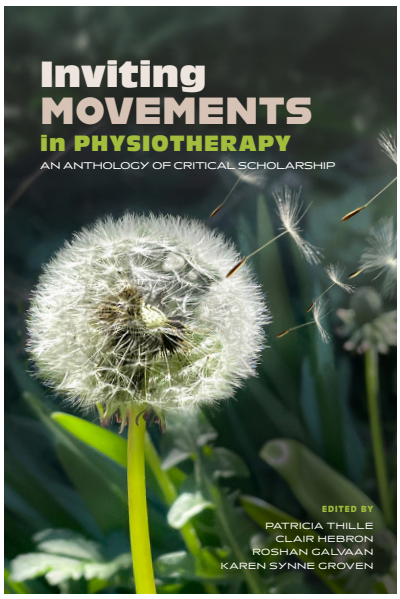

Inviting movements in physiotherapy: An anthology of critical scholarship

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Chapter 3

Unbelonging: The experience of being-in-society whilst living with frozen shoulder

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ABSTRACT:

This auto-phenomenology (hermeneutic) account seeks to explore my first-person experiences of a discrete phenomenon; the experience of shoulder pain and restricted range of movement. I aim to move away from modernist biomedical descriptions and instead, reclaim my existential experience. Taking a lifeworld perspective, I explore the meaning of the world as I subjectively experienced it whilst living with frozen shoulder. I reflect on how a change in my shoulder movement changed my movement in time and space and my sense of being-in-society. Drawing on the work of Talcott Parsons, Susan Sontag, Elaine Scarry and Arthur Frank, I reflect on my sense of unbelonging in relation to the sick role; how my explanations were delegitimized and my search for a socially accepted diagnosis; being a physiotherapist and my changing sense of self and identity. I ask how honouring knowledge from qualitative, post-qualitative research and sociology might offer an otherwise physiotherapy which engenders embodied relational understanding.

CHAPTER 3

Unbelonging

THE EXPERIENCE OF BEING-IN-SOCIETY WHILST LIVING WITH FROZEN SHOULDER

CLAIR HEBRON

Introduction

Frozen shoulder, also referred to as adhesive capsulitis, is a condition which is characterised by severe pain, disturbed sleep, marked stiffness, and associated loss of function (King & Hebron, 2022). Frozen shoulder is a clinical diagnosis based on the painful restriction of active and passive movement in at least two planes of movement, one of which is external rotation (Neviaser & Neviaser, 1987). It is a complex condition and while the exact cause is not fully understood, histological and immunocytochemical analysis of biopsies taken during arthroscopic release surgery suggests the pathology includes a chronic inflammatory response with fibroblastic proliferation (Hand et al., 2007). However, the certainty of fibrosis being a major contributor to the reduced range of movement in all cases has been questioned, since a proportion of persons with frozen shoulder have large increases in range of movement when anaesthetised (Hollman, 2018). Hollman (2018) attributed this to muscle guarding and cognitive and emotional factors. Other factors that may contribute include hormonal imbalances, autoimmune disorders, and certain medical conditions such as diabetes and thyroid disorders with higher prevalence reported in these populations (Cohen et al., 2020; Dyer et al., 2023; Schiefer et al., 2017; Zreik et al., 2016). There are also higher rates in women, and persons over the age of forty (Hand et al., 2008; Kingston et al., 2018). It is considered a self-limiting condition (Struyf & Meeus, 2014).

Frozen shoulder has classically been described as progressing through three different phases (painful, frozen and thawing) each lasting several months with natural resolution expected to occur within eighteen months to two years (Reeves, 1975). More recently this classical description has been challenged and although frozen shoulder will improve over time, it is recognised that resolution may not be complete and can take several years, with some patients experiencing ongoing pain and limited range of motion (Hand et al., 2008; Le et al., 2017; Wong et al., 2017). Treatment approaches include both conservative and surgical options, but no single intervention demonstrates superior results. Early structured physiotherapy, manipulation under anaesthesia, and arthroscopic capsular release were found to have comparable outcomes for shoulder pain and function at twelve months (Rangan et al., 2020). Similar outcomes were also reported when comparing intra-articular corticosteroid injections and physiotherapy (Blanchard et al., 2009; Sun et al., 2015; Wang et al., 2017). It is possible that multimodal approaches result in better outcomes; for example, combined physiotherapy and corticosteroid injections provide greater improvement than physiotherapy alone (Carette et al., 2003) and a combination of hydrodilatation and corticosteroid injection has been shown to improve pain-free range of motion compared with corticosteroid injection alone (Catapano et al., 2018).

These above modernist[1] biomedical descriptions of physiological mechanisms, anatomical structures, symptoms and treatment effectiveness dominate the medical and physiotherapy literature and professional discourse. This knowledge privileges objective and measurable aspects of conditions like 'adhesive capsulitis'. While this is valuable for diagnosis and intervention planning, it marginalises the subjective, lived experiences of individuals with frozen shoulder and neglects the emotional, psychosocial, and intersubjective dimensions of the condition. Incorporating an experiential voice enriches the understanding by capturing the nuanced aspects of living with frozen shoulder.

Only three qualitative studies have explored the experience of living with frozen shoulder and as illustrated here, use participants' quotes to illuminate their findings (Jones et al, 2013; King & Hebron 2022; Lyne, et al., 2022). Common to all studies were descriptions of the loss of sleep, independence and sense of self. All highlighted the severity of the pain, described as "dropping me to my knees" (King & Hebron 2022, p.6) or by the evocative quote:

"You see the Western movies [where] they forge the steel and . . . plunge it into the cold water . . . that's what it feels like, hot, molten lava encapsulated by metal, dragging your shoulder down" (Lyne et al., 2022, p. 3). The experience of healthcare was characterised by delays in access and diagnosis and at times dehumanising communication. Treatment experiences varied with corticosteroid injections providing considerable relief for some, in contrast to the pain of exercise and manual treatments. As one patient describes the experience:

> I done eight weeks of physio and it never got easier, it got harder, and I kept saying to the physios, "the manoeuvres you're asking me to do, it's worsening. You're asking me to do these stretches and these exercise, I can't do them." To have to wait a week to tell someone that and to let them actually witness you trying to do it and then tell you to try again next week and the following weeks and the following week. (King & Hebron, 2022, p. 8; emphasis added)

The experience as a whole was encompassed in the description "living with uncertainty and being in no-man's land" (King & Hebron, 2022, p. 1):

> How am I going to work, how am I going to operate? you wanna know what is it? What's causing it? Why it is happening and what are the repercussions going to be? Where is it going to end up? I feel in no man's land. (King & Hebron, 2022, p. 9).

Two of these studies used a phenomenological approach in which the researchers interpreted participants' descriptions (King & Hebron 2022; Lyne et al., 2022). An alternative approach is auto-phenomenology, which uses evocative insights grounded in my own experiences. For example, Finlay (2012) uses auto-phenomenology to convey the *unhomelikeness*[2] of living with a complex shoulder fracture. This *auto*-phenomenological chapter aims to similarly use my first-person reflections to provide further insights into my experience of living with frozen shoulder.

Methodology and methods

Phenomenology originated in the late-nineteenth and early twentieth centuries as a philosophical movement, with the work of philosophers such as Edmund Husserl and Franz Brentano. It is concerned with the quality and

nature of the human lifeworld and highlights the first-person perspective as the basis of all knowledge. Husserl focused on the description and analysis of conscious experiences as lived by individuals, seeking to uncover the fundamental structures of consciousness (Giorgi, 2009). Husserlian phenomenology emphasises the importance of intentionality, the act of consciousness directed towards objects, and employs the epoché[3] to isolate and study phenomena independently of their existence in the external world (Giorgi, 2009). Martin Heidegger studied under Edmund Husserl at the University of Freiburg in the early twentieth century. His interpretive (hermeneutic) phenomenological tradition shifts from the Husserlian, epistemological line of inquiry, to the realm of ontology and the hermeneutics of "being" (Laverty, 2003). Heidegger (1962) understood the social world in which we live in terms of *Dasein*, or *being-in-the-world*, a view of human beings engaged within a world of people, relationships, and things that brings about meaning.

An interpretive (hermeneutic) phenomenological research methodology seeks to understand and interpret the lived experience of individuals through a detailed exploration of the phenomena they live through (van Manen, 2007). Involving in-depth investigation and analysis, a phenomenological approach emphasizes the importance of context and the subjective interpretations of participants. Adopting a dialectical approach that involves a constant interplay between understanding and interpretation, this methodology aims to uncover the underlying meanings, themes, and perspectives that individuals experience, shedding light on the complex interplay between the self and the world (Finlay, 2011; Smith et al., 2009). A phenomenological approach accepts that it is through our subjectivity that we experience the world, and that our view of the world is always perspectival. Most phenomenological research includes small numbers of participants to enable thick (rich) descriptions and prolonged engagement with the data. Some studies use an ideographic approach focusing on individual experience and can focus on a single case to illuminate particularly evocative experiences (Finlay, 2011, p. 196). In this study, I took an auto-phenomenological approach to explore my (Clair's) view of the world and the meaning of my personal experience of frozen shoulder.

There is a long tradition of autobiographical research approaches involving the researcher actively engaging in introspective and reflexive exploration

of their own lived experiences, culture, and identity to generate rich qualitative data, offering unique insights into personal narratives and social contexts. Autoethnographic approaches aim to explore how the experience of living within a culture is meaningful (Gorichanaz, 2017; Sparks, 2020). In contrast, auto-phenomenology involves an introspective examination of one's own lived experience of a discrete phenomenon and seeks to identify the subjective meanings and interpretations of those experiences. By focusing on the first-person perspective, auto-phenomenology enables researchers to capture the complexity and richness that can create new insights and meanings (Finlay, 2012). In the context of physiotherapy and movement, auto-phenomenology involves the exploration and understanding of a person's own subjective experiences, perceptions, and interpretations of their own bodies, movements, and physical conditions. It aims to uncover the rich and often unarticulated insights they have about their bodily experiences and how they relate to their health and wellbeing. Auto-phenomenological research can uncover implicit knowledge, emotional responses, and personal meanings associated with physical sensations or limitations. This type of knowledge provides a more holistic understanding of the patient's condition, beyond what subjective and physical assessments might reveal. This auto-phenomenological (hermeneutic) account seeks to move away from modernist medical descriptions to explore my first-person experiences as a middle aged, female, academic and (until recently) clinical physiotherapist, with experience of qualitative and post qualitative research.

Both walking/running and writing were used as method. Much of the analysis occurred when walking and running in nature, along the south downs in the UK, often with views of the sea. Philosophers have long discussed the relationship between thinking and walking, with many believing that walking can facilitate and enhance cognitive processes. Jean-Jacques Rousseau stated:

> Never could I do anything when placed at a table, pen in hand; it must be walking among the rocks, or in the woods' (Rousseau, 2001, p. 55). 'Walking animates and enlivens my spirits; I can hardly think when in a state of inactivity; my body must be exercised to make my judgment active. (Rousseau, 2001, p. 77)

Similarly, Nietzche stated, "only thoughts that come by walking have any value" (Nietzsche, 1889 p. 10). When walking I took myself back to moments

that were meaningful to me in relation to living with frozen shoulder. I stayed with these moments, dwelling and asking myself why they were meaningful. I kept a reflexive diary of my frozen shoulder experiences, which I read and reread. When analysing my experiences, I adopted the phenomenological attitude, a position of wonder, in which I was ready to be surprised. What was most unexpected was how surprised I was when I found hidden meanings. As I walked or ran my mind frequently wandered back to a particular conversation. I took these data earworms as subconscious signs of significant meaning (Mitchell & Clark, 2021) and they prompted me to take time to interrogate their underlying meaning. Writing and interpretation are deeply intertwined (Richardson & St Pierre, 2005) and thus I used writing and rewriting to delve deeper and develop a richer understanding of my experiences. This process required me to repeatedly return to and finely craft the text, reminiscent of an artist creating art (van Manen, 2016, p. 131). I deliberately used evocative and poetic writing to engender embodied relational understanding (Todres, 2008).

As a physiotherapy academic and researcher with experience in phenomenology, I looked at my experience through both disciplinary and philosophical lenses. Taking a lifeworld perspective, I first explored the meaning of the world as I subjectively experienced it. I explored my embodiment, my intersubjective experiences, and how time and space presented themselves differently to me whilst living through the phenomenon. As I started to see deeper meaning in my experiences and how they were related to my being-in-society, their resonance with sociological and political concepts became more apparent. Built on the foundation of more traditional phenomenology, this discussion draws on more recent critical phenomenology to examine ways in which social, political, and cultural factors hide, shape, and influence human experience (Roberge, 2011; Salamon, 2018; Zurin, 2021). Drawing on critical theory, originating from Frankfurt School philosophers such as Max Horkheimer and Theodor Adorno, critical phenomenology recognises that human consciousness and experience are not isolated from the broader socio-political context but are deeply embedded in it.

Because this study was a study of self, rather than a scientific enquiry, ethical approval was not sought (Ellis & Bochner, 2000). Unlike autoethnographic work, it was centred on my experiences and did not include observations of a wider community. However, I was mindful of ethical issues

and reflected on aspects of privacy and consent during writing, adopting strategies to protect identities and change places. Although the focus remained with my experiences, it also involved others; I anonymised references except for one to my husband who took the time to read this text. When asked if he would prefer it to be removed, he felt that to do so would be to sterilise my account and remove important meaning. My account offers my interpretations and is influenced by van Manen's (2014) philological, vocative writing methods[4] reflected in the changing tone of the consequent text.

Findings

My experience of shoulder pain started gradually. The changes were subtle, and I pushed them away. Initially it was in the gym that these changes crept in. I had to ask for help from others who lifted the bar onto my back so that I could squat using weight that helped me to retain my exercise and strength identity. As my shoulder movement became more restricted, I resorted to holding weights in my hands. Upper limb work became increasingly restricted, but I carried on lifting weights through whatever shoulder range I had. The mirrors at the front of the class reflected a somewhat humiliating scene of others moving their arms above their heads with free abandon where mine barely left my sides. "Anything is better than nothing," I told myself. But after two years of four visits a week without having broken a sweat and facing an extortionate annual renewal fee, I was defeated. When I told others, some who are physiotherapists, of my challenges in the gym, they offered a barrage of *helpful* alternatives. I felt my irritation rise at their assumption that I hadn't already thought of these things for myself. I nodded in agreement, rather than enter another game of BUT tennis,[5] as I explained why these options won't work for me. I still ran every day; across the downs and in the forest, amongst the trees, with the birds and my dog, and although this enabled me to maintain my exercise identity, I feared my strength identity had gone for good.

I had a strong exercise identity before becoming a physiotherapist and wonder if this was one of the things that drew me to the profession. This identity was reinforced, underlined, and made bold by my professional training and socialisation, including physiotherapy mantras such as "you can't go wrong getting strong." My experiences of shoulder pain and reduced movement started to invade this identity and I began to better understand the

experience of being othered. I felt the sense of judgement that must also be experienced by some persons receiving physiotherapy care, when they are confronted by these mantras. My areas of academic interest meant I was already theoretically sensitive to the strength of our profession's discourse around what it is to be a healthy person which dictates that persons are fit and slim. These expectations and the rhetoric of our society's dominant health and fitness culture were now becoming personally meaningful and provided me with more insight into how persons who don't adhere to the expectation of our culture's 'healthy lifestyle' may feel.

I suspect many physiotherapists are aware of the power of words and mantras, but are they aware of how this discourse others those who do not adhere to this for a range of reasons? If aware, are they attempting to shame others into exercising? Do they acknowledge that there are those with conditions that may respond less favourably to exercise (Lima et al., 2017), those who can't afford to access gymnasiums, or whose mood is so low that getting started is perceived as an unsurmountable mountain? I hear the clinician's voice: "BUT you can use pacing," "BUT you can use body weight," "BUT it will make you feel better." BUT what about persons who just don't want to?

The eroding sense of myself as a healthy person was also the start of my changing perception of time. Before shoulder pain, although chronologically middle aged, the changes in my body had been gradual and expected. This was different. I started to become weak and lose my independence and had to ask for help. I needed help with dressing and simple daily tasks such as opening jars. I recalled research using grip strength as a measure of health and my sense of self as a fit and healthy person was battered as the sense of aging hit me hard. I think back to the time that none of my teenagers were available to help me take off my bra, so I went to my husband's office in the garden, where he was happy to help. But then there was the "walk of shame" back to the house, holding my clothing against my chest to retain my modesty. Not that anybody could see, but I felt the tears prick the backs of my eyes, as I experienced a sense of exposure and humiliation. This was not me.

The loss of sleep was pervading, and I felt my resilience dissolving. Lying down was excruciating and I mostly slept upright, supported by pillows. I felt lonely as I listened to the sounds outside. The late-night chatter of those leaving the local pub faded, replaced by silence interrupted by the occasional call of foxes. Each hour seemed to last forever, until I heard the world outside

start to wake. The meaning of the bedroom space was disrupted; where previously it encapsulated a sense of connection and intimacy, the bedroom now became a place of loneliness and isolation. My carefully constructed wall of pillows supported my shoulders but separated me physically and thus also emotionally from my most significant other. My husband referred to my pillow organisation ritual as "constructing a barrier." It felt to me like it was a barrier between him and me. I lay awake at night next to the person I loved most yet experienced loneliness. During the day my vigilance related to shoulder movement interrupted our established routines of holding each other, touching, of expressing our continued connectedness to one another. For me this was temporary, as when the pain subsided, the barrier was deconstructed allowing a return to our routines of being with one another. But what about others whose physical body prevents them from connecting with their loved ones more permanently? The fear of drifting apart, of disconnecting illuminates the inseparability of mind and body. My body is my access to the world and my relationship with others. I am my body.

My family and I belong to a club. Membership of this club was related to a sporting activity which required moving heavy objects and using your arms to raise your body. Club members were used to seeing me fully involved in these activities and every time I visited with my family, I felt interrogated about why I wasn't taking part. I'd explain that "I've got bad shoulders" but this explanation wasn't well received by anyone and further questions related to the specific cause nearly always followed. I found myself testing out a series of diagnostic labels to find out which one was credible. For some, frozen shoulder seemed to land well, but for others this was met with quizzed looks and raised eyebrows, next I tried the more scientific term "adhesive capsulitis." For some this seemed acceptable and for others it resulted in more quizzical looks until provided alongside a concurrent tissue-based explanation. For one person, what seemed to legitimise my symptoms was explaining that it was the same as the condition experienced by another member of our club (a younger man). I felt relieved that the interrogation had stopped and that I had some vicarious credibility, but also dissonance as I wondered why he was somehow more credible than me. As Elaine Scarry (1985, p. 7) said, "to have pain is to have certainty, to hear about somebody in pain is to have doubt." These experiences meant that the power of a diagnostic label had new meaning for me. I hadn't previously appreciated how important this was

to one's relationship with others, and for me these others weren't my significant others, they were in wider society. I didn't feel the need for a label, but others needed me to have one. It has made me rethink how diagnostic labels might be used in practice, a discussion that is beautifully articulated by John Launer (2017), whose discussion of labels, ironically, uses frozen shoulder as an example. The interrogation I experienced and having to navigate a label that retained my credibility, led to a profound sense of unbelonging which led to me retreat and leave the club.

Others asked about prognosis "when will it get better?" or "Isn't it better yet?" (accompanied by an elevated tone of voice and a raised eyebrow). I would explain that the natural history of this condition meant it was unlikely to get better anytime soon. "It will take a year or two," I would say with a shrug of acceptance. The look of astonishment this was met with was extraordinary. Was this disbelief in the fact that something might take so long to get better, or at my acceptance? These inquisitions resonated with Arthur Frank's (2013) descriptions of sickness being socially acceptable for short periods. It seemed that, for me, time was running out alongside sympathy and belief. I sensed from others it was time to return to my normal roles, and by failing to do so in the appropriate time I was displaying deviant behaviour and thus was experiencing social judgement. These experiences of others doubting my story resonate with the concept of epistemic injustice[6] (Fricker, 2007) and furthered my sense of unbelonging.

The sense of questioning and doubt that I perceived from others dominated my social interactions. When their questioning wasn't explicit, I searched for more implicit signs in their body language and expression, and it was almost always there. I looked for it in my family too, my husband and three teenage children, did they doubt the authenticity of my experience? Again, and again I scrutinised their reactions, I watched their eyes when the "drop me to my knees" pain caused me to shout out dramatically. I never saw the doubt or questioning from my immediate family and this sense of certainty in the trust and belief they afforded me provided me with a safe haven.

One day during a chance encounter, I exchanged social updates with an acquaintance who works as a General Practitioner. I mentioned having frozen shoulder, "Oh . . . that's surprising you're not the frozen shoulder type" they exclaimed. I was a bit taken aback, wondering what that type

was. I ruminated on my mixed emotions. I was secretly pleased not to be "that type," but equally incredulous of the stereotyping that is associated with some conditions. I wanted to ask about "the type," but have learnt to think twice before asking curious questions, having had conversations like this in the past that often don't land well. I wasn't brave enough to challenge this and as I walked away, I questioned whether my lack of action had perpetuated their beliefs. What about my role as an activist for others seeking care?

My intersubjective experiences were also interspersed with thoughtful acts, of persons enquiring about my progress. Often these were the same persons week on week, were they expecting a miraculous cure within seven days? Or was it a sense of care or compassion? Even though I perceived these repeated enquiries as well meaning, they reminded me of my ill body and relegated me to the Kingdom of the Sick: Susan Sontag (1978) illuminated illness using a metaphor of travel, and the notion of dual citizenship, in which we are citizens of two kingdoms, the sick and the well. Sooner or later we will, at least for a while, become citizens of the other kingdom. Again, my family seemed to know what I needed, although I don't remember expressing this to them explicitly. They seemed to understand that I needed them to pay little attention to my shoulder or changing function; thus, allowing me to retain a sense of my "self" at home, and of belonging to the Kingdom of the Well.

I had a procedure (a shoulder distension) ten days before I was due to go on a dinghy sailing holiday with my husband and youngest child. I had resigned myself to the fact that, when on holiday, I was going to have to watch them from the beach. I wanted to be on the water, but this would involve passing the tiller from one hand to the other behind my back and when capsized reaching up to the centre board to flip the boat upright. For me the procedure was miraculous as it reduced the pain greatly and I gained just enough movement to be able to sail (and to sleep). This was the first holiday without our older boys, and, having three children in less than three years, individual time spent with each child was precious. This wasn't about how the sailing was meaningful to me, but what it means to my daughter. Sailing is my daughter's most meaningful activity; her "home" is not one of bricks and mortar, it is the sea. Watching the joy on her face when she sails is a vicarious experience and taking part in her joy alongside her is breathtakingly beautiful. Being an observer on the beach would not have held the same meaning.

My academic physiotherapy lens led to a reluctance to undergo the shoulder distention procedure, as I had a strong belief that natural history would resolve my symptoms over time. Moreover, there was limited evidence of its effectiveness and mechanistically it didn't make much sense to me, so I didn't think it would help. However, through the lens of sleep loss, limited function and low mood, I saw this as a low-risk procedure and felt I had nothing to lose. The procedure reduced the pain enough for me to sleep lying down for the first time in months. I still needed my pillow barrier, but things seem better after a night's sleep. My range of movement also improved slightly. The effects only seemed to last about five months, and I wondered where my improvement would lie in population data: Where would I sit if I had been included in a randomised controlled trial investigating the effects of the shoulder distention procedure and would the study include measurements that were meaningful to me? At six-month follow-up there would have been a good chance that the control group would, on average, have had a better outcome than me and I might have been one of the participants who reduced the average (mean) improvement in the treatment group. Would beneficial outcomes lasting less than six months be considered low value? For me five months of sleep and one sailing holiday with a daughter who would soon be leaving home made this an incredibly valuable treatment. This was not low-value care. It was priceless.

Discussion

Unbelonging and the sick role

My overriding experience of living with frozen shoulder was a sense of unbelonging in my social world. Belonging has been defined as feeling valued and respected in the context of relationships which are built on shared experiences beliefs and characteristics (Mahar et al 2013). My sense of unbelonging was meaningfully related to the judgment I perceived when failing to fulfil my social roles over a prolonged period. These experiences resonate with the concept of the sick role, a theory developed by sociologist Talcott Parsons in the mid-twentieth century to explain social roles and expectations surrounding illness and health (Parsons, 1951). Parsons emphasised the role of norms and values in shaping individual behaviour, suggesting that individuals conform to societal expectations due to internalised cultural values. In Parsons's view, social control is crucial for the smooth

functioning and equilibrium of society, ensuring that individuals adhere to shared norms and contribute to the maintenance of social order. According to this theory, when a person is sick, they are granted a *temporary exemption* from their normal social roles and responsibilities. This exemption comes with expectations to seek medical care and *comply* with medical professionals in order to facilitate their recovery and return to their roles and responsibilities as soon as possible. For Parsons, illness is a threat to social structure and economic productivity. He theorizes social control is one of a doctor's (and physiotherapist's) roles, is insofar as their work includes ensuring individuals fulfil their responsibilities. This includes being wary of patients enjoying the secondary gains of illness and repressing *deviant* behaviour and more permanent dependency. Living with frozen shoulder did not impact significantly on my employment. I did not require a doctor to authorise sick leave or a *temporary exemption* from my roles and responsibilities at work. Thus, for me this social control came from being-in-society.

In my sporting context the sense of unbelonging caused me to retreat as I felt as though my legitimacy was being questioned and judgements were being made about whether my behaviour was *deviant*. There are two models of illness within Parsons's (1951) concept of the sick role: an incapacity model related to one's ability to perform tasks in which they have been socialised, and a *deviance model* which views illness as a form of avoidance behaviour. Both models assume that persons are motivated to withdraw from social obligations (Gerhardt, 1978). Did others like Parsons assume that I was motivated to withdraw from taking part? Were interrogations related to the length of time it was taking to recover assessing my commitment to get better and whether it was time for temporary *role exemption* to be revoked? It appeared that in making this assessment the label/diagnosis associated with my complaint was significant, further resonating with the sick role, insofar as a diagnosis enables exemptions to be applied.

Diagnosis and legitimacy

Not all diagnoses are equal; they can stigmatise or legitimise (Jutel, 2019). A diagnosis can influence self-esteem and identity (Jutel, 2019). Questions related to my diagnosis were ubiquitous and often it was the same persons who initiated this dialogue on different occasions. I will never know those persons' intentions in questioning my diagnosis, but the sociology of diagnosis both as a process and label can provide possible insights. When the

process of diagnosis demonstrates pathology, it legitimises a person's experience and creates order from chaos. Conversely, those with contested or no diagnosis can exist in a liminal state without a way to understand, fix or accept their situation leading to distress and stigmatisation (Jutel, 2023; Nettleton, 2006). Pathoanatomically, unexplained symptoms also create challenges for health professionals. For example, when there is perceived discord between scan findings and symptoms medical professionals (including physiotherapists) are uncomfortable navigating uncertainty and its emotional affects (Costa et al 2022; Myburgh et al., 2021). The process of diagnosis was not something that my thoughts wondered back to; what was meaningful to me was the diagnostic label and the personal attributes associated with it.

The "you're not the type" comment from a GP acquaintance implied stereotyping. This illuminates one way in which diagnostic labels, or at least the discourse related to them do work. This rhetoric can become an accepted and rarely challenged part of every dialogue. Susan Sontag, in her work *Illness as metaphor* (1978), charts the history and challenges the 'concocted' stereotypes for those presenting with certain diseases. She illuminates how contrasting metaphors for tuberculosis and cancer have changed over time. Tuberculosis in popular mythology was perceived to be a disease of poverty, deprivation, sensitivity, creativity and excessive passion. In contrast, cancer was seen as a disease of affluence, excess, boredom (ennui), sloth and repressed passion. Stereotyping patients is also evident in physiotherapy, for example when related to culture (Lee et al., 2006), body weight (Setchell, 2015) and "good," "difficult," "heart sink" (Daykin & Richardson, 2004) or "problem" patients (Thomson, 2000). For me it was in social contexts that a label was meaningful as it contributed to my sense of unbelonging and in this regard my experience resonates with the concept of social diagnosis (Brown et al., 2011; Jutel, 2019).

Social diagnosis is a concept that recognises that diagnosis goes beyond the clinic and is a profoundly social act which reflects society, its values, how it makes sense of illness and disease and maintains social order (Jutel, 2019). At times I felt like a fly on the wall, as though I was observing my social interactions, watching as others questioned me in ways that I perceived to be judging whether this was a legitimate condition. I found myself navigating a label that might be socially credible and am curious how this plays out

in physiotherapy settings. An otherwise physiotherapy may view diagnosis as socially constructed, relational and changeable (Brown et al., 2011; Lund et al., 2020) and, as discussed by John Launer (2017), may provide opportunities to explore with persons how they might develop a socially acceptable narrative which will help them navigate their world.

Illness dramas and identity

My story of navigating a socially acceptable diagnosis, alongside interactions with others and my changing sense of self resonates with Arthur Frank's five dramas of illness (Frank, 2007). Frank's *drama of meaning* flows through this chapter and is illuminated in my story. The genesis drama represents persons making sense of how their illness came to be. Some, for example, form a biological narrative whilst others may attribute it to God. In Frank's stories of his own cancer diagnosis, he describes being clear on his genesis drama stating cancer "just happens" (Frank, 2007). Echoing my experiences, for Frank the drama of genesis was in resisting others imposing their genesis on him (Frank, 2007). Another of Frank's dramas, the *drama of emotion* work draws on the work of Arlie Hochschild (1979) and Erving Goffman (1959). Goffman (1959) understands the self as a fostered impression maintained by others and one's own defensive practices. The impressions of others and my own defensive behaviours reverberated through my experiences. The *drama of self* was evident as I navigated what Bury (1982) describes as biographic disruption, a notion I experienced as I created plans for a new future and a new me. This meant confronting my sense of self in relation to age and ageing and re-evaluating the value I placed on being strong. Frank's *drama of fear* and loss includes the loss of capability, loss of a pain free life or life as it was planned, fear of surgery and fear of recurrence. Frank (2007) claims fears multiply in silence and that naming and discussing these fears makes them liveable.

For me, the loss was of my identity as a healthy person, loss of my exercise and strength identity. Living with frozen shoulder had rendered me to the *Kingdom of the Sick* (Sontag, 1978). I wondered how much of my identity was related to being a physiotherapist and what that meant for persons seeking physiotherapy care. I feel sure that my exercise identity was reinforced by socialisation within my profession. Professional socialisation refers to the process by which individuals learn values, attitudes, and behaviours associated with their profession. It is in part handed down by educators to students who

seek to conform and reproduce those that precede them (Ajjawi & Higgs, 2008). Preceding this, Foucault, (1995, p. 138–169) claimed that power in medical settings produces disciplined bodies that in turn go on to discipline other bodies. This discipline was apparent in the BUT tennis I played as physiotherapist peers suggested ways I could continue in the gym, and also resonates with research exploring physiotherapy as a disciplinary profession (Praestegaard et al., 2015). There was also a sense of my own self-discipline insofar as my strength identity was othering and restricting movement in my emerging identity. An otherwise physiotherapy may be sensitive to a more flexible sense of identity and facilitate persons seeking care to navigate movement in their identity as they learn to live with changes in their health.

Values in physiotherapy

With recent shifts in emphasis moving from treating infectious to "lifestyle diseases" and associated health promotion agendas like the Making Every Contact Count Agenda in the UK (Public Health England, 2016), comes discourse related to economic cost and impact on the labour market. This enables judgement and discipline, and physiotherapists can be seen to act for the state in this regard (Nicholls, 2022). In contemporary Western culture, this is further compounded by the obsession with health and fitness (Galvin, 2002) where health *"approaches sacred status"* (Cheek, 2008, p. 974). In these advanced liberal societies health and illness are matters of personal responsibility, whereby it is individual's *duty* to display healthy behaviours in order to be considered a *good citizen* and individual (Galvin, 2002). Physiotherapists' discourse suggests that their perspectives align with neoliberal agendas insofar as they talk of "good" patients who were proactive and self-reliant, in contrast to "difficult" patients who were passive (Daykin & Richardson, 2004). Studies also illuminate how physiotherapists stigmatise individuals who are not seen as *good citizens*, for example those who are labelled as overweight and obese (Jones & Forhan, 2021; Setchell et al., 2014; Setchell et al., 2016). This neoliberal emphasis on individual responsibility can lead to a focus on individual behaviour change rather than addressing social, structural and environmental factors that shape health outcomes (Lupton, 2013). The economic influences on physiotherapy practice further resonated with my experiences of treatment.

Despite my experience of a beneficial "priceless" outcome from the shoulder distention procedure, its effects only lasted a few months. If others in a clinical trial have similar results, it may have been considered low-value care. Low-value healthcare refers to the use of medical tests, diagnoses, and treatments that provide patients with little to no benefit or cause harm. The suggestion is that money spent on these treatments would be best spent elsewhere (Traeger et al., 2017). Initiatives such as Choosing Wisely emphasise physiotherapists' responsibility as gatekeepers who protect the purse strings of healthcare often using powerful disciplinary discourse such as: *"physiotherapy associations are not the only associations* guilty *of poorly targeted recommendations"* and *"more involvement is needed if physiotherapy is to be viewed as a profession* taking the fight *against overuse seriously"* (Kharel et al., 2021, p. 1; emphasis added). Such focus on efficiency, productivity, and individual responsibility can lead to a dehumanising approach that could be counterbalanced by a physiotherapy practice which takes a more nuanced and sociologically informed perspective on illness by highlighting the experiences of marginalized populations. Frank's (2007) illness narratives draw attention to the broader social and political factors that shape health outcomes and illuminate the role of physiotherapists in advocating for policy change and social justice. In my experience there is movement towards a broader physiotherapy curriculum, but the freedom of this movement is restricted by multiple structural factors both within and outside the academy (such as the modular system, focus on metrics and regulatory body requirements). As physiotherapy education moves forwards, engaging with sociological theories and art may create a deterritorialised physiotherapy education (see Chapter 9). Detaching from traditional structures and embracing diverse knowledge sources aims to encourages physiotherapists to become not only technically proficient but socially conscious, emotional intelligent, self-aware, and non-judgemental.

At home I didn't feel any sense of judgment. The belief my family communicated helped me retain a sense of belonging and mostly this was my safe haven. However, there were moments when the disruption in being with my husband led to a sense of isolation. Togetherness-isolation can be considered as a spectrum between connectedness and separation from our sense of belonging with others. With illness, our everyday social connections can be disrupted, creating a sense of separation from feelings of belonging (Todres

et al., 2009). In healthcare settings procedure and protocols can either exacerbate or mitigate a sense of isolation (Todres et al., 2009), and I am curious how movement in the profession towards an otherwise physiotherapy practice can facilitate persons to connect with their loved ones, retain a sense of belonging, and find a liveable future.

Using an auto-phenomenological approach I explored my interpretations of my experience at this point in time. These interpretations are not fixed or exhausted but remain ready for new interpretations. The importance of auto-phenomenology in physiotherapy lies in its potential to inform person-centred interventions. By understanding and incorporating the meaning of persons' subjective experiences, physiotherapists can collaborate with persons and individualise treatment to align with their meaningful goals, preferences, and unique challenges. This approach fosters embodied relational understanding ultimately enhancing physiotherapy by addressing the person's needs in a comprehensive and individualised manner.

I used a phenomenological lens to explore the meaning of my experiences. Other lenses may have resonated with other theories providing different insights. For example, in this account, I touch on Frank's losses in relation to sense of self. I could instead have drawn on the concepts of Gilles Deleuze who considered the *self* to be an illusion created by enlightenment rationality. Instead, he proposed that individuals are continually being reformed through a process of flows, intensities and desires, and rather than "being" are continually "becoming"[7] (Deleuze & Guattari, 2020, p.7).

Common in scientific research, including physiotherapy academic literature, are sections on the implications of practice and conclusions where researchers summarise how their findings can be helpful in developing practice. Any such conclusion I might make would be limited by my interpretation and thrownness[8] and would draw this chapter to a close. I have chosen not to provide such closure, as there remains much to reflect on in relation to current healthcare discourse, culture, and structures. I wonder whether we as a profession could be prompted to reflect on how our social and cultural identities impact the perceived appropriateness of exercise and persons willingness to participate (Pentecost & Taket, 2011). I am curious how our ways of being exacerbating social, institutional and political inequalities? I ask readers to seek intersubjective, embodied, relational understanding with persons receiving their care, to reflect on and bridle[9] their own assumptions

and biases, questioning the healthcare structures that limit their ability to do so, and advocate for change towards a system that fosters epistemic and social justice. I hope that readers will take time to consider these findings in relation to their context and persons seeking their care, and I would be delighted if, like me, when you walk or run or sit in nature, you revisit these findings and consider how they have resonance for you.

Notes

1 modernist refers to the adoption of methodologies, theories, and paradigms that emphasise empirical observation, mathematical formalism, and the pursuit of objective, universal knowledge.

2 Heidegger's concept of unheimlichkeit (unhomelikeness) refers to an unsettled feeling or breakdown in familiarity.

3 A shift in attitude in which past knowledge and presuppositions are bracketed (Giorgi, 2009, p. 91).

4 van Manen's philological and vocative writing methods involve a reflective and linguistic approach that explores the nuanced meanings of lived experiences and addresses the reader directly, aiming to evoke a deeper engagement with the subject matter.

5 Referring to a conversation between persons in which their responses to one another go back and forward and repeatedly start with 'but', signifying resistance to or rejection of the others experience or perspective.

6 Epistemic injustice refers to situations where people are unfairly treated in their capacity as knowers, manifesting through testimonial injustice, where credibility is denied based on prejudice, and hermeneutical injustice, which occurs when experiences are marginalized due to a lack of shared understanding. It highlights the impact of power dynamics and societal biases on the distribution of knowledge and recognition.

7 For interested readers in Chapter 9 I and my colleague visual artist Dr Shirley Chubb explore concepts of identity and belonging from the different philosophical perspective of a Deleuzian ontology of immanence.

8 Martin Heidegger's concept that we are thrown / born into a specific culture in a specific moment in history.

9 Bridling, as described by Dahlberg et al. (2008), is the deliberate act of slowing down and reflecting on the process of understanding, involving continuous

self-investigation and questioning of presumptions; it fosters heightened self-awareness to be more attentive to the investigated phenomenon, encouraging openness to new possibilities and a conscious dwelling in the realm of not knowing.

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