat. If no longer hungry, the ghost will 'go away'. That is, we are helping others through this compassionate act. Helping oneself and others becomes one and the same in this cosmology. However, if one is overwhelmed by pain and hardship, such as Pasang, the ghost senses this and invades nightmares and waking life. Viewing this notion through the aesthetics of personhood, Pasang's sense of self had 'fragmented' along with his body, and in this vulnerable state, the ghost could intrude (Desjarlais 1992, 66). His *hungsa* was taken and left him more exposed and in jeopardy. Feeding it would not bring this back. Why is Pasang's health important to him? How does the concept of aesthetics of illness delve into the layers of complexities of the cultural constructions surrounding suffering and pain? In the Tamang village, the value placed on a healthy body rather than its meaning was social. As I saw it, Pasang wanted to be whole, healthy, and strong so that he could work. The safety the *Bombo* provided to Pasang by conquering the ghost and retrieving his *hungsa* allowed him to sleep, eat, and gradually become more robust. For Pasang, his *hungsa* was his means away from fear and toward healing, and his idiom of resilience.

To end, the complex web of my and the Tamang community's different worlds of existence and everyday worlds crossed over in small multilayered spaces, informing my ways of knowing and understanding within my research. As I aimed to demonstrate through my and Pasang's illness experiences, these layers were porous. They were embodied; they

were social, intertwined, expansive, and ultimately transformative. I feel that coming to accept chronic pain must be, in all, a transformation. Indeed, something radically altering must spark this new acceptance beyond following a sequence of coping strategies, regardless of how closely the person living in pain sticks with them.

The next chapter will build on the embodied understanding of living with illness and pain discussed here and further develop the themes of the complexities of chronic pain and emotions.

Chapter 3 How emotions shape experiences of pain among Tamang and Hyolmo villagers

“Feelings are not substances to be discovered in our blood, but social practices organized by stories that we both enact and tell.” Michelle Rosaldo (1984,143)

1. Introduction

In this chapter, I begin by exploring the stories of three of my participants and how their pain relates to their emotional worlds, with a central focus on local emotionality within the social-relational context of the experiences of chronic pain and their coping strategies. These villagers told me of their lives and relationships with physical and mental pain, where a common theme of relational and emotional entanglements with the people around them, their physical environment, and their place in the social complexities of their family and village life emerged. Through these themes, each participant’s particular idiom of resilience will be demonstrated. From an enactivist/ecological framework, their pain was not purely physiological but embodied, not purely emotional but embedded, and not purely social but extended.

Through my research approach as an ethnographer and immersion as a clinician, I merged the treatments with my fieldwork as an integrated process. There was a loose plan; however, the process grew organically dependent on the participant's needs at each visit. Adding an anthropological lens, I will focus on the person-centered understanding of the participant’s pain experience. However, I will briefly add a biomedical explanatory model for the reader who may be interested.

The body feels somatically; our emotions co-create pain. In Good’s (1994) chapter entitled, “The Body in Pain-The Making of a World of Chronic Pain,” he writes about an extensive interview with a man with lifelong jaw pain, which had then involved his whole body and sense of self. Good accurately describes the entanglements of pain in one’s physical and emotional life,” when pain is chronic, it extends into the world, shaping the world to itself” (47).

The participants negotiated through their bodily movements and interactions, embodied in their physical environment and social worlds (Ingold [2011] 2022). These dynamic interactions brought the emotional world into a cycle within this multilayered pain experience. Within this landscape, I worked with them to see how they could build on their emotional strengths to develop coping strategies and further build resilience.

This chapter will describe how the complexities of situated emotions can contribute to and often perpetuate pain. It is not within the remit of this thesis to delve into psychological treatments; however, I will address how the people living with pain were able to negotiate change.

To introduce the three participants discussed in this chapter, the first villager described is Asmita, and I have situated her place in the village, where she did not see herself fitting in. How did this impact her pain? She was not a patient, so to speak, in that Asmita did not receive scheduled treatment, but I did feel that her story was interesting and showed a clear example of the emotional entanglement of the living social worlds in the village. What was most impressive to me in Asmita's case was how her emotions, or feelings of mistrust, were expressed. These were some connections that I observed through knowing her quite well, and I did not feel I imposed them on her. She frequently spoke about her insecurities about her social standing in the village and was worried that others might harm her. Again, as with Pasang, whose story I told in Chapter Two of this thesis, there is a recurring thread of fear and vulnerability, particularly with how others viewed them. In this chapter, I discuss more of Pasang's life after his healing ritual and his endeavors to become more mobile and interact more socially. These two research participants communicated to me a sense of being 'exposed,' almost as a target, for spirits or witches. Although I did not schedule sessions with Asmita, we did chat every day at length, and although these encounters may not have fit the more structured progressive sessions that aimed at solution-focused approaches I shared with the others, I was able to follow her journey through her pregnancy and the challenges that the spirits brought in the form of her back pain.

Tenzin's story is the last and the third in this sequence. In my time with him, he talked frequently about his isolation and loneliness following his stroke. He was not particularly fearful or vulnerable to harm, as with Asmita and Pasang, but he had an overarching sense of hopelessness surrounding his inability to walk and go around and socialize despite living in the center of the Hyolmo village. When we met, he could not get up from his chair or walk more than two to three steps. With this lack of mobility, he described profound social isolation and felt that this would not change significantly. Tenzin was not coping well when we met, and most of our time together was spent looking at how the process of walking could extend his limited social interactions, which perpetuated his low mood.

What follows the ethnography is our interactions within the treatment process. Our pain physiotherapy treatment sessions were very open-ended and not structured as a formal interview or a typical physiotherapy session. I often told the participants that I was coming to see them at home to have a chat about their pain, how it affected their everyday lives, and how we could talk about finding ways together to make day-to-day life a bit easier through our chats and activities. This integrative and iterative approach included discussing their challenges with activities of daily living, such as walking to the shop or doing farm tasks. We would typically work through some gentle exercises or physical activities to build strength, balance, and problem-solving by chunking tasks or breaking them down into workable and manageable parts so as not to push through the pain.

Moreover, a large part of working as a clinician with people with chronic pain is to help them see how they cope emotionally and how they relate to those around them. Often, when a family member has chronic pain, it impacts the entire family. Arthur Kleinman (2009) describes his journey as a caregiver for his wife, who lived with Alzheimer's Disease, as "...a moral practice that makes caregivers, and at times the care-receivers more present and thereby fully human"(293). The person with pain also brings this pain story into all aspects of their daily lives when they go out into the community as well. We worked together to develop strategies for how to cope emotionally with any difficulties they may be experiencing related to their pain, informed by these pain narratives. The themes of underlying entangled and embedded emotions emerge within the ethnography as a multi-faceted thread.

The purpose of listening to these stories in the field and now relating the following stories in this thesis is twofold. Firstly, the research participants did not have the chance to talk in-depth about these concerns. This is often the case in the UK, as in my professional experience. By talking about their experiences with pain, they told me they were very grateful that someone was listening. Secondly, by hearing their stories, I could better understand the context, particular to their experiences, which shaped their lives and their challenges to cope and build resilience. I felt, as an anthropologist and through this fieldwork, I was building the tools to explore, with much more depth and understanding, the social and emotional entanglements within a new (to me) medical landscape, to go beyond the biologically reductive biopsychosocial model of most UK pain clinicians and fill in those spaces where that, in my mind, that limited model did not go.

2. Asmita

Asmita was a hard worker. Everyone said it. I lived within a separate building from her and her family, but I was essentially in an extended family compound like most villagers. Asmita never seemed to stop for a break. She was up early in the morning, feeding the chickens and goats and fetching water well before the others awoke. Meena, her eldest, fifteen, was away at secondary school in Kathmandu. Her husband, Sunil, and their two-year-old, Sunita, were usually asleep until they came into the kitchen at about seven for their morning tea and biscuits. Sunita was a bright young child, very active and challenging to keep up with and out of mischief. Asmita constantly checked to ensure that she remained seated during meals and away from any hazards, including the open hearth in the winter. Coercing Sunita to stay on the three-inch tall hand-made wooden stool her mother positioned in front of the fire was always a battle. Her mother always placed her tea on another slightly higher seat, but Sunita typically spilled it on the floor within minutes. Asmita's brother-in-law, who lived in the same house, came in later. The kitchen had a cement floor and corrugated metal siding and was apart from the main house. The earthquake-proof lightweight roofing had a screened gap between it and the siding to allow for ventilation. It was stuffy and cluttered with stacks of eggs, baskets of vegetables, corn cobs drying, and jugs of cooking oil, among the many other items found in rural Nepali kitchens. Decorative brass plates, mostly wedding gifts, were on display, propped up

against the shelf of a large wooden cabinet near the fire. Next to these were the small brass drinking goblets fashioned with patterns of flowers from which Asmita served the warm *rakshi* (Nepali: distilled millet alcohol) following the late evening meal.

I would sit on the low chairs, two to three inches from the ground, knees serving as a tabletop, sipping tea with Asmita most mornings before her work began. We chatted about many things, usually centered around family and children. Asmita told me that older generations arranged and agreed upon most Tamang marriages. I had lived in the house for several months before I drummed up the courage to ask if hers was an arranged marriage or a “love marriage.” Asmita did not hesitate to respond and told me she had met Sunil when she was fifteen and he was twelve.

“Twelve!” I said as I tilted my head in exaggerated shock. “Yes,” Asmita laughed as she responded to my confusion, “He was big for his age.”

“He had an arranged marriage after we met, but we were still in love. So, he separated from his wife, kidnapped me, and took me to his house ²⁹. Then we had to get married,” she said slyly.

After cleaning up and peeling the seasonal vegetables, usually a basket full of small pale eggplant or irregularly shaped *parsi* (Nepali: squash), then soaking lentils for the morning meal at 10, Asmita would head out into the fields to chop grass. The family also ran a small restaurant a few minutes down the rocky dirt road, and often, she would head down there.

Asmita’s grandfather had been a well-known *Bombo*. Although reluctantly, her uncle was also a *Bombo*, as Asmita’s sister had told me. I was finishing a bowl of noodles late one afternoon when her uncle came in, sat on a mat on the kitchen floor, and began making *torma* (Tibetan: flour sculptures). These rice flour conical shapes stood about six inches tall and represented the gods to whom the *Bombo* spoke. I knew then that he was preparing

²⁹ To read more about Tamang marriage practices, see Chapter 1.3 of this thesis titled: Ethnic Identity with the Tamang & Hyolmo: Marriage, morality, and religion

for a *puja*, but I was unclear who it was for and why. He was short and thin and sat with his left leg tucked under his skinny buttock, sitting on his foot. His right foot was flat on the floor, bent at the knee and hip propped up in a semi-squat as he balanced and concentrated on making a group of the seven small brown flour towers he sat on a piece of ripped cardboard. The middle one was sculpted taller and thinner. He then began to fashion a shallow dish from the brown rice flour and, when finished, set it to the right of the *torma*. He pulled out a red strip of cloth from a pouch placed to the side, tied it to the end of a knobby stick, and added a white strip. He stuck this flag-type arrangement at the end of the center *torma*. He tossed unhusked rice kernels into the shallow bowl, scattered them across the altar, and covered the cardboard placement with them. Next, he burned an offering in the brass vessel, lighting a juniper branch. From there, he took some ashes and mixed them with three red chili peppers into the brown flour bowl.



Figure 21. Preparing torma for a puja

I watched him shape another holder from the brown rice dough to hold an egg. The egg sat in front of the middle tower. Fronds from large bamboo-type plants called *Amliso* in Nepali (Nepalese broom grass, binomial name: *Thysanolaena latifolia*) were set between the *tormas* and covered with rice kernels. In the meantime, Asmita brought a worn Styrofoam mat to sit beside her uncle. A steel plate filled with uncooked polished rice sat beside her. She sat crossed legged facing the open hearth while her husband, Sunil, tended

to the fire. The *Bombo* began his purification chants and tossed the rice around Asmita while she tightened her sweater to keep warm. She was pregnant and struggled to sit for a long time.

Asmita had occasionally mentioned her sore back as we chatted in her smoke-filled kitchen most days. When she explained that her pain had been bothering her consistently recently, I was not surprised, given her long hours standing, bending, carrying, and lifting, typical with most women across Nepal. It began eight weeks into this pregnancy, her third, and Asmita was seven months along at the time of the *puja*. Looking at her from the back, with her brightly colored blue print scarf tied tightly around her hips, as many Tamang women did, it did not appear that she was in her last trimester.

Amita's uncle took hold of several plant fronds sitting beside him throughout the ritual. He started chanting and swishing them around her shoulder and head. This flurry of motion continued for several minutes, and he moved quickly, lightly brushing them around her back. He laid them down again, took hold of the egg, and rolled it forward—more branches swishing. The *Bombo* put the egg back in its holder, and Asmita stretched out her legs and leaned back on her hands. The *puja* was over, and Asmita's uncle stayed chatting for a bit, sipping the strong black Nepali tea, and cupping the mug in his hands to feel its warmth.



Figure 22. The Bombo uses plant fronds during the *puja*

I asked more about her struggles after her uncle left following the *puja*. Asmita continued to tell me the story of her back pain and said that she woke up one morning and had difficulty standing. She confided that she had asked her uncle what it could be; he said it was a *syaulamang* (Tamang: type of ghost). Sitting on her small stool and looking at the floor, Asmita explained. “It is a ghost that other people send to you. Yes, it is sent to you because some other people can put the eye on you.” She continued, barely audible, the fear apparent in her tone, “It is from those people who do not like us and want us to feel

bad.” I asked her quietly if she knew who the person was, emphasizing that I did not want her to tell me the name, however. With her eyes still downcast, looking at her folded hands held still in her lap, her shoulders hunching up further with her increasing anxiety, she continued. “Yes, I know who it is, but we cannot tell.” I asked her how that made her feel, “I feel bad. When I see that person, I spit, but not on them.”

Asmita explained in more detail how the pain started five months before. She said that one morning, she woke up, sat up in bed, and felt a sharp pain shooting down one leg and could not place her feet on the floor. Although I did not examine her on this first day she felt the pain, from a biomedical assessment, these symptoms would have pointed most probably to a nerve root impingement in the L5/S1 region (between the fifth lumbar vertebrae and the first sacral vertebrae of the spine). I kept it in mind, did not dismiss it, and knew to watch for other signs and symptoms of progression.

She knew immediately upon waking that it was a *syaulamang* and that a particular person would have done this to her. That person was a local witch, well known for doing this sort of thing to others. “Almost all Nepali knew about this and that witches exist,” Asmita divulged. “The witches want to win over the *Bombos* and want to give us pain and hurt,” she said. “Only the *Bombos* can tell who the witches are. Even if you know that they hurt you, you have to pretend that everything is normal. I am not scared of them.” Asmita explained that the afflicted people often do not have evidence that the witches have done anything to them, and the witches could sue people who accused them. “Everyone talks to them nicely in case they will do something to them in the future.”

I asked about the spitting and if that meant she was angry or scared, and she said everyone did that. She was not sure why, but she heard that is what you do, so the thing that they sent to you will not come so quickly. “It is a kind of protection. But we can’t do it in front of them. It makes me feel a little bit stronger when I do the spitting.”

Asmita had already had the *puja* with her uncle when she started the spitting. She said she used it to reinforce the effects of the *puja* afterward. It seemed that the spitting was a

purification ritual, and Asmita felt it was a meaningful practice. She did it because she was told that it would help, and it did seem to, as she described feeling “stronger.”

We chatted again in my room about the *puja*; I wanted to know if it had any effects. I was concerned that Asmita felt the witch still had a hold on her, and more importantly, why?

The small community consisted of a few extended families. Everyone pitched in during rice planting and harvesting, the main crop in the region. The houses were close, and it was not easy to tell where one compound ended and the other began. I first arrived in the village in June, and I was unsure who lived where or what the immediate relations were; it became more apparent when I helped plant rice several weeks later.

I was surprised at how much fun the women had doing this arduous work. The women chatted and giggled while the men were struggling knee-deep in the freshly flooded paddies to prepare the soil, pushing, and pulling the massive oxen with heavy wooden yokes. Doubled over from the waist, young girls, teenagers, mothers, and middle-aged women worked quickly and deftly, pushing the tufts of transplanted young rice plants into the muck. During the breaks, we sat on the slippery banks above the paddies, and it became more evident following the chatting just who lived where and with whom.

There seemed to be mostly women and older men working on this hot summer afternoon. I asked around to clarify what I could to begin to fit together regarding familial ties. This working brigade consisted of two extended families living along the bumpy road where my house was in the middle. The youngest young woman looked to be about twelve but carried herself with the confidence of someone who had planted rice many times before as she hiked up her baggy cotton trousers. She smiled broadly and patiently showed me how to push the plant roots deep with my thumb. I soon realized this was also a circle of trust, those who supported each other financially and emotionally through hard times. These bonds were strong, and although Asmita was not planting that day because she was pregnant, she showed her involvement by coming out and bringing tea.

Asmita extended her hand to me and pulled me up the impossibly slippery bank to sit and drink the tea. My feet were covered in the nearly black mud, and she laughed and told me not to worry while she explained who was who.

Many months after this day, Asmita divulged that she did not like most people in the village and that one could not trust them. They were out to get her, she said. I sensed a strong resentment toward those who had more money, and Asmita often mentioned that some people were unfair with business transactions. She said gossip affected her; Asmita explained that she often avoided people she felt were talking about her. This wariness included her deceased mother-in-law.

The earthquakes of 2015 directly impacted this family, as they did nearly all families in this region of Sindhupalchok. Missing from the day's work in the rice paddies were Asmita's in-laws. I heard the story several times from several people: her mother-in-law was in the house at noon when the ground shook and the roof collapsed. Her husband was out in the fields and ran back to save his wife. However, both were then trapped and died under the rubble.

Asmita would tell me about the difficulties she had with her mother-in-law. It was usually about money. There was the added pressure of the expectation that Asmita would give birth to a son. Then there was the issue that her marriage did not meet the family's approval as she had broken up the previous marriage her in-laws arranged for their son. After her mother-in-law's death, Asmita returned from working in Dubai to settle back into life in the village and rebuild the house. Despite this hard work and dedication, Asmita described a feeling of pervasive judgment that she was not good enough. Although her mother-in-law was deceased, she continued to have a strong presence and hold on Asmita's life.

She felt this insecurity long after the disaster hit the community. Asmita continued to feel an overwhelming sense of responsibility to keep her family together and show that she was a good wife and mother, but she always felt that she was the target of gossip and potential harm. She ran the small family restaurant, looked after two children, cooked all

of the meals, including mine, and worked in the fields before she was pregnant. She coped by being busy and taking on responsibility for others. We talked a lot about how she thought she could manage her activity and stress levels; Asmita felt comfortable withdrawing from specific tasks, the more public ones, such as working in the fields, attending cremations, or showing up at village meetings. This she found comforting since she did not have to interact with the wider community. However, when we chatted about how she felt about delegating some household duties, she did not accept that as readily, again feeling the need to demonstrate her role as being responsible.

As I sat under the unrelenting sun that afternoon, looking across the half-sown paddies, it became clear that Asmita trusted and felt comfortable with this extended family, this rice planting/ plowing work brigade. Although I did not know many people then, and the witch would come much later, within this group sat Asmita's world and her safety.

Returning to the question, did Asmita feel that the *puja* for her back and leg pain was effective? Had the ghost gone away? Did she now feel safe and free from the fear of harm?

Asmita told me more about her grandfather, who had died of natural causes the year before, who was a prominent *Bombo*. His son, her uncle who performed the ritual, was another *Bombo* in the family, and Asmita had a younger half-brother who was next in line, so the expectation was that he would also practice this male family tradition. The pressure for another boy in the family, in the newest generation, was likely also related to this mostly male hereditary lineage. When Asmita called on her uncle to perform the *puja* that would scare away the ghost the witch sent, she was reassured, knowing it was family she could trust. Although there was this looming concern in the family and for Asmita herself that the baby would not be a boy, I felt that the *puja* did lessen her pressure. Her back and leg pain was not completely gone, although her leg pain subsided somewhat. Asmita was very private and did not want anyone outside her circle to know about this ailment. With this reassurance from the *puja* and the wider family, Asmita began to develop resilience: to feel safer, less stressed, and less pain.

Could the *puja* have been as effective if the *Bombo* had not been a family member? I am doubtful. I saw that for Asmita her idiom of resilience was her family.

There are direct links between pain, mood, emotions, and the context enabling these feelings. In reviewing Frank, Frank, and Cousins (1993), citing H. K. Beecher (1956) provides an interesting anecdote concerning post-operative surgical pain and context. Beecher explains that 90% of civilians report pain requiring a prescribed narcotic, whereas only 25% of combat soldiers at Anzio Beachhead with similar wounds experienced pain severe enough to be administered similar medication. The soldiers were evacuated and removed from the battlefield, thus out of harm's way. This work is an older citation; however, more recent experiences may be similar, demonstrating that the context and environment will provide reassurance and comfort, essentially the placebo effect, as was likely with Asmita. As has been a common theme throughout this thesis, there is an interconnectedness and dynamic integration of the body and emotions. From a physiological standpoint, the body is well equipped to release natural painkillers during exercise, improved mood, or during relaxation (endorphins, oxytocin) and increase other neurotransmitters through the Hypothalamus Pituitary Adrenal (HPA) Axis, such as cortisol, when stressed ³⁰. This framework works on many levels and extends to bring emotions into the dynamics of how we may act with people we love and trust and those we fear. This relational aspect can, directly and indirectly, impact pain levels physiologically and perceptually. Wall (1999) brilliantly describes the role of anxiety and fear in easy-to-understand terms below:

Fear generates anxiety and anxiety focuses the attention. The more attention is locked, the worse the pain. There is therefore a marked correlation between pain and anxiety. The anxiety here is not the free-floating variety with the feeling of general disquiet that something is wrong but cannot be identified. The anxiety of pain is generated by the unknown and grows worse as the pain persists and short-term expectations of relief fail to be fulfilled. (Wall 1999, 157)

³⁰ Read Giles et al. (2014) for further discussion on the HPA axis and the role of stress physiologically using experimental psychology methods.

Wall goes on to explain that the purpose of therapy is then to “identify, understand and treat the anxiety.” (1999,157)

My role as a clinician ethnographer allowed me to glimpse into the nuances of the ‘in-betweenness,’ the interstitial spaces, beyond the biopsychosocial framework, not seen by physiotherapists practicing in the clinic or even those who did domiciliary work and, therefore, identify, *understand*, and treat. The emphasis on ‘understand’ here is mine, as this is where I see the value of the anthropological lens.

3. Tenzin

Tenzin lived in the next village where most people were Hyolmo. Their language was different from Tamang, which Maila, my research assistant, spoke, so they spoke in Nepali when we first met outside on his veranda. It was a humid July day, and we were tired and thirsty after the thirty-minute walk along the muddy road from home. Tenzin’s wife brought us some hot tea, and he told us what happened the day he had his stroke.

Sitting tall in his chair with his cane propped next to his left unaffected hand, Tenzin began his story:

So, first, what happened was, I was walking around here, there was trash all around, so I was cleaning the area. There were many slippers and shoes on the way. I was clearing them, and then there were tall grasses too, so to clean, I thought of cutting those grasses, and as I was climbing up to cut those grasses, suddenly, I felt a tingling sensation over my leg. (Tenzin)

I asked, “What happened after that?”

Tenzin continued measuredly, “After that, I was taken to the hospital, ummm...what was it...reached at 10 pm and then.... from there they said they could not do CT so then I went to a place called Dirghaayu. I was sent there, and then there it was done. That is it.”

Tenzin then explained that he had to arrange a private jeep as an ambulance. There was a bridge over a river, and he had to change vehicles to eventually get to a hospital in

Kathmandu many hours later, where they told him that he had a bleed in his brain. He stayed for the next four days in the ICU and another ten days in the general ward.

“When were you able to start to walk?” I asked.

He described some of his treatment in more detail, “They gave me some saline, and then I tried to walk a little at about day seven.”

I was curious, “Did the physiotherapists see you?”

“No, I did not know about it,” Tenzin said as if he did not receive care because he had not asked.

Tenzin had a follow-up appointment not long afterward with the cardiologist and the neurologist; he explained:

I did an X-ray, and after that, the medicines went wrong. And I felt my body was thrown suddenly, *hutta hutta* (Nepali, meaning like someone pushing your body suddenly). I used to take correct steps and felt my legs were fine. I felt like I was getting better, and then they gave me four tablets. Those four tablets, I stopped them on my own. If I had not stopped, I would have died. I showed it to the heart doctor and said what I did, and the doctor said I did the right thing by stopping the wrong medicine. (Tenzin)

Telling this narrative of the events was still fresh to Tenzin, and his wide eyes showed his worries about his future health as he spoke. That day, he appeared to be describing an underlying mistrust in the management of his care. He said he was hoping I could help get him walking again. Despite the local clinic being across the street, there was no physiotherapist capacity.

Tenzin was trying his best. He had changed his diet, he said, avoiding the usual three times daily rice with meals. Instead, he added millet as a substitute. “This is what we always used to eat when I was a child; I prefer it.” There were other such alterations to his lifestyle. However, when he described his loneliness, I knew this was the hardest for him. Tenzin did not live far from the scattered shops in the village where he used to walk and sip tea and catch up on the news. He was sixty years old and worked as a carpenter before his

stroke, but now that social contact was gone. I saw that Tenzin had a strong sense of wanting to drive his rehabilitation on his own, especially following the miscommunication surrounding his medications. He was motivated to walk; however, I felt he lacked the guidance. His mood was low as he did not see a way out or know where to begin.

I visited twice weekly for many months and then tapered to once weekly. Tenzin always sat in the high-backed straw and wooden chair on his front porch with pink children's shoes scattered haphazardly when I arrived. He had a hand-carved wooden walking stick about four feet long, which leaned against the chair and was always within reach. He said his wife and son lifted him up from the bed, and he leaned on them both as he took several slow steps to sit each morning. Tenzin could not walk independently and relied on both for maximum support.

I decided to begin by watching Tenzin try to stand up from the chair on his own.

"Can you show me how you try to stand up from the chair, please?" I asked, knowing that he could not complete the task but wanting to see how he approached this effort motorically- using strength and balance- and how he coordinated the movements or utilized what was termed 'motor planning.' Observing would provide me with some ideas about his cognitive skills, but I was also interested to see how he emotionally approached this functional everyday task. Would he get frustrated, impatient, or angry? Or be scared?

Tenzin remained back in his chair, grabbed the long walking stick with his stronger hand, and planted it upright several inches from his knee. He leaned forward as he struggled to budge from the chair.

Seeing his lack of progress, I suggested, "First, let us see if you can scoot to the end of the chair, but not too far out. I will show you the steps ".

I told him what we would try, then broke it into manageable chunks and demonstrated the process myself on a chair beside him. I instructed, guiding his hands in the position," Put your hands on either side of the chair, great, now rock a little side to side, then push, lifting your bottom a bit each time." The process was slow, mainly because he could not

put much pressure on his affected hand, but this activity would also help build strength on that side.

Once Tenzin was further out on the chair seat, we continued with the next step. He was patient and followed the steps well.

“Now we will try to stand. But we will not use the stick to help you get up, which is really hard to do,” I explained.

I sat in the chair next to him and demonstrated the steps of tucking my feet behind my knees, bringing my head forward to see my feet. Then, sitting at the edge of the chair, I pushed with my hands to slowly lean forward and come to a standing position. Lastly, I asked Maila to hand me the walking stick.

“Now, do you want to try to copy what I did? You can try this, and I will help you along the way by guiding you, but I will not pull you up or have you lean on me. We don’t have to take steps today, but let’s see how it goes,” I said.

“Yes, let us try,” Tenzin said with some slight hesitation.

Needing much encouragement, understandably, Tenzin successfully stood after several attempts. I stood in front of him and slightly off to the side in the event that he teetered, and in looking at his face, I surmised that he was anxious to take some steps, but I wanted him to do well and enjoy some success.

“Now, let’s just stand here for a moment and get your bearings,” I cautioned.

I asked Tenzin how he was feeling, and he said he felt fine and was not dizzy. With this, I thought he was ready to take a few steps, and I asked him if he wanted to try, but that I would not be holding his hand but would be very close by with one hand on his waistband and the other one close to his shoulder to support him if he teetered. Tenzin said he felt ready, and he took three slow shuffling steps. I explained that we needed to circle back, and we headed back to the chair. I told him that I would help him back up to the chair until

he felt it behind his knees and that then I would guide him down, the reverse of the standing-up process.

This process was repeated similarly on each visit. After I demonstrated this sequence to family members, they helped him practice several times daily, and his confidence grew as he progressed, taking more steps and improving his strength and balance.

We chatted about how he was feeling, and he said he had more energy and was happy that he could get around more. It became apparent, though, that despite his improved mood, he began to understand that he would not return to his previous level of functioning and that his isolation was not going to change immensely. He knew that his social life would not be what it was and that he would not return to carpentry. We talked about the gains he had made and how his walking was also helping his overall health, as he did talk about his fear of a cardiac episode or another stroke during visits. Acceptance of his limitations was hard for him, as it can be for most stroke survivors. What gains can be made regarding returning motor function is typically seen within the first year.

Tenzin could now walk independently around thirty feet to the end of his garden, down the stone steps and another thirty or more feet along the village road, and return, covering the same distance, with someone standing alongside. He also worked to use his affected hand to feed himself more independently, which, for most people, provides a sense of accomplishment and improved independence so that he does not have to rely on others for this essential activity of daily living. Having to wait for family members to be available for the most basic tasks, in my experience, can create a feeling of infantilization and frustration, and Tenzin did not talk openly about this but was pleased when he could eat the mashed millet on his own.

Several weeks before I left the village to return to the UK, the clinic, which was across the street from Tenzin, hired a physiotherapist. He could walk to the treatment room with her assistance, and this independence gave him a genuine sense of pride. At the clinic, he continued with the exercises and the walking progression we had started. I was relieved he had this opportunity to receive additional care after my departure. When I last visited

him, he smiled as we spoke and talked openly about how he felt hopeful that he would make yet further gains.

Tenzin is an example of how a person living with pain and disability and their surrounding environment and experiences can have a profound impact on their progress toward regaining function and independence. Angela Rong Yang Zhang (2023) weaves together moving stories of aging people following her ethnographic work in nursing homes in Australia. She asks, “What is home?” following her account of a resident who desperately wanted a day out with family, only to insist that he return to the nursing home mid-visit. Zhang discovered that location was significant for receiving good care. However, this did not necessarily mean they felt at home in the facility. Instead, what made the difference was that the residents felt that they could move and receive the attention and ability to do what they wanted with their bodies.

People cannot learn to cope or build a sense of resilience without hope that circumstances may change for the better. Tenzin held some mistrust in some aspects of the biomedical care he had received ³¹. In my experience, people living with pain who do not receive care and attention may learn to feel that they are undeserving and lose hope. This sense of lack of worth can lead to low mood and lack of motivation to try, understandably. Tenzin wanted his circumstances to change, but he did not know where to begin to try; he felt abandoned. He was not able to cope with his limitations physically or mentally despite there being a part of him that desperately wanted to. His hopelessness, however, gave Tenzin an incentive to change, to become transformed. This desperation became a vehicle for his mode of expression, or idiom of resilience of social engagement.

4. Pasang

I introduced Pasang in the previous chapter, describing his physical pain and soul loss and how he regained much of his life through the *pujas* with the *Bombos*. He was a man with

³¹ Trust in healers and healthcare workers will be discussed in more detail in Chapter Seven.

whom I spent a good deal of time, and I learned a lot from him. Therefore, he will reappear throughout this thesis as the themes apply. In Chapter Two, I wrote about his healing *puja* and its impact on his health, including lifting his mood, daily activity level, and social interaction. With this, the previous chapter highlighted how I also underwent traditional healing and how this embodied experience assisted my own understanding of Pasang and his experiences living with chronic pain, his coping strategies, and his journey toward building resilience in his individual way. Descriptions of the treatment process within my immersed clinician ethnographer approach I used with him follow, emphasizing the role of Pasang's emotions, namely fear and resulting vulnerability, in the complex dynamics of his developing and implementing coping strategies.

Pasang and I met for our chats and treatment sessions at his house or the surrounding property, usually after the mid-morning meal. He would report that his appetite was feeble, and his wife often had to insist that he eat at least a few mouthfuls of *dal bhat* (Nepali: standard basic Nepali dish of lentils and rice) to replenish his strength. He was of relatively short stature like many Tamang men, but Pasang was emaciated rather than the solid muscular build most others gained from the years working the fields. His apparent and ever-present pain was embodied in his posture and movement. Sitting next to him on a tattered straw or Styrofoam mat, he would stretch out his one thin, painful leg rather than tuck it under in a crossed-legged fashion, customary and considered a sign of respect in his Tamang Buddhist culture. Pasang told me each visit of his unrelenting thigh pain that had not diminished since a wooden support beam and the heavy wood and stone roof crashed down and fractured his femur. Many deaths occurred when the traditional Nepali roofs collapsed on people in their homes. Since it was noon, most were fortunate and out in the fields away from falling structures. However, those who were elderly or lacked the mobility or strength to farm were inside at the fateful time.

Pasang's upper back curved inwards in a C- shape. This severe disfigurement reduced his height by many inches, making him look small and almost doubled over. His clavicles and shoulder blades protruded, and the taut skin stretched tightly over the visible bones. Pasang said he was almost always cold, explaining why he wore a wool cap and oversized coat throughout the year. I did think this may have also served to hide his body. On most

visits, Pasang would complain of his persistent upper back pain but never divulged the true story of the assault, which left him with two fractured vertebrae ³². I was interested in why he would change his story; I thought that he was embarrassed that he had been attacked by a younger man and could not defend himself. I began to see how a story of vulnerability and subsequent fear began to run through much of his narrative. Underlying the compression fractures, he most likely also had osteopenia or osteoarthritis, which would further curve his spine in addition to the wedge fractures. Thus, he began a cycle of persistent pain; fear of people and their intentions to harm him and their judgment of his physical appearance, fear of movement that may exacerbate his pain, and in general - avoidance of participation in village life.

When Pasang's pain progressed, his wife was admitted as an inpatient to a psychiatric hospital. He told me that he started to drink more of the locally distilled millet spirit called *rakshi* (Tamang). He ate less and less. Previously, he worked in the rice and millet fields, helping with the seasonal plowing and keeping bees. He carried heavy loads of grass for animal fodder and firewood on his back. When I met him, he was isolated. So, when he witnessed his friend die suddenly without warning while walking on a village road a few years before our meeting to Pasang, it was not a surprise that the man's ghost entered him and took his *hungsa* (Tamang?) he explained this as his mind/life force). When I asked why the ghost picked him, he said he was weak. He did not say as much, but I felt he meant this weakness in his body and mind. As detailed in the previous chapter, Pasang suffered from constant pain in his back and leg but was now disturbed by nightmares and daily intrusive thoughts or compulsions. He dreamt of the dead man coming after him. During the day, he told me he would run into the jungle filled with dread.

The government did not provide adequate financial assistance to rebuild their houses following the earthquakes. Several people told me that they received payment equivalent to about \$150 to rebuild according to new earthquake specifications. This money was received the year before I arrived, around 2018. These new builds cost about \$3000.

³² Pasang's story of how he injured his upper back is first told in Chapter Two. He said he fell from a thirty-meter-tall tree, but he actually had been a victim of an assault.

Consequently, with Pasang's family and many others in the village, a younger family member left to work overseas to contribute to this shortfall. Pasang's son left for Dubai when he was in his late teens.

I first went to chat with him the day after his first *puja*. I sat with a group of villagers through the last night until after three in the morning, witnessing the *Bombo's* attempts to ask the ghost to relinquish his soul and bring it back to Pasang. Through the clamor of the non-stop beating drum, with bells shaking louder still, the *Bombo* called his inner guru for guidance to confront the ghost. A chicken was sacrificed and offered as appeasement. Nevertheless, Pasang said he did not have his soul returned. He knew this by the continued haunting of his dreams.

I attended a second *puja*, which I will recap. This time was different. Pasang sat through the night, leaning his slightly shaking body against men who took turns supporting him and holding his limbs as he rocked and flailed. The fear was evident on his shocked face as his eyes stared widely at a presence not visible to me. Many hours later, the drumming stopped, and he relaxed, exhausted. I revisited Pasang soon afterward. His previously pinched face was noticeably relaxed. The ghost was gone, and his *hungsa* returned. I was curious about how these changes would impact him and looked at this opportunity to begin the conversation about the changes he would like to make.

Pasang and all of my participants knew about my position in the field, working with the clinical ethnography approach. As we also do in the UK pain services, the patient's goals are value-based and meaning-centered, focusing on changes they may want to make, which can lead to functional coping strategies. This model has its basis in ACT (Acceptance and Commitment Therapy)³³. Over the subsequent few sessions, we discussed what he

³³ McCracken & Vowles summarize that ACT relates pain and suffering as an everyday part of normal human experience (2014). This approach strays from the analytical and problem-solving based approaches of CBT (Cognitive Based Therapy), that is, that thoughts or behaviors need to be 'fixed'. Rather than taking a direct approach to changing thinking as with CBT, ACT aims to adapt responses to symptoms in a more experiential way, described as psychological flexibility. It

might really want to do and could do in the future, knowing now that the ghost no longer tormented him. Pasang explained that he wanted to walk more to spend time with people. When we met, he spent most of his time lying down or sitting in several of his favorite spots in or outside his house. I also often saw him sitting on the porch of the main house where I lived, just watching the occasional person returning from the fields and waving hello to them. I sensed that at this time, he felt vulnerable and most comfortable observing and not engaging directly by sitting in a group, as many other men did who spent their time around a cup of tea and lively conversation. He did not say, but I thought that he, like Tenzin, did not know where to start; he did not want people to see him struggle, as is often the case with people in pain who say to themselves, why try? Getting to this point, however, was a slow process. I was unsure how Pasang could overcome his fear and vulnerability, which seemed to stop him from walking more. However, I felt he could progress with the iterative approach of gathering more of his story and applying his feelings surrounding the challenges he voiced to his therapy.

Pasang began to talk about his renewed energy. He seemed to genuinely experience a sense of liberation, knowing that his *hungsa* was back. His sleeping improved with the knowledge that he was freed from the unrelenting nighttime stalking. With his renewed motivation, nonetheless, he began to focus more on the experiences of physical suffering he experienced daily. The persisting pain from his thigh spread to his hips, causing a deep ache that spread to his lower back. It is common with long-term pain that it often ‘spreads’ to other areas. This picture of what is termed ‘referred pain’ in biomedicine can be complex, and it is usually challenging to find an accurate source of pain with physical exams or imaging once the symptoms of pain have been longstanding. There are changes in the

can, however, aim to reduce the frequency or intensity of feelings of sadness or pain. Psychological flexibility, rather like resilience, according to Hayes et al.(1999) is made up of the following concepts and processes: acceptance, cognitive diffusion, flexible attention to the here and now, the self as the observer, and value based and committed action.

neurochemistry of the body that ‘wind up’ neural pathways with changes that may cause hypersensitivity, resulting in a lower pain threshold and altered perception in the body³⁴.

Of course, Pasang’s posture was fixed in the severe curvature; however, I saw he was not as drawn into himself and closed as we chatted that day, a week after his last *puja*. His mood improved, and he talked more animatedly. He sat on the usual frayed woven bamboo mat with his outstretched leg, while that day, I perched awkwardly on a folded dusty carpet. He insisted that I have the higher, more important position as the guest, as is expected in Tamang Buddhist households. However, even with the extra padding, I felt the chill of the bare cement floor and could only imagine the penetrating, sharp pain he must feel. The monsoon rains were quickly approaching, and there was a noticeable chill inside, away from the sun.

We talked in depth about his recent daily routines and activity levels. He said he often stayed at home resting but may venture out a few times weekly to walk the short distances between the cluster of half-built houses and corrugated metal sheets where his extended family and close neighbors lived, stopping to sit and catch up. Pasang continued to talk about wanting to walk more and increase these visits. At this time, he could walk about fifteen meters. The paths between the houses were hard to negotiate for him, and depending on the seasons, gushing water streams could run through during the monsoon. Soy, millet, and spreading plants also covered the paths between the unsteady rocks, so it was challenging for him to get a foothold, and he was fearful of falling. We started to take these walks together, resting when he chose and talking about how it went. I encouraged him to continue the walks independently between my once or twice-weekly visits. I did not usually see him walking about, but I would bump into him sitting outside around the village, often in a chipped, high plastic chair, which would accommodate his lack of

³⁴ Refer to the Introduction of this thesis for a brief synopsis of chronic pain from recent research on pain science.

movement in his hips and legs. The other men sat on the usual three-inch tall hand-made wooden stool, which required much more flexibility.

I knew his reluctance to walk further was due mainly to his pain, but I felt his sense of vulnerability was an overarching component. It was scary to him to venture out; he opened himself to stares and criticism. Everyone knew his past, but Pasang still did not feel accepted. He considered himself weak and unable to work in any capacity. In this agricultural community, most people did not earn a wage and depended heavily on family members helping in the fields. He told me he felt that he had let his family down.

Several weeks later, I heard that his son, Aryan, was back from Dubai. I quickly walked down the slippery rocks outside Pasang's house and recognized his son. Holding the oversized umbrella, attempting to shield us from the downpour, I awkwardly directed the drops of water down his face instead. We talked about his Dad. Aryan's concerns were mostly about his drinking. He said that it was less than several years before but continued. We agreed that he probably would not stop altogether but could slow down with our support. Aryan visibly struggled to tell me this story, and his eyes looked down. He told me that he did not get the opportunity to finish school due to his father's incapacity. Aryan had to manage and work their fields. Aryan said that he had now returned from Dubai to work at his uncle's carpentry shop to help further and to be close to his parents and his teenage sister finishing school. We talked about his resentment towards his father. He felt his childhood had been lost. I sensed that he also went overseas to remove himself from this despair.

Pasang continued to have stops and starts with his walking progress. He said that he enjoyed our visits and felt that they were helping. I demonstrated two gentle hip stretches for him to do a few times daily with the instruction 'little and often.' The nightmares had not returned, but it appeared that the day-to-day struggles of living with pain haunted him all the more strongly now. One day, I was walking up to his house through a back path to avoid the mud that covered every turn, and his daughter told me Pasang had been lying down for two days and could not get up. He was eating very little. I walked into the corrugated metal outbuilding that served partly as the kitchen with its open fire, smoky

pots overhanging, and the adjacent storeroom piled high with bags of rice. Pasang curled up on his side, lying on a large piece of broken cardboard. He lifted his thin arms and slowly bore weight through one hand to sit in a semi-reclining position. He said that he had felt severe pain in the last few days. I asked how much *rakshi* he had been drinking, and he said his usual three to four cups a day. He spoke quietly and said that Aryan explained that he would go back to Dubai once he knew that his Dad was doing better.

This set of circumstances understandably was upsetting for Pasang. He wanted his son to return to Dubai to make money but wanted him to be home. His son would leave if he began to walk more and drink less. My approach at this moment was to direct Pasang to the practical and here and now to support him in understanding that he could walk that day and right then. Pasang stood up and mumbled that he was dizzy. He stood for a minute or two, regained his balance, took five steps, and sat down again.

I saw that there must be a connection between Pasang's setback and his sense that Aryan would be leaving since he was making progress. I did not feel that his low mood and change in motivation to walk were intentional, and he may not have seen the dynamic between his feelings of fear and vulnerability arise with the prospect that his son may soon leave. I attempted to meet with Aryan to discuss his Dad's progress, but he was unavailable. He would have seen us walking together in the village, and I always gave him the thumbs up when we passed. I decided not to speak directly about his feelings with Pasang but rather to focus on the walking regime that we had established, emphasizing how well he was doing and bringing it back to the benefits, as he was out and about more, and we would sometimes stop in to chat with friends along the way. In this way, Pasang did not dwell on his low mood, but through exercise and increased social interaction, these activities directly and indirectly helped him develop resilience.

Shortly before I left, Pasang expressed an interest in returning to beekeeping, which was a big step for him. I was delighted to hear about this plan, and we continued to work on building up his walking distance and breaking down how he might set his goals into a manageable project. When I did leave, Aryan was still in the village working with his uncle. He had plans to leave to return to Dubai, but nothing had been set.



Figure 23. Walking in the village after many months of building up.

Pasang's journey with living with pain was long and multifaceted. He faced many challenges, and his thoughts and feelings surrounding fear and vulnerability directly impacted his motivations and functional levels. Linda Green's (1994) heart-wrenching work with Mayan women in Guatemala who lived in constant fear under violent militarization speaks to its pervasive nature, "Fear is elusive as a concept, yet you know it when it has you in its grips. Fear, like pain, is overwhelmingly present to the person experiencing it, but may be barely perceptible to anyone else and defies objectification" (230). A very different context to Pasang's environment (although following the earthquakes, I did hear reports of a global sense of terror of a recurrence); however, for him, I did think he felt a palpable

threat and constant fear before his healing ritual. Within this extended world of his nightmares and day-to-day struggles in the village, his coping abilities progressed and faltered. His close family supported him emotionally; nonetheless, it may not have been how he had hoped. These social and relational worlds, which are so crucial to people with pain, are a challenge on both sides to negotiate. Pasang did see that he could break free; however, to him, this may have been due to the *puja* rather than him seeing this strength as coming from within himself. The construct of his *hungsa*, the fear he experienced in its absence together with the process of its return was Pasang's idioms of resilience. Nonetheless, the hope and confidence that he could achieve, regardless of source, could assist not by curing the pain but by breaking the cycle of perpetuating the suffering.

5. Conclusion

In conclusion, I have chosen three participants to ground their pain narratives and make sense of their challenges through the lens of the construct of idioms of resilience as conceptualized in relation to their emotionality. These stories brought to light their emotional worlds and their impact on their experience of living with pain and how they worked towards coping within the social relations of their families and the village. I saw that their emotional responses to their complex environments served as drivers and incentivized them toward adopting their individual idioms of resilience. This is not to say that the other participants were not affected by the same entanglements as all people living with pain (Coninx and Stilwell 2021). Moreover, people, in general, will be entangled in their emotions. As everywhere, awareness of context is crucial, and I aim to show some unique aspects of Nepal and discuss contrasts within the UK ³⁵. These vignettes tell stories of circumstances that are particular to my field site but can also extend to others living with pain in similar settings and in other settings.

³⁵ Refer to Lee and Kleinman (2007) for a discussion regarding contextual aspects of somatoform disorders in China and how this/they changed with time.

The anthropology of emotions, primarily in line with Beatty (2013; 2014; 2019), ties in well with my narrative person-centered approach to the relational and relatedness aspects of my participants' emotionality. As Beatty suggests, this theoretical framework addresses individuals' psychological states, context, and life histories, as I observed and heard from Asmita, Tenzin, and Pasang. In my study, I am interested in how the feelings go well beyond the individual in pain and out into their world and back again, including other people, the environment, and the medical landscapes. Beatty describes this dynamism of the emotional world of our participants as emotional episodes that are more entangled and organic rather than categorizing or attempting to interpret and formulate an emotion in the field (2019). Emotional episodes are framed so that we do not define emotion but that they are captured in a broader sense within "feeling, meaning, relationship, circumstance, action, implication, and history " (Beatty 2019, 20). Of course, as the researcher, I do not claim to have a direct line to what people are feeling, and I am careful to try only to discuss what my participants have told me about how they said they felt.

Nevertheless, people may also hide emotions or any number of different behaviors in ways that may be confusing and counter to the expectations of Western ethnographers. Beatty (2013) provides several examples of how he and other ethnographers found it a challenge to their expectations to 'interpret' emotions in the field. He recounts a story of a man in Java, whom he had known for two years, whose buffalo, his only source of income, had died. When they met, the man smiled broadly and did not mention his loss, contrasting what Beatty had expected him to display or bring up in conversation. He continues regarding the ethnographers' understanding of emotions in the field in general, "It is not always clear, for example, whether a reported instance of 'shame' refers to a feeling, a form of etiquette, or an unemotional evaluation of a situation" (2013, 416). Beatty even goes as far as to say, "Mistake the emotion and you mistake the scene; misread the scene and you confound the disposition of the actors; get that wrong and you bungle the whole story" (2019, 3). He does, however, relate that in the field, knowing the context and histories, emotions are elusive and a challenge to understand cross-culturally.

Also, we should consider how we ask people about their emotions, as illustrated in Walker and Kavedzija's (2015) ethnographic study on happiness. They explain that in their

research, they did not ask people if they were happy, knowing that this may be a very challenging question for the participant to know if they were happy and then to articulate it in such a way to be of value to the research. Moreover, the study was not seeking to find the level of people's happiness, but rather, how they made themselves happy and what brought meaning to their lives. I am framing my study similarly in that I never asked people if they were in pain; I did ask how the pain made them feel and how these feelings may have influenced how they went about things and built their resilience.

In contrast to emotions as initially an individual psychological state that 'spreads' out to others and our surroundings, Aulino (2016) describes how two family members care for their chronically ill mother with a relatively unattached performative stance, which provides quality care but at a distance emotionally. Herein lies a relational ritual, provided with care, entwined in Buddhist notions of karma. By providing care to family members, merit is earned in perpetuating 'good' karma and erasing 'bad' karma for those carers. The internal emotional states of the carers do not figure in these interactions, at least in the ethnography, despite the narrative being intertwined and embedded in family relatedness. This dynamic may have been at play in some of the households I observed with the people living in pain and their family members.

Asmita was a copier. She sought experiences and activities to keep up with her responsibilities as a wife, mother, restaurant owner, and farmer. She dealt with issues of personal freedom in this role; her mother-in-law was deceased but had a strong influence as if she were living. Asmita's pain was embodied- her pressures were everywhere. Her body was expected to produce a boy to fulfill the family tradition of male *Bombos*. Within these pressures was the everyday feeling of her mistrust in the villagers. She felt that she was constantly being judged. She may not have felt outwardly vulnerable, but she was... Why else would the witch pick her to bring a ghost to inflict the pain in her back and leg? Asmita did not see herself as being safe in the village; she was only free from harm within her family circle, including her husband, but not his side of the family. Her close family served as protection, and a construct, an idiom toward and of resilience.

In considering the threads of this chapter surrounding emotions either contributing to or perpetuating pain, I saw that Pasang's central theme was fear. It made him open to his soul loss, in his own words. When his soul was gone, he lived in fear, extremely vulnerable to the ghost and his ongoing intrusions into his dreams. Once I saw this underlying emotion that wove through his life, connecting events and experiences, I wondered how I could help him make sense of this.

Pasang felt vulnerable, but for very different reasons from Asmita, whose physical and emotional pain was invisible; she showed a brave face. Pasang, on the other hand, had an obvious disability and was stigmatized for the severe disfigurement of his curved back. He felt targeted and weak in this way and had been assaulted, leaving more reasons to mistrust and be fearful. Hence, Pasang's sense of confidence and self-worth was greatly diminished by his lack of social standing in the village. Not having the foundation on which to build coping strategies impeded him. Asmita, however, had said she was not afraid of the witch, but I felt she could not publicly accept her fear. The *puja* performed by Asmita's uncle was effective in that Asmita felt safer afterward, validated by her family. The battle was over her body during the ritual between the *Bombo* and the spirit, with the spirit returning her health (body) back to her *and* her family. Both Asmita and Pasang displayed fear and vulnerability as drivers toward their journey to resilience, however, their idioms and modes of expression differed.

Hopelessness and feelings of loneliness³⁶ preoccupied Tenzin's days. He suffered a massive stroke, which left severe residual weakness in his left hand, more so than in his left leg, which was also affected. Like Pasang initially, he often talked as if his circumstances could not change and lacked the agency to make these changes. Many of these thoughts were based on his mistrust of the biomedical workers. Tenzin had seen *Bombos* in the early days after his stroke, but since a stroke was not seen as the result of soul loss or the workings

³⁶ I use the term 'loneliness' with Tenzin which may not fit the category of an emotion; it may be that he felt profound sadness, but I am not being pedantic with the word choice. As a subjective state, Ozawa-de Silva chooses to term loneliness in her study of Japanese teenagers and suicide as 'afflictions of subjectivity' (2021).

of a witch, as with Pasang and Asmita, their care was not sought later. In Cheryl Mattingly's *Paradox of Hope: Journeys through a Clinical Borderland* (2010), she follows African American families through navigating the US healthcare system and searching for care for their disabled children. Mattingly explains, "Hope most centrally involves the practice of creating or trying to create lives worth living even in the midst of suffering, even with no happy ending in sight" (6). Tenzin knew that he would never regain the full mobility he had previously.

Nevertheless, he had been entangled in the daily anxieties of never knowing and, in my opinion, when I met him, had given into hopelessness. The paradox of hope, as Mattingly argues, is precisely this: the suffering that hope brings; that to hope means to develop a future where things have changed significantly, and in this practice is the daily reminder of the possibility of a poor outcome. This liminal space of not receiving timely rehabilitative care and mistrust of the health care system, embedded in Tenzin's loneliness, compounds his lack of hope, co-creates, and perpetuates it. I found that with my participants in Nepal and my patients in the UK, many frequently mentioned "how it used to be" and felt a genuine sense of loss and isolation. This sense of loss can be embedded in a loss of ability, leading to a lack of productivity or a sense of safety. Tenzin did not feel valued. In their rich ethnography, Biehl and Eskerod (2013) describe life in a residential 'rehabilitation' center in Brazil called Vita, where people have a profound sense of abandonment and loneliness. Moreover, since there is no end in sight, they are just waiting to die. This position of hopelessness is intense and pervasive. As I saw it, with Tenzin and all of my participants, my role was to understand his hopes and fears and help him ground them in what he could manage as reasonably possible.

However, circumstances changed, and all three developed coping skills and strategies. It was not that they 'confronted' their emotions or 'challenged unhelpful thinking' as may have been recommended in a UK Pain Service. Nonetheless, all three were ready to make changes either through the external assistance of the *Bombos* or by changing activity levels and strategies, or both. To build resilience, Ozawa de Silva (2021b) saw in Japan, following the Fukushima nuclear disaster in 2011, that her participants showed a sense of agency, connection, and support from the community, and contact and friendship with others in

similar circumstances to go through it together, but this was not so apparent with my three participants living with pain. These affordances would have been possible during the aftermath of the earthquakes in 2015 when everyone was affected. I felt it was perhaps an individual change from within themselves, coming from their embodied awareness of the interconnectedness of their emotions and the opportunities surrounding them to move. With the modification of activity and help from the *Bombos* came a lifting of mood for Pasang and an improved sense of safety for Asmita. Tenzin showed more confidence and less isolation through significant improvements in his general mobility and walking distance.

The next chapter will explore two very different participants from Asmita, Tenzin, and Pasang, who showed a sense of hope and self-reliance from the beginning. I was curious about how this developed and how I could help them develop it further. I will discuss in detail the attributes and traits that people may display when working toward coping and resilience building, according to the research.

As an anthropologist working embedded as a clinician, how could I go beyond the biopsychosocial model and try to understand the lived experience of a person with chronic pain living in a small Nepali village that was hit by a severe earthquake?

Chapter 4 Looking outside: The copers

1. Introduction

This chapter introduces two people, Bharat and Tashi, who coped well with their persistent pain. Coping through adversity and challenges led to the developing resilience of these two villagers. Psychiatrist Michael Rutter (2006) defines resilience as “some form of successful coping with the challenge or stress or hazard. This is likely to involve physiological adaptation, psychological habituation, a sense of self-efficacy, the acquisition of effective coping strategies, and/or a cognitive redefinition of the experience” (2006, 2). Further expanding on resilience, anthropologist Catherine Panter-Brick, in her article “Health, Risk, and Resilience: Interdisciplinary Concepts and Applications” (2014), describes some of the complexities surrounding people’s understandings of resilience: “To many, resilience is an intuitive, albeit opaque, concept, akin to fortitude in the face of adversity. It is often conflated with toughness, elasticity, and resistance, but also with insensitivity or invulnerability” (2014, 432). This characterization of people who ‘are resilient’ appears to be a static, fixed personality trait that cannot be adaptive or learned, either on one’s own or through the assistance of others. Panter-Brick appears to be uneasy with this attitude people may take and simply states that she sees resilience as, ...”the process of harnessing key resources to sustain well-being” (2014, 432).

Kiari Kinnie and colleagues (2024), a group of pain specialist nurses, were also not satisfied with the broad or vague definitions in the literature and reviewed thirty-one related articles specifically on resilience in chronic pain. In this work, the authors identified five key attributes of resilience for chronic pain: (1) maintaining a positive psychological equilibrium, (2) seeking support, (3) engagement in meaningful activities despite pain, (4) buffering against negative mental outcomes, and (5) self-empowerment.

This chapter will explore how Bharat and Tashi showed some of these above components of resilience and how they negotiated their coping skills to build towards it within their particular idioms of resilience. Many of these components appear to be fixed categories; however, there is overlap, and this chapter will not deconstruct the differences in detail.

For example, for my purposes, I will not make a qualitative distinction between Rutter's psychological habituation versus Kinnie and colleagues' attribute of psychological equilibrium or Rutter's self-efficacy with Kinnie and colleagues' self-empowerment in the above definitions. It is understood that for some trials and reporting, specific terms are utilized in line with an instrument or questionnaire that may have been administered; for example, the Pain Self Efficacy Questionnaire (PSEQ) used by many pain clinics would report outcomes in a patient using the term 'self-efficacy' to describe their confidence in performing certain activities despite the pain (Raman and Sharma 2022). This attribute also demands being ready to make changes or being willing, which also requires positive psychological equilibrium, and so on. This interconnectedness is part of an integrated approach; such attributes as Kinnie and colleagues' 'engaging in meaningful activities' may be described separately, despite the requirement to not demonstrate parts of other attributes as separate parts. However, to be self-empowered also requires confidence; therefore, I may use some terms somewhat interchangeably.

All three definitions cited above are helpful, and the components will be addressed with Tashi and Bharat's coping skills; however, Rutter's components align with my approach and findings most readily. Rutter's holistic concept of resilience above applies most directly to the integrated enactivist biopsychosocial model approach described in the thesis introduction (Cormack et al. 2023), which I took in my fieldwork and have further applied and developed in my thesis. However, the following assists in situating the model with understanding the lived experience of people with pain:

An enactive-BPS approach helps us to appreciate the complexity and totality of human experience that is intrinsically embodied and embedded in an environment. It also allows us to avoid the potentially reductionist and fragmented perspectives that have developed from the BPSM focused on causative factors. In general, enactivists argue for an integrative framework whereby experience is not located in an immaterial mind abstracted from the living body (i.e., dualism) or simply reduced to neural processes (reductionism). Instead there is an appreciation of the whole embodied person and how interactions in their environment, including other people, enact or bring forth experiences of ourselves and the world. (Cormack et al. 2023, 2280)

The reasons for stating that Rutter's definition is most applicable in my work is its broad coverage of the biopsychosocial and the component of 'acquiring effective coping skills.' However, the component termed 'cognitive redefinition of experience' was most helpful. This process could be explained as the notion of reframing the role pain plays in one's life. To add more layers to this approach, I also applied and interpreted my participants' experiences and stories (which I then extended onto the modifications or advice given) based on the Acceptance and Commitment Therapy (ACT) model, which is consistent with Rutter's thinking. Hayes and colleagues (1999) write that ACT follows the processes of acceptance, cognitive diffusion, flexible attention to the here and now, the self as the observer, and value-based and committed action.

This integrated framework of ACT is used in many pain clinics and is a form of psychological treatment, which I introduced in the body of the thesis through a footnote in Chapter Three. However, ACT's concepts were discussed first in the Introduction. Pain physiotherapists' work is psychologically informed, and ACT is integrated into their work and the transdisciplinary approach in the pain clinic. Essentially, ACT assists in helping the person in pain to understand that there are psychological factors that impact pain and to not solely focus on the intensity or frequency of the pain and surrounding symptoms. These psychological factors are how we 'see' pain in our lives, its role, and how these symptoms can affect what we do and how we do those activities by our choices. ACT does not aim to reduce the intensity of the pain but to help with day-to-day functioning by modifying the effect pain has on our lives. To lessen pain's control over people's lives, ACT uses methods to gain acceptance, which can be achieved through working towards psychological flexibility (McCracken and Gutiérrez-Martínez 2011). Psychological flexibility is acting on our values and goals despite challenging and obstructive thoughts and feelings (Hayes et al. 2006). Psychological flexibility is the overarching theme in ACT, which integrates the six cohesive therapeutic processes mentioned previously: acceptance, cognitive diffusion, contact with the present moment (flexible attention to the here and now), self as context (or self as observer), value-based and committed action.

Nevertheless, keeping with the integrated layers of the enactivist biopsychosocial and enactivist/ecological approach – embodied, embedded, and emerging, I see the emergent

concept as vital in discussing psychological flexibility in general terms and Rutter's notion of cognitive redefinition of the experience. That is to say, these processes are not only integrated but build on what is experienced and learned to create a trajectory (ongoing, so never static) of which the sum is greater than its parts. Anthropologists contribute significantly to the study of resilience and ask essential questions that allow for the ongoing process of emergence. For example, once resilience is defined, Panter-Brick (2014) asks why are resilience and coping talked about, what is the significance? In my case, why talk about it concerning a group of people with chronic pain from three small villages in Nepal? Once it is observed and understood what they did to cope, my participants could reflect on what works and what may not. As a clinical ethnographer, with this understanding, I could better think through modifications in lifestyle and opportunities for change with my participants.

Towards the end of the chapter, I will circle back to some aspects of coping and resilience and align their stories with some of the literature. The thesis Conclusion will describe similar or unique attributes of resilience identified in each of my participants' stories and aims to come to a revised definition of resilience appropriate to my field site. Regarding future applications, how and with what resources the villagers could use to help others in similar environments will be explored in the Conclusion.

Through ethnography, I build a sense of the everyday lives of people with pain in Nepal, including pasts, presents, and possible futures. This chapter emphasizes what the two 'copers' ³⁷ did, their actions, and the dynamics surrounding those actions, hence the title of this chapter, 'Looking Outside.' This narrative differs from the previous chapter, which focused on the participants' feelings, that is, 'looking inside,' though taking into account the environment surrounding those emotions. The medical landscape and the social-relational entanglements and embeddedness are similar for the copers; however, a different perspective follows, which became part of the experiences of the villagers' lives as they learned to cope with chronic pain. The central question is how all my participants

³⁷ In the UK pain clinics, I often heard the term 'active copers' used for patients who were managing their pain well and had a relatively good level of function and well-being.

coped or did not, as was more likely the case. Looking outside, in the way it is framed here, refers to not dismissing introspection or emotionality, but instead the coping style of looking beyond oneself towards the environment and social relations. For example, Bharat's life revolved around helping others, and Tashi negotiated to continue with her habits and everyday tasks. We often heard the term 'getting on with it' in the UK pain clinic. The view is toward the external, that is, something outside oneself- such as social support, finding new activities or maintaining old ones or modifying old ones, separating themselves from the pain with cognitive diffusion or cognitive redefining of experience. Bharat and Tashi *did* look to themselves as the center of this change. They used all their resources, beginning with the awareness they had inside and extended to the outside. To paraphrase Panter-Brick (2014), they used their key resources, both internal and external, to create well-being for themselves. In coping with their struggles, they co-created an extended and interrelated dynamic with and for others and their surroundings to live with their pain.

What follows is an example of the minority of the cases, those who were self-reliant. How did Bharat and Tashi develop those skills? What were their past experiences and foundations that may have assisted in building their resilience and guided some of those choices is of interest. Also described is how Bharat and Tashi approached the sessions with me as the clinician ethnographer; methodologically, these sessions were a very contextual type of physiotherapy. I modeled or demonstrated the activities or exercises, a type of ethnographic practice different from most anthropologists' work in the field ³⁸.

2. Bharat

Bharat knew everyone in the village, and it seemed at first impression that he also knew people from most neighboring villages. His knowledge of many things surrounding general

³⁸ To clarify, this is the usual manner in which to teach exercises as a physiotherapist, the point here is that, for an anthropologist, this is a different way to gather data.

health care, human and veterinary, was in high demand. He said that people walked all day from the hills across the river to visit and seek his advice for their animals.

We met through our mutual friend John, an Englishman who had worked at the local clinic for many years but was now retired in Nepal. They had known each other since Bharat was a boy. The shop he ran sat on the old walking path between our small village and the next one up. Walkers no longer used it so frequently as it was replaced with a dirt road, the 'bus road.' This path was left overgrown with tall grass from disuse. It was clear someone lived along there; on either side of the track were large tarps covered in yellowish-brown spices and shriveling plants left to dry in the sun. Bharat sat on a high stool behind a glass case that contained vials of cattle dewormer, various electronic components for sale, and jars of assorted hardware items. He was cutting up some plums when we entered his shop from the slippery, overgrown path, and he offered me one as he pointed to the tree opposite full of ripe fruit, smiling at the knowledge that I knew they were his homegrown treat. Bharat, who was born into the Newar Hindu ethnic group, looked to be in his early fifties and was tall and trim. He was good friends with my friend John, and he spoke with a warm smile as they caught up on the local gossip. My friend translated his Nepali and explained that I was attached to the clinic and was conducting research. John said I visited people in their homes, listening to them talk about how they managed their pain and helping them learn to live with the struggles it caused them daily.

The sun was hot, and seeing that I sought shade, Bharat moved some cluttered boxes to the side and offered me a seat on a Nepali stool woven from recycled tires, bamboo, and brightly colored thread called a *mudha* (Nepali). It was rice planting season, so Bharat's services were in high demand. The fields were plowed with the traditional wooden beam and share, yoked to two oxen. The animals needed to be kept healthy at this time of year. Within several minutes, a customer came by, leaned on the glass case, and left with a box of dewormer.

During our first visit to his crowded open storefront, Bharat described how he was often called out in the middle of the night to assist with a problematic delivery of a farmer's calf.

This arduous work had caused him chronic shoulder pain through the years as he pushed and pulled to bring this new life into the world, which the farmers could ill afford to lose.

Bharat told me he worked in the clinic as a healthcare assistant when he was much younger. Here, he learned basic first aid and, to my mind, more importantly, how to listen to his patients and their needs. I visited his home many times following our first meeting and was always struck by his dedication to help. His concern for others became central to how I saw he approached coping with his chronic pain, which was quite different from other research participants, but also, in general, in my experience. Quite early in our work together, I began to piece together that Bharat strived for meaningful activities, often helping others as his idiom of helping, to build resilience. I wondered what it was about Bharat's life that placed him in the role of helper, often despite his pain and struggles.

He told me of his youth growing up in a family of subsistence farmers who all worked together in the millet fields, "When I was young, we were often very hungry. My older siblings saw me as weak." I thought his childhood struggles might have been the basis of his never-ending energy and commitment to serving others. This relation was just my impression, but this narrative was consistent as I got to know him more through my many visits with him.

Bharat had a keen interest in native plant species used for medicinal purposes. However, he did not restrict his cures to derivatives from plants. One remedy he used was a powder derived from crushing a dried frog³⁹, which is known to have healing properties. The application to wounds or insect bites helped clear infections. He told the story of visiting a woman living in the forested foothills who caught the frogs and prepared them for sale. I heard of this remedy on my first visit to his house. I was sitting in a high-backed wooden chair in his room while his grandson performed somersaults on the bed on the other side. Bharat said he would return with the frog and left the room before I could object. I

³⁹ "*Paha* (Nepali) is a generic term used in the hilly regions of Nepal for stream-dwelling frogs, represented by the genus *Nanorana* (former Paa), *Ombrana*, and *Amolops* and harvested by the local community" (Shrestha and Gurung 2019, 2). They are used for medicinal purposes and for food.

imagined a frog leaping across the floor and escaping through the window or a different scene of the youngster catching it and squishing it with his tiny hands. I was relieved when he returned with a dead, dried frog in a jar a few moments later. I began to sense that not only was Bharat competent in basic biomedical knowledge for people and animals, but he also utilized local medicinal plants and healing practices for people who came to him for assistance.



Figure 24. Paha (Nepali) frog used for medicinal purposes

Bharat's son, Prasad, ran a small café in a line attached to a parade of shops, the only ones on the bus road in the village. Bharat's family owned the half-finished building, and he ran yet another side business selling chicken feed next door. The cafe was across from the furniture shop and a smaller corner place that sold everything from phone data cards to imported Indian crackers and fresh beef. Young children and toddlers often played on the steps leading up, and it was never that busy except with family members outside chatting.

I was sitting at an outdoor table at the café late one afternoon after the monsoon rains had passed for the day when I saw Bharat bolt across the street to the small shop. A middle-

aged woman wearing a short-sleeved cotton Nepali top (Nepali: *Kurta*) whom I had seen chopping meat with a cleaver on an old, worn chopping block many times had her bare forearm outstretched in her lap. She was visibly distressed. From my view, I could see that Bharat quickly set to work to help by squeezing her painful arm. He sat calmly with her and remained focused, reassuring her while he worked. About half an hour later, he joined us at the café.

“People come to me with snake bites. She was out cutting tall grass, and the snake bit her. Her arm swelled up, but I know what to do,” he explained.

“How do you know if it was poisonous or not?” I asked.

“No, it wasn’t poisonous. There are not those kinds near here. I can tell by the bite. She will be fine. I got to her quickly, or her arm would have swollen up and become very large. She can go back to work now,” Bharat said with quiet confidence.

I was not surprised when Bharat agreed to be part of my project to assist with his shoulder pain and assist me in discovering how he had learned to cope. I was also hoping that I could aid him in his understanding of his pain. He was apparently keen to learn about caring for people’s and animals’ ailments in many forms. I had seen his skill and knowledge and had witnessed it firsthand.

He showed me the medicinal plants he grew on his patio, one of which was a sticky vine whose leaves also helped with inflammation in wounds. On one visit to his shop where we had first met, at the electronics shop, which doubled as the vet medicine dispensary, out from a box under the stool, he brought out a rough grey rock the size of a large grapefruit. It was covered with a dark crust. I thought it might be a type of lichen. Holding the rock carefully and turning it so I could see the black substance closely, he said he scrapped its

crust to use it as an anti-inflammatory for cuts and abrasions for cattle and people. He called the substance *Shilajit* in Nepali.⁴⁰



Figure 25. *Shilajit*

Bharat had an easygoing manner that helped build his circle of small businesses. He was a ‘jack of all trades;’ as mentioned, he had been a health assistant at the clinic, continued his work as a veterinary paraprofessional, and sold chicken feed and electronic goods. Additionally, he used a truck he had purchased to transport people and products. Bharat was a savvy businessperson and a ‘fixer,’ but some people in the village were resentful of his success. His four sons all ran successful businesses locally as well. However, Bharat was always willing to help, regardless of pay, and it became apparent that this was his way of coping with his pain. It may have been his way of living with his childhood suffering, as demonstrated by his ambition. He benefitted from his service despite their jealousy, as did the recipients.

⁴⁰ For interest’s sake, to read more about this substance *Shilajit*, found on rocks in the Himalaya region, refer to Carrasco-Gallardo, Guzmán, and Maccioni (2012), who have written on its use for cognitive decline with Alzheimer's Disease. It is known as a phytocomplex and is described as forming from several plant species depending on location, which have been decomposed by microorganisms. The active ingredient is fulvic acid.

I saw the tireless and steadfast work ethic that Bharat held, always keeping busy, maybe even distracted, as a coping strategy in addition to helping others. In both instances, avoiding introspection and ‘going outside of ourselves’ can take one’s mind off the pain.

During one visit to Bharat’s home, I watched as he stood in his small room, dim from the power cut that day, rustling through a stack of tattered books and magazines on a corner table. He pulled out a worn and faded notebook. He said it was about nutrition. He explained that he had diabetes, controlled it with diet, and did not take medication. The notebook was a scrapbook of sorts that had cut-out faded photographs of various fruits and vegetables and other non-processed foods found in a typical Nepali diet. The book was old, with the pictures peeling on the edges. He had leafed through it many times, or it had come to him secondhand. “I took a course in nutrition,” he said, confirming my notion that he was keen to learn and was self-determined and self-sufficient in looking after himself.

This self-efficacy, Bharat’s ability to follow through with what he had learned and apply this knowledge to his own life to remain healthy, carried over into our physiotherapy visits. He was not a ‘typical chronic pain patient.’ Bharat was active, engaged in work, and did not display signs of low mood. His persistent and long-standing shoulder pain was a common overuse musculoskeletal condition that resulted from the position in which he placed his arm when assisting with difficult calf births. I surmised that he most probably had some rotator cuff tendon fraying and scarring as a result. The pain was then perpetuated by frequent overhead work from lifting and reaching in his day-to-day role in the shop. Sometimes, it could be aggravated by reaching his arm behind his back to get dressed. I was very familiar with these signs and symptoms in my physiotherapy work.

Nevertheless, in my experience, this type of condition is quite recalcitrant and difficult to treat. I was sure through my physical exam that Bharat had not torn any tendons and that the shoulder was not dislocated or had any other tears that would necessitate a visit to an orthopedic surgeon.

A large part of what a specialist pain physiotherapist does is to explain the condition in simple and helpful terms. Helping someone understand their pain from a fundamental

biomedical and biopsychosocial standpoint often enables them to dispel most anxieties, accept their condition, and be more prepared to develop coping strategies that assist them to engage again with functional movement and improve overall well-being. This component of treatment is not entirely viable in a classic clinical setting for apparent reasons: the number of visits is limited, and the opportunity for the clinician to hear the whole story and establish that kind of rapport is also restricted in that environment. My choice to conduct a clinical ethnography for my research allowed me to provide a more dynamic approach, participating and collaborating in an extensive and informed experience for the participants in Nepal.

A pain physiotherapist also approaches why and how people do what they do to perpetuate their pain experience. This process is collaborative but hard going for both. As a medical anthropologist, this takes on other shapes. Living in and participating in the community can provide a deeper understanding. For Bharat, he did not avoid any tasks or movements; I felt he pushed through activities and emotions, as he explained, “When a farmer needs me in the middle of the night, I have to go.” This statement of his irreplaceability gave me some clarity into how he coped; he soldiered on. The question then becomes, is that coping? During the time spent chatting with him about the village and life in general, and during our physiotherapy sessions, Bharat opened up to me. I considered that he maintained this superficial positivity in his reports regarding his progress. It was never wholly evident if he persevered despite the pain, putting on a brave front. However, I did have a keen sense of this. This fortitude and resilience were his strategies when approaching most things. Why would it be different when asked if he continued to be in pain?

With Bharat, we discussed his shoulder pain and what he thought was the concern. I avoided jargon in the UK, which was also crucial in Nepal. Bharat was among the few participants in my study who had his own straightforward biomedical explanatory model for his pain. I saw this as part of his basic training in the clinic since he had most likely seen similar conditions. He was a devout Hindu but did not appear to follow a direct religious explanatory model, unlike most of my participants. The role of the pain physiotherapist and a large part of my role as a clinical ethnographer in Nepal was to assist the participants

in making connections between the experience of the physical understanding of chronic pain and their emotional and general well-being. This approach was and had been a 'hard sell' in my many years in the clinic in the UK, and it was no different in Nepal and when working with Bharat. The medicalization of the pain experience is prevalent in chronic pain patients, as perpetuated by initial encounters with GPs (Stilwell and Harman 2019). If referred to a specialist Pain Service, where I worked in the NHS in the UK, this is often the first introduction to chronic pain as a biopsychosocial experience. In another chapter, I will unpack more precisely the place of religion in the villager's understanding of pain and how it pertains to their explanatory models and coping approaches. Bharat, however, as previously stated, did uphold a more biomedical model.

Bharat chatted a bit more about his experiences going hungry as a child, "I was always hungry. We all were. Back then, we did not plant rice but millet, and there was never enough to go around. I was small and weak, and although there were many jobs to do, I was not expected to help so much because of my weakness," Bharat divulged as we sat in his room while his wife brought us the steamy Nepali milk tea and biscuits. The pervasive hunger had been told to me by several of my participants.

Nonetheless, Bharat did focus on his position in the family as being unable to work. This explanation was offered without prompting, and I always felt that people talk about what is important to them. This story was important to him; however, it may not have been clear how this related to his current work ethic, as I surmised. Nevertheless, I did not feel it was essential to discuss the possible link with him at this point in his life. He was proactive, had his strategy to get through, and appeared happy. However, his tendency to 'push' was a behavior worth exploring with him, as well as the emotional and psychological effects and their impact on him physically. Bringing this together with him, that is, the mind's impact on the body and vice versa, is often an approach in pain management called pacing. It could help his pain levels but also provide him with insights that he was soldiering on. The root cause of this may not come to light, and in my role as a pain physiotherapist ethnographer, I was not going to delve into past traumas or provide therapy for this.

In addition to ‘explaining pain’ and focusing on interweaving the mind/body connection of pain, part of my clinical work was instructing the participants in therapeutic exercises to improve their function. Movement indicates the state of mind and people’s place in their environment (Ingold 2011). Those with chronic pain will avoid certain activities that they determine aggravate their pain (Coninx and Stilwell 2021). I demonstrated some basic exercises to Bharat and recommended that he try these every day. One was what I call a heel-hand rock.



Figure 26. Practicing home exercises

Bharat was in a quadruped position on the rug in his small room. Here, equal pressure was placed on all four limbs. With guidance, he used his outstretched arms to gently push his body posteriorly so that he was sitting on his heels, his forehead touching the rug underneath.

“How is that?” I asked, attempting to avoid a focus on the usually painful shoulder.

“That is fine,” Bharat responded without hesitation.

I continued, “Now lift your hips and come back through the all-fours position, and then let your hips come down towards the ground. Your arms are straight but not locked at the elbows. Try not to hunch your shoulders.”

Moving smoothly and effortlessly, Bharat stayed in the final position with his weight on his hands and turned his head slightly to me, looking for approval. Flies were buzzing in and out of the open window. There was no breeze, and the room was hot.

“Exactly!” I said. Now continue from those two positions, rocking from your heels to your hands without stopping in between.”

“Sl-o-owly,” I emphasized.

He pumped out twelve repetitions, the sweat dripping from his forehead.

Bharat approached the simple exercises the same way he approached his life; this is what I typically saw with pain patients. He saw more as better and pushed through.

“How did you feel doing the exercise?” I asked, attempting to tap into the experience he felt while moving. As is typically the case when I first ask this question, people focus on the pain rather than the thoughts and feelings I hope they notice. When doing gentle exercise or activities, people in pain in the clinic in the UK often said, “I hate this!” “How is this going to help anything?” “I must look stupid doing this.” “When will this end?” or even, “This is easier than I thought.” So, for Bharat, I was not surprised by his response.

Bharat again answered with a positive spin, “That was easy.”

The movement/exercise serves several purposes: to encourage ease of movement by increasing the fluid production in the joint spaces and by providing graded strengthening to the muscles to improve function. However, equally important is the experience of movement to bring the person into the present moment to become aware of their thoughts and subsequent feelings while performing the movement. Feelings of fear of more pain are common. The anticipation of more pain can lead to anxiety. The subsequent behavior is avoiding movement, which begins a cycle of decreased movement and more loss of function and pain, termed the Fear- Avoidance Model (FAM), first described by

Lethem et al. in 1983⁴¹ How Bharat approached the exercises, ‘just getting on with it,’ also demonstrated how he tackled tasks as I saw him going about his everyday life when I saw him in the village. I saw that a large part of his coping and the basis for his resilience was to have a positive spin on his thoughts, feelings, and activities and always to be there for others.

During my further visits to Bharat, he consistently demonstrated the exercises to me, giving me the confidence that he was practicing them between our sessions. He also explained that the exercises were helping and that he no longer felt the pain. Our discussions centered on affirming his steady commitment to maintaining an active exercise regime and healthy diet, but he always returned to his reports of helping people in the community. I did not inquire about his pain directly, as was the same with all participants. The path in pain management is not to rid one of the pain but to enable them to understand it, try to accept it, and be aware of what works for them in terms of coping. I felt that Bharat had established coping patterns, and I had just added the exercise component, which he embraced as another ‘project’ for his health. However, I did not stop our visits or ‘discharge’ him. This pattern of soldiering on I had seen many times.

Several weeks passed, as Bharat canceled our sessions, saying he was busy with the many side jobs in which he was involved. He was rewiring the electricity cables outside of his house; I saw as I passed by on the bus road. I waved hello, and he turned to greet me with both arms stretched overhead, holding the heavy cable. This activity indicated to me that his shoulder pain must have abated. He asked that I come in two weeks to catch up.

When I went by his house two weeks later, Bharat’s wife came to the door and said that he had gone to Kathmandu to the hospital about his shoulder. This type of flare-up is expected with an overuse injury; often, people with chronic pain will go through periods or cycles of higher levels of pain and then minimal pain. Sometimes, this boom or bust

⁴¹ Numerous publications have written on and expanded the FAM, for useful developments in clinical practice application refer to Vlaeyen and Linton 2000 and Bunzli et al. 2017.

cycle is related to pushing through and aggravating it (making hay while the sun shines), or often, there is no apparent causal factor. I suspected it may have occurred sooner and was surprised that Bharat had managed to go for such a period without pain. I also was unsure if his wife was the one who had asked him to go to the clinic in Kathmandu. I was interested in knowing the outcome of the hospital visit and how Bharat was progressing. We met several times again before I left Nepal. His function was good, and his pain levels were low. He downplayed the flare-up and reported that he continued the exercises enthusiastically. Exactly what I expected to hear as we sat in his room for the last time, his attention always on the window, expecting the next customer.

Bharat was a man who did not sit still and always had an ongoing project. Many of these endeavors would bring him cash, and many did not, and money did not seem to be his motivation. He seemed to cope and develop his resilience with his ongoing pain through labor – serving others, using his body. Engaging in meaningful activities as an attribute of resilience, as his idiom of resilience, and was crucial to Bharat's coping skill set (Kinnie et al. 2024). What would happen when he could not do this? Bharat was flexible and could turn to many things. For many people, as with Bharat, psychological flexibility is the underlying skill or trait for coping, moving towards building resilience, not so much his pushing. I was convinced that he would persevere and assist in many new ways once he was older and could not perform his duties and help others through his physical strength.

3. Tashi

Tashi was eighty-four when we met. Her story, like Bharat's, tells of how she learned to cope and build a solid sense of resilience. I saw that she negotiated through her many challenges by modifying her chores and keeping a supportive social network. Occasional visits to the local healers brought her a sense of reassurance and improved her mood for several days so she could continue with her chores. Tashi was not a typical person of her age with chronic pain, as I would have seen in the UK. However, her experiences were more common in the village as I saw people her age carefully walking along the uneven stone steps winding down from the hills or bending down to lift a basket of grass, slowly coming to stand rubbing their backs when feeding the water buffalo. Tashi had taught

herself to accept her pain, and with her idiom of acceptance, as her idiom of resilience, she lived a full life.

When I first arrived at the field site, I spent four days observing the doctor and the health care assistants at the nearby University attached satellite fee-paying hospital. That first day remained burnt in my memories. The winding 'shortcut' through the fields took me up terraces with yet more labyrinths of paths at each level. At one point, the rocks and dirt opened up to a ledge where I took a break from the sun, sitting in the soft yellow hay strewn about. I had chosen this spot for the shade of a straggly dry bush and was bemused to see two smiling baby goat kids chomping with that goat sideways grind, green forage dangling from their mouths a few feet away. A makeshift rusty corrugated metal roof sloped over their heads, protecting them from the sun and away from marauding larger animals. Their loud bleating did not sound like calls of distress, only curiosity. I looked at the haphazard pile of leafy bush branch forage taller than the small, speckled kids. My first thought was that someone had to labor to chop that every day; why didn't the goats graze openly, perhaps with a tether as I had seen in the Caribbean, or else venture out in a herd alongside their mothers?

With this small scene, I began to see the nature of the region's labor-intensive agricultural practices, thinking of the workers and their painful bodies.

Many months later, watching the school children return from the high hills carrying bundles of thick-bladed grass in baskets on their backs, the *namlo* (Nepali: basket strap) tight across their foreheads, Maila, my research assistant, said to me. "I used to cry and cry when I was small, and my father made me go with him into the jungle to cut grass." Other than being amazed that such a young child was expected to carry such loads, I asked, remembering the goats from that day, "Why are the animals kept enclosed, with the feed brought to them rather than allowing grazing?" "That is how we have always done it," she answered. Later, John told me there were tigers or leopards in the past; he was unsure which, and they would attack the farm animals. Much of the forested habitat is gone now. Nevertheless, the practice of enclosing the livestock continued despite the daily task of at

least one family member walking up the steep hills to chop the grass by hand with the small *hasiya* (Nepali: sickle) kept tucked in their cloth belts, always at hand for work.

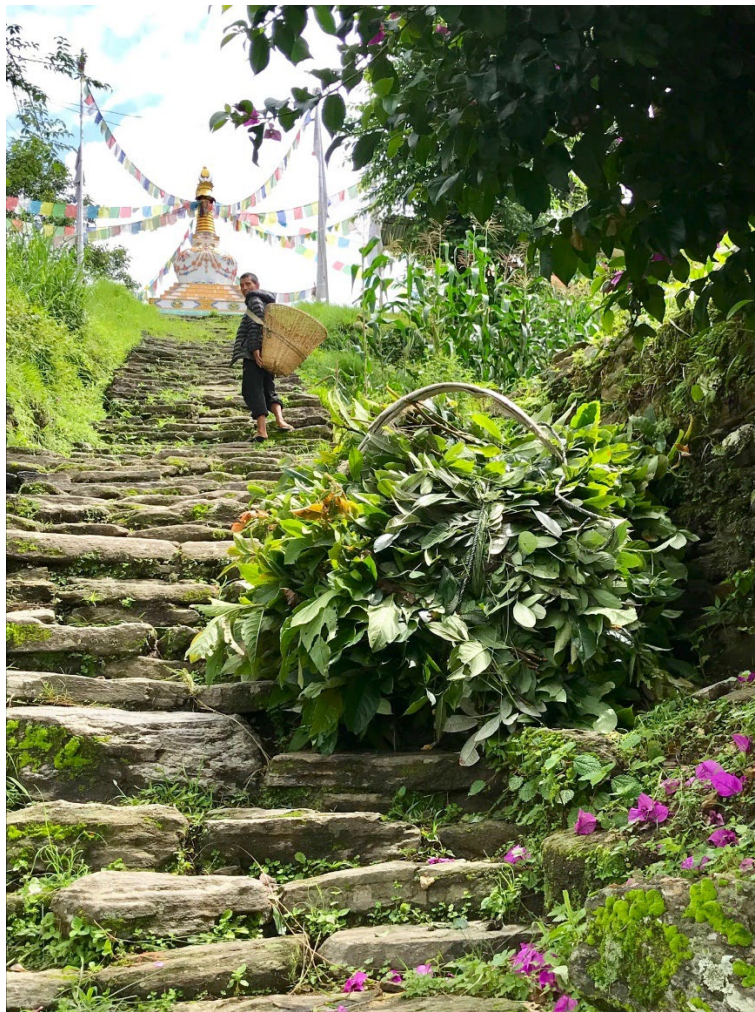


Figure 27. Steep stairs on the way to cutting animal fodder

At the entrance to the clinic, a health assistant in his early sixties sat behind a wooden desk. He had worked there for many years and was seated conducting triage. Sudip was well respected; it was clear. Close-shaven, his short hair was slick with oil under his Nepali *topi* hat. He sat with a broad smile for the patients. After taking basic vitals- blood pressure and heart rate, then name and age- the patients sat to wait for their turn, huddled up along an extended wooden bench. I greeted him, and he invited me into the larger adjacent

room. I met the staff the day I arrived in the village several days before. They were expecting me that day.

The exam room at the clinic was large, with six beds relatively far apart to accommodate many family members and the staff. The senior health care assistant was seated with an older woman describing her persistent cough; another staff member tended to a young man with a small wooden splinter in his eye. The young doctor, Sundar, trained in Kathmandu, was in his late twenties and had been assigned here for the past few years. As I walked in, he stood by a bed, adjusting a saline IV hooked to a thin man positioned side-lying, curled on one of the beds. The patient had come in from the fields, black dirt still caked on his feet. I had seen many men guiding oxen through the muddy paddies in my short time there. I could only imagine his fatigue and pain.

I asked, "What is his condition?" Sundar replied with some mild impatience directed to the farmer, "He is tired and dehydrated. Many of them come for the IV to get the energy to return to the fields. My predecessor started this treatment, and many villagers are used to it. I tried to stop it but received threats, and rocks were thrown at the clinic windows."

This response was troubling and provided some insight and context. I did not respond directly but packed this knowledge away in my efforts to understand the complex entanglements of rural healthcare services in the region and the pain and overwork that led to these desperate attempts to receive care.

We walked over to another patient. Tashi had shiny apple cheeks that hid her eighty-four years. She was expecting me, which I had not realized. We chatted briefly; I asked for basic information, knowing that the clinic was busy, and she described that she had recurring longstanding low back pain and had been taking paracetamol, which did not seem to help. Additionally, Tashi had not been given any activities or stretches since her initial pain a year previously, and no physiotherapist was attached to the clinic. Although I would spend only four days at the clinic during my fieldwork, I concluded that often, the recommendations were to take an ibuprofen/paracetamol combination for musculoskeletal conditions rather than activities or gentle exercise. Moreover, there was

a small fee for medications and a clinic visit. After showing her straightforward stretches to hug her knees to her chest, I asked if I could visit her at home.

I arrived accompanied by a recent physiotherapy graduate from Kathmandu, a friend of Sundar's who was visiting the village. Tashi's house was on the bus road and was a two-story, solidly built cement house, one of the few structures that remained livable following the earthquakes in 2015. This village where the clinic was located was predominantly populated by Hyolmo people, the same village where Tenzin and several of my other research participants lived. There was a secondary school, whose name some children told me, translated to mean 'itchy.' I often walked there, avoiding the bus road, and preferring to navigate the narrow paths bordering the rice paddies, which then opened up to flattened grey boulders resembling an obstacle course under the hot sun.

Tashi welcomed us at the door and ushered us into the living room, pointing to cushions on the floor to sit on. She quickly disappeared to another room and returned with a thermos filled with hot Nepali milk tea and a plate of biscuits. She bent over from the waist to place the plate on the low, long box-like table, and poured our tea. I looked at her movements, assessing her ability to navigate her environment. There were old photographs of Lamas wearing ceremonial gold pointed hats on the walls.

We introduced the research and explained the consent forms. Tashi said she was grateful we could visit her to help her manage her flare-ups and possibly prevent their recurrence.

"Tell us the story of your pain, from beginning to end," I said, encouraging her to explain it in an open-ended narrative. I began most of my first sessions with all the participants with the request⁴².

It was about a year ago. It was about eight o'clock in the morning when I went to tend my buffalo and cut grass. I felt quite a sharp pain that seemed to worsen throughout the day. Later the same day, when I felt the pain, it was just little, and I was picking some vegetables as well, and I wanted to sell the beans. So, I picked those vegetables, and then I went to sell them. It was like mid-afternoon, and I

⁴² I modified this specific 'opener' line of open ended questions from Mattingly (2010).

thought...because I had the pain, I thought of going to *Lama Jhangkri*⁴³, but then if I go later, then I thought there would not be anyone who could call them when it was late. So, after I sold some of the vegetables, I went to a *Jhangkri*. And then, after meeting the *Jhangkri*, I came back, and by the end of the day, it was getting very bad, and I could not even get out of bed. That was in the month of Asar, so Asar, Shrawan, Bhadra, for like three months...three more months, I had the continuous pain, and it was very painful. Then my son asked about going to Kathmandu and then getting the checkup and medicines. So, I went to Kathmandu, and then, after three months, I started taking medicines for my bones. (Tashi)

"Tashi, what did you do during those three months when it was quite painful?" I asked, interested in how she managed to cope with the pain and how she may have modified her activities.

She responded,

Asar, Shrawan, Bhadra....What did I do.... *Lama* said it was *chaalaak*⁴⁴. So, I went to see so many people and asked to blow⁴⁵... Nothing happened. Did not get better. And then I went to see so many *Lamas* from Raithaane⁴⁶, the *Pujari* (Nepali: Hindu healer), they blew on me, did so many *puja*... so much...I also went down to a village; it is called Sheley, there I went and even stayed for a night for them to blow. Everybody said it was *chaalaak*, but it never got away. After that, I saw our big *Lama*, and he also blew on me... everybody blew for me, but then only after I went to Kathmandu, they did an X-ray and video X-ray and found that this bone was affected... the bone was affected, they said. After that, again Asoj, Kartik, Mangsir, Poush, Magh, Falgun (Nepali months) ...25th of Falgun I went again and on 26th they again did an X-ray and found that my bone was fractured actually but the crack was going to join (Gesture: Pointing her back). They said it had started joining so the pain would disappear, but it never actually disappeared. After that again, I went to the hospital here, there was Sudip Sir. He is my son's friend... they are good friends, and after that when I went there, he said to come tomorrow

⁴³ My Hyolmo participants used the Nepali term *Lama Jhangkri*, which is the same as the Tamang term *Bombo* which I use more frequently.

⁴⁴ The Nepali term *chaalaak* is first described as 'the sound made when something is tearing apart' in Chapter One section 1.7 .

⁴⁵ Refer to Chapter Two for further reading about *ngaba*, Nepali term for the blowing ritual healing.

⁴⁶ This is the nearby village mentioned in Chapter Two where the Tamang *Bombo* live to be near the holy lake.

because the next doctor would come who could look at her case better...it was her...I found that later...and today. (Tashi)

I realized Tashi was referring to me as the "next doctor." I continued chatting about how she had managed over the last months, knowing she lived alone. She said she still had to give water to the buffalo and cut grass, but she would rest if the pain had increased. Her house was tidy and swept, and I commented on how nice it looked, prompting her to tell me if she needed help to maintain her house. Tashi explained that she kept up with the housework on her own. If there was any fruit growing, she also tended to the plants. She left the room abruptly and returned with a Velcro cloth back brace. She explained that she had been given this at the disability hospital in Kathmandu. Her first words were that it cost 3500 Nepali Rupee (£22), a substantial sum for a farmer. I also thought that it was expensive for a similar item in the UK. She said she wore the brace continuously for three months and had only recently stopped using it with flare-ups. Tashi summed up, "And I never stopped working because there was so much to do, but then I did not do difficult tasks, just normal household work, but then since I have cattle as well, I had to look after them, and then I also did some gardening because I had some plants for fruits and all."

I was curious about what Tashi had said the *Jhangkri/Bombo* called *chaallaak*, the reason for her back pain. She explained that all of the *Lamas*, and *Jhangkri/Bombos* had told her this.

"*Chaalaak* means like when you carry a load, (Tashi gestured carrying weight on her back) stressful heavy things, if that happens, it does *chaalaak*, and after that, we cannot walk, and it gives pain all the time. If you blow or do *puja*, it disappears". I thought that Tashi was confused and unsure if her pain was from *chaalaak* because I surmised that she thought it would have gone with the rituals. She continued:

Before, I thought like that, but then it was not like that. It was because of my bones... like trees...like wood also rot.... like I am an old lady, so as you become old, the bones also become curved. So, now I know about this; before, I did not know these things. I was confused before. Maybe it was due to *chaalaak*, but it was not like that. (Tashi)

Tashi explained further that the doctor in Kathmandu had shown her an X-ray of her spine. He had told her that her pain was from a "crack" in the bone, but it had healed. Tashi relayed this information and the reassurance that it would slowly get better and not to worry. She was perplexed as to why the pain persisted. Again, Tashi repeated how she had been to several *Jhangkri/Bombos* and had the blowing ritual and the chicken sacrifice without relief. After the X-ray explanation, she came to the clinic in the village. "No matter how often I went to blow, it did not go away." Tashi said she heard that a doctor in another village could give an injection for pain, so she traveled there. When she visited him, he said he did not have the equipment with him. Tashi went again to the *Jhangkri/Bombo* in that village; "After the blowing, you feel better too. You feel it is very comforting in your heart, so maybe because of that. I did not call him for the injection," she laughed.

Tashi said her pain was on and off after talking with the doctor who could inject. Afterward, she went to the hospital in Kathmandu, where they gave her the brace, explained the X-ray, and gave her the medication. Recently, she said that she had been doing the exercise I instructed her at the clinic, was feeling less pain, and could resume some of her activities. During that first home visit, I realized that my task during the several subsequent sessions would be to reassure and explain to her that the longstanding pain was typical. Despite the "crack" (possibly a wedge fracture from osteoporosis) having healed, often the pain persists. I liked her tree metaphor and felt that it was a valuable way to frame our future talks in imagery that was meaningful to her.

I was interested in how she talked about the *Jhangkri/Bombo* blowing ritual as comforting, which was helpful to her. "I feel happy. I think after they blow, it goes away, and I will get better, but I still have the pain a little all the time. I feel happy for about two days after. But if I have a fever or my blood pressure is up, I go to the clinic. I think the *Jhangkri* only work with *chaalaak*."

We chatted about *chaalaak*. I did not want to say directly that this framing of overuse injuries and typical age-related degeneration as a condition that only the *Jhangkri/Bombo* could help was slightly contradictory as I saw these explanatory models as much the same but within different contexts. I ended up saying that the doctor's explanation from looking

at the X-ray, her tree metaphor, and the explanatory model of the shamans were similar, reassuring her that they all were 'right' in many ways. I hoped this would ease some of her anxiety without challenging her meaning-making. To Tashi, these represented her back pain differently, not based on the cause but the treatment. It was fascinating how she categorized them intellectually.

However, she emotionally knew she felt better from the *Bombo's* blowing ritual and kept returning.

"If I have heart pain and for *chaalaak*, if *Jhangkri* blow, then it would disappear, or else for other...If I have a headache, I take paracetamol, which takes it away (laughing). If I have a fever, I take medicines, and the fever goes away. *Jhangkri* cannot do more ".

I rephrased a question about feeling happy for a few days. I felt that this was powerful and asked again in a different way as I sensed that talking about the emotional aspect of her back pain was not easy, especially given that this was the second time we had met.

Tashi continued by talking about the days when her mood was low when thinking about her mother and how she sometimes cried when she remembered how she missed her. She said she wondered if only she felt this way with the pain, how she looks at other people and sees them moving around. "I am just here, and I cannot do anything. I tell my mother to come to take me with you, but I have to live with the pain. I do not want to, but I have to. If my friends come and if I talk, then the pain goes away".

After one session, I walked up a steep shortcut with her. She said this was a quick way and always used it, pointing out the clinic helicopter pad as we passed it. Tashi leaned forward at the end of the hill, only slightly short of breath, and with the last step up to the dirt road, she put her right hand on her right thigh for that last extra push. "I will go left here; my sister lives just down the road."

We talked quite a bit throughout our many visits about how she kept up her friendships and family contacts. She clearly saw these connections, as she mentioned above, that her

pain went away when she was with people. This simple strategy may appear obvious. However, none of my other participants stated it so plainly and logically.

That first day, we said it was time to go, and I thanked her. I told Tashi how impressed I was that she was doing the exercises and thought she was moving around very well. I asked if I could come in a week to see her again and discuss how she was doing with the exercise. She was very thankful, and as we said our goodbyes, she added, "You come to me! I do not even have to go to the clinic. I feel nice".

The next time I saw Tashi, I knocked on her door and heard a shout coming from the back of the house. Walking down the slope, I saw her bent fully forward to spread out peppers to dry in the sun. The tarp was about fifteen feet square and covered with hundreds of tiny red plants. Again, leaning on her thigh, she stood upright and wiped her forehead, saying she would be up momentarily. Once back in her living room, Tashi said she had been doing the stretches I added with each visit. She ensured that we had our tea and biscuits and then began to demonstrate the exercises we agreed we would do several times daily. Lying on the carpet on her back, Tashi slowly brought her bent legs with her hands behind her knees and gently rocked side to side. I called this The Baby Roll, and it helped relax the back, stretch the spine into flexion or forward bending, and improve hip mobility. I counted with her as she breathed in, counted to three, and breathed out, counting to three in time with the movement, which aided in relaxation.

"How is that?" I asked purposely, not asking about the pain levels. "That is fine. I do these every day," Tashi answered.

Next, still on her back, she placed her feet flat on the floor with her knees bent, facing the ceiling, and with both knees together, she brought them slowly side to side.

"That is perfect; this one helps to twist your back a bit; your back likes that movement," I said.

It was clear that Tashi enjoyed doing the simple exercises and was confident when doing them. I explained to her again that it is helpful if they are done little and often to help your

back loosen up. I continued that it is nice to take a break during the day and lie on your back, too, that she did not have to push through them and that the exercises should be manageable. Sometimes, it is painful at first, and then the pain lessens as one continues with them, I reassured her.

She began to tell me more about her childhood and how she had worked hard all her life. She pointed toward the steep hill, one thousand feet high, over the village. I walked up it many times to visit a temple that had been mostly destroyed during the earthquakes, the center of Hyolmo's life in the region. Walking up further still were more shrines. There were no houses due to the incline; however, villagers still accessed it to cut their forage. I had heard that much of the forest cover was gone due to a fire. Attempts were made to build a dirt road that vehicles could access. However, it continued to wash away during the monsoon. She said her sister had always been with her working on the hill.

Tashi talked about how her daughter left for Dubai and, from her remittance money, was able to build her house that withstood the earthquake. Her son lived in the village, and often, I sat at his tea shop across from her house before I visited, checking in to see if his mother was home. As she felt more active than before, she was not always home when we planned to meet. I was happy that she was out and visiting.

Tashi laughed a lot but sometimes looked down when talking about her younger life, how it had changed with age, and the pain she felt in her back. She worried about her future with her daughter away, saying that although her son lived nearby, he had his own family. Tashi's husband had died many years before. Her coping style was simple but effective. Rather than taking on new activities, as may be the case with aging people in the UK, Tashi adapted and modified what she had always done. There were no new things to do specifically for the elderly, no new approaches, new hobbies, or new groups to join as in the UK. Tashi found her way, navigating between what made sense to her. McCracken and Eccleston (2003) compared coping strategies against working towards acceptance of pain, and their findings showed that there were better outcomes with acceptance. However, I feel that my participants' outward-focused coping strategies were effective and also included acceptance. Tashi and I chatted about how she had a good sense of judging her

limitations when working and some ways that she could modify them. The cows always had to eat, so that was a priority. Tashi based her activities on her values, on what she thought was important and meaningful. However, some housecleaning and other chores could be done at a slower pace.

4. Conclusion

This chapter brought to life some details of what two relatively resilient ‘copers’ told me during our sessions. Both grew up in the area. Tashi is an elderly Hyolmo woman and Bharat belongs to the higher caste of businesspeople and traders in the Nepali Hindu community.

Bharat coped by helping. He was a ‘fixer;’ people came to him to assist with their health needs and animal health concerns. Moreover, Bharat ‘fixed’ himself, was self-reliant, and was eager to learn, for example, how to control his diabetes through nutrition. By surrounding himself with projects to help his neighbors, he essentially helped himself ⁴⁷. Bharat’s idiom of resilience situated him in creating meaningful activities but also placed him in a position where people counted on him and believed in him. I saw that he was self-disciplined in following through with his self-care. With these coping styles, he showed psychological flexibility⁴⁸. If something did not work, he changed it, or in his business ventures, he started a new one. He diversified. Putting oneself out there also shows vulnerability and self-sacrifice; things may not always go according to plan. Like Liisa Malkki’s (2015, 4) work with the Finnish International Red Cross, “...people sought to be something greater than themselves, to help, to be actors in a lively world”, Bharat chose value-based, meaningful activities that helped him and others.

⁴⁷ See Riessman’s foundational article on the Helper Therapy Principle (1965) which describes how people improve self-esteem and self-worth by helping others.

⁴⁸ “...psychological flexibility which is defined as the capacity to persist or to change behaviour, including a conscious and open contact with discomfort and other discouraging experiences, guided by goals and values and is regarded as a resilience factor among individuals with chronic pain” (Moens et al. 2022, 2).

Karoly and Ruehlman (2006, 90) write on resilience:

Although 'resilience' resembles the more familiar concept of 'coping', the former is, in fact, considerably broader in scope. Resilience not only denotes potentially protective factors such as self-conscious efforts at mastery (i.e., coping) but also encompasses genetic, neurological, developmental, interpersonal, contextual, spiritual, affective, and non-stress-related cognitive attributes (such as intelligence and values) as well as individual difference dimensions that impart relatively stable levels of stress resistance to at-risk populations.

How did I know that Bharat was resilient? I can say that my time spent with him and getting to know him forged empathy (in myself as a 'fixer,' as a clinician). However, I felt I could deepen this connection as a researcher. Bharat showed empathy toward the people he helped; indeed, resilience becomes emergent through caring and valuing others and oneself. The components of coping- self-efficacy and self-reliance were evident in his actions and behaviors.

Is doing the right thing, or feeling one is, a solid foundation on which to build a strong sense of resilience to overcome the challenges of living with pain? Regarding karma, villagers told me that motivation for and intentions of actions determine the authenticity of earning karmic merit (Aulino 2016). Bharat said several times that he was the weak one growing up, which must have impacted his choices. However, it is difficult to say how.

Aligning with Mattingly's ethnography, *Paradox of Hope* (2010), is Tashi holding on with some hope for the pain to go away? This desire can exist at many deeper levels, as we naturally have an aversion to pain. Does this hope hold her back as the paradox of hope, the wish that something will change, which may in some sense prevent acceptance and moving on? Often, when people in pain stop looking for a cure, this can foster acceptance (Karoly and Ruehlman 2006). I saw that Tashi left room for change, change that she would have to be the one to make, hence demonstrating her idiom of resilience as an idiom of acceptance with her pain, but also acceptance and trust in herself and her choices. Tashi clung to notions of *chaalaak* as an explanation by the *Bombos* when it is the same as the biomedical explanation, which she also accepts. She feels that the blowing ritual should

not work because it is not ‘really’ *chaalaak* (or only *chaalaak*), but she feels comfort from it, which has been the most helpful – in addition to the exercise and modification of the activities with pacing. The blowing is not about the ritual in this instance. However, it is around the meaning that she attaches to it, how it affects her mood, and the self-soothing and familiarity it brings. In all, Tashi has choices; she has agency and the affordances upon which to act (Coninx and Stilwell 2021). As with many aging people, an unknown for her is who would care for her when she could no longer look after herself. This insecurity was not a subject she brought up often, however.

Returning to Rutter’s definition of resilience, “some form of successful coping with the challenge or stress or hazard. This is likely to involve physiological adaptation, psychological habituation, a sense of self-efficacy, the acquisition of effective coping strategies, and/or a cognitive redefinition of the experience” (2006, 6); this chapter has illustrated it as the lived experience of these two villagers. Tashi and Bharat both underwent numerous stresses in their lives prior to developing chronic pain. Not everyone can and does cope well living with pain, mainly if they have not built up the resilience prior. However, Rutter (2012) describes that when people are exposed to stressors, this provides an opportunity for adaptation, habituation, and redefinition to use Rutter’s words. The last term in the definition, paraphrased as changing one’s perspective, as mentioned previously, is the most crucial in my mind and was apparent in both Tashi and Bharat. In other words, if one sees it as a problem, it becomes a problem. This viewpoint can be complicated to maintain living with constant bodily pain, however.

Both Bharat and Tashi developed inner flexibility to ‘look outside,’ pursue social support, engage in meaningful activities, and the other attributes of resilience described in this chapter are seen in the literature cited. Nevertheless, they had to build those inner resources through their own early experiences and hardships and then have the self-efficacy to know what opportunities to seize and which to pass over.

To redefine the experience of pain, and this was evident with Tashi, we chatted extensively about her explanatory model (Kleinman 1980). My in-depth understanding of her explanatory model of why she was in pain was crucial to demystifying and decreasing

anxieties surrounding concerns of sinister causes or outcomes, much like Jadhav (2001) when working in East London. Within the anthropologist's fieldwork and research, this process is far more possible than in the clinic. In the UK, the patient's understanding was often biomedical in terms of causality, that is, that it stemmed from an injury, and it was a very 'hard sell' to communicate an integrated model of biopsychosocial or enactivist biopsychosocial to them to begin to develop coping strategies (Cormack et al. 2023). However, Bharat and Tashi had an eclectic and integrated understanding of their pain, and I believe this broad view led to more acceptance. What I sought to do together with them was to seek to normalize their experience; it is possible to gain acceptance when we perceive something without anxiety or fear. Many people with pain in the UK I treated had a history of stressors; however, they insisted on a unidirectional, biomedical/biomechanical perspective with their experience. This view often limits acceptance. Tashi saw and understood that the X-rays revealed the vertebral fracture and that she may or may not have *chaalaak*, which was the Indigenous understanding of what would be termed nonspecific musculoskeletal low back pain in the biomedical sense, which is non-neuropathic, and without one specific cause, which is the majority of cases.

Nonetheless, Tashi did see these explanations as different, one Indigenous and one biomedical. Furthermore, she had her own powerful description, metaphorizing her back as a tree, subtle when young and curved when mature. This imagery brought her to normalize her experiences as a part of her environment, her landscape, and one she sees daily in the hills surrounding her.

To continue with the theme of coping and resilience, the next chapter tells of a middle-aged Hindu man for whom life after his accident was very challenging. He struggled to find a balance and was reluctant to change and adapt. I attempted to assist in understanding the complexities of his psychological inflexibility without much success.

Chapter 5 “Kasko bauko ke lagnu” (Nepali: nothing can be done)

1. Introduction - Ram

I met Ram during my first week in Nepal when John, the British nurse who had known him for many years, led the way through the dense, tall grass and trees toward his house, mainly made from corrugated metal. Desperate to keep up, I found myself scrambling small boulders, gripping their slippery surfaces unsuccessfully. John said I might be interested in meeting Ram, that he had sustained a spinal cord injury after falling through a roof. He subsequently became paralyzed in both legs and was now using a wheelchair. Knowing that I worked with people with chronic pain, John explained that his friend had complained of back and hip pain since using his wheelchair and thought I might have some ideas to share. I was fascinated to know how, in this rural and remote region, someone living with lower limb paralysis and pain coped day by day; what resiliency skills did he have? Could he develop more, and what would the strengths and challenges be?

I rubbed my scraped knees after jumping down from another big rock. My thoughts turned to accessibility. "How in the world does this man propel his wheelchair through this terrain?"

I thought we might be lost, but I also trusted that John knew the way. Trudging uphill after crossing a small stream that trickled through, carrying the runoff from the newly planted rice paddies, I looked up, perplexed at what I saw. I felt a silent sigh of relief, realizing this was evidence that we were nearing Ram's house. Beyond some more jagged boulders and sharp jutting rocks was a wheelchair sitting on the rooftop of a small shed-like structure surrounded by boulders.



Figure 28. One of Ram's six wheelchairs

I laughed and commiserated with John, who knew this common situation all too well. Often, well-intentioned healthcare providers source wheelchairs and other devices without conducting accessibility assessments or talking to people with disabilities in depth about their needs and intentions for the assistive devices. Nevertheless, this happens everywhere. It was amusing that it was perched up high on the shed roof, an invisible sentry keeping watch? Or a tempting but potentially dangerous playground for naughty neighbor children.

In this chapter, I tell Ram's story. He was quite challenging in terms of personality and expectations. He struggled to cope on many levels. I will develop his story into issues of

accessibility/mobility, access to care, patient choice, and family involvement with underlying themes of emotions of anger and hopelessness. Weaving through his narrative are his challenges with acceptance and psychological flexibility as a process towards coping and building resilience. My position as a clinical ethnographer working with someone who has declined care will also be explored.

When John and I finally reached the dirt courtyard on that first visit, Ram sat outside in the shade of an awning, slightly slouching in his steel-framed wheelchair. He had a wooden lap tray on the armrests, where he placed a cup of steaming tea. I wondered how long he had been sitting in that one position, conscious that his feet were swollen and dangling down but supported by the footrests. He told me what happened the day he fell through the roof. His words were measured and deliberate; he sounded almost bored in the retelling. I was sure he had recounted this story many times. He told us how he repaired a roof twelve years ago as a carpenter, and the wood gave way. Ram had a sense of resignation as he asked John why I was there and how I could help him. I asked him what he remembered explicitly about the day.

Ram described how he came to, finding himself on the debris-filled floor. Having lost consciousness, he was disoriented and confused. His attempts to stand were futile. Still shaken, he naturally tried to stand again, but without success. Three men helped him up, and at that moment, he saw that his lifeless legs could not support him. His colleagues dragged him, one on either side, to a nearby work vehicle and drove him speeding up the bumpy road to the nonprofit/nongovernment hospital. The doctors and health care workers quickly assessed that treating him was beyond their scope and advised him to go to Jorpati, the hospital outside Kathmandu, called the Nepal Orthopedic Hospital. Ram told me he underwent surgery once there.

He described what happened afterward again with an air of distance. I did not know if this was the usual recounting of his story; perhaps it was due to John's presence. Ram was pleasant, and he and John laughed about old times between his recollections:

After the operation (the doctors told me), your spinal cord has broken, and you have broken your backbone too. That time, my

hands also were not moving. Then, one month later, they discharged me, then I came home. Then, at home, my hands and legs were not moving. Then, to move that again, I went to a center. I exercised there after my hands started moving, and that is all. (Ram)

Ram seemed to accept the explanation from the medical staff. It was clear to him that his spinal cord had been injured, and his lower limb paralysis directly resulted from this lesion. When we met, he did have full strength and function in his upper body and was non-ambulatory; however, his main complaints were his persistent tingling nerve pain (*jham jham*: Nepali), as he described it, in his hips and legs. He also said his back was often *kat kat* (Nepali for achy pain). Nepali descriptions of pain can be onomatopoeia, which are usually two words repeated⁴⁹. The medical personnel also were straightforward and realistic in terms of his prognosis. Ram said he was told this was permanent; he did not expect to regain his feeling below the waist or his leg strength. He did say this with conviction. However, as discussed in previous chapters, this did not signal 'acceptance' as a step to resilience, as I would later learn. I did not feel that Ram took the regaining of the function of his arms as a sign that there would be similar further progress with his legs, especially given the time since the injury. Often, there can be prolonged swelling around the injury in the early days post-trauma, which can reduce, allowing for further recovery. However, this must occur within a short time frame.

I asked Ram what he wanted to change and how I could help him reach that. As I often heard, he described the *kat kat* pain in his back and hips. My first thoughts returned to how long he spent in his wheelchair. He said he sat there about eight hours a day, right where we were under the awning, away from the direct sun. I wondered if he needed help transferring from the bed to the wheelchair. He said he did this independently with the help of some wooden blocks to gain leverage with his arms. I said we would look at this during our next visit. As I usually do in the UK, on the first visit, I do not ask too much and

⁴⁹ Refer to Sharma, Pathak, and Jensen, (2016), a study done in collaboration between Nepali and US physiotherapists who looked at local words used to describe pain in Nepal in comparison to those used in the United States. Also Kohrt and Schreiber (1999) describes a mixed methods study based in a Nepali village where a high incidence of *jham jham* (pronounced *jhum jhum* in this case) occurred.

do not ask people to do much physical activity, especially if I know it will not be easy. I kept it in the back of my mind to bring up at the next visit- the probable relation of the back and hip pain in particular and how the prolonged sitting could exacerbate this. Again, I felt it was necessary just to try to listen to him and not tell him what to do.

The topic of a new wheelchair came up, as I had suspected. Ram said that he had had six wheelchairs in total, each being unsuitable in one way or the other. One had been destroyed in the earthquakes. The nonprofit/nongovernment main hospital in Kathmandu to which the local satellite hospital was attached had supplied one, another from a private hospital in Kathmandu, one or two from the local nonprofit/nongovernment satellite hospital in the nearby village, and finally, his wheelchairs which friends had provided. When I asked Ram why he felt he needed a new one, he was unsure; he thought I perhaps had access to one. Again, I did not feel it was the time to address my suspicion that replacing the wheelchair itself would not help the things he wanted to change.

We chatted about medication. I usually bring this up first. However, sometimes, a person with a disability might do so as well. It gives me a clear indication of what other conditions they may have, some insight into their pain levels and how they may be coping, and notions regarding the local prescribing practices. Notably, the medications they take provide helpful information about how they see the role of the pain, their narrative surrounding it, and its place in their life. Does it control their life? Is ridding their bodies of the pain their primary focus? These are some questions that may become clearer. Such as with Ram:

It is not useful to take medicine. I had to take medicine for my whole life, and it is not good to take medicine. I can bear this sometimes. I feel tingling pain, which is ok, but I did not take medicine. Of course, that will happen to the body when it hurts. That is what it is. It is tingling I have to bear, like when a fire burns us, we can bear that. Like that, I had to bear. What to do? It is impossible to throw out that tingling. I should bear this. What to do? To reduce it, my wife uses some oil and massages around when she has time, maybe once daily. But she is a busy farmer; we have no income and must eat. It makes it a little bit better. Otherwise, it is impossible. (Ram)

I was beginning to formulate how Ram saw his life living with pain. Often, people desperately try to rid themselves of it, understandably. However, with long-term pain, as

Ram states, it is impossible. Accepting is often seen as a failure, giving in, and losing the fight. He suggested that he had accepted his tingling pain and had to bear it. However, as I spent more time with Ram, this did not apply to many things in his life. I also began to see some contradictions; when I first asked what he wanted to change, he mentioned the *jham jham*, but now Ram told me he had to bear it.

I asked if he could be in bed when I visited next to see how he got up and maneuvered. We timed the visit, so I arrived around when he was due to get out of bed.

2. The second visit- personal activities of daily living

When I arrived the next time, only with Maila, my research assistant, Ram was in his room. All four walls were corrugated metal and with a bare cement floor. Flies were in the entrance, and the air was stuffy as we entered. Ram was lying on his side facing the wall as his granddaughter played in a nearby bed with some Mickey Mouse coloring books. His wife Akina held a gentle hand on his hip and a long strip of gauze in the other bare hand. She was dressing a very large deep bed sore (decubitus) with the non-sterile discolored cotton. Flies surrounded the wound, and some sat directly on it. The edges were discolored with infection. The discussion quickly turned to wound care⁵⁰. Akina explained that she dressed his bed sore daily but did try to ration the dressings as they did not have an ample supply. She picked up the replacements at the nonprofit/nongovernment hospital, about thirty minutes from their home, walking the rough path I initially followed. The health assistants at the clinic had instructed her in the technique, and she was diligent in following through. It was difficult for him to visit the clinic himself due to the rough terrain surrounding his house. The staff did not provide home visits, and in the event of an urgent need for an appointment, Ram said that he was carried on a homemade stretcher, which

⁵⁰ Ram's decubitus was stage IV, the most advanced, and extending through the skin, fatty tissue, and through the muscle. It was draining pus, a sign of infection. Decubiti are common with people with spinal cord injury who use wheelchairs daily, and if quality care is not provided, can lead to septicemia and death. The US (where quality care is more accessible than in Nepal) showed between 23%-40% incidence of decubiti with this population (Fogelberg et al. 2009).

required four to six men. He said he did not like to ask his neighbors to help, and his son lived in Kathmandu. There were no physiotherapy services to access even if Ram was better able to travel.

I asked about his bed positioning, and Akina said he preferred to be on his back. We chatted about turning Ram regularly to avoid pressure on his wound. The preferred position was on his side but not entirely on his hip and to support him with pillows. This standard care for bedsores appeared new to them. We explained this to Ram, and they agreed to try this routine. Ram could transfer himself with the blocks to the bed, so I thought this might be the best place to start. However, he would need help positioning the pillows and turning. Ram said that he had some form of bedsore for many years, and sometimes it became smaller, and sometimes it would grow bigger. He said that recently, "Green fluid was leaking from it when I sat in my wheelchair." There were many issues to ask about, and the list kept growing.

I was interested in the routines of his care and how Akina managed it. Ram was a huge man, and his wife was his primary carer. Their daughter often visited, but she had young children. Their son, Bhupendra, lived in Kathmandu while he was waiting for a work visa to be processed in Japan. Knowing that the daughter's obligations were to her mother-in-law, I considered involving their son, so I made a mental note to contact Bhupendra through my Nepali physiotherapist friend after the next visit. I wondered if Ram stayed in his wheelchair because that was his preference or if Akina was busy in the fields and could not return to move him and change his position to relieve the pressure. I waited for this information to come out in conversation or the right time to ask, as I did not want it to appear that I was judging Akina for not being there. We chatted about the surface under him when he sat in the chair.

When people have no sensation from a spinal cord injury, they cannot feel the pressure or pain from a bed sore. They would not know a sore was forming, so family and/or medical staff often do regular checks. The next obvious concern was how and when he used the toilet. Every village home I had visited had a 'long drop' toilet that required squatting. Akina pointed to the wheelchair against the wall behind me. She walked over and lifted the hand-

made seat from between the frame. I tried to hide my shock; however, it was probably apparent on my face. The seat was an old, frayed bicycle tire chosen to cushion, with many threads of multicolored twine (customarily used to weave baskets and stools) loosely stretched across. In its center, a hole was cut. It was not clean. The smell was unbearable. I stammered, trying to collect my thoughts and choose my words carefully when asking about the details of the toileting regime.

The dressing was done, and I watched Ram sit up, using his arms to prop himself on the edge of the bed. He began to explain. "I can smell when I have gone, and then I will call my wife to change the bowl underneath. I can't feel anything, and my muscles don't work, so it happens this way". Akina mentioned that she was often not near to hear his call since she worked in the fields most mornings. I looked in the corner where there was a folded, dusty, unused commode and started formulating a plan to help. Initially chatting about what Ram wanted to do differently, he did not mention his toileting and focused on his pain. This choice may also have been because I worked primarily with pain, but I always framed it as "helping you to do things easier in your day-to-day life" rather than focusing on pain itself. Chronic pain is not cured but managed, and often unpacking people's daily routines and looking at them to make tasks less difficult for carers and provide more independence functionally for the person with a disability leads to less pain and a better sense of well-being. I knew the bottom line was that Ram sitting in his wheelchair for eight hours daily was the basis for many underlying issues, including back pain, hip pain, and pressure sore.

He was halfway there since he could transfer from the bed to the wheelchair; this skill could be applied to transferring to the commode. I explained that we would talk about the schedule and how it would be done in detail first since it was different for him since he could not feel. Ram's demeanor changed. He seemed confused and became agitated, raising the volume of his voice and speaking in abrupt sentences, repeating the same: "I cannot feel. I do not know when I have to use the toilet." I sensed his anxiety and lashing out at me, and perhaps it was because I had not explained the process well enough. I attempted to break it down again that the pain, pressure sore, and unhygienic toileting all had the prolonged wheelchair sitting in common. I was careful not to place blame; he was

very aware that sitting in the chair was not the best. I told him this system was for people who could not feel or move their muscles to go to the toilet. I asked if we could find a piece of paper and a pencil or pen. I drew a column with the next three days on the left. I asked him and Akina to mark when Ram has a bowel movement and passes urine for the next three days. When I returned, we would look at the pattern in the diary. Then, we would have a rough idea of when to transfer to the commode, emphasizing that it would not be exact. The point was to move before he needed to go and to find that 'window of opportunity' based on the diary they would keep, which would show us the pattern and timing.

I demonstrated how he would move first from the wheelchair to the bed and then from the bed to the commode. I emphasized that I would break that down and instruct him later and that it would take practice and be challenging at first. He would need to come inside to use the commode. Ram was able to propel the wheelchair independently, so I thought that this system might be possible based on his physical ability. Ram repeated that he could not feel, remaining cross, but said he would try it. Before I left, I asked Ram's permission to discuss his case with the local government clinic to see if they could make a home visit to check his decubitus and perhaps provide more dressing. He said he did not trust that clinic despite it being free of charge. I had heard this from every research participant and villagers in general, without any details as to the reasons. However, without my encouragement to persuade him, he did say that I could try it. I initially thought of this clinic since it was closer, although Ram would still have to be carried in a stretcher to an access road and helped in a vehicle if a home visit was unavailable. I planned to contact the nonprofit/nongovernment hospital if they could not examine his bedsore.

We also chatted about changing the tire cushion to a foam egg crate cushion to ease the pressure when sitting in the wheelchair. Again, as it is approached in the UK, the message is not that they are doing it 'wrong.' I said effectively that this was good problem solving, but maybe there was a better way to do this, whereas Ram was not so reliant on his wife in addition to a more hygienic approach. For people to effect change in any circumstance, they must be informed about the benefits of the change and only then agree to it and be

ready to make that change⁵¹. As a clinical ethnographer, with all of my participants, I faced the ethical dilemmas surrounding his care, but more urgently with Ram. I felt that I first had to inform him about the health concerns I had and then provide him and his family with options once the plan of action was decided (of course, subject to change) and again encourage him to make the changes he wanted.

Since we agreed to try the commode, this new egg-crate cushion would not have a hole in the center. I did not want to navigate the process of obtaining the pressure relief cushion myself, thus encouraging self-management, and Akina mentioned that Bhupendra could perhaps help. I felt that involving their son in this task was beneficial. I aimed to see how the family cared for Ram and what Bhupendra's current role was since he lived in Kathmandu, where it could be purchased. *Dashain* (Nepali: religious festival of light) was coming up, and his son planned to visit the village to see his parents. I asked if I could give Bhupendra's contact details to my Nepali physiotherapist colleague, who knew the system and where to find an appropriate cushion. Ram was surprised that he might have to pay for this, and I said that I would have my friend sort the details and that perhaps there was another option that did not involve payment. Meanwhile, I would ring my friend and explain the needs.

After several back-and-forth calls between Bhupendra and my physiotherapist friend, I spoke with Bhupendra on the phone. He confirmed the visit for a couple of days during *Dashain* and was to stop by the center of the National Disabled Fund in Kathmandu before his trip to the village and pick up the new foam cushion. We chatted a bit about his plans to go to Japan; I was surprised he chose this destination as most of the young men in the two villages where I worked aimed to go to Dubai. He said he thought the opportunities were better and could save more money. While I had him on the phone, I asked what he thought of organizing a visit to the clinic in the next village by planning and contacting the men needed to carry the stretcher. He said that although he was home just for a few days,

⁵¹ Prochaska and Velicer (1997) designate that the Transtheoretical Model of Health Behavior change follows six stages: precontemplation, contemplation, preparation, action, maintenance, and termination.

he would try knowing that most of the villagers living in Kathmandu for work would also return home for the festival. In the meantime, I set out to contact the two local health facilities, the government, and the nonprofit/nongovernment.

I had never been to the government clinic, but I passed by it many mornings while walking between the Tamang and predominantly Hyolmo villages. I obtained my research visa through the nonprofit/nongovernment satellite hospital (as a sponsor for the Ministry of Health's requirements for the project's approval), a nonprofit establishment funded primarily by European donors and grants. The main teaching hospital was outside Kathmandu and affiliated with the Kathmandu University Medical School. Eleven satellite clinics were spread like bicycle spokes, with the main hospital as the hub. It was still sweltering hot despite being the end of September as I walked up the bus road to the clinic. No one was sitting outside as I walked up. I said, "Namaste," as I entered, my voice echoing slightly in the empty rooms and hallways. It was in stark contrast to the nonprofit/nongovernment hospital (they collected a small fee for services and medications) in the next village, about another twenty-minute walk. They were full to capacity and busy from opening until closing, with at least ten to fifteen people waiting on the benches inside. That hospital served the two villages as well as some surrounding areas. Women went between the two to deliver their children, and a new maternity ward was under construction at the larger, better-equipped nonprofit/nongovernment hospital. I was told women preferred to have their babies there.

I turned to the right, following the voices, and saw a familiar dog sprawled out, cooling himself on the cement floor. Two women were chatting, and neither looked up as I entered. They continued their conversation, glancing up and down from their phones. I recognized one from the shops. I knew that she was a nurse there. I was never sure of the hours, as the doors were often closed when I walked by. However, I took a chance, and it was open today. "Are you busy?" I asked, already knowing the answer. "Oh, no, not now," turning to her friend and introducing her. I asked her if she had some time to chat about Ram, and she said ok. After the nurse motioned to her friend to give us a few moments, I asked her if she was familiar with his case, and she said she knew about him. I told her that I was concerned about his bedsore, and would she be able to go to the house to look? She

was anxious to tell me that she had just returned from a ten-day course in wound care in Kathmandu, and with that, I assumed that she would be willing to walk the fifteen minutes to his house. I was surprised at her answer, a flat "No." She explained that he had had it for a long time, and nothing could be done.

Additionally, she could not leave the clinic if someone came by. I described the wound and showed her a picture I had taken, saying that it appeared to be worsening and infected. I said that I was also concerned about the dressing technique and supplies. I thanked her and left.

I knew the young doctor, Sundar, at the nonprofit/nongovernment hospital and that if the stretcher was arranged, they would likely see Ram there. He was also more comfortable there, as he had told me previously. I chatted with Sundar on the phone and sent him the picture I had shown the nurse. I also asked him if the staff there could review the dressing technique with Akina and provide them with an ample supply of dressings. He agreed to see Ram. I would leave these arrangements with Bhupendra and make the call to him that the doctor agreed to see his father and that he could arrange the transport for him.

3. Reaching out to family

When I next returned to visit, Ram was in his chair. Bhupendra had not arrived, so I knew his new cushion was not in the house, and the visit to see Sundar had not occurred yet. I mainly wanted to check on the diary I had asked them to keep of his bowel and bladder habits and chat about the positioning in the bed to relieve pressure. Ram and Akina said they had been following the three-quarter turn roll with pillows as props, doing that a couple of times a day. We looked at the diary, and I scanned it and pointed to the entries for the times for the bowel movements. "See, you have written between 1100-1200. That is a pattern. That is what we were looking for, so we know that is a time to move to the commode ", I explained.

Ram was not convinced and looked away, saying nothing. He then said, "I cannot feel anything. I might not come at that time every day". I explained that the bowels can get used to emptying roughly around the same time daily. He said he passed water at all

different times, and the diary reflected this. I explained that this was often the case, depending on how hot it was outside, what we ate, and many factors. We now knew when to transfer to the commode, but it could be done about four times daily. Ram expressed quite emphatically that he did not see how this could work if he did feel when he needed to use the commode. I felt it was essential to focus on the positives and things going well (such as the bed positioning) instead of explaining the logic of the daily transfer to the commode four times.

I mentioned to Ram and Akina that I had spoken to Sundar, the doctor at the nonprofit/nongovernment hospital, and Ram agreed to visit there once his son came and made the arrangements. He also said he would try the new cushion that Bhupendra would bring. We chatted for a while. I did want to take the focus away from transferring and bed sore management, but I was uncertain how Ram would accept it if I asked if he wanted to do stretches. I was torn as I did feel that he would benefit from doing a few gentle movements when he was in bed to ease his back and hip pain, but I felt that he would not necessarily take this onboard. His mood did seem to be changing each time I visited. He was more withdrawn. Understandably, making changes in one's routine is challenging. I gave Ram a chance to decline what we were doing. However, he continued to say that he would try, admitting that it would not be easy and not fully understanding how things would work if he could not feel. I thought it was best to wait until Bhupendra came home to have the next visit and to gain his input.

Ram was outside under the awning when we arrived for our next visit, his wife sitting next to him. Bhupendra was home but was out fixing the water and would return shortly. I looked forward to meeting his son and gaining more insight into the family dynamics surrounding Ram's care. I asked about the cushion, and Ram said his son did not get it because it was not in the shop. I said that this happens, and it was understandable. He said, "It is better if we can make it, but we can't make this; it was only in the shop." I wondered if they could not purchase the cushion and if there was no donation to obtain it. I left the topic and recommended that Ram get out of his chair every hour and into the bed in a pressure-relieving position bed for about ten minutes. We looked at the bowel diary again, and the pattern was as before.

"I do not care about the bowel movement. Listen, one thing: I do not care about the bowel and urine, and I do not come out for that. Sometimes, I have a bowel while sleeping, and sometimes, I have this outside. I do not feel that..." Ram insisted on speaking over Akina and me, and I felt we had met at a crossroads. Having Bhupendra there today and his input would govern how I would proceed now.

A tall young man in his twenties came and joined us and introduced himself as Ram's son, Bhupendra. He visibly sighed as he sat down. He said that he had organized moving his father to the clinic with the help of his neighbors carrying the stretcher through the rough paths and rocks. The doctor checked the bedsore, emphasized the need for sterile conditions with daily dressing, and provided them with some ointment. I was happy to hear that the health assistants had reviewed the technique with Akina and given her more dressing supplies. I explained what we had been discussing; Bhupendra sat close to his father and said, "Let her talk." Ram continued excitedly,

You do not have to say that I know about that. If I sit all the time, I will have a wound. I have knowledge that I have to get up. I have experience with the wound. There is not any reason to sleep. I get up and walk around out as I can. This is not the thing to teach me. I can do this on my own; this is not the thing to learn. I can do this on my own. (Ram)

At this juncture, I decided to leave this issue regarding the timing and reiterate that it was also about the unhygienic routine of sitting on the bicycle tire while waiting for his wife Akina to clean him, not solely about the pressure. I told Bhupendra I would show them how to move from the wheelchair to the bed and from the bed to the commode. We could do that in the other room, and as I always did with any person with disabilities, after I showed the steps, we would try to do it with Ram step by step. I said it was helpful to show first. I reassured them that it could take several weeks and that we practice just one step at a time. Ram looked away and said, "I do not have the ability to do that."

Bhupendra introjected, "We will not have to do the whole thing now."

Ram anxiously said, "I might fall."

I repeated to Ram that we did not have to try today. It was his decision. We will remove the armrest from the wheelchair and move to the bed and from the bed to the commode, which is three steps. The situation became increasingly tense with repeated crosstalk and interrupting among family members, translations between Nepali and English, and Ram's overall anxiety level. I said in so many words that we needed to have Ram try since we did not know what would happen by just talking about it. It was clear that Bhupendra was trying to calm the situation and find a solution.

It was my mistake to describe the steps without performing them first; people are often less anxious when they see what the steps will be rather than talking about them. It is a judgment call about when to introduce this, and I should have waited until we were in the bedroom where I could have demonstrated it and, at the same time, explained it. On the other hand, many anxious people's fears are lessened when they know what others expect of them. Regardless of Bhupendra's assistance in explaining, Ram continued to doubt his ability. Ram then said that it was harder to get from the wheelchair to the bed than to get from the bed to the wheelchair, which was a bit lower. I said yes, it was, thinking that a piece of wood for sliding could be used, but I left it at that. I ended with, "It is not like a recipe we follow; we can practice and see and work it out but let us wait until next time." Ram said that when he was in the hospital, some people could not move their legs but could get from the bed to the wheelchair and from the wheelchair to the bed. But they could feel. He said that since he could not feel, that is why it was impossible. He also needed help to get back to bed, and nobody was around to help him during the day. Ram ended our visit with "Kasko bauko ke lagnu "(Nepali: Nothing can be done). Then, surprisingly, "It would be fine to work with the trying."

Several weeks later, after the celebrations of *Dashai*, we returned to see how Ram was getting on as he had agreed. I also felt he would have had time to consider if he wanted to try the transfers. Again, he was sitting in his wheelchair outside, this time alone. Akina must have been in the fields. Bhupendra would have left for Kathmandu. Ram's face was expressionless when we approached and asked how he was. "Go away, stop bothering me," he said flatly. I felt that that was as definite a statement as it could be. I told him that

I apologized if he felt we were bothering him, said that we would no longer be coming, and wished him well.

4. Conclusion

In this ethnography, I have brought to light processes of the embedded, extended, and embodied complexities of living with a disability and chronic pain in rural Nepal from several perspectives and the many challenges that Ram was presented with in his attempts to build coping strategies that could foster resilience. The theme of access to care in a resource-poor region situated in a remote and challenging terrain is a significant consideration but only a small part of the multifaceted picture. Once accessed, albeit with many challenges, Ram's willingness to accept or negotiate care is a central issue. Ram compared himself to others and saw that trying was futile in the end. Surrounding this is the subsequent ethical considerations of patient choice. Complicating this is the family's availability to assist. From my positionality, I ask: when, how, or even if to intervene as a clinical ethnographer. Weaving through these complexities is the emotionality of Ram's psychological pain and how this may have been expressed through anger as he progressively became more resistant to change.

Nonetheless, Ram would not say he declined my visits until the last. He said he would try. As a researcher clinician, do I treat him differently? When working with people with disabilities or any rehabilitation or injury as physiotherapists, we encourage people but let them decide if they want care. If they want to stop, we tell them this is their choice from the beginning. When we think it is in their best interest to continue, and the path is difficult, we may change the method or process, knowing that it is not easy for them. Understanding the dilemmas from a culture different from my own is what we learn from ethnographic work; for example, the daughter was unavailable due to her own role in caring for her mother-in-law.

4.1 Anger and the challenge to accept

Ram was angry, and in my clinical experience, these intense feelings can challenge change and acceptance. Kleinman (1988) states the impact of emotions such as anger on pain and illness succinctly and in a way that drives home the desperation of those living in pain:

The words *depression, anxiety, guilt, and anger* do not do justice to the deeply indwelling, self-defeating psychic forces that create and intensify the experience of illness. There is still something important left unsaid, an aspect of our unique character usually hidden even from us, that can make a life a living hell and of illness life (193).

Something else may have shaped his anger surrounding his accident. Many people sustain unfortunate accidents and gain acceptance; I felt that the challenges in Nepal with access to care, family obligations, and low family resources contributed to this reluctance. However, perhaps Ram felt that the accident was his fault or someone else's negligence, and he could not forgive them. Scarry (1985) writes of people in pain and the 'unmaking' of their worlds and how, without the language to articulate their experiences, they 'remove' the pain from themselves, thus objectifying it. Similarly, Good (1993) tells of the 'haunting' story of a young man with persistent temporomandibular (jaw) pain and argues that this unmaking is partly formed by the interrelatedness of the social connections involved and experienced. For Ram, alternatively, perhaps his reluctance and recalcitrance were directed at me. As Jadhav (2001) describes, both in India and in London, when he was met with the refusal of his psychiatric sessions, he relayed that what they wanted was jobs and money, not care. Or perhaps I was a target for his anger or what I represented as a clinician ethnographer; he did ask for yet another wheelchair early following our first meeting. Regarding my positionality, I did not struggle with his rejection and strong words at our last visit, and I suppose I have heard worse from people living with daily frustrations and did not take it personally.

4.2 Family dynamics and self-worth

What was of interest were the family dynamics surrounding his care. His wife, Akina, was responsible for tending to the fields, running the house, and caring for Ram. It was a huge

task, and the kinship obligations in the village followed that the daughter who lived not far away was central to helping at her husband's household. Therefore, Akina followed the hospital's and Ram's protocol of care. Bhupendra had authority after Ram. However, he was obligated to his family in Kathmandu and to follow through with his plans to work in Japan. Once there, of course, he was expected to send remittance money back, which would include Ram and Akina, so like Pasang's family in the preceding chapters, the dilemma existed between having an adult child nearby to care for aging disabled parents or emigrating to send much-needed money back home.

Within this dynamic of care with the family were issues of trust and value. This also extended to me as an outsider and as a clinical ethnographer. What was the value placed on health care? And from an outsider? Dow and colleagues (2012) studied a group of people living with pain who expressed real frustration at not 'being heard' or feeling that not enough was being done to help with their cases, as one of their primary concerns, second to not being believed or treated as they were invisible. In Nepal, I saw that being an outsider clinician brought expectations that I would be the one to solve the mystery of their pain; therefore, people were usually open to new ideas.

Nonetheless, I heard and observed that the highest value was placed on emigration. It, of course, brought money, but it also brought status and marriage prospects. In Ram's family, was healthcare undervalued or not trusted, or was it not trusted and therefore undervalued? It is an odd position; however, I usually saw that foreign healthcare providers were valued.

Health care was not placed in the highest value, but was it Ram who, as a person using a wheelchair, was it him who was not valued? By family, by the local health care providers? In Julia Lawton's article, "Contemporary Hospice Care: the Sequestration of the Unbounded Body and 'Dirty Dying'" (1998), she describes her work in a hospice where the patients' bodies in their end-of-life illness had become unhygienic and degraded. Although Ram was not dying (however, he was at risk), a similar analysis is applicable in that Lawton saw that those with 'unacceptable' bodies were hidden and depersonalized and referred to by a nurse as "rotting away below" (127). The patients' conditions resulted in

incontinence, which was usually the reason for admission, in addition to other symptoms that resulted in degradation of body tissues and fluid leakage, similar to Ram's decubitus. Lawton refers to the people in the hospice with these symptoms as having 'unbounded' bodies. Alternatively, those whose symptoms could be controlled, for example, the treatment of urinary incontinence with a catheter, were described as having bounded bodies and were usually sent home. That is, they had some value, some worth. Those living within the unbounded bodies showed symptoms involving strong offensive smells; therefore, the discomfort shown by staff but also, in general terms, with people with bodies that could be controlled created distance and rejection. Of interest is how those people living in 'unbounded' bodies, in this case, had detached themselves from the social relations surrounding them. They mirrored how they were treated by others who saw them as not having worth or even a self. One of Lawton's interlocutors described living with her husband with an 'unbounded' body when he was at home, now happy that he was in hospice,

Things got very difficult after he became incontinent. I had to help him change his pads. It made me feel really sick . . . Sometimes he had an accident, and it went all over the place. I still can't get the stench of urine out of the carpet . . . I'm so glad he's in here now (Lawton 1998, 133).

I saw shifts in the value system in the village, whereas I expected health care to be a high priority. However, financial support was more highly valued. I wondered if I had paid for a new wheelchair for Ram, as he asked when he first met me, would have changed things; however, I did not conform to the expectations.

The hospice ethnography described is a more blatant case compared to Ram. However, the process may be the same. The family and local health care providers had, in a manner, depersonalized him. Moreover, he had given up on himself, reflecting this attitude. Everyone accepts that a baby will not be able to control their bowels and bladder. However, when an adult is incontinent, we abhor it and blame them.

Following the above analysis, I felt that my approach to suggesting fundamental changes was dismissed by Ram due to his strong sense of futility with change and hopelessness with his predicament based on his lack of sense of self and self-worth. Often, people living

with pain are not able to directly control their bodies and, thus, their lives, compounding their hopelessness. (Bennett and Bennett 1984).

In Chapter Three, Tenzin displayed a sense of giving up, losing hope, and thinking he did not have the power to change his abilities or experiences or the role that his disability and pain played in his life. Nonetheless, he could see that he could shape his perceptions of his situation through improved self-efficacy and self-empowerment, whereas Ram was not. Ram's anger, as I saw, prevented the psychological flexibility needed to affect change but was effective in the moment to push away those challenges he faced.

To bring the discussion back to the components of building resilience, central to the embeddedness of the components to bring one living in pain to the goals of acceptance, the overarching experience to build resilience, vital to this process, is that the person in pain has social support. What Ram wanted and what he needed ultimately was not available. The government clinic would not see him (how would that make anyone feel?), essentially saying he did not matter. Tenzin had family around and available, and after my sessions, he was followed up with the non-government clinic physiotherapist, thus demonstrating an idiom of social engagement as his idiom of resilience, driven initial by his hopelessness. Nevertheless, Tenzin did not require the more complex care needs for Ram, making it more manageable; however, he was also not incontinent. Ram did not have a large family like Tenzin, and his wife, his only carer, spent all day in the fields. Engagement in meaningful activities, as with Bharat, and social support as with other participants, needed to work towards resilience were absent in Ram's life (Panter-Brick 2014). Sadly, Ram could not distance himself cognitively from challenges (cognitive diffusion). He said he could not transfer himself to the commode on the schedule because he could not feel it. Instead, he depended on his wife, which was not her fault, but she was not available to help with the toileting. However, families often feel that providing a duty is providing support (Aulino 2016), which is a complex arena to negotiate, as seen in Ram's story. Ram's anger pushed all these dilemmas away, and effective coping strategies were not given a chance (Rutter 2012).

The next chapter will show yet another contrasting story of a young woman living with pain and disability who sought other means to challenge resilience through her religious community.

In closing this chapter, was Ram correct in stating “Kasko bauko ke lagnu,” that is, “Nothing can be done”?



Figure 29. Ram's house

Chapter 6 Saved: Coping when acceptance may be going too well

1. Introduction

This chapter will portray a young woman called Janeesha and her experiences, for whom religious conversion plays a central part in her life, and hence her coping, resiliency, and living with chronic pain. People convert for many reasons, and this trajectory has been seen to correlate for a large number with improvements in overall mental health (Dein and Littlewood 2020; Ferreira-Valente et al. 2022). In this instance, for Janeesha, the Christian community's role was unconditional acceptance afforded by the Christian doctrine and community support of her disability and her choices. I query whether Janeesha had indeed reached a level of internal acceptance through self-empowerment through her faith and their support. Moreover, can we reach resiliency without self-efficacy and the internal resource of psychological flexibility to live with pain independently if reliant heavily on others (McCracken and Morley 2014; Panter-Brick 2014)?

In previous chapters, the definitions of resilience were drawn from nursing (Kinnie et al. 2024), anthropology (Panter-Brick 2014), and psychology (Rutter 2006). Another applicable definition comes from the American Psychological Association, "the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioral flexibility and adjustment to external and internal demands." This broad definition encompasses the significant points in this chapter, mainly the concept addressed so far of psychological (here detailed as mental, emotional, and behavioral) flexibility. The breakdown of the external and internal demands component is also of interest; although the other descriptions of resilience probably cover it, it is demarcated here, albeit these components are probably more integrated.

This chapter will look at the dynamics of Janeesha and her faith as it helped her cope and work towards acceptance and resilience, and as in previous chapters, through the lens of Kim and colleagues (2019) and Mendenhall and Kim (2021) by way of their term 'idioms of resilience,' inspired by Nichter's (1981) seminal work on idioms of distress. To further

illustrate idioms of distress, I add from Nichter's work where he writes of his fieldwork with Brahmin women in South India and their alternative socially mediated modes of expressing stress as illness (among other idioms). He theorized that this was due to restrictions on expressing emotions and physical mobility, such as leaving the house unaccompanied. Here I will expand on the preceding chapters analysis on idioms of resilience. In contrast to investigating modes of expression of illness from adversity, Kim and colleagues (2019) studied personal strength gained from adversity when working in the South African township of Soweto with people living with cancer. They sought to find how they negotiated their illness and what constructs they used to describe and reach resilience and came to their concept of idioms of resilience: "We define idioms of resilience as socially meaningful and culturally resonant means of experiencing and expressing positive adaption and well-being in the midst of adversity" (724). Their study revealed broad themes from the interviews, including acceptance (*ukwamukela* in isiZulu), social support, religious support, and medical care. For this chapter, the addition to the discussion thus far of the concept of religious support and acceptance from the religious community as an idiom of resilience is particularly valuable.

Previous chapters have described the need for the embeddedness of social support and medical care, and as seen in the South Africa study and the other work discussed here, acceptance is a recurring theme. Kim and colleagues (2019) worked in a different setting compared to my participants with chronic pain in Nepal in that their participants were facing a terminal disease; nonetheless, the notion of not having the capability to change many aspects of chronic conditions is similar. How is that achieved, and how is that different for all? What guidance can be provided to people in pain that is socially meaningful and culturally resonant in line with their idioms of resilience?

The idioms of the resilience framework is valuable as it moves beyond the biopsychosocial model, and as seen in the enactivist/ecological view, it encompass the socio-ecological, thus extending the internal psychological lens discussed in the previous chapters. "Such an approach supports the shift from a focus on individual traits to recognizing the broader social, cultural, and political factors that affect what makes people resilient" (Kim et al. 2019, 737). These developments/extensions describe, as I introduced in the Introduction,

a move 'beyond' the enactivist biopsychosocial model of Cormack and colleagues (2023), with the added lens of the idioms of a resilience framework. Therefore, Janeesha's story progresses on from the preceding chapters, where there was a focus on the individual process of building resiliency internally, to the broader integrated approach, moving more towards an anthropological perspective than an internal psychological one framed through Rutter and McCracken. Both coping strategies are integrated, as seen in Chapter Three - The Copers. Tashi and Bharat did look 'outside' (such as with meaningful activities), but they had to feel a sense of self-efficacy before moving out and interacting beyond themselves. Of interest with Janeesha is how the faith-based support moves between both.

2. Janeesha

Early in the monsoon season, the rains usually came midday once the heat had risen. We left after breakfast to cross the river to a neighboring village, where primarily Tamang people lived. We would meet a young woman who had had leg pain for many years. I did not know why and was looking forward to meeting her. Passing through a small gathering of shady pines, it was evident that we were nearing the river. The air cooled, and the path winded down a steep, slippery slope, tiny frogs jumping across my feet. I had taken this walk previously to visit the water-powered millstones, called *ghatta* in Nepali, dotted along the narrow decline. Once we descended closer to the river, the trees were dense, and lush green cardamon bushes grew along the path. Ahead were the boulder-sized grey rocks common to the area before we reached the small suspension bridge. Once across, the path followed quickly ascending through the flooded paddies to the small village. We walked another fifteen minutes straight up the uneven dirt road, household wastewater running through the middle of the track as it streamed through the channels at the edge. Again, it struck me how difficult, if not impossible, it was for anyone with a physical disability to travel between villages, work in the fields, or visit family. An unpaved road led between this and the next village; it was long and hilly and not an option unless one had a sturdy car or jeep, which was financially out of reach for most villagers.

An older woman was sleeping on a handmade wooden bed outside the entrance to the three-story house. There was no mattress or pillow. She was expecting us, but we still startled her awake as we came up the path. Maila and the woman chatted for a few minutes in Tamang, and we were invited in for tea in the indoor downstairs kitchen. The house appeared relatively newly built, made of cement, and probably constructed after the earthquakes. We were invited to go up to the top floor to visit the young woman we came to see.

We walked up an outside iron spiral staircase to the top floor. It was much cooler inside, away from the hot sun, as we entered the single room on the floor. The curtains were open, and two bookshelves lined the walls with neatly arranged family photos. A pretty young woman sat up in her double bed, her long light brown hair and fair skin distinctly different from the villagers I had met. We said, “Hello,” and I said in Nepali, “Oh, are you resting?” I was surprised she would not have gotten out of bed knowing we were coming. She replied politely, “No.”

Wanting to keep some initial structure to the interview, I asked her the same questions as the other participants, conscious that asking her directly why she was still in bed may put her in a defensive position. I had no background information and only knew she had had leg pain for many years. I introduced myself; she said she was Janeesha and twenty-nine years old.

She began to relate the story of her pain.

I was in India working as a babysitter. At first, I started to have so much pain in my knees, and then later it moved, and after that, the pain started to move everywhere, and later it became worse and worse, and later I saw the doctor. Then they told me that it was because of my weakness. They gave me a few medicines. Later, I came to Nepal before I was in India, and it became more and more. I saw *Lama Jhangkri* and many things but did not see the doctor. The *Jhangkri* did not help. Six months later, it got completely worse. (Janeesha)

Janeesha said that she went to various hospitals upon her return to Nepal after seeing the *Jhangkri*, but they would not see her. She explained that she “was forced” to stay in one hospital she visited, and they admitted her to the ICU. She is still followed there and goes

to Kathmandu every three months for checks. At this point, Janeesha asked if I wanted to see her legs, which were covered by a mass of blankets. Strewn across the bed were pillows of different sizes, with her mobile phone nearby. We had been following the trajectory of her widespread pain, and still, there had been no specific mention of her legs. She pulled the blankets away, and I saw her pale, atrophied limbs in a loose, crossed-legged posture. I only then realized that she was paralyzed in both. It has always been my manner to approach people as “people first” and not “disability first,” and this is most widely accepted in working with people with disabilities. Part of this approach is to listen to their stories, not continuously steer the conversation around, and have the pain or disability be what defines the person. Of course, it was a nuanced conversation, and I carefully chose my words. Janeesha volunteered that she was not able to move her legs. I continued the conversation, acknowledging what she told me. I began to get a clearer picture of her day-to-day life and struggles and asked, again, back to the recounting of events. Janeesha said she could no longer move her lower limbs six months after the first pain began. She recounted that she was unclear about what was happening to her body.

I asked her, “Tell me a bit about, personally, emotionally, what it was like for you these first few months when you did not know what was happening and were in a lot of pain. How were you feeling?”

Janeesha responded,

Very bad. When I was in the hospital, I had a wound and sore and had much pain. I felt very bad; they said there were no medicines for that. They dressed the wound daily, and when my wound got better, they discharged me. I stayed in the hospital for eleven months, and then my wound got better, and then I came to the house, and from then, I have been living with my parents, and I go to the hospital for check-ups every three months and if I had pain before that, I go there in two months otherwise in every three months. I go there for a whole-body check-up and blood test. (Janeesha)

I was curious about what care the hospital provided during her extended stay. Janeesha said that her brother came to help with her personal and toileting needs. She remembered that she did not receive physiotherapy; I was unclear why. Janeesha said her family ran out of money to pay for the hospital. Therefore, her brother went to Dubai to work. Without

her brother there, there was no one to lift her. Throughout this time, I was unsure how well she understood what was happening, and I asked her what she was told about the diagnosis. “Something like joint pain and the SLE, transverse myelitis, you know?” Her medical records showed me that she had rheumatoid arthritis, SLE (Systemic Lupus Erythematosus – commonly known as lupus, an autoimmune disease affecting the connective tissue), and transverse myelitis. I asked her if she knew about these conditions, and she said she did not know what they meant.

Knowing about your condition often reassures people and provides a sense of agency(Butler and Moseley 2013)⁵². I continued, sensing that Janeesha wanted to know more and that it may benefit her in terms of acceptance and coping skills and evaluating her present and future.

I began to tell her a bit about her biomedical diagnosis:

I will just explain a little bit about what they mean. Rheumatoid arthritis is, yes, joint pain; as you said, you have it in your elbow. Yes, and in lots of places. This pain is because, with rheumatoid arthritis, the blood is kind of fighting... certain parts of your blood are fighting with other parts of your blood. We all have an immune system. This is the system that fights off infection, and it is in the blood. I get an infection with a cut; my body can fight this. But if you have rheumatoid arthritis, it is mixed up; it fights itself. It causes pain and swelling. (researcher)

Janeesha also said she did not know about lupus; I thought it was essential to describe the conditions on the same day and ask if she had questions afterward. I also thought she might have questions on another visit as well.

I tried to explain clearly, “Lupus is something similar. Lupus is in your body, not just in the joints but in other areas. Some people have problems with their stomach, and some people

⁵² This is most often the case, and I saw that Janeesha was interested to know. Although a different context, but applicable, Scott Stonington writes eloquently of the practice in Buddhist Thailand where family members withhold medical information from loved ones to provide them with hope and to protect their ‘heart-minds’ (2020).

have other problems, but it is kind of a different disease, but it is kind of the same. The part of your body that fights off infection is fighting itself.”

I asked her if she knew why her legs were weak. She did not know, “No, I never asked them.” I explained transverse myelitis as a swelling in her spine that blocked the messages from her nerves to her legs so she could not move them. I said that we did not know precisely how people developed it, but sometimes it was more common in conditions where the body was ‘fighting itself,’ as I described. I wondered if she received steroids when hospitalized to decrease the inflammation. Janeesha said that she could feel her legs- and could feel stool coming but could not control it. She explained that there was a pot in her room and that her mother carried her. For urination, she has a catheter all the time. I was curious about how she traveled to the hospital appointments in Kathmandu every three months. She said someone carried her down to the bus. Janeesha was petite; I envisioned a family member; she mentioned cousins when her brother was not home, carrying her down the hill to the bus road in the village. I did not ask but assumed they accompanied her and carried her on the other end. I had seen some people carried in various ways; ‘piggy-back,’ on a handmade stretcher with at least four people helping, or in a large basket on one’s back intended for animal fodder cuttings, a strap across the forehead bearing the weight.

Following my explanation of the transverse myelitis and SLE, Janeesha remained pleasant and smiling, checking her phone, and asking if we wanted a refill of tea that her mother had brought in at the start of the session. My experience showed me that often, when people with chronic conditions receive an explanation, they may have many questions or become anxious regarding the prognosis of their condition. Therefore, I was confused when Janeesha did not appear to require any further reassurance or have any questions. This accepting demeanor gave me clues to her level of acceptance, which she had developed over the years. Or was it resignation? It was not easy to tell at this first meeting.

The bright sun peeked through the curtains next to Janeesha’s bed, and she leaned forward to draw them closed. “Tell me a bit more about just your day-to-day. What do you do every day when you are at home?” I asked her. “I watch TV, my friends come, we chat, and

sometimes I read the bible. I am Christian; when I feel sleepy, I sleep, and my day goes like that.” Janeesha responded in a positive manner, which surprised me. I did not know if she was trying to convince herself or if she genuinely felt this way. She continued to tell me about her “church friends,” “They are very good, they come to visit and pray for me, and sometimes if there is some problem arises, they help me.” On occasion, there are no family members to assist her on the bus and the journey to the hospital in Kathmandu so the church friends will step in. The local church was in the village, but she did not attend. Instead, a few members came to visit her every Friday night.

3. The village church

Janeesha’s Christian church community was reliable and provided a consistent support network. She told me how she first encountered the Christian church while working in Darjeeling, India, and made many friends there. Her family was now mostly Christian, except her parents. Her brother had taken her to a Christian healing ritual in Kathmandu. I had not met any other converted Christians during my fieldwork, but I knew there was a small handful, and their homes had been pointed out to me. My general sense was that they were viewed with suspicion. One home was more prominent and larger than most, with a garden and surrounding wall. The house had been one of the first rebuilds after the earthquakes; the rumors were that the Christian householders had received a relatively large sum of money from their church. Generous donations during disasters are familiar worldwide and seen as ‘the right thing to do.’ However, I felt that the non-Christian villagers thought it was unfair to select a member of the Christian faith as a recipient of the donation. From my conversations, I gleaned that, in a strange sense, the general thinking was that the villagers converted to benefit from the donations. I had heard some terrifying accounts of how church members were told to stay in the church buildings during the earthquakes and pray, with the horrifying result of their meeting their deaths when the building collapsed.

Moreover, the government did not want Christian preachers in the country, and I was told it was illegal to attempt to convert the predominantly Hindu population to Christian doctrine in Nepal. Though the village was primarily Buddhist, I thought there was a

pervasive mistrust of Christians attempting to convert in the region. I met one woman, Sita, who was anxious to see me and participate in the research; however, she questioned my motives over time. She had widespread joint pain and struggled despite taking non-steroidal anti-inflammatory medication. My first visit to her was friendly, and she sat on the mat on the floor in her tiny room, insisting that I be in a higher position on the bed as a sign of respect. Although it was mid-morning, she had been drinking the local *rakshi* and offered some to me. I politely declined and continued asking her about her pain. I had met her husband, a local *Bombo*, and I felt that connection helped her open up. It was her husband who recommended that I visit her initially. She offered me a drink several more times as she continued to chat. She told me how she had been with her husband for many years and that they were very happy, except that they never had children. Her husband had an arranged marriage and “took me to his house,” thus ending the previous marriage. When it was time to leave, she invited me to come by anytime and join her in a glass of *rakshi*. Laughing a bit, I reminded her that I would come back at the same time the next week to chat some more about her painful joints and how she coped working in the fields with her pain. When I entered her small, dark room the following week, it was clear she had been drinking. Her mood was different, and she answered in short, clipped sentences. When I declined a drink of *rakshi* this time, she blurted out, “You have come here to convert me! You are a missionary!” I took a moment and said, quite bemused, “I am not even Christian!” I recounted what I had said on the first visit when I explained the research, ending that I felt that perhaps it was not a good idea to continue. I left it on a good note and wished her well. In retrospect, I do not know if Sita felt I must be a missionary because I did not drink when working, or she might be uncomfortable discussing her struggles and could not articulate that. Either way, her clear message confirmed that the villagers might have had unpleasant experiences in the past with Christians.

Following this encounter, coupled with the unwelcome presence of foreign missionaries, I felt more strongly that there was pervasive resentment and skepticism toward the locals

who were seen to benefit from their new religion⁵³. I did not, however, doubt Janeesha's convictions. I asked her, "Tell me about your religion, how it helps you, and how you feel inside about it." "I feel very happy, and they are very good. I cannot go against the other religions. All are good, but I feel very good with Christians. They are very helpful. Even if we need a little help, they come to help." Janeesha focused on the church members as helpful and kind people in the practical sense; I hoped to hear more about how the Christian practices and dogma helped her cope, but I continued the conversation with her topic and what was central to her, the supportive congregation. I saw the church members showed up to help with appointments, but I was also curious about her emotional needs. "If you are feeling a bit sad? Or things are difficult, not just so much about practical things but your feelings. Do you ring them on the phone? Tell me about that," I asked. "I do not feel sad. I almost always feel happy. Sometimes I am sicker, I call them, and they come and pray for me and massage my hands. Sometimes they give me medicine, and I go to the hospital."

I allowed Janeesha to talk without steering the conversation too much.

"Why am I very happy? Because my Jesus gives me many blessings, I do not feel how my day ends, and it has been ten years. I do not remember how the time went, but I do not feel that kind of sadness. Sometimes it comes. Otherwise, I do not feel sad." It was the first time Janeesha had mentioned Jesus as a source of support and strength. This, combined with the involvement of the "church friends," provided a solid basis to enable her to cope and remain content. Janeesha diverted the topic from herself and her happiness to her family, "In the last year, they had many expenses. We can afford it because my brothers

⁵³ For an brief history of Christianity in Nepal refer to Fricke (2008). Prior to the change of government in the 1990s, Christians practiced 'underground' and were often beaten or jailed. However, it remains to be illegal to proselytize. Fricke's article continues with narratives of Christian conversion in a Tamang village, with one interlocutor describing his conversion to heal his sick daughter where the *Bombo* and the *Lama* had failed. One the appeals of conversion, apart from the lasting health of his daughter, was that he did not have to sacrifice his farm animals as instructed with the Indigenous and religious healers (now illegal but still done) which was more cost effective.

went abroad. They might be sad, but they are happy and accepting me.” I could believe that she was indeed happy with her life.

4. Janeesha’s future plans

Janeesha was twenty-nine, and I wondered if she had any plans or aims. I asked her if she wanted to do things she could not do now. “I do not know,” she said. I was surprised by her answer. Besides her disabilities, most young people think about their future and how they might change. I rephrased, “You are happy with how things are now?” She nodded and said she did not know what to say. She looked down at her hands as if remembering something and then clearly said that she would like to go to the toilet on her own. Her father was planning on building a toilet under the stairwell outside her room, and she thought if she had an electric wheelchair, she could maneuver there on her own. Her hands were weak, she said, and she had been provided with wheelchairs in the past but could not self-propel them. Janeesha said that she had a wheelchair outside in the hallway. I went to take a quick look; it was a bent steel frame with a plastic outdoor chair set in place of the standard wheelchair sling seat. I thought to myself: another example of a well-intentioned but inappropriate donation.

On Janeesha’s behalf, I traveled to Kathmandu to visit my Nepali physiotherapist friend Barsa, who worked at an NGO helping people with spinal cord injuries. I had gotten her a job there, paid for through my UK-registered charity, which I started after the earthquakes in 2015, through a partnership we set up when I first arrived before my fieldwork began. One person had an electric wheelchair at that center, and I was curious how it was obtained. Barsa explained that a Japanese donor had arranged it for the young man. However, there was no way for her to get one through the Nepali NGO. The cost was 50,000 Nepali Rupees for a new one in Kathmandu, equivalent to about £300. I chatted with Janeesha about how she might raise money if her church friends could help. She said that she had not asked them, and I somehow thought that, despite their support, she found it uncomfortable to ask. A family member had given her some money towards it, but Janeesha said it was not enough. Following my conversations at the center in Kathmandu, I told Janeesha that I could get her a more appropriate manual wheelchair through my

charity partner and that her hands could become stronger with time practicing. Her family could propel her in it rather than carrying her to the newly built toilet. Janeesha declined, saying she had had two to three before and now wanted the electric wheelchair.

It came up while visiting Kathmandu if Janesha wanted to move to the residential center there. It was a place where about fifty, primarily young people with spinal cord injuries, lived. The goal was to teach marketable skills such as thangka painting (Buddhist iconography), incense making, weaving, sewing, and other traditional Nepali handicrafts to people with disabilities. They lived in dormitories and enjoyed a close community. There was a full-time nurse. Now Barsa was there, a full-time physiotherapist, where there had been none before. The NGO's founder told me that many residents had been involved in farming accidents when they were young. Much of their childhoods and young adult lives were spent isolated inside, sometimes tied to a bed. They were not permitted to go to school. Families were often ashamed, and there were no prospects of marriage. Physical (and mental) disabilities continue to be stigmatized in Nepal and causes of such accidents or conditions at birth are seen as the result of karma from a previous life.

Alternatively, a Buddhist nun friend, whose views also saw disability as a karmic debt, felt that it was uncompassionate to have people with disabilities work as they should be 'tended to.' This dynamic served a dual purpose: to permit people with disabilities to lessen their struggles and to provide an opportunity for a helping person to show their compassion and gain karmic merit⁵⁴. Moving to Kathmandu would be a big step for Janeesha. I respected her happiness at home with her family and church community. However, I did want to approach her with the invitation for this hard-to-come-by

⁵⁴ Tim Shakespeare (2006) frames models of disability as social and medical. Although he calls for a more inclusive model beyond the social, that model views disability as a person-centered impairment that may become so due to social and structural/physical obstacles. The medical model sees disability as pathology that needs to be fixed. The example above is more aligned to the charity model which sees people with disabilities as needing help and donations, which may prevent self-empowerment.

opportunity. Barsa and I thought we would contact her brother and have him chat with her. We received the expected response, “No, I am happy with my online friends.”

I visited Janeesha several more times and was interested in learning more about how she adapted and adjusted mentally and physically. It could be said that she *was* coping and accepting her pain disability and limited opportunities. She said she was happy, and she appeared happy. Regarding dealing with the pain, she said that the medication helped about 30-40%, which is about average efficacy (Hansford et al. 2023). Janeesha explained that she felt that the pain would always be there. “The disease is about the pain. I accept that I will always have to take the medication and that the pain will always be there.” As a physiotherapist, I knew she could control the pain better if she moved and exercised. However, I did not broach the topic of gentle exercise at this point and planned to bring it up at a future visit.

“What do you think you would be doing if you did not have the pain/illness?” I asked another time while Janeesha was sitting in the same place in her bed, dressed in loose pajama-type clothes, her long hair tied in a ponytail. She smiled and said, “I would be earning so much money and making my parents happy. I would be traveling and seeing different lifestyles, but it is a dream.” I asked if there was something she would like to do in the future. “I also do not have money and an education. I would just be working and earning.” I could assume she would have stayed in India and worked as a domestic as before. As was fairly typical in the region, Janeesha explained that she studied until 4th grade. Her uncle then took her to India, where she started work at the age of nine. She told me how much she earned; again, I thought people tell you what is important to them. “How did you feel about leaving and working then?” I asked. “I did not feel anything. It was common at that time for poor families to send girls to work.” I heard the phrase, “I did not feel anything,” from Janeesha again.

Janeesha’s village had been decimated by the earthquakes in 2015; she mentioned before that their house had been destroyed. I was interested to hear how she experienced that day and how that might reflect her resilience. At that time, she had been in bed for five years. “On that day of the earthquake, I was reading the bible in bed. Our house only had

one floor then. It got dark outside, and I felt sleepy, so I pulled the covers over and wanted to sleep. My father came running in to get me and carried me outside. The house fell. After that, I saw people crying, and their houses were falling down. I was just sitting there.” Janeesha retold the day’s events matter-of-factly.

Many aftershocks were felt, up to three and four hundred a day, and I heard from friends in Kathmandu that they slept outside under tarps or tents for at least four months before they could consider going back inside. More houses remained standing in the capital. However, people were in constant fear and anxiety about another earthquake. A second significant one did occur a few weeks later but was not felt near my field site. (First one: 25th April 7.8 Richter scale, second: 12th May 7.3 Richter scale) Thousands stayed outside in makeshift corrugated metal huts while their houses were rebuilt. Janeesha said that they stayed outside for three years until their current house was completed.

“You were not hurt. Tell me about that because many people were hurt,” I asked.

“I wasn’t hurt. I was saved,” Janeesha stated with conviction.

5. Conclusion

This chapter has detailed the story of a young woman and her sense-making and journey to coping with her pain and disability. As with the previous chapters, living with pain in the villages where I worked demonstrated how the physical, social, and medical landscapes presented many challenges. However, in each chapter, the people living with pain have had somewhat different obstacles, albeit with some aspects the same and some the same but different. Of course, each individual had their own challenges and strengths regarding coping and acceptance, and they faced them in their own way. However, Janeesha had a somewhat different relationship with acceptance, in my view primarily due to her Christian faith's role in her life. In framing her journey through the findings of Kim and colleagues (2019) and Mendenhall and Kim (2021), I conclude that Janeesha worked within an idiom of acceptance under an idiom of resilience through her Christian faith and its community.

I saw her experiences, as she explained to me, with pain as the nexus, circled by her family and church relations and the circumstances of the village - the earthquake and migration, but overarched by her relationship with her faith. The other participants placed their pain central to their lives; it was a living part embedded in their daily lives and underlined most of their decisions. However, pain was not central for Janeesha, probably owing to her severe physical disability and lack of mobility, her young age and gender, and her faith. Pain and disability were not the only aspects that revolved and extended. Ram, in Chapter Five, was also non-ambulatory; however, perhaps due to his age and the lack of expectation that he fully participate in the village, his pain and disability were placed somewhat differently, they controlled him. As stated above, each participant showed a different embeddedness, which was always in flux. Through this interconnectedness, I have described, ran an arc of acceptance through Janeesha's Christian faith and friends.

Moreover, was her acceptance of her pain and disability, with the lack of opportunities afforded her, true acceptance? Was it resignation? Alternatively, was it 'acceptance going too well' as the title of this chapter reads? Returning to my questions posed at the beginning of this chapter, had Janeesha built a level of internal acceptance based on self-empowerment and psychological flexibility supported by her faith and its community, or was acceptance of her pain and disability not hers but acceptance *from and by* the church community (to include her family)? I do not think that Janeesha made some of the changes described in psychology studies by McCracken and Morley (2014) regarding the attributes of building resiliency. However, she did come to accept her condition.

Moreover, is giving the power, control, and pain over to Jesus a form of acceptance of a chronic condition? The preceding studies cited (Kim et al. 2019; Dein and Littlewood 2020; Ferreira-Valente et al. 2022;) pointed to improved function and mental health when religious support is practiced; therefore, does it matter if the person in pain has taken on these challenges internally through self-efficacy and the other attributes and components (McCracken and Gutiérrez-Martínez 2011)? I do not think it is relevant *how* Janeesha came to her acceptance; moreover, she appeared content, certainly more so than many of my participants.

However, despite feeling content, was the world Janeesha and her family and church support network created disconnected from opportunity in her best interests? The church's acceptance of her disability and reliance through social relations and Janeesha's acceptance of that may have been the reasons why this situation went too well for Janeesha and those involved. Additionally, Janeesha accepted her situation to stay in bed; she declined to go to Kathmandu to live and work in a community. There may have been many reasons for this, which she did not divulge to me. I felt these judgments were not mine to make as a clinical ethnographer, or as a clinician, or an ethnographer. However, this showed me that she was happy and accepted living in the village with her friends and family.

Janeesha's family was always there for her; they were also Christian. The impact of the rugged landscape is a running theme through this thesis; its physicality, embeddedness, and challenges for the villagers, but more so for those physically disabled. In this instance, was the geography also the Christian struggle and suffering as her brother and the church friends carried her up and down the mountain? The church community did not gain karmic merit as Christians, but perhaps they were gaining 'grace,' bringing them closer to heaven⁵⁵.

Several interdependencies can be gleaned from the Nepali context in Janeesha's story. Janeesha told me many times that she was happy; I wondered if she had the choice to be otherwise. There were few expectations from a young woman in her community other than to be a wife and mother. Nonetheless, it appeared that this opportunity was not available to her as a young woman with a disability. It was not my place to say, of course.

The intricate theology of her Christian faith is beyond the remit of my work; however, the role of acceptance of suffering and salvation in her worldview and how it pertains to her

⁵⁵ The Catholic nuns who taught me as a child reminded us often that good deeds and helping others would bring us grace. I was too young to conceptualize this and imagined I would somehow earn piles of rice since the words were similar.

pain experience is of interest. During my time in Nepali villages, within the Hindu and Buddhist perspectives, events (and health and illness, for that matter) were almost exclusively framed by an explanation of the workings of karma, that is, cause and effect, which was central to public health and daily life. The understanding is that the impact of events from a past life, both good and bad, carries over to impact one's life now lived. Early in the morning, when I walked through the village after my morning tea, I saw incense rising from small shrines outside of the few Hindu houses as they gave offerings to deities to keep the harmony and earn karmic merit, performing this ritual soon after waking. I might also greet some Hindu villagers returning from the *mandir* with the red vermillion *tika* (Sanskrit: a form of protection) on their foreheads. In the Buddhist households, morning offerings were also given, where the seven offering bowls were filled with water beneath *Guru Rinpoche's* image. Within Christian traditions, as is commonly known, the notion of reincarnation is not addressed, and suffering in this life (one's only life) is not paying back a 'karmic debt' as is explained in Hindu and Buddhist traditions. In the Christian faith, Jesus suffers and is resurrected, saved, and reborn. Janeesha did not address her suffering parallel to Jesus; nevertheless, was her suffering a 'cross to bear' for salvation/heaven at the end? I found it interesting that the Nepali word for physical pain, *dukhai*, (sadness is *dukha*), was the same as the one used by the lamas for suffering in the Buddhist context⁵⁶.

However, religious doctrine or religious practice is not the principal issue in this chapter; what is a central theme is *how* Janeesha coped using her faith as a pathway for acceptance by not having to make many changes, a form of passive coping rather than active coping as seen with Tashi and Bharat in Chapter Four. Within a Nepali context, how does a young single Christian village woman with a disability navigate? When discussing their future, I found that nearly all young people in their teens, twenties, and older pointed to their parent's wishes for them. It could be our judgment that Janeesha's life is unfulfilled; to her, she is happy. But if not ill, she "would be working and making her parents happy," as

⁵⁶ For more engagement with this analysis of suffering from Buddhist and Christian doctrine, refer to Luis O. Gomez's chapter entitled, "Pain and the Suffering Consciousness: The alleviation of suffering in Buddhist discourse" (2007).

Janeesha told me. This response highlights issues that might not be voiced similarly in the UK Pain Clinic. I did work there in a predominantly Asian community, so the duty to parents may be voiced, however, not as single-pointedly. Another difference could be that Janeesha was not expected to work, as she may have been in the UK, regarding government expectations (not to be provided with benefits) and societal and family expectations.

I ended the chapter's ethnography with a poignant statement, with Janeesha telling me she was saved, saved from the earthquake by her father. To my mind, her words "being saved" by her father from the earthquake and 'saved' in a Christian sense carry an obvious double meaning.

The final chapter returns to care within and around social support, a necessary component of creating resilience. Inherent in the provision of care is trust, and the next and final chapter will detail one *Bombo's* story of gaining and maintaining social trust and how this provided his power to heal within the social support network he cocreated. The biomedical clinicians and their relationship with the community are included within the dynamic of their extended and multifaceted nature of trust.

Chapter 7 "My reputation means everything": The healers.

1. Introduction

This chapter will focus on the *Bombos*, and healers I encountered in my research who also worked closely with my participants and how the notion of social trust between the two can be shaped to interpret the experiences of those living in pain within traditional modes of healing and coping. Within the components of creating resilience, I have thus far in this thesis provided examples in the village of how my participants gained coping skills and the attributes and components of 'learning to live with their pain.' That is to say, how they learned to accept it as described in the multidisciplinary literature (Rutter 2006; 2012; McCracken and Morley 2014; Panter-Brick 2014; Kinnie et al. 2024) under a framework which moves beyond the biopsychosocial model currently seen in most pain services to a more integrated and dynamic approach (Stilwell and Harman 2019; Coninx and Stilwell 2021; Cormack et al. 2023). As with preceding chapters, to create the integrated model, the framework of idioms of resilience fills the fragmented spaces and creates a more holistic understanding of the lived experience of chronic pain. As will be demonstrated through this chapter is the idiom of trust as an idiom of resilience as it relates to the *Bombos* and the community. These socio-ecological ways of healing and care of the *Bombos* are performed and negotiated through a nexus of trust, which was vital to my participants' acceptance of pain⁵⁷.

This will be followed by a brief contrast with the approach taken by the healthcare workers at the local nonprofit/non-government clinic. The ethnography will center on the Indigenous healers as individuals, describing and tying in their social dynamics and the impact of their roles and obligations in their immediate family as heirs of a healing tradition and the trust this involved. Following Stacey Pigg's article, *The Social Symbolism of Healing in Nepal* (1995), "It is important to not only take into account the social factors implicated

⁵⁷ This Hsu (2008) may term medical landscapes, however, I do argue that the *Bombos* stories describe another layer.

in medical interactions but also to consider how attention to the realm of healing can shed light on social concerns that are not strictly medical." (19)

The *Bombos* were placed in a position of constant negotiation to maintain their reputations within the community and feel secure in that they were entrusted with their prominent roles. I aim to illustrate how this trust was the basis of their power as healers and the foundation upon which many of my participants built and strengthened their coping and resilience with chronic pain. As I will show through this chapter, for the Tamang, in this tradition, this social trust was framed within and extended through the ethical and moral practices within the community. I saw social relations as the source of their power to heal, and despite their significance in maintaining their status, the *Bombos* saw that source as supernatural.

The villagers with chronic pain preferred the familiarity of the *Bombo's* treatments over the biomedical clinic, but why? I ask. Continuing with my participants' strategies of coping as the central theme of this thesis, I will show how the *Bombos* gained trust, in essence, their power to heal, and how this enabled one of my participants, Pasang to accept and develop strategies to negotiate and cope with living with pain. Part of this process was my collaborative work with him in my role as a clinical ethnographer, or what could also be described as a clinician ethnographer. I describe the outcomes of a healing ritual (*puja*) and how Pasang's trust in the *Bombo* and this process allowed him to cope better with his longstanding pain and mental anguish. Pasang trusted the healing ritual and benefitted by feeling accepted and reassured through social support. This ritual changed his mood and motivation, creating a 'readiness' so he was better positioned to work using my pain physiotherapy strategies. He was not 'cured,' as was not expected, but he was more active and functional, living a less isolated and more fulfilling life before starting his sessions with me.

As used above, the concept of the power to heal is worthy of discussion for understanding the Tamang *Bombos* and the social and anthropological stance. Power can be viewed in this context from someone living with pain, as related to individual agency, but more specifically, validation, that is, 'being believed.' Chronic musculoskeletal pain can be an

invisible disability; one cannot 'see' pain. People with pain are told by the medical profession, family, and friends to 'empower' themselves to take control. In this chapter, I draw from Jean Jackson's (2011a) ethnography of a U.S. chronic pain program facility, *Camp Pain: Talking with Chronic Pain Patients*, as a point of analysis⁵⁸.

It is also an environment with which I am very familiar, having worked extensively as a pain specialist physiotherapist (U.S. physical therapist) in the U.K. in these settings. In Jackson's ethnography, the underlying theme described in this self-management program, where the people living with pain learn coping strategies, was that the patients felt a sense of validation, which stems from a foundation of trust. People are legitimized and feel more accepted by having received recognition of their pain. For some, this acceptance leads to changes they make as individuals that improve overall well-being, physical function, and mental health. Pain levels may decrease somewhat but are more manageable using the coping strategies learned in the groups. They report that they do not feel so isolated and can make choices about changes to be more active and socialize more. This approach was not without its problems, which will be tied into the discussion near the end of this chapter.

Feeling believed is a topic heard frequently in any pain clinic. One of Jackson's interlocutors tells her, "I would rather have cancer" (2011,3). I heard this repeatedly in my work in pain clinics. Interestingly, I did not hear this at my field site. I can only surmise why this was not something my participants discussed with me. Perhaps because there would be social pressure to participate, and it would be unusual in a small village agricultural community that a person would exaggerate symptoms to escape physical work, that is, 'not doing their share,' to sow or harvest a crop that is crucial for sustenance. In the UK, social structures provide (for some) paid sick days. Non-participation visibility is not as relevant, and the community's stakes are not as high. The attitude that a person in pain may be malingering is not uncommon in the UK; therefore, the notion that the pain is seen as 'real' was crucial to my patients in the NHS. My UK patients' concerns regarding validation of their pain were often for personal reasons, that is, frequently heard in the clinic setting phrases such as, "I

⁵⁸ For other anthropologists/social scientists' studies about pain clinic, refer to Bazanger 1998; Csordas and Clark 1992.

am not crazy...” or pressure from family not to expect increased demands for caregiving. Some of these contrasts will also be further discussed.

By coping, within the understanding of chronic pain patients, and as Jackson alludes to, it is generally seen to be an acceptance that the pain will not go away (and improvement in 'self-esteem') and consequently that those living with pain can still be functional and find enjoyment. At *Camp Pain*, this acceptance stemmed from a 'change in attitude.' Not coping would be self-destructive behavior. (Coping and resilience are defined in the thesis Introduction and Chapter Four: The Copers). I will detail in this chapter how this was triangulated within spheres of the *Bombo's* healing, then build on my work with Pasang as a physiotherapist and how this was situated within his community.

Within the Tamang understanding, a *Bombo's* power (*shakti*: Sanskrit) is derived from supernatural sources through his ancestor's influence and divinely through *Mahadeva* and defines their strength and special abilities (Holmberg, 1984, 2018; Miller, 1997; L. G. Peters, 1998)⁵⁹. Nicoletti (2004) describes their ability to retrieve lost souls as “reestablishing order within the patient's s psychophysical structure” (88). He explains how it is understood that the shaman possesses magical powers, but as I will argue, his role as the one in charge and negotiating with the spirit world gives him this position. The *Bombos* first divine the cause of illness but then are required to mediate with them to allow the ill person's soul to return. This position of power, his authority as a *Bombo*, is central to the healing itself. Moreover, I saw in my field site that this trust in this authority to negotiate on his/her behalf, I will show, also permitted a sense of validation to the ill person, and hence a validation in a different sense from *Camp Pain*, to create a place where they could begin to make changes to reintegrate socially. Also seen in my ethnography and with Holmberg's (2018) study, this trust is developed and brought into being for the *Bombos* as guardians of the Tamang traditions and their moral and family values.

They do know that they will probably not 'get better' and will not be cured of long-term back pain, for example. However, the steadfast reliability of the *Bombos* and the familiarity

⁵⁹ Mahadeva is seen by the Tamang as a divine ancestor (Peters 2003; Tautscher 2007).

with the *mantras* reassure the person in pain. The villagers view the *Bombo* family structure as example; a good reputation for raising their children was in line with Tamang ways. The *Bombos* are part of a Tamang tradition that has endured generations and is 'alive' through teachers who are deceased in the human realm.

As I detailed in Chapter One, in my interviews with the local nonprofit/nongovernment hospital staff, the local population tends not to seek their care in the first instance but instead visit the *Bombos*. I asked the clinic staff how they treated a patient with persistent pain.

"We tell them that their pain will go away, that they will get better if they take medicine."

I was curious why they would say that, knowing this was not the case with chronic pain.

"We tell them that because we know they are under stress and do not want to worsen that. Plus, if the pain does not go away, they will return and tell us we were wrong. We just tell them to take the paracetamol. Some people do not do what we say."

I asked about talking with the patient about their pain and how they coped, and consistently, they referred to the medicine. I wondered if the *Bombos* provided the psychological support that was unavailable due to time constraints at the Health Clinic, at least not the grounded, sincere support to assist the patient in navigating through the unchanging pain.

During Pasang's first *puja* with Karsang and second with Meme, neither *Bombo* spoke directly to him nor looked into his eyes. There was no evidence of what would be described as rapport, 'being listened to' as is considered necessary in biomedicine for good outcomes (acceptance and management) with chronic pain. Instead, many villagers attended the healing ritual, which provided support and validation. Moreover, the *Bombo* brought solace, familiarity, and fulfillment of a family obligation to uphold these traditions and trust in the community. Through the 'tinkering' and ebb and flow of far-reaching negotiations centered mainly on the family as a community, the *Bombos* could assist in healing.

2. The Bombos

"My grandfather was a sort of *Lama*" (Tibetan: highest principle, highest parent; meaning spiritual teacher), Maila said as we sat eating our *dahl bhat* (Nepali rice and lentils dish) that her sister had left us on the table. It was 10 a.m., and I was not accustomed to eating so early. It made sense in a farming community where the hard work of plowing was best done before the sun was overhead. Most were in the fields following the brief 7 a.m. morning tea; they returned home for a complete meal by midmorning. Maila told me about her grandfather because she knew of my interest in Buddhist practice in the region. She had said that her family was Buddhist, as were the village Tamang people and the Hyolmo people in the nearby village. However, I did not think any more about her comment at the time. At this point, I knew nothing about the local Tamang religious healers called *Bombos*. She pointed to the faded and water-stained framed photograph on the wall near where we sat. Her sister Asmita had told me several days before that both of her in-laws had been crushed under the house during the 2015 earthquake, and this boded more on my mind when I chanced to look up at the two blurred faces staring back, unsmiling in the photo. However, I had not heard any stories about their father's father.

I arrived in the village at the end of May; the monsoon rains were still not heavy, so I could walk and explore the area. During my first week there, I followed some schoolchildren and their English teacher down a path, "We are going to a shrine. Come with us!" they shrieked. They ran ahead, and when I caught up, after stopping to pull off the dried plant seeds attached to my trousers, they stood outside a rusty waist-high fence enclosure that surrounded an old tree. The tree's leaves were dried and withered, and on the branches hung brightly colored scarves that fluttered in the slight breeze. Most striking was a five-foot-tall metal trident, its red paint peeled. Seeing this shrine was my first encounter with the blending of Buddhism and Hinduism, which was pervasive in the area. Buddhist ritual objects, prayer flags, and the trident symbolizing the Hindu deity, *Shiva*, or *Mahadeva* to the *Bombos* were haphazardly displayed together.

Nevertheless, when I asked Maila again if they were Buddhist, she reiterated that they were. Initially, I was primarily curious about the religious beliefs of the local people in terms

of how their devotion and practices may contribute and relate to their coping and resilience when faced with chronic pain. However, this would come later as I got to know my research participants more. During these first few weeks, I became aware of the role of the *Bombos* and their prominent place in community life and in assisting people in pain.

I enjoyed taking the long way from where I was staying in the predominantly Tamang village en route to meet with people in the Hyolmo village. What drew me was a small lake, a pond in all respects. In the heat of the monsoon season, it was covered with a thin film of green algae, with various-sized trees lining the shore. Curiously, there was a half-sunken wooden rowboat lonely on a bank. An enclosed shrine (Nepali: *mandir*) was dominant at one end of the pond. I had visited the pond several times before venturing into the small cement structure. No *lungta* (Tibetan: wind horse) or prayer flags were outside the *mandir*, nor any other typically Buddhist iconography. The wooden doors were open. I walked in to see two adorned statues standing about six feet tall. Here, *Mahadeva* stood prominently, holding his trident, and *Parvati*, his female consort, stood beside him. At the time, I did not know the strong connection between the Tamang *Bombos* and *Mahadeva/Shiva*, nor did I know that it was customary for them to choose to live near a lake or pond.

Several months later, when I went on a pilgrimage with the *Bombos*, one told me they "got their power from this lake; that is why we live close to it." That pilgrimage would be to Panche Pokhari, where they went every year, to a group of five lakes in the mountains, at an altitude of 4,117 meters; this site was a source of great power to them, and where the *Bombos* and Hindu pilgrims also traveled to receive the blessings of *Mahadeva*. Other anthropologists' accounts can be read in *Himalayan Mountain Cults* by Gabriele Tautscher (2007) and Larry Peters' chapter in the book *Pilgrimage and Healing* (Peters 2005) about their research and travel with the *Bombos* to other holy lakes in Nepal.

A week or so later, I was sitting at the top of a long stone set of stairs, a shortcut through the steep paths, and heard a loud, steady beat⁶⁰. After more than an hour, curious, I followed the monotonous drumming, which echoed through the small valley where I sat. I

⁶⁰ I recount this scenario and the following events in more detail in Chapter Two.

peered unobtrusively into the house I finally found, to which the rhythms led me. Seated on the floor in a wide circle sat two *Bombos* and their young apprentice. The beat I heard vibrated from large drums (Nepali: *dhyangro*) held upright by the shamans. Having come closer, I could hear small brass bells (Tibetan: *ghanta*), the size of plums, clanging alongside the drumbeats' thumping. The bells were worn across the shoulder of the central *Bombo*, and he shook his shoulder and upper chest with strong rotations of his body to coordinate the sounds. I quickly darted back, feeling I was intruding. It was my first glimpse into this world that would change my ideas of healing in the village and surrounding area.

In this thesis, I detailed my first meetings with the *Bombos* in Chapter Two, "Try Feeding the Ghost More." There, I describe a *puja* or healing ritual to "scare the fright away" or the *Bombo's* practice of confronting a ghost who has to take away a man's *hungsa* (Tamang for life force, or an aspect of the soul, without it, one would die) (Peters 2007; Holmberg 2018).

Later that night of my first meeting described above, when I followed the drum beats, I returned to observe this healing drama, displayed as a 'battle,' as Nicoletti describes, between the *Bombo* and the thieving ghost (Nicoletti 2008). In this chapter, however, I aim not to detail the rituals so much as to recount the place the *Bombos* held in the lives of the people with whom I worked. All of my participants sought the care of the *Bombos* initially. Some were treated only by these traditional healers. Some sought biomedical care at the local non-government hospital, then did not return to the *Bombos*, while both treated others simultaneously, much as Pigg observed in the 1980s (Pigg 1995). The *Bombos* were also eminent members of the community. Apart from their skills in healing, they held authority. Their reputations were critical. After sitting long into the night with my neighbors and family of the ill man observing this first *puja*, and then another shortly after, Pasang, who suffered from chronic pain, nightmares, and loss of his life force, was to become one of my central research participants.

3. Pasang's healing

Pasang continued to be more social as the months went by, and he no longer had nightmares after the healing ritual. We had been discussing his pujas, what had happened, and if they were helpful to him. I saw a distinct change in terms of his overall mood. He felt more motivated and was confident that his hungsa had returned to him. Additionally, Pasang described his neck and back pain as somewhat reduced. With a more relaxed arm swing, I observed his walking to be less stiff overall. Since the severe curvature in his spine would not change with any intervention, his flexed posture persisted. However, he appeared more at ease and could get up and down from the floor more fluidly.

With this change in him, I knew I could begin to talk with him about what day-to-day activities he wanted to improve, such as easing his movements needed to wash and perhaps increasing his walking distance from a few feet at a time. As a clinical ethnographer, I would spend many sessions discussing his thoughts about managing his pain and mood and then building on that to find activities or basic exercises to repeat and refine what he could do on his own that would carry over into ease of movement. Lengthy discussions centered on how Pasang felt about his pain and mood while doing these activities and how he could perhaps think about it differently. These tactics may be the same loose method taken in the pain clinic as a pain physiotherapist; however, in my field site, this was far more embedded and far less formalized and structured. Pasang's sessions are detailed in Chapter Three. I felt that his improved mood allowed him to be more active, thus helping with his physical pain, as is usually the case. Pasang's face no longer pinched with every movement, thus convincing me that there had been a fundamental change in his mood and physical pain levels following the second puja. I understood this to be the result of his confidence in the *Bombo*. However, he admitted that he felt that the first *puja* was not as effective, and he did not blame the *Bombo*.

I did not ask him pointedly why he felt this; it was evident that the second ritual met his needs. Looking back, I attended both *pujas*; they were different rituals, and two different *Bombos* conducted them. I had a flash in my mind as I thought about looking over some pictures I had taken, not realizing who the central *Bombo* was in the second, more effective

puja until, surprisingly, yesterday, when I began to write and document this chapter. I instantly realized that the main *Bombo* was the father of the first *Bombo*, Karsang. I am not clear why I did not realize that. Perhaps it may have been that this man passed away about two months ago, and he was in my mind now. Of course, I did not know either of the two men then. However, I came to know Karsang reasonably well, and he became one of my primary research participants and a close confidant. I visited his family several times and was invited, especially since they knew I liked buffalo milk, to which they added their home-harvested honey, which was a special treat.

During one of these visits, I met the older *Bombo*, whom they called *Meme* (Tamang: grandfather). He was amiable, however, imposing, and commanded respect throughout and within the extended family. What I remember most about his appearance was that he had small gold earrings, one in each ear. This jewelry was quite distinctive and memorable to me. However, I made this connection regarding family ties again. This is important because, at the time, I thought there may have been some rivalry between the two *Bombos*, knowing Pasang had been healed during the second *puja* with Meme and not the first with Karsang. Was there a trust issue with Karsang? Was he not considered reputable, so a second had been called in? Only now do I realize this may have been the case. Alternatively, perhaps it was father and son working together as a team. It might have been that Karsang had been called elsewhere as his services were quite in demand, as I learned. However, the issues of trust in the *Bombos* that were primarily built on their reputation became a central and vital theme in how I came to understand the 'efficacy' of their healing.

I found myself wondering where and when I would meet them again. I felt I would see them in my everyday walking, traveling, and meeting new people. It was a small village where I lived, and the neighboring villages were within a fifteen to thirty-minute walk. Everyone seemed to know each other, especially those of Tamang heritage. Everyone contributed and pitched in with farming activities and certainly socialized. However, I found it surprising that I was not bumping into the two *Bombos*. During my research, I would frequently see the same people repeatedly. Moreover, I learned that if I could not

contact someone, it would not be helpful to make appointments to see them once I eventually met them.

I felt the best way was to walk on the roads between the villages, especially at certain times, knowing that people would be on the way to the fields, coming back, or going home for a meal. I would run into people rather than prearranging, which generally fell through. The concept of an appointment did not exist, which was fine with me as I was accustomed to strict appointment-keeping within the National Health Service, and it was quite a relief not to feel encumbered by this in the field. For weeks, I wanted to meet these two gentlemen again to follow up, interview them, and spend time with them. Nevertheless, it did not seem to be happening within the local concept of karma. Within the local understanding, following the laws of karma meant everything happened in line with cause and effect. Events happen for a reason due to past deeds or circumstances. Therefore, everything happens for a reason. When that karma ripened was not usually known. Consequently, when I met him, I was 'meant' to meet Karsang again.

Regarding his and my karmic connection, he did tell me months later that he felt that we had been brother and sister in a past life and that he hoped we would be again in a future life. So, not meeting him soon after the *puja* could be interpreted as maybe it was not a good time for all of us. I did ask my research assistant where Karsang lived. She responded that he was in a different ward. So, to my mind, which meant he lived very far away. Essentially, she was saying he was unreachable in her tone.

For Pasang, he was slowly coming back and feeling himself again following the pujas. We moved on in terms of looking more at his day-to-day activities. Pasang wanted to be able to venture out more. I gathered from observing and talking with him that he was a social person and felt relatively isolated. Frankly, he seemed bored, staying at home. I had met him sitting on the front porch of Maila's house, listening to adults' conversations, and commenting when jokes were made. He did not seem fully engaged and often had a faraway look, maybe from fatigue. Alternatively, maybe he was in a place of wishful thinking that he could walk down to the village. I sensed that he did not thoroughly socialize with the adults, especially not the men or his peers. That day, he sat half chatting

with the women darting in and out of the kitchen during mealtime and exchanging pleasantries. It seemed to my mind that Pasang also liked to sit and watch the children. That day, a new puppy was quite amusing to them.

Pasang enjoyed joking with them and sat in his chair as they jumped around him, throwing pebbles in a game. It is worth mentioning again the marked change in his demeanor following his healing. I told him he looked ten years younger the day after his second *puja*, and I was sincere in this comment. His eyes changed; they were focused and more interested. Again, not the semi-glazed look of being lost. Worry had shown on his forehead several weeks before, and the creases were deep. His eyebrows pinched together, and he held his mouth tight. Now, his face seemed more relaxed, and his smile was broader.

We did talk, quite frankly, about his drinking habits. The local *rakshi* was consumed in every household. I usually had a small brass bowl every night after dinner, which helped to keep warm, especially in the winter months. I was always warned that it was powerful, but I did not feel the effect so much. Pasang's son divulged that he was concerned about his father's drinking. However, he did feel that his father's habit had improved since he drank a glass or two a day compared to far more consumption when Aryun was younger. In discussing it with Pasang, I felt that, given his renewed motivation, he considered changing his drinking habits. He did say that he would try to cut it down again. In further discussions with his son, what was Pasang's incentive to change? What was it that he felt? What did he want to do or do more? I saw that he was incentivized by the prospect of being more social, visiting his peers, and interacting more in village life. In that he described when his *hungsa* was gone that he felt like running into the jungle, I knew he was struggling immensely. He was highly anxious and fearful of other people and did not feel like talking, only wanting to be alone. This situation had changed. I knew from my work with chronic pain patients that having a personal motivator and goal was always valuable.

I discussed with him how he could be more engaged with others, which involved walking, which he closely tied with the social. Not only would he be able to walk down to meet friends at their homes or the shops, as mentioned previously, but it was also customary to walk through the village, a sort of rambling, to meet people along the way. In Chapter

Three, I focused on Pasang's fear before his *hungsa* was returned. He self-isolated and preferred to be on his own. Villagers always stopped to chat, and it was generally the same conversation. Where are you going? (Village Nepali: *kaha janay?*) Are you going up, or are you going down? That was generally the conversation, with a hand gesture with one palm pointing up for going up or down for going down. My sessions focused on building on his renewed energy for the next several months. He had had his *hungsa* returned; he was ready to begin living again. Walking, building on endurance, and then chatting about some of these obstacles were some of the central themes. Furthermore, Pasang remained mostly engaged, having been healed by the *Bombos*.

This progression of treatment with Pasang brings the narrative to a dilemma regarding understanding the processes and transformations the people living with pain create. Are they healed, or are they 'merely' coping? When is someone healed? Moreover, who determines this, the healer or the 'healed'? How does the term heal relate to 'cure'? Indeed, my many years spent working in a biomedical pain service aimed to bring the chronic pain patient to an understanding and application of acceptance or coping. Clinicians and clinical ethnographers commonly understand that everyone would prefer a cure, that is, to be rid of the unrelenting pain, once and for all, never to have it return. However, through concepts surrounding notions of management, that is, changing perceptions concurrent with a lifestyle change to include gentle exercise is thought to make a significant difference; this can be termed 'coping.'

However, what are the effects of the *Bombo's* work? I will illustrate this through my interactions and conversations with them surrounding their negotiations to solidify their social standing in the community.

4. Pilgrimage to Panch Pokhari

I stood in the blazing sun in a dry sandy clearing across from the high school, watching the *Bombos*. Long streams of red, green, and white scarves spread with each fast twirl, white linen skirts billowing like Sufis. Almost five weeks had passed since I attended the two *pujas* the *Bombos* performed with Pasang to when I began this pilgrimage with them to Panche

Pokhari. It was their starting point for the journey during the August *Purnima* (Sanskrit: full moon) to travel to the five holy lakes of *Mahadeva* and receive his blessings. They would stop along the way to take 'messages' from people to bring to the festival, and on the return trip, we would stop again to visit the same villagers, returning with the renewed power of Mahadeva. I had been asked by the family where I stayed if I wanted to join the pilgrimage to the *Panch Pokhari* with three *Bombos*, their families, and friends. It was a four-day walk round trip up through the mountains.

Leaving the starting point from the pond, the group continued up the winding road, stopping every ten to fifteen minutes to perform their dance. It was a long way up to Panch Pokhari, but most of these stops would be in the more populated areas, allowing the villagers to request offerings. People came out of their houses when they heard the *Bombos* arriving, eager to share their 'messages' for *Mahadeva*. Within seconds, the elder man of the family would carry out a small wooden bench to serve as an altar. Quickly, a liter of Mountain Dew soda would be placed as a *sagun* (Tamang: offering) in a prominent position wrapped with blue, green, red, or yellow *katas* (Tibetan: prayer or offering scarf). The wives of the three *Bombo* played an essential role within the entourage and continuously sang *Seho le Bombo se ho se ho* (my research assistant told me that this song is "old Tamang" and could not be translated) as the men danced (the *tirtha nach* name of the dance in Tamang), skirts swirling around the altar. One always carried a heavy brass vase filled with brightly colored plastic and nylon flowers; this was also placed on the altar. (The woman carried this vase during the entire trip to the high altitude of Pache Pokhari and back). The road was lined with people; everyone seemed to be out, and when we reached any small cluster of houses, the people were pushing to get a view. Young girls were dressed in their best *chuba* (traditional female Tibetan dress) with their hair neatly plaited. It was a religious and social event that clearly carried meaning for everyone.

Halfway to the next village, after the group had stopped at least three times for offerings, I saw that Karsang had joined the *Bombos* dance. I had not seen him since Pasang's first puja and wondered if I would. I thought talking with him about the *puja* from his perspective would add to the time spent with Pasang. In this way, a perspective from the healer's point of view may be compared to Pasang's judgment of any changes he felt or

saw. Karsang would not go on the entire journey to Panch Pokhari, so I planned to meet again soon.

Soon after returning from the pilgrimage, Karsang said he was eager to meet to talk about something that involved his middle daughter. When we met, he was visibly worried. We sat on the floor in my house, and as he left his tea to turn cold, he got straight to the point. He said he was honored that I sought him out again and knew I respected him. He said he respected me in return, as we both helped people get well. "My reputation is everything," he continued. "People will not come to see me if they do not regard me highly." He then asked me to spend time with his daughter, as she had run into some trouble.

Karsang underwent his initiate year as a *Bombo* when he was eighteen. As described in Chapter Two of this thesis, Karsang did not choose this life, but a deceased relative who was a *Bombo* had 'chosen' him. One of his father's relatives had died while harvesting honey high on a cliff, falling from the bamboo ladder erected to reach the hives. He said that some *Bombos* do choose this path, however. Karsang explained that the spirit of one of his three grandfathers' sons was his inner *guru* (Sanskrit: spiritual teacher) and guide, and he spoke to him during the *pujas*. His *guru* instructed him in the rituals to find the ghost and how to challenge it, allowing the ill person to heal. He talked about some of his early experiences; one day, he was fixing the buffalo's rope after working at an old house when he started feeling an electric shock type of pain (Nepali: *siring siring*) course through his body. He could not stop this feeling, and his mother took him to their local *Bombo*, who started the ritual blowing *Ngaba* (Tamang) on him. He, too, started to shake, and it eventually stopped. The family realized at this time that Karsang would be a *Bombo*. There was another type of *Bombo*, Karsang said, called *Ban Jhangkri* (Nepali: wild, forest *Bombo*)⁶¹. They are not "forced" along familial lines as he described it had been with him,

⁶¹ There is a delightful children's book in English and Nepali which tells the tales of the *Ban Jhangkri* called *The Spirits of the Forest: a short story between reality and fantasy* (Sironi 2017)

but they choose to live this life. They are invisible and live in the forest. If they happen to touch someone, they become invisible, too.

The next evening, the shock-like feeling returned, and he felt something forcing him to revisit the house where he was working the day before. When he approached the door, the padlock suddenly slipped open, and he entered. He walked to where he saw a box sitting on a table. Despite the dark room, the contents shone bright like a light bulb through the locked box, Karsang said. The lid also opened on its own, and Karsang took the object, a *ghanta mala* (Tibetan: a string of bells worn by a *Bombo*). For the next four months, Karsang began to control the shaking by accepting or "cutting the *chhi* " (Tamang: the impulse from the *Bombo* relative, the guru). His *guru* could not eat or enter a higher realm without Karsang accepting his transference through this process. By accepting and listening to his *guru's* instructions in his dreams, Karsang began to develop his skills. His relationship with his relative thus provided him with the knowledge he needed to heal, what *puja* to conduct, and what *mantra* (Sanskrit: prayers) to say to what ghosts, each causing different conditions. He explained the different types of ghosts who, when hungry, entered people and caused different ailments. When he performed the 'blowing ritual' *ngaba*, he was making a pact with the spirit that the ill person would feed them more if they promised in turn to leave. He explained each spirit:

"*Shyaula Mang* (Tamang: ghost type) gives us back pain. We must use different *mantras* to blow; it depends on your problem. When somebody has swelling, it is from *Sauptu Lu* (Tamang), and we use that mantra, and the *Shinde* (Tamang) ghost causes stomach pain. When somebody has leg pain, we must use the mantra for the *Shikhare* ghost (Tamang)".

It became clear how vital a role negotiation played. Within the realm of the living, amongst themselves- Karsang was continually 'working' his reputation as a *Bombo* and his social standing in the community. His reputation cemented the trust of the people who sought his help. (He did not ask for payment for his services). He also had to relent to the instructions of a deceased relative in his guru, keep the peace in his immediate family in the living realm of humans and guide his children in the right direction, uphold the *Bombo* traditions and obligations under Meme, his *Bombo* father. Lastly, Karsang had to make

promises to the hungry ghosts on behalf of those suffering from ailments. The continuum stretched from gentle persuasion to force across three planes of existence.

He returned to his concerns about his fifteen-year-old daughter, Sapena. Word had spread through the community that she had gone with a group of young men from a neighboring village to a hotel in a town several hours away. Karsang told me some of the events, but I met with her a few days later and heard the details firsthand. Sapana was confident in describing what happened as she spoke without hesitation. A group of young men had said they could find her an overseas job. She was in school, but because she was worried about her family's finances, she decided to run away and seek a job working as a domestic. Unfortunately, this dubious process happens frequently with the young people in the region. (Refer to Chapter One – The Village for a thorough discussion on emigration for work). Many successfully travel to the Emirates and gain legal employment as builders for the males and cleaners or childminders for the women, albeit at a high price. Those less lucky have their money taken by the handlers; sums of up to \$10,000 are standard.

Sapena told me she was in a hotel room with one of the men and overheard his phone conversation. He was talking to someone, explaining that he had a girl with him. It became clear to Sapena that they were negotiating a price for her and that she was being sold for sex work. She realized that she would have to find a way to leave quickly. Waiting until the man went out for a cigarette, she snuck downstairs. Sapena hid quickly behind some debris in a side street and rang her older sister to come to pick her up.

This attempt to traffic Sapena had happened several months before, and she had since returned to school. She told me she frequently stayed home because of the bullying from the other students. I was unsure how the rumors started, but it was becoming increasingly difficult for her to go out in public. People said she planned to elope with one of the young men and that they had sex in the hotel. She told me that her older sister was a tremendous source of support and that she believed that she innocently was hoping to get access to an overseas job. Sapena told me her sister had eloped and was now happily living with her husband, in-laws, and young son.

Karsang explained that the young men had been identified, and he planned to submit a case to the courts against them for attempted trafficking. Since this event, he had sought advice from senior *Bombos*. He said his daughter could not marry for at least a year once her name was cleared. He felt that this was impacting every aspect of his life, understandably. Karsang worried that people would not call him for pujas and that their trust in him was significantly impaired. He placed his hopes on the court case's outcome to restore his daughter's reputation. The credibility of Sapena's story directly impacted Karsang's power as a *Bombo*, his power in the community, and his power to heal as a *Bombo*.

I visited Sapena many times at her father's request. He wanted to know, in my opinion, if she was telling the truth. I did think she was. We went on a five-day-long trek together to give her a break from the stress she felt in the village. I gave her English lessons as a distraction as well. Despite being fifteen, she was childlike in many ways. At this point, she was not going to school for weeks, preferring to stay home, saying that her parents needed her in the fields. I told her father that I had a UK-registered charity that worked in Nepal with children and that we could fund her education in Kathmandu. I felt that this would remove her from the bullying and provide the opportunity to continue her schooling. Karsang agreed and said the *Bombo* he visited had said she needed to leave the village until her name was clear. Sapena thought this was a good idea, and she was committed to attending school in the city.

Before *Dashain* (Nepali festival in October), Karsang and several neighbors acting as character witnesses accompanied him to file the complaint to the court. Sapena also gave her statement. He felt relieved that some progress had taken place. He said the outcome would come several months in the future. I left my field site before the verdict. I heard that about a year later, Sapena had eloped, married at age sixteen, and remained in the village. Her younger brother had also gotten married.

The family was seen as one unit without necessarily distinguishing between each individual. One's children usually married a partner of the parent's choosing, which was quite strategic for supporting family cohesion. Refer to Chapter One – The Village, for

further description of Tamang practices. This vignette regarding Karsang's daughter is included to demonstrate this point. Karsang's reputation as a *Bombo* was closely tied to the reputation of his children. When he said that Sapana could not be married for a year, that told me that he had wished for her to be married earlier and that he had someone in mind to solidify bonds with another family, most likely one within the *Bombo* community. Many families encouraged their teenage children to withdraw from school and send remittances home from overseas; however, the marriage of Karsang's daughter was most important. It was unclear if this was to calm the tension from his eldest daughter's eloping. Young people increasingly disobey their parents' wishes, run away for a 'love marriage,' and then return.

The life of most *Bombos* is 'inherited' and not chosen. This link creates a sense that the deceased relative, his guru, or teacher never died. The obligations are continued. The 'deceased' come to the *Bombo* in their dreams, providing knowledge passed down to them from the preceding generations from their guru. Karsang told me that there once was a book of mantras, but that had been burned by one of the *Lama Bombos*, and in recent times, the mantras were passed down 'orally' through dreams.

At the start of a *puja*, the drumming and intentional shaking of the string of bells (*ghanta*) worn across the shoulders induces a trance. During this phase, which can last many hours, the *Bombo* listens to their *guru's* instructions in an altered state. Familial ties are reproduced and enhanced in this tradition. Arranging marriages for one's children into another *Bombo* family continues the lineage. It is a way of life. Children in these families play *Bombo*, dressing up with child-sized ritual drums and strips of red, white, and green cloth tied around their heads. The adults stand by laughing and clapping, encouraging them.



Figure 30. The Bombos overnight at a temple on the pilgrimage to Karejung

Anil was one of the three with whom I traveled to Panch Pokhari. He was in his mid-forties and had been a *Bombo* for only five years. In talking with him, I read between the lines that he had a sort of *Bombo* imposter syndrome. This hidden insecurity existed even though he was diligent, hard-working, and eager to prove himself. He told me a man had visited him

for healing but was skeptical of his ability. The man carried a live frog in his pocket when he visited Anil, wondering if, when he asked the 'new' *Bombo* to pick it up, somehow, the frog would change in appearance. Anil told me he was perplexed, became slightly irritated, and told the man to leave. When I first met him en route to *Panch Pokhari*, I noticed that he was barefoot for the entire trek, through rocky and slippery paths, with our final destination at 4117 meters. He told me matter-of-factly that they all were supposed to be barefoot. That is how *Bombos* danced. Before I knew his name, I called him 'The Barefoot Bombo.' His conscientiousness was in stark contrast to his non-working personality. He was playful and mischievous when he was not with his elder *Bombos*. Their diet restrictions are inflexible, and they are prohibited from eating garlic and onions at any time. My Buddhist practice taught me this rule was also for particular *sadhana* (Sanskrit: spiritual practice). Maila told me that Anil's wife, whom he had been with since she was twelve and he was fifteen, through an arranged marriage, would purposely cook with garlic and onions to get back at him. Of course, he could taste it and then be seen running through the village to the *mandir* to pray for forgiveness to *Mahadeva*. I was told everyone laughed when they saw him bolting towards the *mandir* in desperation, knowing precisely what had happened. I surmised that Anil's reputation was still precarious, but due to his commitment, he would be a trusted *Bombo* in the community in the future.



Figure 31. Early morning preparations

One of the other three *Bombos* was another Tamang man, Tshering, aged about fifty. He had a prominent nose, and looking at him in silhouette, he resembled a Native American. His skin had fine lines, and he rarely smiled. He carried himself in a dignified manner with his chest open and broad shoulders square when he danced. He was soft-spoken and did not speak as often or laugh loudly as Anil did. Tshering was serious when he danced and displayed a graceful style, moving his arms in an almost balletic form. When attending to the rituals, he paid attention to every detail. He appeared to carry an air of authority; however, he was not the leader of the three. Often keeping to himself during the off time, I saw him sewing his garments or cleaning or repairing some of the ritual objects.

I did not speak at length with Tshering. However, his son Ajay, aged twenty-one, traveled with us on the pilgrimage, sometimes beating an extra drum as the *Bombos* danced. We chatted around the open fire the second night along the way after a day of villagers offering, followed by eight hours of trekking up to an altitude of about 3700 meters. The group stayed in an expanded cowshed rented out by farmers for the pilgrims traveling to *Panch Pokhari*. Ajay told me that he had eloped to have a "love marriage" and that his father initially did not accept it. They now had a two-year-old son; he, his wife, and his son lived with his parents. This 'disruption' in disobeying one's parents' wishes for an arranged marriage was becoming more common, as I learned when I spoke with young people. I could see that Tshering was in high standing in the community and respected by his fellow *Bombos*. Of interest was that I did learn later that Ajay's wife was Karsang's eldest daughter. (Whom I referred to previously, who came to bring her sister Sapena back from the traffickers). There was a time when this union was not acceptable, at least to Karsang, as he was rumored to carry around his *khukuri* knife (Nepali: curved knife for farming and general use) in his bag, ready to injure Ajay if he happened to see him.



Figure 32. On the trail to Panch Pokhari

We awoke at 0400 to start the final leg to Panch Pokhari. The Tamang women lit cigarettes immediately upon waking and rolled up their heavy blankets. The third *Bombo*, I called Thulo, which means big in Nepali, because he was the group leader. He was tall and thin with gangly limbs. His arms flailed in uncoordinated but joyful movements, unlike Tshering, who had a more dignified comportment. I thought that for all four *Bombos*, their dancing mirrored their approach to life. Thulo had a toothy grin and was talkative. He was not the apparent leader, but everything did run to plan without much stress and anxiety throughout the pilgrimage. It was a task to organize a group of twenty or so (some came and went along the way) over the four-day trip over challenging terrain. The lakes were at an altitude of 4,117 meters, it was monsoon, and leaches were everywhere. Thulo had an easygoing manner, and he was trusted.



Figure 33. Bombos dancing in a village on the way to Karejung

In December, I accompanied another group of *Bombos* from Karsang's village on a pilgrimage, with him leading. See Chapter Two of this thesis, 'Try Feeding the Ghosts More,' for details of this *yatra* (*Sanskrit*; religious journey). He told me how he had all of the forty pilgrims counting on him, that he was responsible for them. He was attentive to everyone and ensured they were warm enough and had snacks, in addition to tending to the trip's logistics. He was dependable but also anxious that things ran smoothly. This trip was before the outcome of his daughter's court case, and he was conscious that he might be judged if there were any incidents along the way or events to fuel gossip.

5. Trust as a foundation for coping

The *Bombos* rely on trust, trust that people will come to see them and access the knowledge their ancestors have entrusted to them. Moreover, there is the issue of trust in the method of healing that they provide. This chapter argues that this process of seeking the help of the *Bombo* is the crucial initial step many villagers, and many of my participants in particular as I saw it, take to prepare to cope with chronic pain and other ailments.

6. Conclusion

In conclusion, the Indigenous healers see their power as supernatural, directly from Mahadeva, but through their ancestral guru as a medium or conduit. I do not contest the supernatural but also seek to understand the social complexities. My participants' trust in them was absolutely crucial. The *Bombos* also see the power to heal from the ethical and moral dimensions as seen in Karsang's family and hence his reputation. Often, power is understood as the efficacy of the ritual, that is, 'Did it work'? Instead, I argue that it may be through the cycle of negotiations on many levels. Firstly, on the spirit level, with *Mahadeva* and the *Bombo's guru* from another realm in their dreams and trance but maintained through the waking life world through their reputations. This power is reinforced through pilgrimages, following the rules, and family relationships that further bring into being their trust as healers and as the idiom of social trust toward resilience for those who visit them.

How do the *Bombos* view themselves, and what their power can accomplish? Clearly, Karsang felt a moral and ethical responsibility to his calling as a *Bombo*. This duty was maintained through his reputation in the community. Karsang validated those he healed; it was a mutual respect and negotiation between them. This validation included believing in a source of the pain or soul loss, believing in its existence, finding it, and showing the bravery to confront and retrieve it. Pasang was validated in his community in that he was believed to have had his *hungsa* taken; he did not have to try to convince the villagers that he was ill, they knew why, and Karsang had said it was so. He was indeed stigmatized, nonetheless. I felt this was because of his physical deformities, lack of physical strength,

and inability to work in the fields, based on his comments and those of the villagers and their responses to him. There was a 'name' for his soul loss and pain from his accidents. Returning to Jackson's *Camp Pain*, there was not *really* a name for chronic pain; it was not *real*. Many chronic pain patients do not have any positive tests or imaging to 'explain' the cause of their pain. Biomedicine looks for an organic cause, tissue damage, or finding on imaging such as an MRI (refer to Introduction) as a source of pain. This erroneous view is understood differently in the specialty of pain management; however, often in my professional experience, this is not always the case, and patients continually have to 'prove' why they have pain.

Finkler (2003) agrees with Jackson's interlocutor's concerns: "Subjective reports are usually ignored as valid measures. In this manner, biomedicine defines reality by denying human subjectivity" (321). Is this more of an issue in the biomedical pain clinic, as seen with *Camp Pain*? In my NHS pain clinics, I found that the first ten minutes of any consultation often involved the patient trying to justify to me that they were in pain. We have been told, "It is all in your head," which I knew was not the phrase the previous clinician would have used. However, this is what the patient took away.

I find it paradoxical that the 'reality' of subjective pain in biomedicine is invalidated; however, the 'reality' of the ghosts, which is often more readily questionable in biomedicine or post-modern societies, who took Pasang's soul, was more tangible. The ghost's existence within the Tamang community was believed, given a name, and acted upon with good effect. See the Introduction titled *The "Really" Real* in the edited volume *Other Worlds, Other Bodies: Embodied Epistemologies and Ethnographies of Healing* (Pierini, Groisman, and Espirito Santo 2023) for an engaging discussion surrounding the notion that as anthropologists, we may theoretically view and construct supernatural experiences as extraordinary. However, they are seen as common in many societies. Refer to this thesis' Introduction and Chapter Two for more details regarding embodied epistemological methods in anthropological research with spiritual healing practices, as described in this volume, which I have used in my research in many regards.

Following Fiona Bowie's (2002) retelling of another anthropologist's story, grappling with the notion of his personal 'belief' in spirits when asked if he 'believed' in the ancestral spirits he was studying in Africa by one of his participants⁶². This example brings the theme of trust full circle; what we 'believe' as anthropologists may be irrelevant; this power from the belief brought to the community is real, demonstrable, and experienced. Bowie is asking herself in reflection in the text and rephrasing the question to have meaning to her by asking below:

'Do the ancestors exist?', 'Do the ancestors have any ontological reality?' which may have been the meaning conveyed to a native English speaker by the term 'belief,' However, Bowie reframes and asks, 'Are the ancestors effective?' 'Do the ancestors still have any power?' In answer to such a question, I would personally have had no difficulty answering, Yes, I believe they exist; that is, they are still effective if one believes that a certain way of seeing the world has its own logic and reality - even if I could not honestly claim to accord them external ontological being' (Bowie 2002, 5).

In my reading of this statement, Bowie acknowledges that the ancestral spirits have 'logic and reality;' that is, they have meaning for her *because* they have power and are effective for the people in the field site described. This is not to say that Bowie is stating the fact that they exist as beings in her understanding. She is reframing it because she believes their beliefs exist as a cultural reality and cultural ontology because of the effects and psychological impact the spirits could exert. Pigg (1996) saw that the villagers she worked with in Nepal did not rely so much on the acceptance of the belief in the rituals but on the trust they held in the individual shaman, which follows my argument throughout this chapter.

⁶² Here Bowie describes having some trouble with the term 'belief' in anthropology, "The term 'believe', 'credo' has overt Christian connotations, it is associated with heroic faith in the face of religious persecution. Terms such as 'belief' are culturally contingent and the concept conveyed may have no ready cross-cultural significance or translation" (Bowie 2002, 5).

A public gathering/forum and support may not be present in the biomedical clinic until accessed through the long waiting time to participate in a pain management program, and even then, do the staff 'believe' or does the program structure take away the agency and institutionalize them to fit into a program that sees progress towards standards not supportive of the participant's needs (Sheppard 2020a). I am biased, as I would hope that when I worked in these programs, I understood the personal trajectories. Despite as a physiotherapist knowing that if people moved more, it would help them, many felt it would "cause more damage." Pasang was also reluctant to move as it generally caused more pain, but only initially.

Jackson (2011) titles one of her chapters, "Getting with the Program.", which I found very apt. The patients often felt that they were presented with mixed messages and needed to get on board with a way of thinking contrary to how they had been managing their lives before going to the program. In Finkler's review of the book, she sees a sense of blame by the staff on the patients for their pain. Another example was regarding the role of emotions in pain; however, many also understood these concepts by the end of the program. Due to the dichotomy in non-specialist pain biomedicine, the separation that if your body is in pain, there must be something 'damaged,' it is often a challenge to understand the role of emotions. At *Camp Pain*, this is seen by the patients as not being heard or validated, especially with psychological factors. People told Jackson that they were made to feel like they were 'crazy.'

Sheppard (2020) echoes the lack of trust from the biomedical community and the general public in understanding pain to be 'real' and sets this as a theme that leads to coping strategies known as pacing:

The drive to engage in and perform pacing relies on disbelief/uncertainty; ... pacing, practiced by chronically pained and fatigued people, is both a normative and non-

normative way of moving through time, and can be read as both a practice of normalisation-rehabilitation, and a practice of crip self-care (Sheppard 2020, 39)⁶³.

People living with pain live in a different temporality, always cognizant of time: time to negotiate stairs, not sleeping enough, and arranging flexitime if working, for example, it changes their experience of the world (Carel 2016). Modern life, to Sheppard, pushes people in pain to be 'normal' to adjust their own time to suit the abled-bodied world. Despite this, her participants (only five in the study, interviewed three times each) defied this pacing approach and did what they wanted: to enjoy the experience. Kleinman (1994) describes his interlocutor's modes of coping, similar to Sheppard's, as resistance and compares those interviewed at Harvard and those living in China. In my opinion, many nuances of the methods of programs are based not so much on 'non-belief' from the medical community or well-intentioned family and friends, but that the participants cannot judge their needs on their own, they cannot be trusted with their own bodies, their own pain.

Chronic pain is, of course, seen worldwide; however, examining how it is understood locally and what role the *Bombos* play in the lives of people in pain is an opportunity for anthropologists to collaborate to inform planning, which will contribute to making constructive, evidence-based changes. In reviewing the management of people living in pain at the local clinic and hospital in Nepal, I can say there is a role for the person-centered biopsychosocial pain management approach used in pain clinics in the U.K., with which I am most familiar. Nonetheless, I would suggest a more integrated and dynamic biopsychosocial approach *and* beyond, as this thesis advocates, informed by embedded and integrated approaches by well-trained staff between the local knowledge and biomedical pain services in collaboration with the village clinic/hospital.

⁶³ Crip theory developed from the field of Disability Studies which grew out of the civil right movements of the 1960s and 1970s. It follows that people with disabilities not be viewed through a medical model in need of 'normalizing'. This framework questions the dominant view of disability as a form of inadequacy. The term 'crip' is taken from the pejorative term 'cripple' and is seen as a cultural rewording as a form of empowerment (Hanebutt and Mueller 2021).

Those methods described in *Camp Pain* are a bit dated in my professional experience; current programs take a more 'person-centered' approach that is directed more at what the patient finds useful for them and with goals directed to their needs and are not as manipulative or coercive and directly by the clinic's guidelines or method.

In my opinion, I do feel that the *Bombo's* rituals are more effective in promoting healthy coping strategies than the local nonprofit/nongovernment hospital approach where I conducted my research, which was not forthcoming about how medications cannot help, as just one example. This misinformation is taken as mistrust (rightly so) once it becomes evident to the patient that the medication has been wrongly prescribed and does not contribute to any effective coping, empowerment, or resiliency on behalf of the patient. Another alternative is to provide more helpful medications (non-opioid) combined with traditional healing, but that discussion is beyond the scope of this thesis. The conclusion chapter will provide more details regarding recommendations for collaborative methods in helping people with chronic pain based on my participant's stories using their idioms of resilience. with anthropologically informed pain physiotherapy and traditional healing as applicable to other settings within the Himalayan region, as demonstrated in this research.

Conclusion

The anthropological construct of idioms of resilience and local understanding of personhood helped to shape and inform my research as I aimed to study how people living with chronic pain in rural Nepal learned to cope and build resilience. Significant influences and central contextual themes throughout the ethnography were the omnipresent ghosts/spirits and local conceptions of the life force (*hungsa*) within the harsh environment of the Himalayan landscape. Coping consists of acceptance and psychological flexibility which enabled the research participants to gain resilience. Within the coping strategies are the perpetual negotiations that the person living in pain endures under the emotional and interpersonal spiritual relations bound between the continuum of hope and fear. Extension beyond this is not a show of grit, but is transformative as the participants work toward resilience living with the struggles and challenges of life in a harsh environment. How they negotiate this is described through the ethnography as in terms of my work as a pain specialist physiotherapist working as a clinical ethnographer. This work sought to further integrate the standard model of care within pain clinics internationally known as the biopsychosocial model (BPSM) and extend beyond and fill the lacunae in the newly emerging frameworks of the enactivist BPSM and the hybrid enactivist/ecological approach of Coninx and Stilwell through the exploration and further application of idioms of resilience.

Within a Buddhist context the struggle my participants underwent between hope and fear is seen as part of *samsara* (Sanskrit: wandering), that is the perpetual worldly cycle of existence. However, this is part of everyday life, and this realization can foster acceptance and psychological flexibility. Nonetheless, this journey is precarious and laden with obstacles literally and figuratively. Gender roles and the complex social structures surrounding marriage, high levels of emigration, political changes, and the 2015 earthquakes further entangle navigating a life lived with chronic pain in rural Nepal.

In Mattingly's *Paradox of Hope* (2010), the dichotomy of hope and fear is played out in the paradoxes between a life lived within their boundaries. As one of my participants, Tenzin, strived to overcome his physical limitations following a stroke, his hope to one day walk

into the village to see his old friends was continually dashed as the harder he tried the harder it became. His fear that he would remain restricted to his veranda was slowly diminished as his family showed invaluable support and encouragement. Thus, breaking this cycle for many depends on components to provide the affordances to enable the transformation to resilience, and the participant's individual idioms of resilience, for Tenzin the idiom of social interaction, aid in this negotiation between hope and fear.

Fear is a pervasive and raw emotion which takes shape in the practical and everyday, as with Tenzin, or can come in the form of ghosts to the vulnerable such as with Pasang and Asmita. They both displayed and shared their fears of village scrutiny, leaving them vulnerable to ghosts who would essentially take away a major part of themselves, leaving both distraught and in pain. They were not whole. The continuous internal negotiation between hope and fear can be assisted by the intercession of the Indigenous healers, the *Bombos*. Following the *Bombo's* rituals, they were made complete and could work toward resilience, they were transformed. Pasang's *hungsa* or life force was returned, and he was 'more' than he was before; he was now stronger than before the ghost came. Pasang did not have the family support that Tenzin was fortunate to have, and to him the trust in the Bombo was all the more crucial. Counter to fear is hope, but also trust, to root the journey to hope, to have a solid foundation and grab hold, and the *Bombos* assisted through trust.

Tashi and Bharat had experiences in the past on which to build coping skills and had relatively more stability and less fear than some of the other people I worked with living with pain. They did not have the battles with fear and as a consequence did not so desperately cling to hope on the other end of the continuum. Their lives were more balanced; Bharat through his involvement with meaningful work in helping others and for Tashi her overall acceptance with her life, knowing that she could modify her activities and remain active and sociable. Her manner of acceptance of her pain brought her a full life at age eighty-four.

Ram was caught in a different and more difficult place with fear and surrounding anger. The obstacles were made more challenging by inconsistent social support despite the best efforts from family and others who could assist. There was little room for hope and

subsequent coping and reframing his disability and pain. Alternatively, it seemed that Janeesha was filled with hope and viewed her chronic pain and disability through the idiom of religious acceptance. She was unclear regarding her medical conditions when we met, however, she did not display anxiety and worry about her future, knowing that she could rely on the full support of fellow Christians in her Buddhist community.

In terms of the methodology for my research, to be positioned to undertake a clinical ethnography was an exciting role. I was able to gather data through my own bodily experiences, as described in Chapter Two, and undergo the local Indigenous healing practices as a way of knowledge production and to learn more readily the embodied epistemologies of *Bombos* and my research participants. Inherent in the immersive quality of my work, and using my body to learn, I was working with my participant's bodies as a source of data and their perceptions and communication of their bodies in pain. This perspective created, yet again, different positionality in which to work and understand the participant's needs through sensory anthropology. This allowed me to be situated to think reflexively in terms of how to intervene and when to not, querying the role of clinical practice in anthropology and anthropology on clinical practice.

Regarding future directions and applications for my research, there are several paths to some improvements in working with people with chronic pain in the local community in Nepal, but also which could be expanded to and adapted to international interventions. These I have also described in The Impact Statement in a similar fashion. These recommendations may also be applied to work with minority and marginalized communities in the Global North.

I had the privilege of working in Bhutan where I develop and delivered a teaching program that applied the principles that I learned and developed through my doctoral work in Nepal. Firstly, emphatically, I would propose that at each level, most importantly at the upper levels of care delivery management, that from the research phase to the delivery phase it be wholly collaborative and integrated within all domains and their intersections, of the lives of people living with pain.

Within the local communities, employing the social model of disability, people with disabilities and people living with pain can self-organize and facilitate community-based self-help groups. These groups meet on a regular basis to discuss coping strategies and challenges and provide emotional and social support for each other. Initially the facilitators would have trained as community-based rehabilitation (CBR) workers and are often people with disabilities or people with pain themselves, but as time passes members can self-organize new groups. These groups form the basis of community support and self-management of their conditions. The CBR workers would be trained by experienced CBR workers who would have initially been trained by pain physiotherapists experienced in development work, medical anthropology, or International Non- Governmental Organization (INGO) work.

Continued research is vital for new knowledge production and data on which to publish and disseminate new findings particular to each region and cultural context. The aforementioned self-help groups, and the individual participants would provide a rich source of ethnographic data to directly inform researchers to disseminate to clinical practice in pain services in hospitals, and community pain services in government and non-government facilities. Other self-organized groups, and INGOs would have access to this work. This would take the form of collaborative research the outputs of which could include community workshops led by those in the groups and produce local non-academic publications. Lead researchers in academia could provide outputs in the form of collaborative academic publications and conferences and workshops.

From this grassroots level work and research, commissioners, managers, and clinicians who are in the position to develop new services and modify existing ones, can draw on evidenced based ethnographic data from their collaboration with the CBR workers, the self-help groups, and their family members.

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