

Simon van Rysewyk *Editor*

# Meanings of Pain

Volume 3: Vulnerable or Special Groups  
of People

 Springer

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# Preface

The *Meanings of Pain* book series, published by Springer, describes how the meaning of pain changes pain experience—and people with pain—over time. Immediate pain is a compelling source of danger or threat to the person with pain. If pain persists, more complex meanings about the pain can supplement this primitive meaning of threat. These additional meanings include anxiety about the future consequences of the pain, tolerating a heavy burden over time, or the prospect of irreversible harm. Such meanings can nourish negative existential sufferings, which are more about the person than the pain, such as loss, loneliness, or fearfulness. Traditionally, scientific research has had much to say about the physical nature of pain, but much less about the personal experience or meaning of pain. Indeed, the meaning of pain remains a blind spot in knowledge.

This book series offers a vocabulary of language about the “meanings of pain” and a clinical framework with which to use it. It is hoped that the series contributions stimulate a degree of personal self-reflection about the use of meaning in clinical or non-clinical pain settings. *Meanings of Pain* is intended for people with pain, family members or caregivers of people with pain, clinicians, researchers, advocates, and policy makers. Volume I was published in 2016 and Volume II in 2019.

Although chronic pain can affect any person, there are some groups of people for whom particular clinical support and understanding is urgently needed. *Volume III*, the final volume in the series, describes common meanings of pain in groups of vulnerable people. According to the World Health Organization, “vulnerable populations” include children, pregnant women, malnourished people, people who are ill or immunocompromised, or older adults. These minority and underserved groups may be burdened by poverty, with limited access to health care. People with chronic pain may become vulnerable due to the disabling effects of pain, or pain-related suffering. In potentially vulnerable groups, older adults are more likely to experience pain than other subgroups of the adult population. This volume describes meanings of pain in critically ill neonates, infants, the fetus and pre-term baby, African Americans, rural Nigerians, military veterans, older adults, and people with acquired brain injury.

In developing this volume, my hope was to present meanings of pain across diverse vulnerable groups. This original plan encompassed 15 chapters. However, with the intrusion of COVID-19, recruiting authors to achieve this goal became a challenge, forcing me to rethink the scope of the book. I hope that the current volume, an offering of 7 contributions, offers a glimpse into the complex needs of vulnerable people with pain, and prompts self-reflection on the question of what pain means to them.

I warmly thank the book authors for their valuable contributions to the field, and for the team at Springer for its support in producing this book series.

Hobart, Australia  
December, 2021

Simon van Rysewyk

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# Chapter 1

## Conceptualising Pain in Critically Ill Neonates or Infants



Emre Ilhan and Simon van Rysewyk

**Abstract** The belief that neonates or infants can feel pain is a relatively recent development. Historically, major cardiac surgery was performed in some neonates or infants without anaesthesia, based on the belief that infants had immature nervous systems; therefore, they were incapable of pain and were fatally vulnerable to the side effects of anaesthesia. What was standard medical practice in the past is now considered medically unsound and morally unjust. Given that neonates or infants cannot linguistically describe their pain, researchers and clinicians have considered behavioural, physiological, and neurophysiological cues to determine pain in neonates or infants. Pain assessment based on behavioural cues is not an “indirect” means of inferring pain in the neonate and infant because pain experience is not totally separable from its behavioural manifestations. Since pre-linguistic neonates or infants do not possess the concept of pain, in social settings involving pain, the neonate and infant expresses pain only by virtue of a courtesy extended to signs of pain by linguistically competent adults who have already mastered the practice of using “pain”, who treat these signs as genuine expressions of pain. Thus, the aim of this paper is to describe how clinicians and researchers have conceptualised neonatal or infant pain, and what implications these may have in the study of neonatal or infant pain. Craig’s social communications model emphasises how intra- and inter-personal factors surrounding the assessment of infant pain influence the caregiver’s ability to decode the behavioural, physiological, and neurophysiological expression of the neonate’s and infant’s pain. Although the neonate’s or infant’s ability to express pain through behavioural signs is an essential aspect of pain assessment, the role of pain detection falls heavily on the caregiver. In some circumstances, such as severe disease acuity, neonates or infants may not have the capacity to respond behaviourally or physiologically to pain. Therefore, it is argued, examining the caregiver’s conceptualisation of the pain is even more important in these circumstances, as it has obvious implications for pain management.

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## 1 Introduction

The meaning or concept of pain in neonates or infants, especially those who are critically ill, has changed dramatically in the last four decades. Prior to a pivotal shift in our knowledge around neonatal pain in the mid-1980s, most clinicians and researchers believed that neonates or infants were incapable of experiencing pain. This was mainly due to the belief that this population had an underdeveloped nervous system, which precluded them from the experience of pain. In addition to this erroneous belief about the neonatal nervous system, researchers historically held an extreme experimental caution when interpreting what was deemed as “psychological” phenomena such as pain (Rodkey and Pillai Riddell 2013). A look at the development of neonatal or infant pain literature up to the present time (Anand et al. 2020) reveals that although the earliest documented philosophical discussions around neonatal or infant pain occurred as early as 1951, serious empirical investigations into the expressions and the short and long-term effects of pain in neonates or infants did not happen until 1982. In his study looking at the effect of analgesia in neonates, Steward (1982) found that preterm infants had greater postoperative respiratory complications following inguinal herniotomy with general anaesthesia compared to term infants. Such a study may have reinforced the prevailing perception that given the insensitivity of the neonatal or infant nervous system to pain, the provision of pain relief may result in worse outcomes for neonates or infants.

Despite research being conducted to investigate the effect of anaesthesia on neonatal postoperative outcomes, research on how neonates or infants express pain did not appear until 1986. Johnston and Strada (1986) were the first to shine the spotlight on how pain could be assessed in critically ill neonates by highlighting the importance of a multi-dimensional approach to pain assessment. Thanks to this study, and the preceding years, which laid the foundations of neonatal or infant pain research and clinical practice, a fundamental shift occurred in 1987 in how clinicians conceptualised pain in this vulnerable population. Anand et al. (1987) showed that neonates who did not receive analgesia during a patent ductus arteriosus ligation, a major cardiac operation, experienced greater postoperative complications than those who received peri-operative analgesia. This study, understandably by modern standards, stirred controversy. Public outcry after the paper was published, deemed the study unethical because the neonates in the control arm of the randomised controlled trial did not receive any analgesia (McGrath 2011). The public, however, was unaware that the practice of performing surgical procedures in neonates without analgesia was standard medical practice in many neonatal intensive care units (NICU) globally. The unfolding of these events and the drive by the clinical community to learn more about neonatal or infant pain demonstrate an evolution of how researchers, clinicians, and the general public conceptualised pain in neonates or infants. Our conceptualisation of neonatal or infant pain continues to

evolve as we learn more about how neonates or infants feel and express pain (Butler 1989), and how pain may have short and long-term consequences on neurodevelopment, psychosocial wellbeing, and growth.

Various paediatric societies now consider neonatal or infant pain management in the NICU as an essential aspect of care. The growth in our knowledge of neonatal or infant pain in the last few decades (Johnston 2020) has had substantial implications for how pain is managed in the NICU. While setting the scene for neonatal pain assessment, Johnston and Strada (1986) showed that neonates or infants responded uniformly to acute painful procedures and routine immunisations, through abrupt changes in heart rate, crying, body movements, and facial expressions. Many individuals today would be surprised to learn that there are now 57 pain assessment scales that have been created to measure pain in patients admitted to NICUs and paediatric ICUs (Giordano et al. 2019). These are based on detecting and analysing physiological and behavioural signals, and contextual cues in a population whose clinical and developmental complexity changes dramatically across the gestational age spectrum and different disease states. Indeed, not all pain assessment tools have been validated for use in all clinical circumstances. The reliability and validity of such tools need consideration before they are used at the bedside with an infant. A recent study by Olsson et al. (2021) showed that 16% of neonatal or infant pain assessment tools used in clinical trials lacked validation. Moreover, while 90% of studies used validated pain assessment tools, these were often not used in the correct neonatal or infant population, or the correct pain type; for example, an acute pain assessment tool used for postoperative pain assessment. Due to the clinical complexity, gestational ages, and non-verbal nature of neonates or infants admitted to NICUs, pain assessment tools must be selected to fit each clinical scenario. The plethora of pain assessment tools may help clinicians to monitor pain. However, such tools rely on behavioural expressions of pain that may or may not be detected by a given tool or observing individual.

Prior to the research on neonatal or infant pain in the 1980s, many clinicians believed that neonates or infants were insensitive to noxious stimuli. Thus, at this time, some surgical procedures were performed on neonates or infants without provision of pain relief. Today, with greater knowledge about neonatal or infant neurodevelopment, the nature of pain in this group has been re-conceptualised. This shift has, in turn, changed how we respond to pain in this vulnerable population.

This chapter has two main aims. The first aim is to reflect on whether neonates or infants have a concept of pain. The second aim is to describe the factors which influence how we conceptualise neonatal or infant pain in terms of its non-verbal signals, and the implications these have on pain management of this vulnerable group.

## 2 Do Neonates or Infants Have a Concept of Pain?

To answer the first aim of whether neonates or infants have a concept of pain, we must refer to the former and current definition of pain developed by the *International Association for the Study of Pain* (IASP). Pain was defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. While the definition appears unproblematic for individuals with linguistic competence, there is an over-emphasis on language as a requirement to understand or communicate the experience of pain.

The IASP definition of pain was updated in 2020 to “an unpleasant and emotional experience associated with, or resembling that associated with, actual or potential tissue damage”, where the verb “described” has been removed (Raja et al. 2020). The revised definition removes the requirement for certain groups of patients, such as neonates or infants, to verbally describe their pain as a condition of having, or communicating, immediate pain. The lack of linguistic ability does not negate the possibility that a human (or a non-human animal) can experience pain. This undermines the idea that language provides the foundation for pain experience. However, does it undermine the converse: to understand the word “pain”, do we need to have the corresponding experience of pain?

A person who uses and explains the word “toothache” correctly, but has never had a toothache, arguably knows what “toothache” means (Danziger et al. 2006). Further, if such a person can say of himself “I haven’t got a toothache”, we have reason to think this person has mastered the first-person use of “pain”. A scenario in which a person could be said not to have first-person competence in using “pain” is if he suddenly screams out in distress, holding his cheek, but insists that he has not a toothache. Thus, to state meaningfully that another person is in pain, it is arguable that we do not need a pain, but the *concept* of pain (Wittgenstein 1953).

A person who understands the word “pain”, or its substitute in another language, possesses the concept of pain (Wittgenstein 1953). The person can tell that something is happening to him, which causes him to react in certain ways—the ways that human beings react when there is actual or potential tissue damage (or the ways associated with, or resembling, actual or potential tissue damage). When an individual can signal that she is in the requisite state, then she has a conception of pain, or knows what pain is. In the practice of using “pain”, she can register pain as a private experience. But more than this, she can organise informed responses to the experience. Being able to tell that one is in pain, for example, means having the ability to tell the cause of the pain, describe the pain’s sensory or temporal qualities, intensity, duration, location, if it changes over time, or spreads, is worse in mornings, and so on. Thus, our concept of pain connects to a network of skills, including reasoning, deliberation, analysis of causes, mobilisation of suitable responses, all of which contribute to an understanding of what is going on and how to respond to the event (Wittgenstein 1953). Learning this symbolic mode of describing one’s immediate experience develops later into understanding more complex sentences about pain,

which may involve using the word “pain” in certain contexts to dissemble, excuse, lampoon, or sympathise.

Following this line of thought, pre-linguistic neonates or infants do not possess the concept of pain (Derbyshire and Bockmann 2020; Derbyshire and Raja 2011). They cannot know that what is happening causes certain reactions when human beings experience actual or potential tissue damage. Rather, similar to the foetus, the neonate or infant “. . . experiences a pain that just is and it is because it is, there is no further comprehension of the experience, only an immediate apprehension” (Derbyshire and Bockmann 2020). For the neonate or infant, experiencing pain is not *knowing* that this is pain. Experiencing pain becomes a state of knowing only if the individual is a competent language user, and has learnt the concept of pain. To think that a neonate or infant, without exposure to learning, knows that she is in pain when she is in pain, is mistaken. The infant without learning is causally embedded in the world, though in the way that non-human animals are. Experiencing pain is endured by the infant or newborn without understanding or recognition. A consequence of this argument is that pain experience is not necessarily immediately transparent to some individuals. To be in pain is not always to know pain.

### **3 The Meaning of Neonatal or Infant Pain in Health Professionals**

The meaning of the neonate and infant’s pain behaviour is a function of the status extended to such behaviours by masters of the concept of pain (Derbyshire and Raja 2011). In this setting, the “master” is the sensitive and competent adult, who may be a parent, caregiver, health professional, or other alert observer. The attending adult is one whose judgement is autonomous because she has mastered the practice herself, and so how she judges the neonate or infant sets the standard for “what is going on” in the young child. The neonate or infant, as argued in the previous section, does not have, and is not required to have, the skills or knowledge that are necessary for the successful participation in the practice of using “pain”. This differentiation of role enables the adult to extend a kindness to the neonate’s or infant’s behaviour. The neonate or infant manifests behavioural signals of “pain”, “pain-related distress”, or “disability” by virtue of a courtesy bestowed to the neonate and infant by those who have already mastered the practice of using the word “pain”. The alert adult treats these behavioural signals as genuine signs of pain. The status accorded the neonate or infant in the practice of pain is therefore not as a special knower—privileged access to personal pain—but as a special actor. The background and cognitive competence necessary for language use to occur is provided by those who have been acculturated into the practice, while the neonate’s or infant’s behaviour is gradually shaped and made intelligible by this background. This interaction underscores the complete dependence that the neonate or infant has on the adult, and by extension on the social environment (Derbyshire and Raja 2011; Wittgenstein 1953).

However, pain assessment is not straightforward, especially for the neonate and infant, as we discuss below. It is therefore essential to understand how health professionals conceptualise neonatal or infant pain. Health professionals in the NICU interact with neonates or infants on a daily basis, and are often aware of the potentially painful procedures neonates or infants undergo. Accordingly, health professionals may be able to anticipate the need for analgesia or other comfort measures depending on the expected intensity of pain that neonates or infants may experience. Comfort measures that are commonly used in the NICU include oral sucrose, non-nutritive sucking, skin-to-skin or kangaroo care, and breastfeeding. For example, in anticipation that a lance to the heel for a blood test will be performed, a nurse may ask the infant's mother or father to cuddle and soothe their baby before the procedure takes place, but also have oral sucrose on stand-by in case more pain relief is required after the procedure has been performed.

Not all procedures require the same pain relief strategies. Post-surgical pain relief may consist of an intravenous opioid infusion, whereas other potentially painful procedures may require non-pharmacological strategies. The need for different pain relief strategies may also depend on disease states, length of critical illness, severity of illness, and previous experiences with potentially painful procedures by the neonate in the NICU. While the intrinsic need for pain relief should be guided by the patients themselves through the expression of pain signals, health professionals are influenced by several intrinsic and extrinsic factors that determine how they perceive and conceptualise neonatal or infant pain.

#### **4 Intrinsic Factors that Influence the Meaning of Neonatal or Infant Pain**

Several studies have explored the intrinsic factors of the health professional that influence the meaning of neonatal or infant pain. Quinn and Baker (2001) showed that in a sample of health professionals consisting of medical doctors and nurses of varying clinical experience levels, nurses tend to perceive neonatal or infant pain in different clinical scenarios as being 7.3 points higher in intensity on a 60-point scale, compared to doctors. Furthermore, nurses felt the need to provide analgesia more often compared to medical doctors. Quinn and Baker suggest that the results highlight a difference in the concept of neonatal or infant pain between medical doctors and nurses, which can influence the provision of pain relief. Similar professional differences in the meaning of pain in neonates or infants were noted by Andersen et al. (2007), who showed that nurses were more likely to use pharmacological agents for lumbar puncture and insertion of a chest tube compared to medical doctors.

In addition to the *type* of professional training, the *level* of professional experience is another intrinsic factor that may influence health professionals' concept of neonatal or infant pain. Ishak et al. (2019) assessed paediatric medical doctors in

Malaysia on their knowledge of neonatal or infant pain. They showed that specialists, consultants, and medical doctors with more clinical experience tended to correctly agree more with the statement that neonates or infants could feel pain and that they were more sensitive to pain than older children and adults, compared to those with less clinical experience. The effect of the level of professional experience on the conceptualisation of neonatal or infant pain is also found amongst neonatal nurses. Pölkki et al. (2010) showed that higher levels of education and clinical experience in neonatal nurses were associated with more accurate perceptions of neonatal or infant pain, including the fact that preterm infants are more sensitive to pain than their full-term counterparts.

Another intrinsic factor that may influence the conceptualisation of neonatal or infant pain among health professionals is evidence-based knowledge. In a study by Schultz et al. (2010), 76% of junior medical doctors correctly believed that adequate pain management could reduce mortality and morbidity in neonates admitted to the NICU; however, 24% of junior doctors believed incorrectly that sedation was appropriate for neonatal pain management. Consistent with other studies (e.g., Ishak et al. 2019), junior doctors in this study with at least 1 year of neonatology experience were more likely to believe that pain assessment tools were psychometrically valid. More experienced junior doctors who graduated more than 5 years ago and had at least 1 year experience in neonatology, believed more often that neonates are more likely to experience the long-term consequences of pain than older children.

The meaning of neonatal or infant pain may also be influenced by the health professional's self-perceived role as a *carer*. When neonatal nurses were asked about how they cope with "inflicting pain" on extremely preterm infants, nurses responded by stating that the hope for a good recovery helped some nurses cope with inflicting pain as a form a caring behaviour (Green et al. 2016). However, nurses noted that as soon as this hope diminished, any act of caring that involved inflicting pain was considered torture, and nurses begun to view themselves as torturers, thereby challenging their self-perceived roles as carers. In this instance, nurses' concept of pain switched from being a necessary evil that was conducted in the best interests of the patient, to an act of torture and source of suffering for the neonate or infant. In a similar way, physiotherapists place a smaller valence on potentially painful procedures because they are often restrained in their roles as pain alleviators, and thus must cognitively minimise the amount of pain they perceive in their patients by focussing more on the potential benefits of their interventions instead (von Baeyer and Tupper 2010).

Nurses' self-perceived roles as carers were also discussed by Korhonen et al. (2013). Korhonen et al. examined the meaning of suffering by nurses in the context of pain in preterm infants. Because nurses are often responsible for alleviating pain, exploring how nurses conceptualise suffering is essential. While the concepts of suffering and pain are distinct, they are often used interchangeably, especially as pain can lead to suffering, at least as assessed in linguistically competent individuals. The concept of suffering is much less easily ascribed to neonates, precisely because we cannot determine empirically non-linguistic behavioural signs, or physiological

correlates, of pain-related suffering. Nonetheless, suffering is a critical concept in health. In healthcare, health professionals are often entrusted to relieve the suffering of their patients. Korhonen et al. (2013) rightly point out that to relieve suffering, health professionals must be able to perceive it in the first place in order to respond appropriately. Nurses in this study believed that the younger the neonate or infant is, the higher their propensity to suffer, but the lower their ability to express suffering. Nurses also believed that infants had variation in their thresholds to suffer. These beliefs about the experience of pain and suffering, and neonates' or infants' ability to express it, highlighted that nurses' conceptualisation of pain may change as the neonate or infant grows older.

The ascription of different concepts of pain may also depend on who the patient is and whose suffering is more "meaningful". Beliefs about when a neonate's perception of pain develops may differ according to a health professional's "work object", or the patient which the clinician is professionally and ethically responsible for (Andaya and Campo-Engelstein 2021). Andaya and Campo-Engelstein (2021) found that obstetricians who performed abortions believed that fetuses were only able to perceive pain between 22 and 29 weeks of gestation, which was also considered to be the period of foetal "viability" and out of the acceptable range to abort fetuses. In contrast, NICU clinicians believed that neonates could perceive pain at any gestational age after birth, even as early as 20 weeks of gestation. Andaya and Campo-Engelstein (2021) noticed that obstetricians' and NICU clinicians' concepts of neonatal pain were intimately tied to their institutions' concept of "viability". To extend this concept, Andaya and Campo-Engelstein (2021) propose that the "meaningfulness" of pain that is ascribed to fetuses or neonates may be shaped by their patient's expected futures: neonatologists may use pain relief sparingly in situations where there was an increased chance of survival of a neonate, and used less judiciously in situations where a neonate was not expected to survive. Similarly, neonatologists were often uncomfortable performing painful procedures, knowing that a neonate had little chance of survival to avoid "meaningless suffering".

The above findings present an obvious dilemma, which is unique to the neonatal or infant population. Unlike older, linguistic populations, the complexity and diversity of clinical scenarios and gestational ages of neonates or infants admitted to the NICU suggest that the meaning of pain in this population is highly dynamic, and may change considerably from health professional to health professional, and from infant to infant, and across time within the same infant. Health professionals may struggle to make subtle pain ascriptions based on simple criteria, but need to take into account the broader medical context of the patient and previous events. As discussed in more detail below, differences in the meaning of pain between health professionals partly reflects an indeterminacy in our concept of pain. Some pain behaviour is unpredictable, and health professionals' reactions to it diverse and, as already noted, relative to multiple interacting factors, including clinical speciality, years of clinical experience, professional role, and level of education.

## 5 The Meaning of Neonatal or Infant Pain in Parents

Parents of neonates or infants admitted to the NICU also apply meanings of pain. In addition to being primary caregivers, alert parents are able to detect pain in their infants and, in turn, act as advocates for the management of their infant's pain. Franck et al. (2005) asked parents of neonates or infants in the NICU about their perceptions of neonatal or infant pain. Parents either used the terms "discomfort" and "pain" synonymously, or as distinct concepts, which demonstrates that the meaning of pain may differ between parents. Most parents in their study were concerned about the short and long-term effects of pain on their infants, as it related to their medical progress, physical development, and psychological wellbeing. Some parents expressed that they were worried about how their infants were handling pain and described their own feelings as "utter helplessness". Parents were also aware of potential discrepancies between how they and their health professionals perceived pain in their infants. At times, parents thought that their infants were not given any analgesia when they felt it was required. It appears, however, that beliefs about the cognitive capacity of neonates or infants do not influence parents' perception of pain in their own children. A study by Pillai Riddell et al. (2004) showed that any beliefs about memory and how much their infants understood about pain following an immunisation did not influence parental judgements of pain intensity. This is in contrast to health professionals, where beliefs about nervous system development may influence how painful they perceive certain procedures.

In a thematic analysis of interviews with parents of neonates or infants in the NICU, Gale et al. (2004) showed that parents perceived pain directly in relation to their own parental stress. In other words, parents' own conceptualisation of their infant's pain were intertwined with their own emotional reactions. Parents felt helpless, sad, angry, fearful, disappointed, guilty, and frustrated, knowing that their infants experienced pain. This highlights how much a parent's own conceptualisation of pain is influenced by their own emotional states, a conceptualisation that may not appear in some health professionals. An emotional closeness, or at times emotional distance, due to attachment issues between an infant and his or her parents, influences the level of emotional reactivity to pain. Parents of infants admitted to the NICU may be hyper-vigilant of distress compared to health professionals, who are exposed to and inflict potentially painful procedures on infants on a daily basis. In this way, parents' concept of neonatal or infant pain may be much more visceral and empathic than health professionals, although some health professionals may also respond empathically to neonatal pain.



## 6 Meanings of Neonatal or Infant Pain and Implications for Management

The conceptualisation of pain in neonates or infants by health professionals differs according to factors inherent in the health professional. These include clinical speciality, years of clinical experience, professional role, and level of education. There are also factors that are inherent in neonates or infants, which influence how we conceptualise pain in them. These include gestational age and knowledge about nervous system maturation and pain sensitivity across the gestational age spectrum. The preceding sections have argued that the concept of pain is applied to the neonate and infant in virtue of a courtesy gesture by those who have already mastered the concept, treating signs of pain in the neonate and infant as authentic. In this setting, the “master” is the linguistically and cognitively competent adult. This has obvious implications for the management of pain in neonates or infants—that the caregiver, whether the health professional or parent—is automatically entrusted with the special role as someone who is able to suitably detect, and respond appropriately, to signs of pain. How well they execute this role relies on their conception of pain, and on the specific setting in which the concept is applied, among other factors.

Health professionals’ concepts of pain will invariably affect how pain is managed in the NICU. After observing nurses and neonatologists in NICUs, Shirazi et al. (2020) showed that the management of pain was influenced by knowledge and attitudes, inter- and intra-professional collaborations, the culture within the NICU, and the facilities available in the NICU. Sometimes, health professionals considered pain management as being unnecessary and were not always considered. Indeed, there is a difference between those who become indifferent to pain management, and those who respond appropriately to potentially painful procedures or expressions of pain in neonates. Simply making evidence-based knowledge available may not change pain management practices. In fact, Shirazi et al. (2020) found that, despite the growing evidence base for neonatal or infant pain management, attitudes towards neonatal or infant pain remain a barrier to adequate pain management.

## 7 Signals of Pain

It should be clear by now that the assessment of pain in the NICU forms an integral part of neonatal or infant pain management. While standardised assessment tools provide a useful means to assist health professionals to detect signals of pain, such tools are not always employed in NICUs. Without pain assessment tools, some individuals may rely on different signals to detect neonatal or infant pain. While pain assessment tools help to standardise pain assessment in the NICU, and therefore help to ensure adequate pain relief is provided, Bellieni et al. (2018) showed that 39% of neonatal clinicians stated that their department did not use any pain assessment tools. In fact, Ishak et al. (2019) found that most paediatric medical doctors (81.6%) agreed

that vital signs were not reliable indicators of pain intensity, which further highlights why there is a slower uptake or trust in pain assessment tools in the NICU.

Pain assessment, in clinical and non-clinical settings, can be a challenging and uncertain task. Pain assessment in non-linguistic neonates or infants is especially complex, even with the use of standardised pain assessment tools. In addition to gestational age, pain assessment of neonates or infants is further complicated by the unpredictability, inconsistency, and subtlety of pain responses, the short duration of such responses, which are dependent on the neonate's or infant's state, including disease states. Pölkki et al. (2010) showed that nurses agreed that many factors influence the neonatal or infant expression of pain, which is not necessarily associated with the intensity of pain they experience. These include the neonate's or infant's overall health, other stressors such as hunger, and their stage of physical and cognitive development. Nurses tend to disagree on the physiological and behavioural signals that indicate whether neonates or infants are experiencing pain.

The possibility of disagreement or uncertainty about the pain of neonates or infants reflects an indeterminacy, which is constitutive of our concept of pain (Wittgenstein 1953). That indeterminacy in turn is due to social patterns of behaviour: our concept of pain must be flexible because pain behaviour, and our complex reactions to it, is diverse and unpredictable. Care-giving in pain settings can involve a threat to the caregiver, and is conditional on the authenticity of manifest pain behaviour. As observers of pain behaviour, we are sensitive to signs of exaggeration, suppression, or malingering, in behavioural displays of pain. Accordingly, our concept of pain does not always connect behaviour, situation and personal experience, in a rigid way.

The assessment of pain in neonates or infants by health professionals is sometimes perceived to be an "indirect" means of inferring their pain experiences, in contrast to the "direct knowledge" of pain through personal experience (Prkachin et al. 2007). However, the person with pain does not know directly or indirectly of her being with pain—she *has* it—and for observers, there is no more direct way of knowing pain than by seeing her grimace, moan or writhe. In many cases, observers do not infer that she is in pain, we *see* that she is with pain. Nevertheless, one might object I cannot notice the pain itself, only the behaviour which expresses it. But this is like claiming that I cannot see sounds or hear colours. Rather, it indicates a categorical distinction between mental and behavioural terms, not that statements involving the former are always inferred from those involving the latter. In this sense, clinical pain assessment is a "direct" means of obtaining knowledge about pain in the patient, provided the assessing clinician has the required skills and knowledge.

Our concept of pain is essentially tied to manifest behavioural signals of pain, since mental phenomena, including pain, are neither totally separable from, nor reducible to, their bodily and behavioural expressions. It is part of our concepts of particular subjective or mental phenomena, including pain, that they have a characteristic manifestation in behaviour (Wittgenstein 1953). If we encountered a people who used a word that lacked any connection with pain-behaviour and the

circumstances in which we display it, we would not translate it as “pain” (Wittgenstein 1953).

A challenge remains for some health professionals whether neonates or infants have the capacity to express the physiology of pain in behavioural signals. While health professionals in the NICU are encouraged to assess pain regularly throughout admission, they are often only prompted to assess pain when they suspect that their patients are experiencing pain. Most pain assessment tools are based on the assessment of physiology in neonates or infants, which include assessment of heart rate, blood pressure, respiratory rate, and oxygen saturation. On their own, these signals are not exclusive to the perceived experience of pain (e.g., hunger, stress). When considered in conjunction with other physiological and behavioural signals, they may strengthen observer confidence that the infant or neonate is in pain. Gibbins et al. (2015) noted that the pain response in extremely low gestational age infants may be expressed by the combination of heart rate, respiratory rate, blood pressure, and oxygen saturation; however, Gibbins et al. point out that there was disagreement among clinicians about whether an increase or decrease of these vital signs were indicative of pain. The unpredictability, inconsistency, and subtlety of physiological signals of pain, against the background of the indeterminacy of pain, increases the uncertainty of assessing pain in extremely preterm infants. Given the same physiological evidence, one health professional can be convinced and another not be (Gibbins et al. 2015). However, we do not on account of this exclude either from the medical profession, as being unaccountable or incapable of judgement. This reflects, not professional incompetence, but the indefiniteness of pain.

Health professionals are aware that neonates or infants born at younger gestational ages, such as those born extremely preterm, display more subtle signals of pain in response to painful procedures than term neonates or infants. But, this also increases health professionals’ uncertainty with detecting pain in this group (Gibbins et al. 2015). Gibbins et al. (2015) showed that health professionals generally relied on three behavioural signals of pain in preterm infants: facial expressions, body movements, and functional activity (eating and sleeping), but noted that a “shut down” response to pain, where the infant would show no facial expression or activity, was commonly cited by health professionals as signalling pain. Although the assessment of pain intensity during and after a potentially painful procedure such as a heel lance may be obvious, pain assessment following surgery, or outside the context of a painful procedure is much more difficult. Indeed, the difficulty with conceptualising other types of pain such as chronic pain can make it difficult to identify it. A study by Boyle et al. (2018) showed that, without a tool designed to assess persistent pain in neonates, health professionals and parents found it difficult to identify pain that persists.

Finally, recent advances in imaging and other neurophysiological assessment methods have allowed a more nuanced assessment of pain in neonates or infants in the NICU. For example, in a study by Slater et al. (2008), neonates demonstrated cortical haemodynamic changes, which were associated with pain following a heel lance, in the absence of obvious behavioural cues such as facial grimaces of pain. This suggests that such tools may be useful in alerting health professionals and

researchers to a potential pain experience, even when subtle forms of expression are absent. While the use of brain imaging and other neurophysiological measures of pain have ethical and legal implications in the verbal adult population (Davis 2016), these have potential benefits in the non-verbal population but require further investigation. Moreover, it is questionable whether such advanced techniques to detect pain could be readily applied at the bedside. Nevertheless, the use of these tools highlights the urgent need to describe biological correlates of pain in neonates or infants.

Physiological and behavioural signals play a role in enabling health professionals to detect neonatal or infant pain. In this way, these signals form a part of a health professional's or parent's concept of pain in neonates or infants. For instance, one health professional may believe that an increase in bodily movements indicates pain because the infant is trying to let their carers know about their distress. Another health professional may deem a lack of normal bodily movements, or "shutting down", as indicative of pain as a reaction to feeling overwhelmed by the pain experience. Yet another health professional may use both as indicating pain. Physiological and behavioural signals of pain in the neonate and infant form a highly complex syndrome.

Health professionals must also be skilled and experienced enough to detect subtle changes in behaviour. In addition to the skills required to detect these signals, health professionals use contextual cues to make decisions on whether a neonate or infant is experiencing pain. Contextual cues include factors within the infant, such as their gestational age, their chronological age at assessment, and any co-morbidities that could affect their experience and expression of pain; e.g., neurological conditions affecting movement, such as cerebral palsy. Other factors may include the presence of medical devices which could obstruct or inhibit the observation and assessment of pain. For example, neonates or infants who are mechanically ventilated are unable to cry. Thus, any pain assessment tool that requires the assessment of crying may not be useful. Furthermore, neonates or infants who are sedated or muscle relaxed may not respond uniformly to pain as those who are not. The frequency of painful procedures neonates or infants undergo should be taken into account, as their capacity to respond behaviourally or physiologically may diminish overtime as they undergo more painful procedures (Gibbins et al. 2015).

## **8 Craig's Social Communications Model of Pain and the Concept of Pain**

Detecting signals of pain in neonates or infants is influenced by our concept of pain. This is aptly explored in Craig's social communications model of pain (Craig 2015). Craig outlines how the detection and interpretation of pain in others is a social exchange influenced by the integration of biological (e.g., the physical trauma, tissue injury), psychological (e.g., intra-personal factors, including personality, empathy),

and social (interpersonal factors including sensitivity to others' pain, knowledge, and professional training) dimensions. Because health professionals and parents are entrusted with the responsibility to detect and respond to pain in neonates or infants, the social communications model in the context of neonatal or infant populations focusses substantially on the psychological and social perspectives adopted by health professionals and parents. For example, a parent's own personal distress after witnessing distress in their infant may increase the intensity of pain they perceive in their child. As Patrick Wall put it so well, "Fear generates anxiety and anxiety focuses the attention; the more attention is locked, the worse is the pain. There is therefore a marked correlation between pain and anxiety" (Wall 1999, p. 185). Alternatively, a physiotherapist who believes the beneficial effects of a tracheal suctioning to reduce the risk of respiratory complications may reduce the intensity of pain that they perceive in their patient. The purpose of the social communications model of pain is to highlight the various factors *beyond* the neonate's or infant's experience of pain that can influence the concept of pain that we extend to them.

## 9 Conclusions

Neonates or infants represent a special and complex patient population. The existence of over 50 pain assessment tools to assess pain in this population attests to the complexity of the expression of pain in neonates or infants. This is partly reflective of uncertainty and disagreement in clinical judgements of pain in neonatal or paediatric patients, due in turn to the constitutional indefiniteness of our concept of pain. We have argued that, since pre-linguistic neonates or infants do not possess the concept of pain, the neonate and infant expresses pain only by virtue of a courtesy extended to signs of pain by those who have already mastered the practice of using "pain", treating them as genuine expressions of pain. What this argument underscores is the dependence that the baby has on the adult caregiver, and more broadly on the social environment.

Health professionals' professional attributes, attributes within the NICU, and context influence the conceptualisation of neonatal or infant pain in health professionals (Gibbins et al. 2015). Health professionals' attributes include professional discipline, education, level of empathy, and skill at observing pain in neonates or infants. A lack of skills and education may increase difficulty in detecting pain in behavioural signs. Health professionals' self-perceived role as carers and their understanding of suffering are also major determinants of their concept of neonatal or infant pain. In addition to these intrinsic factors, attributes within the NICU and the context in which care takes place influence our concept of neonatal or infant pain. These include care priorities within the NICU, institutional benchmarks of viability, current workload, and the frequency of emergent issues that can take precedence over pain, such as the severity of critical illness. For parents, the concept of pain is heavily influenced by emotional proximity to their child. Parental reaction to distress

in their baby will invariably affect the meaning of pain they extend to their infants, which is often associated with helplessness or fear, and how they respond to pain in their child.

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# Chapter 2

## Pain in the Fetus and the Preterm Baby



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**Abstract** The presence of pain in the earliest phases of human development is a recent acquisition of modern medicine and physiology. The main arguments against fetal and neonatal sentience and pain have been overcome: the full development of the cortex is not necessary to feel pain because the main structures needed for pain are in situ after the first half of pregnancy: peripheral receptors, neural spinothalamic fibers, pain neurotransmitters, the thalamus, and the subplate. Fetuses have a rudimentary though essential sense of experience. They have a primordial consciousness that becomes more and more efficient as the brain cortex is developing, and that will bloom with the arrival of the multiple stimuli given at, and after, birth. If we associate the “meaning of pain” with the ability to self-ascribe “pain,” it clearly does not exist at this stage of human development. But if we use the word “meaning” to express how pain affects the fetus/newborn, this has three levels. First, suffering and the changes it provokes, that can help bystanders to care correctly; second, the impact of pain on fetal development; and third, the anxiety, that we cannot measure in the fetus and newborn, but that is presumably present, because both the fetus and newborn have active centers (amygdala and thalamus) to experience these feelings. Conclusion: Fetuses and very preterm babies live in a world of drowsiness, similar to adults’ imageless dream; when external stimuli disrupt the fetus/preterm-baby, this sort of dream can become similar to a nightmare.

**Keywords** Pain · Fetus · Preterm · Baby · Analgesia · Pain scales

### 1 Introduction: The Meaning of Pain

Giving a meaning to pain has been the ambition of generations of thinkers: if pain has a punitive, redeeming, or warning meaning to avoid physical damage, remorse, or a spur to combat. There is still debate in the pain field about the meaning of pain (van Rysewyk 2016). If we apply this question to the unborn baby or the baby born

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immature, who cannot express themselves, then we arrive in an area that can only be accessed in dreams or poetry. We have high-quality clinical and experimental pain data on the fetus and neonate, but we do not have the voice of the protagonists: pain is a subjective experience; it can only be expressed by those who are experiencing it. Pain is associated with several meanings. These include a meaning of threat or danger, which is experienced as immediately distressing or unpleasant; cognitive meanings, which are focused on the long-term consequences of having chronic pain or of the background illness that provoked pain; and existential meanings such as hopelessness, anxiety, and depression, or a sense of resilience, which are more about the person with chronic pain than the pain itself (van Rysewyk 2016). But the concept of meaning implicates that someone can recognize or know what he or she is experiencing (Mursell 1920; Wittgenstein 1953/2009). For example, knowing or recognizing that one is in pain involves the ability to self-ascribe the word “pain” when one has it (Wittgenstein 1953/2009). So, what can we say about “meaning” when a person’s brain is not fully developed to allow the person to recognize an experience or sensation? If we exclude fetuses and neonates from the realm of recognition, we should also exclude mentally disabled people, as well as those who momentarily or definitively are in a vegetative state or coma (Belton 2019). But the word “meaning” has also a wider application. It can be used in three areas. The first is the sensorial though unconscious meaning: someone can experience pain, and this has important consequences for his body and psyche, even if he is not able to recognize it. The second is the meaning for the personal future: how pain can negatively influence the development of the person and his or her recovery from a disease or condition. Third, the meaning that pain has for the caregivers: when we consider a patient, we cannot analyze him or her as a monad, but as part of a familiar story and of a society: in this case, pain of the unconscious patient has meaning for bystanders. We will discuss these three points in Sects. 7–9.

With the aim of highlighting the meaning of pain for the fetus or newborn, we will discuss first what can be identified as the fetus and newborn, and we will see that the two stages of life overlap in many features; second, we will discuss if fetuses can really feel pain; and finally, what pain could mean to them. We will attempt to dispel the main myths that would deny that in this first phase of life human beings feel pain, and we will understand what kind of pain fetuses and preterm babies could feel. But we will have to make a great effort supported by scientific evidence. We will then try to understand the meaning of this pain, to approach gently this silent and mysterious world, where we will find interesting and compelling data and scenarios.

## **2 What Is the Fetus and the Newborn Baby?**

First of all, the border between fetus and newborn is blurred: there are fetuses that come out of the womb prematurely (“premature babies”), and fetuses born after 9 months of pregnancy that are more developed than premature babies. This state of development is still extremely fragile and immature. Until a few decades ago, this

was the realm of health problems and of high risk of death. Today, preterm survival is higher, and negative consequences for health after preterm birth are reduced.

The fetus and the newborn are not without the capacity to sense, since they are neurobiologically active subjects (Als 1997). In fact, from the middle of pregnancy, various types of sensations—acoustic, vestibular, gustatory, and visual—begin to be experienced by the fetus (Marx and Nagy 2015; Bellieni et al. 2003a, b). Obviously, we will have to wait months before the awareness of these sensations becomes behaviorally expressed in the baby, but we know that these sensations have two functions. The first function is to modulate the development of the fetus' nervous system by determining the growth or death of certain populations of brain neurons (Timor-Tritsch 1986): if the aforementioned sensations did not exist, the growth of the nervous system would be unbalanced. Still, within this first function that we can call “centripetal,” we must remember that the sensations and the environment determine the activation or the deactivation of some genes of the chromosomal kit in the fetal subject, which can cause complications for the subject for the rest of its life (Provenzi et al. 2018). We call the second function “centrifuge”; that is, it serves to prepare the fetus and the newborn for life: the sensations that arrive at this stage of life generate a memory pattern that is fundamental for the baby in order to be prepared for post-natal stimuli (Podzimek et al. 2018).

We know that the subject at birth remembers the vocal sensations that he perceived in utero, and will behave differently depending on whether he hears mother's voice or the voice of a stranger; the gustatory sensations will serve the subject to prepare to search for breast milk that he “learned” to recognize during pregnancy since the taste of the amniotic fluid, in which the fetus is immersed and which it sucks during pregnancy, is similar to the taste of mother's milk, its characteristics largely due to the mother's eating habits; we can say that our food tastes started to form before birth (Paglia 2019). Even the movements of the mother, differentiating between excessive or absent, are learned and sought by the fetus after birth: we conducted a study in which we saw that more children born from women who had continued to dance during pregnancy needed to be rocked to sleep during their first year ( $p < 0.05$ ) (Bellieni et al. 2004). Of course, this memory will not be a conscious memory, but it will be an “implicit memory trace” that the fetus and the newborn absorb passively (Mobbs et al. 2016).

The newborn is defined as such up to 28 days after the “physiological” birth limit, which usually occurs after 40 weeks or 280 days from conception. UNICEF recently launched the “1000 Golden Days” campaign to emphasize the importance and fragility of the first 1000 days of the subject's development, i.e., those that go from conception to the completion of the second year of life (Bellieni 2016). This attention above all concerns the nutrition and the right of access to breast milk and the right diet of the pregnant mother. The diagnostic and therapeutic possibilities in this era of development have greatly improved in recent decades. Today, it is possible to perform on the fetus surgical interventions in the uterus, i.e., opening the uterus, inspecting the fetus without cutting the umbilical cord, operating it, and closing the uterus (Nelson et al. 2020). In this way, it is possible to carry out repairs to the lungs, diaphragm, heart, kidneys, or spine. In preterm babies, it is possible to

guarantee breathing by administering surfactant into the lungs with a small catheter inserted into the trachea, which prevents the lungs from collapsing. This has saved the lives of millions of children. Premature babies are very sensitive to stimuli and must be preserved from unnecessary invasive maneuvers but also from light, cold, and noise in the weeks that will pass outside the uterus, inside an incubator, before being able to go home (Cheong et al. 2020).

### 3 The Fetus and the Newborn Feel Pain

Scientific research has shown that pain is a sensation that is experienced from the earliest ages of life. To experience pain, the pathways that transmit nociceptive signals to the brain need to be active. Which ones are they? Firstly, the specific nociceptors that are present in many organs and throughout the skin and mucous membranes. Then, the nerve fibers that transmit the stimulus to the spinal cord and those that transmit it from the spinal cord to the thalamus; note that for these fibers to work, the neurotransmitters that put them in contact with each other must also be produced. The presence of the myelin sheath that covers the fibers and that develops over time is useful, but not essential. The connection with the thalamus is the indispensable condition for experiencing pain (Anand and Clancy 2006; Sotgiu 2001). Key mechanisms of consciousness or conscious sensory perception are not dependent on cortical activity. Consistent with this evidence, the responses to noxious stimulation of children with hydranencephaly are purposeful, coordinated, and similar to those of intact children (Shewmon et al. 1999). Then, this sensation will become conscious and will produce suffering as long as the centers of consciousness are involved: the cerebral cortex, or its fetal predecessor, the subplate zone (Kidokoro 2020).

Consider that the connection with the thalamus occurs around 20 weeks of gestation and the connection with the cortex between 20- and 40-weeks' gestation in a progressive connection (Kostović and Judas 2010). The fact that the fetus already feels pain in utero in the second half of pregnancy is shown by several experiments. One of the most refined experiments measured the production of stress hormones (adrenaline, endorphins, and cortisol) during a noxious stimulus to a group of fetuses for therapeutic purposes, and compared hormone production with an innocuous stimulus administered to a similar group of fetuses. The increase of stress hormones is a reliable marker of stress or pain (Chapman et al. 2008). The increase in stress hormones was high in the first group, but absent in the second group (Giannakouloupoulos et al. 1994, 1999). The same group of researchers then examined the matter a second time, but in a group of fetuses that received the noxious stimulus without opioid analgesics, and in another group of fetuses that received the same noxious stimulus after receiving opioid analgesics. In the first group, the increase in stress hormones was high; in the second, the increase was zero. Thus, not only does the fetus feel pain, but the administration of analgesics reduces this sensation (Fisk et al. 2001).

Current ultrasound techniques allow us to observe the spontaneous facial and bodily responses to stress and pain of the fetus, which appear in all respects the same as those of a newborn that receives noxious stimuli (Reissland et al. 2013). Prematurely born fetuses also feel pain, and this is measured in various ways (see below). Today, the evolution of fetal surgery has brought to the fore the problem of fetal pain, though in some cases surgical operations are still performed on the fetus without analgesia. Today, we know that giving drugs directly to the fetus that not only block its movements but also analgesic drugs are essential, because fetal pain can threaten normal brain development, as well as being an aversive sensation (Bellieni 2019). The premature infant is another subject that faces numerous noxious stimuli: it has been calculated that on average the fetus experiences approximately 10 painful episodes per day (Carbajal et al. 2008), a number that would be intolerable for an adult. These data were obtained from a study performed in 14 tertiary care neonatology centers in France; during the first 14 days of admission to the participating units, prospective data were collected on all neonatal procedures causing pain, stress, or discomfort with the corresponding analgesic therapy. At the same time, the fetus often does not receive adequate analgesia (McPherson et al. 2020; Field 2017).

Yet today, we have very effective drugs to treat the pain of the newborn in an anticipatory way, that is, without waiting for its movements, behaviors, or cries to capture observer attention. These drugs include nonsteroidal anti-inflammatory drugs (NSAIDs), acetaminophen, or opioids. Non-pharmacological analgesic techniques can also be used (Locatelli and Bellieni 2018). Analgesia can be administered to the fetus or newborn with single (e.g., oral sugar or handling) or multiple administrations. The latter are based on the activation of the “gate control” mechanism present in the spinal cord, which works by activating interneurons that block the noxious stimulus, and by tactile stimuli given simultaneously as the noxious stimulus. In addition, the administration of oral sugar produces endorphins, increasing the analgesic effect of the tactile stimulus; this technique is called “sensory saturation.” It is important to remember that, until the 1990s, it was denied by the majority of the medical community that the infant felt pain; consequently, surgery was conducted without the use of opioids; studies published by Sunny Anand in 1987 began to change the opinion of the scientific community (Anand and Hickey 1987).

## 4 Consequences of Untreated Pain Later in Life

Causing pain in the early stages of life has a morally negative meaning, because it harms human beings who cannot defend themselves. It also has long-term consequences, because the fragility of the immature organism is indelibly affected by pain. Infants who underwent surgery without anesthesia showed greater brain damage than infants who instead underwent surgery with analgesia (Anand and Hickey 1987). Today, we know that pain-related developmental damage is due to several reasons: pain increases heart rate and intracranial pressure, causes oxygen

desaturation, and produces excitatory amino acids and oxygen free radicals. All of these are risk factors for brain damage. Years ago, we measured that even a simple withdrawal of blood with a needle from the infant's heel causes an important increase in oxygen free radicals, a signal of oxidative stress (Bellieni et al. 2003a, b). In another study, we showed that blood sampling dramatically increases intracranial pressure well above the level of diastolic blood pressure (Bellieni et al. 2009). We know that the newborn who experienced more pain in the first days of life will develop a thinner cerebral cortex than the average child of the same age (Field 2017; Ranger et al. 2013). We also know that the pain suffered in the first days of life causes an increase in the pain threshold after several months following birth. This last phenomenon is explained both by the increased production of cortisol in the infant following noxious stimulation and by genomic imprinting. Pain-related stress activates the hypothalamic–pituitary–adrenal (HPA) axis with the production of cortisol which, if prolonged, stimulates the amygdala, a brain structure associated with stress, which in turn will stimulate the HPA axis, triggering a vicious circle that will lead to chronic hyperproduction of cortisone (Field 2017). The epigenetic scenario is determined as a result of the action of environmental stimuli, including pain due to noxious stimulation, on the expression of some genes. In particular, we know that repeated pain alters the expression of the brain-derived neurotrophic factor (Kundakovic and Champagne 2015), and of the gene for the production of cortisol receptors (Hatfield et al. 2018).

From a psychological point of view, the question remains very open: pain-related arousal due to genomic imprinting will mark the fetus post-birth. Today, we know that stimuli the fetus receives before being born will increase the possibility of developing signs and symptoms of depression when the fetus is an adult. Studies show that if a stress-causing stimulus, such as mourning or trauma suffered by the mother, occurs during pregnancy, years later, the child will suffer more than children whose mothers suffered mourning or trauma after their birth: the passage of stress hormones from mother to fetus could explain this finding (Sandman et al. 2012). We keep in mind that the fetus and the newborn do not yet have sophisticated conscious experiences and therefore cannot experience pain-related suffering, such as existential distress, but only immediate pain. Stress structures in the brain such as the amygdala are already active, even though only on the unconscious level.

## **5 False Myths: Neuro-Inhibitors and Immaturity of the Cortex**

The possibility of feeling pain in the fetal-neonatal period was initially opposed on the basis of the poor development of the structures that transmit and decipher unconscious nociception into conscious pain. Some authors (e.g., Derbyshire 2001) discuss the impossibility of feeling pain due to a lack of myelination of the nerve fibers and others (Lee et al. 2005) due to lack of development of the cerebral

cortex and of the connections that from the thalamus carry the stimulus to the cortex. In fact, the absence of myelination of the nerve fibers does not prevent the transmission of pain: pain is transmitted in the adult also by non-myelinated fibers, called C-fibers; therefore, that the fetus and newborn baby are partially lacking in myelin, or some other fiber type, is not necessarily an obstacle to pain experience (Anand and Clancy 2006). Further, the lack of connections with the cerebral cortex is not an impediment to the perception of pain. Firstly, the connection between peripheral receptors and the thalamus, the nucleus of the base of the brain, is sufficient to perceive pain (Sotgiu 2001; Anand and Clancy 2006; Shewmon et al. 1999). Secondly, from 20 weeks of pregnancy onward, an early version of the mature cerebral cortex, called the subplate, develops. The connection between peripheral receptors and the thalamus is active from 20 weeks of gestational age (Anand and Clancy 2006).

Some authors argue that the fetus actually has the structures in place to feel pain, but it is immersed in amniotic fluid, which is rich in neuro-inhibitory substances that cause a state of continuous sedation and sleep, thus preventing or greatly inhibiting the perception of pain (Mellor et al. 2005). Here, we must distinguish between sedation (or sleep) and analgesia/anesthesia. Sedation is a reversible state of decreased consciousness and sensation, while analgesia/anesthesia is a permanent state as long as the exposure to the agent that caused it lasts. In studies produced by the supporters of the “neuro-inhibitor” hypothesis, the authors discuss sedation, not anesthesia/analgesia (Royal College of Obstetricians and Gynaecologists 2010); nonetheless, they conclude that the fetus does not feel pain for this reason, which appears to be an obvious contradiction. Moreover, it is worth thinking about the experience of any person who has witnessed a birth: the fetus comes out of the vaginal canal and cries, spontaneously reacting to new and intrusive stimuli. Surely, this would be impossible if it were anesthetized by the substances to which it was exposed in utero. Moreover, neuro-inhibitory substances, such as prostaglandins, progesterone, and others, have a sedative effect only if given in high doses in the vein, doses much greater than those that the fetus has in utero (Hering et al. 1996; Powell et al. 1992). Even in the blood of the fetus, these substances have been found at doses equal to those circulating in the blood of their mothers when mothers have health problems such as gestosis; certainly, mothers in gestosis are not anesthetized by these substances (Moon et al. 2014; Yoneyama et al. 2004).

## 6 How Is Fetal and Neonatal Pain Measured?

The pain of the developing subject can be measured. This is achieved in the fetus born early, who has not yet reached the 40th week of gestation, the normal term of any pregnancy. There are many ways of measuring it. First, multifactorial scales. There are over 50 scales for measuring pain at this stage of life. Most were developed to measure pain for study purposes, i.e., pain from medical interventions (Maxwell et al. 2019). The remaining scales are more useful from a clinical point of view,

because they do not measure the sudden level of suffering but a level prolonged over time. This enables the doctor to introduce, increase, continue, decrease, or remove analgesics, and at the same time, to understand the cause of pain and its changes over time. The scales for measuring pain are important because obviously the fetus and the newborn cannot express themselves in words or verbally respond to analog visual instruments; even individual physiological parameters that change in response to pain, for example, the duration of crying or the increase in heart rate, are neither specific nor sufficiently sensitive to pain. For this reason, scales must be used that sum several parameters related to pain, assigning a score to each individual parameter based on its severity and adding the individual scores to arrive at a final score. The pain assessment scales must undergo a severe mathematical assessment to be validated, i.e., accepted by the scientific community. The validation process measures the degree of specificity, sensitivity, usability, and concordance of the scale.

But scales are not the only tools used to assess pain in the prelinguistic fetus or newborn. For example, stress hormones can be measured, such as adrenaline, cortisol, or beta-endorphins (Gonçalves 2010). In particular, cortisol can be dosed, in addition to blood, in saliva (Mörelus et al. 2016). Another way to evaluate the level of pain is to evaluate the response of the autonomic nervous system, which can be obtained in two ways. The first is to evaluate the variability of the heart rate, that is, the infinitesimal, but real irregularity of the duration between one beat and the next (Hashiguchi et al. 2020); the second is the measurement of the electrical conductance of the skin, which is measured with simple devices and which is a reflection of the activity of the autonomic nervous system (Maillard et al. 2019). In the fetus still in utero, we do not yet have validated tools to measure pain. Studies have been made to measure the hormonal response to a noxious stimulus administered to the fetus in utero, and it was observed that the response of the fetus was following the application of a noxious stimulus to an adult subject, noting moreover that this hormonal response is canceled if opioids are administered to the fetus (Fisk et al. 2001). These measurements are important for the aforementioned reasons of diagnosis and analgesic therapy. But they also have an important further use: they can help us in difficult end-of-life cases (Bellieni 2019), when clinicians cannot obtain a verbal response on the acceptability or unacceptability of a treatment or continuation of care, and therefore we can only rely on the “language” of the child through the aforementioned tools: indirect in nature, but capable of telling us if the child tolerates or no longer tolerates treatment.

## **7 What Qualities of Pain Can the Fetus Experience and What “Meanings of Pain” Are Open to the Fetus?**

The pain that a fetus can have is real, although arguably qualitatively different from that of an adult. We can say that it is quantitatively analogous, because pain inhibitory pathways are not yet fully developed, but it is qualitatively different,

because the fetus cannot as yet know that what is happening to it is pain. This is because experiencing pain is not knowing that this experience is pain. Arguably, pain becomes a state of knowing only if the individual is a competent language user (Wittgenstein 1953/2009). The fetus can feel pain, but what it feels is endured without understanding or recognition. In the same way, perhaps the fetus can suffer, but it cannot know that it suffers? Still, it seems clear that the fetus cannot realize sophisticated sufferings, including existential sufferings related to persistent pain, such as despair or loneliness. We must draw a line between suffering and immediate pain. Pain is an unpleasant immediate reaction of varying intensities that causes neuro-hormonal responses in a subject; suffering is a psychological response that implies a perceived unbridgeable gulf between what a person expects and, in a negative way, what can be obtained (Encyclopedia of Pain 2007). Suffering is a derivative of pain, but not all pains cause suffering, just as not all sufferings cause pain. Suffering is the perception of serious threat or damage to the *person*, and it emerges when a discrepancy forms between what one expected of one's self and what one does or is (Encyclopedia of Pain 2007). Thus, suffering is autobiographical and focuses on memories and reflections that sustain the identity of the individual, which includes a sense of history and self. The fetal subject does not have a personal identity in this sophisticated sense and cannot form complex personal expectations, even at an unconscious level, so we cannot speak of pain-related suffering in the fetus, only of the capacity to have immediate pain. Further, although the fetus feels sensations, it is hard to say if these can be called "experiences," i.e., recognizing "what it is like" to have pain. However, after birth, stimuli from the external world act as catalysts for certain desires in the newborn, such as desires for heat, milk, sleep, or silence. Little by little, conditions arise that clash with these desires, causing suffering in the newborn. Some causes for this sufferance are the absence of the mother's warmth, or her voice, which are usually one of the main desires of babies.

We can say that pain arises in utero toward the middle of pregnancy (Derbyshire and Bockmann 2020; Smith et al. 2000) and increases in sensitivity as the pregnancy progresses and the fetus grows and matures; put this way, pain-related suffering has a primitive dawn before birth, but fully develops in the months and years after birth. Nonetheless, the fetus has an important brain nucleus dedicated to the experience of fear and anxiety, the amygdala, and for this reason, we cannot exclude in a minimal way that the fetus feels pain-related fearfulness or anxiety (Lautarescu et al. 2020). The meanings of fetal pain then encompasses two levels.

The first is the meaning for other people, namely, the advantages to knowing that another human being is in pain. Observing a fetus with pain could mean danger, and paying attention to it could provide important information concerning the source of pain, its meaning (e.g., a source of threat), possible consequences, and how to intervene in its defense. Above, we reviewed fetal reactions to noxious stimuli, which are part of the spontaneous natural reactions that human beings display when hurt. Pain is thought to be a private experience, but the fetus who spontaneously cries when emerging from the vaginal canal at birth is the picture of a human being whose psychological life is transparent to us. This kind of transparency suggests that, in the fetus or neonate, there is no private mental domain at all: it is still in the state where



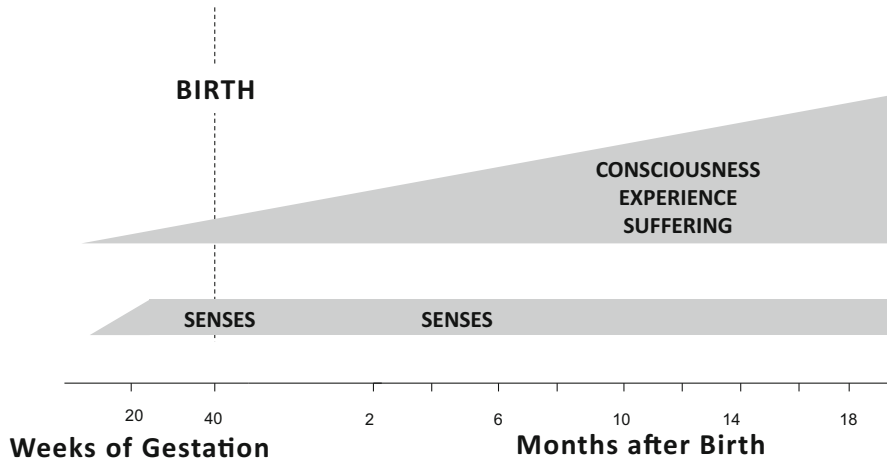
the ego, and the distinction of the ego from the environment, has not yet appeared (Freud 1920). That transparency, however, is occluded with learning the concept of pain. As Wittgenstein writes: “The child that is learning to speak learns the use of the words “having pain,” and also learns that one can simulate pain. This belongs to the language game that it learns. Or again: It does not just learn the use of “He has pain” but also that of “I believe that he has pain” (Wittgenstein 1988).

The fact that the fetus is unlikely to recognize its suffering—i.e., to integrate pain with the perceived impossibility of fulfilling certain desires or hopes—does not mean that its capacity to feel immediate pain can be ignored. Fetal pain is unpleasant though hard to describe, as in all subjects who have only rudimentary consciousness who nonetheless can experience sensations, such as people in a coma or with severe brain damage (Lukaszewicz and Perez 2016, Golkowski et al. 2021).

The second plane of fetal pain meaning is more nuanced, because it is about the sense that pain can have for the fetus itself: pain facilitates a “flight or fight” reaction. Unfortunately, the fetus cannot escape from the noxious stimulus, but it can respond with changes in its hemodynamics, blood pressure, and hormonal production, which can shield it against noxious events. For this reason, although to a limited extent, fetal pain means “self-defense,” but minimally, compared to the mature adult. Let us remember that we are considering a human being who lives in a unique and protected environment, which seemingly leaves little room to noxious stimuli, other than those that physiologically derive from the mother. During pregnancy, however, for reasons of human intervention or for fetal or maternal pathologies, noxious stimuli can impact on the fetus, thus intruding on its insulated world. Entering this world is like exploring the vast seabed: immense meadows and caves and invisible life forms are discovered outside; pain breaks this spell. Metaphorically, fetal pain when a silent morning is broken by an intrusive and alien presence. The same can be said for pain of preterm babies.

## 8 Fetal “Experience” of Pain

The experience of pain can be devastating for a fetus, even if its level of consciousness is relatively low. We have seen that it is not completely correct to apply “experience” to the fetus, because it implies the ability to self-ascribe the word “pain” and the presence of a sophisticated level of consciousness. Consciousness implies two preconditions: sentience and a brain cortex to support this sentience. In the case of the fetus, this is still ongoing, in progress. As Padilla and Lagercrantz (2020) puts it, “The human emergence of consciousness depends on the activation of the cortex by thalamocortical connections around 24 weeks after conception. Then, the human fetus can be rudimentarily conscious, as it is aware of its body and reacts to touch, smell and sound and shows social expressions in response to external stimuli” (Padilla and Lagercrantz 2020). Thus, “fetal pain” is an experience, but like an obscure scenario where we perceive a phenomenon, which we cannot fully describe (Fig. 2.1).



**Fig. 2.1** The possibility of feeling pain and of having sensations appear at about 20 weeks of gestation, and remain almost stable in the following months. Suffering, experience, and sophisticated consciousness appear later. The development of the cortex (at 22–24 weeks of gestation) initiates the development of a rudimentary consciousness, and its consequences: experience and suffering. Consciousness and suffering expand at birth following the sudden arrival of external stimuli throughout development

To talk about fetal pain, we must use metaphorical or evocative language. Consider that the fetus can remember sensations perceived before birth, and that it can experience anxiety (Lagercrantz 2014); however, the mixture of pain, anxiety, and memory becomes aversive and at the same time difficult for us to understand. But certainly it is present: we cannot describe it in words; we should rather use metaphors or the expressions through which we try to express our nightmares, but it is present. And it is so damaging that it can affect brain development and even its DNA. We cannot say that the fetus feels pain as an existential threat to its “self”, because that would seemingly require a high-level of self-consciousness. But we certainly cannot say that pain is just a mere change of physiological state because fetal natural reactions indicate that it is unpleasant. One thing remains clear: when we want to express what pain is, even adults have difficulty expressing it. If we do not try to express it in words, we are sure we know what it is, but if we try, we cannot express it. The official definitions of scientific societies are perhaps unhelpful in this case, because they presuppose innate concepts, such as “unpleasant” or “experience” (Raja et al. 2020). With the fetus, this difficulty becomes greater. We can only imagine something disruptive but indefinite, a paradox, like saying “a deadly dream,” which remains a real dream, but at the same time is really deadly. Clearly, the fetus cannot apply the word “pain” to an experience in the first-person way, as for normal adults. Yet, as the International Association for the Study of Pain (IASP) makes clear, verbal description is only one of several behaviors to express pain. The inability to communicate in language does not preclude the possibility that a human (or a nonhuman animal) experiences pain.

We commonly use words tailored to the adult, but not applicable to the human life still at its dawn. The dawn has characteristics that are not found during the day: the shadows of the evening or the heat of the sheer sun, the frenetic activity of the afternoon, or the rest of the night have nothing to do with that reddish warmth of quiet and sunshine that you see at dawn. It is another world. So it is, for fetal life, compared to the day of adult life. Can we express the inexpressible? No, but we can go by exclusion and say what it is not: it is neither “calm” nor “anxiousness” as we understand these terms; it is not “pain” or “sleep” as we understand these. It is a related, but different, concept. And when something disturbs or damages the fetus, its reaction is called pain, but we can also call it “nightmare”.

## **9 What Is the Meaning of Fetal-Neonatal Pain for the Subject and Their Caregivers?**

From all we have just explained, it is difficult to say what is the meaning of pain for a prelinguistic subject like the fetus, who cannot recognize or know its experiences. Nonetheless, it cannot be ignored. It cannot be the subject of a deep analysis, because we know the stimuli that arrive to the fetus, how he or she can spontaneously elaborate them, but we have only clues of what fetal psychological elaborations are.

On the contrary, for those who care for the fetus, fetal pain has an important meaning. It paradigmatically shows how a developing human being has human characteristics, even when it is not yet visible or yet able to express them. It is a paradigm, because the pain of the fetus teaches us to respect every expression of human life, even when it does not have the characteristics of perfection or fashion that make people acceptable in our consumer society. It is the case for people with severe or extreme disabilities or people in a coma, the elderly with dementia, or prisoners: in all, we can recognize those expressions of human dignity that make the individual respectable regardless of his or her condition. On the opposite side, we see the myth of the “Prometheic Envy” described by Gunther Anders: people of the twentieth century wishing to become copies of machines, to lose their distinctive human features, all in a bureaucratic, stereotyped society (Anders 1956). Western society has built a myth of a human being that is valid only for what he or she produces, or for the fear he or she inspires in others; this has resulted in a dehumanization of the person, which has made those who do not have the gift of self-determination or autonomy, “inhuman” or “non-persons”; having autonomy is too often and improperly the feature used to define the human beings (Blanchette 2020). Recognizing human traits in the human fetus, starting from pain, makes us more human, because it reminds us to view everyone with respect, even for non-autonomous human individuals. This encourages inclusion and acceptance, to recognize our common humanity, and also to appreciate those who are weaker (Bellieni 2015). Learning to treat a fetus that has emerged early from the womb and needs intensive respiratory care, weighs a few hectograms, and is as long as the

palm of a hand teaches carers to be patient, to be sensitive, to look, and to observe why there are no questions to ask someone who cannot answer: you have to look better, look more.

## 10 Conclusion

This chapter has posed an important problem: the meaning of pain in those who are unable to reason, to have a full consciousness, or to express themselves intelligibly. This problem is a significant challenge, because normally we consider the desires and thoughts only of those who are like us: autonomous people who can assert their perceptions, desires, or expectations. In the case of the fetus and the newborn, this does not clearly apply, because they are special people. We have explained in these pages that the fetus can feel pain as well as the preterm newborn, but the frontier between the two is not clear. We cannot express in words, what is shown and lived in an uncommon type of experience. For this reason, we invite you to understand well that although the fetus is not a miniature adult, it is like us; you just need to take the difficult step of learning to read its answers and know its physiology. The conclusions of this chapter are that fetal language and its meanings have not yet been fully explored: there are only descriptions of fetal reactions, attempts to measure fetal pain, and some more in-depth ones to measure pain in the newborn. But their language has not yet been accurately deciphered. The challenge for the future is exactly this: to use technological means to understand this currently obscure language: to give a voice to these small beings who do not have gotten their voice yet.

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# Chapter 3

## Developmental Influences on the Meanings of Pain in Children



Joshua W. Pate

**Abstract** What does pain mean to a child? As a child develops, so does their meaning of pain. In this chapter, developmental influences on a child's meaning of pain are explored. It is argued that a child learns the meaning of pain when they can understand the word "pain," or its equivalent in another language, and if a child is a sufficiently fluent participant in the practice of using "pain." Cognitive, affective, social, and experiential factors influence a child's personal meaning of pain in unique ways. Pain science education, where learning is focused on the "what," "why," and "how" of pain, is considered foundational to education about pain treatment strategies. A child's meaning of pain is theoretically impacted upon by pain science education, an approach based on conceptual change theory. Individual conceptual changes over time are a key consideration. Next, the meaning of pain in disadvantaged or vulnerable children is discussed. More research is needed, particularly in terms of clinical assessments. Then, the effects of linguistic competence on the assessment of pain in children are evaluated. Here, vocabulary development, novel assessment approaches, and specific assessment tools are explored. Finally, emerging research gaps are considered, and clinical implications are offered in light of the identified developmental influences. Terminology, age appropriateness, and targeted pain science education are unpacked in this section. Complex concepts develop in children as they develop, and so pediatric pain science education should gradually increase in complexity, building on a child's previous conceptual developments.

**Keywords** Children · Concept of pain · Pain science education · Pediatric pain · Conceptual change

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## 1 Meanings Change Over Time

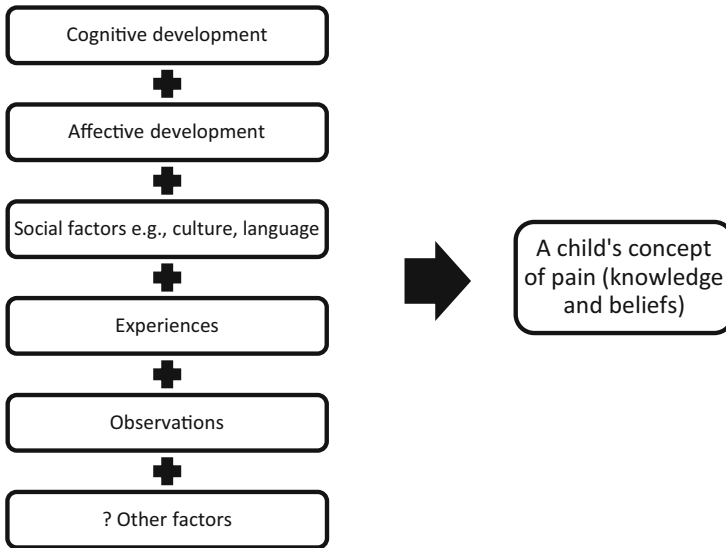
Children rely on competent and sensitive adults to assess and re-assess their painful experiences. Thus, children are a vulnerable or special patient group requiring focused adult attention. Socially, children express pain in their behavior and facial gestures, both of which can be observed, interpreted, and acted on by parents and/or health professionals. Poor assessment and misinterpretation of pain expressions in children may lead to misdiagnosis, under-medication, over-medication, or inappropriate treatment. For example, a recent paper using hospital data highlighted a high frequency of undertreated pain in children (Birmie et al. 2014). Due to the influences of cognitive and affective development and family dynamics throughout childhood, the experiences of pain in children can be considered unique compared to adult pain (Steinberg 2005). What meaning children ascribe to their experiences of pain, and the influence of personal meanings on their pain experiences during development, is therefore also developmentally unique.

Following Piaget's model, as children aged 8–12 years move through the cognitive developmental levels of “concrete operations” and “beginning formal operations” (Fischer and Silvern 1985), their beliefs and knowledge about personal experiences, including pain, are developing. How this happens exactly is a matter of controversy. Piaget's theory proposes that a child's cognitive development is formed by actively engaging with the world. This is in contrast to maturational theories, such as proposed by Chomsky, which view cognitive development as passively emerging from the activation of prewired, genetically controlled brain modules (Inhelder 1978).

On the view adopted in this chapter, the concept of pain is a complex sum of both knowledge and beliefs regarding what pain is, why pain exists, and how pain is experienced. Thus, a child's concept of pain comprises its knowledge and beliefs of the “what, why, and how of pain” (Pate et al. 2019). The unknown composition of its influencing factors is depicted in Fig. 3.1.

Learning the concept of pain throughout childhood depends on a range of complex interacting factors. Figure 3.1 shows potential factor interactions, synthesized using the results of qualitative interviews (Pate et al. 2019), and hypotheses based on broader developmental literature. The relative size of each influence in Fig. 3.1 is not yet known, and the “? Other factors” box suggests that the composition of an individual's concept of pain may involve other influencing factors well beyond knowledge, beliefs, experiences, and perceptions. For example, affective development may contribute to learning the concept of pain. Affective development is similar to cognitive development in that it is multifactorial and individual throughout childhood (Steinberg 2005). Given the emotional nature of the pain experience, affect is also likely an important factor in a child learning the concept of pain.

Early adolescence is a time when young people develop a sense of self. Adolescents develop their abilities to make hypotheses, consider multiple perspectives in decision-making, engage in meta-cognition, and evaluate their social or cultural values (Collins and Steinberg 2007). Adolescents with persistent pain may have



**Fig. 3.1** Factors possibly influencing a child’s concept of pain

existential worries, such as hopelessness, which could influence the meaning of pain for them (Maciver et al. 2010). This higher-level cognitive feature is likely not evident in the relatively less cognitively sophisticated younger child, although further research is needed to make a clear determination.

Family dynamics, as part of the background context for concept acquisition, are an important consideration, because influences from parents and siblings change throughout childhood. Parents can influence self-reports of children (Verstraete et al. 2006). Specific to pediatric pain, it is known that parents’ cognitions and behaviors regarding their child’s pain, such as catastrophizing and reinforcement, influence their child’s symptoms and cognitions postoperatively (Noel et al. 2015; Palermo and Chambers 2005). It may be, as parents respond to the utterances and pain behaviors of young children and teach by example how to react appropriately in different “pain situations” (Morris et al. 2007), children begin to learn the meaning of pain. When the meaning of pain is mastered by a child, it could be said that it has acquired the concept of pain. A child is a master of the meaning of pain when it can understand the word “pain,” or its equivalent in another language, and if it is a sufficiently fluent participant in the practice of using “pain.” This claim is elaborated on in Sect. 2.

I could not identify any published research of parents specifically neglecting their responses to a young child’s utterances and pain behaviors, but a testable hypothesis would be that failing to respond to a young child’s pain behaviors will directly affect a child’s concept of pain and ability to participate in the practice of using “pain” (Fig. 3.1). For example, a recent review emphasized the effects on accessing health care: “...People without expressive skills, particularly those in vulnerable

populations, are less successful in attracting care than people who acquire a full complement of verbal and nonverbal skills” (Craig 2020).

## 2 A Child’s Experience Affects Their Concept of Pain

One key influence on a child’s concept of pain is personal experience with pain or injury-related pain. The impact of persistent pain is highly individualized and relates deeply to past experiences (von Baeyer et al. 2004). Therefore, the resultant meaning of pain will also differ between individuals. In the qualitative study referred to above (Pate et al. 2019), we found that children with persistent pain appeared to have a broad understanding of the meaning of pain, spanning a range of personal experiences, such as the impact of surgery, effects of feelings, the idea of healing, and the diverse influences of health professionals: topics which were not explored by children without persistent pain.

A further outstanding theme from these interviews (Pate et al. 2019) was the personal nature of a child’s concept of pain. All children interviewed clearly articulated stories of physical aspects of pain and injury to explain their concept of pain. In contrast, emotional aspects of pain were relatively unexpressed without verbal probing and drawing tasks, and these aspects were only present in children with experience of persistent pain. For example, when undertaking a drawing task, participants with persistent pain tended to draw emotional elements to describe pain, whereas participants who were pain free did not. Further to this, treatment strategies such as distraction via listening to music were only mentioned by children with persistent pain. Perceptions of previous experience appear to play a pivotal role in future experiences of pain (von Baeyer et al. 2004).

Participants reported they learnt about the science of pain from family members, particularly parents, as well as at school and via media on television and the Internet. This process of learning, termed “pain science education,” has been increasingly implemented in clinical and research settings (Harrison et al. 2019; Moseley and Butler 2015) since 1998, when educating patients about pain was first considered a treatment in itself with Louis Gifford’s teaching tool (the “mature organism model”) (Gifford 1998). How caregiving adults respond to a child in pain, such as catastrophizing and solicitousness, influences both the child’s immediate perception of pain and how they learn to verbally and nonverbally express pain with others (Riddell and Craig 2018). A child may learn the concept of pain through direct experience, conditioning, associative learning, and observation (Riddell and Craig 2018). For example, imagine a 2-year-old boy is injured by falling onto his knee. He may cry. The boy is tended by an adult, who may teach him exclamations, and later, sentences, to communicate about pain. In this fictional scenario, the child learns when it is appropriate to talk of himself as being in pain, and this experience teaches him what “pain” means. The child learns the meaning of “pain” by learning that the occasions on which he shows certain reactions fall under the concept “pain” and make it appropriate to talk about being in pain. Learning this new and symbolic

mode of telling “what is going on” develops later into understanding sentences about “pain.” Initially, the child’s pain-related behavior consisted of crying. But, in learning “pain,” he learns a verbal component, and this becomes the basis of more sophisticated language uses. Once pain has a verbal expression, new options open up to a child, and new types of pain-related behavior become possible. For example, learning the science of pain via pain science education could potentially modify these conceptions and behaviors. The mechanism why this type of learning could modify pain-related behavior is currently unknown. Given that pain science education improves coping (Watson et al. 2019), and that two Pain Self-Efficacy Questionnaire (PSEQ) items (Nicholas 2007) assess perceived coping ability, it is logically possible that conceptual change may cause improvements in pain self-efficacy, and in turn change behavior and reduce disability (Lee et al. 2015). Alternatively, pain science education may increase a person’s pain vocabulary, which could increase their confidence and sense of agency regarding the biological underpinnings of their experience, which could reduce fear avoidance and reduce disability (Asmundson et al. 2012; Simons and Kaczynski 2012). Research using longitudinal mediation analyses is required to test potential causal mechanisms between conceptual change and behavior change.

An interesting fundamental question is: could a child learn the concept of pain without having had a pain experience? Consider a child with congenital nociceptor deficiency. Here, the child does not display the expected emotional responses associated with tissue damage (Weisman et al. 2019). But, if this child is able to use the word “pain” correctly, in reference to self or others, or is able to discriminate pain from negative emotional experiences that are not pain, then it could be argued that, despite having congenital nociceptor deficiency, the child has a concept of pain. For example, when 8–12-year-old children were interviewed about their concept of pain in the aforementioned qualitative study (Pate et al. 2019), children *with and without persistent pain* used examples of observing others with pain to communicate their concept of pain:

*My mum ... she has ... and my teacher ... they might have to get knee replacements. My teacher had one. And my mum has to get one. And my neighbour got one. (Girl, 9, persistent pain)*

*I guess some people who play like full contact sports, they would be more tough because they are used to the punching and everything. (Girl, 10, pain free)*

Here, for one child with persistent pain, the treatment for all types of pain was argued to be a knee replacement, due to observations of the experiences of three influential people in this child’s life. The second quote illustrates how a child without persistent pain similarly provided examples of observing others with pain to communicate their concept of pain.

### **3 What Do We Know About the Meaning of Pain in Disadvantaged and Vulnerable Children?**

Minimal published research has investigated the meaning of pain in disadvantaged or vulnerable children. We know that spinal pain is more common among children in more disadvantaged families (Joergensen et al. 2019). Significantly more research is needed to investigate the effects of socioeconomic disadvantage on the meaning of pain. Logical links can be hypothesized about the effects of being disadvantaged on cognitive development via mechanisms such as malnutrition (e.g. Johnston et al. 1987), but limited data is available to evaluate these potential links with the meaning of pain in these children. The lack of research data in these pediatric populations may in part be due to findings demonstrating that, in children with non-communicating intellectual disability or severe cognitive disability, even assessing one dimension of pain, such as intensity, is challenging (Casella et al. 2019). Future research is essential to unravel the meaning of pain in disadvantaged and vulnerable children; one starting point may be to implement standardized assessment tools that have been developed for children who cannot self-report pain intensity (Voepel-Lewis and Von Baeyer 2019).

### **4 What Do We Know About the Assessment of Pain in Children, Given Their Linguistic Competence?**

Assessing pain in children is potentially more challenging than in adults, and one contributor is linguistic competence. Children rapidly develop an extensive vocabulary to describe pain between 12 and 30 months of age, beginning with words related to injury such as “ow,” “ouch,” and “boo” (Franck et al. 2010). Because pain science education to date has commonly used complex neuroanatomical terminology (Harrison et al. 2019; Moseley and Butler 2015), it is important to consider the terminology that children use when communicating about pain. In the aforementioned qualitative interview study, children typically conceptualized the nervous system without the spinal cord (Pate et al. 2019). These 8–12-year-old children considered the human nervous system to have two parts: the brain and a peripheral component. Uncertainty was expressed regarding how these two components are connected. Phrases such as “spinal cord,” “nerves,” and “real” are potentially prone to being misinterpreted by children. This aligns with other research, which has found that children potentially make a distinction between the origins and sensory aspects of pain based on their pain-related experiences (Franck et al. 2010). Participants in the aforementioned qualitative study appeared to understand the concept of the brain receiving warning messages (interpreting the education provided which used the phrase “danger signals” in their own words) and, based on these messages and many other factors, in producing (“making”) pain to keep the body safe.

Other assessment approaches may complement verbal assessments of pain in children. For example, drawings can provide more data and/or more accurate data when compared with narrative methods of data collection, and drawing activities can increase comfort, facilitate memory retrieval, and assist children in organizing their verbal reports (Liamputtong and Fernandes 2015; Gross and Hayne 1998). In the qualitative interviews previously mentioned (Pate et al. 2019), multiple approaches were implemented including open-ended drawing tasks, diagram-labeling tasks, vignettes, animations, and text. The helpfulness of using a variety of approaches in this study appeared to relate more to a child's comfort with the medium or their level of engagement, as opposed to their age which may have been expected.

Specific assessment tools have been developed for children, such as the Faces Pain Scale-Revised (FPS-R) (0–10) to assess pain intensity (Tomlinson et al. 2010), the FLACC scale to assess pain behaviors in 2–7 year old children (Willis et al. 2003), and pain diaries to assess pain duration (Palermo et al. 2004). However, tools are not available for all pediatric age groups, nor for other pain-related variables, such as localization, pain quality, impact, context, or meaning. In addition, inconsistencies in interpreting scales may confound the results of self-report questionnaires. When interviewed about the meaning of the points 0–10 on a pain scale, adults commonly redefine labels on rating scales (Williams et al. 2000). Williams et al. (2000) concluded: “The action of arriving at a rating is better conceptualized as an attempt to construct meaning, influenced by and with reference to a range of internal and external factors and private meanings, rather than as a task of matching a distance or number to a discrete internal stimulus.” For example, one was a common redefinition of the minimum endpoint (labeled “no pain”) to indicate “normal pain” for that patient, pain that was “manageable,” or “a warning to slow down or suffer the consequences.” Given that parents influence the self-reports of children (Verstraete et al. 2006), it is possible that parents of children with pain are influencing children's self-reports in this manner of redefining labels. Taking these findings together, it is important to carefully consider word meaning when discussing pain with children (Johnson et al. 2016).

Examining child–parent interactions during painful events can provide further background information for the assessment of pain in children. One qualitative study found that the majority of verbal interactions between toddlers and their parents addressed current pain as it occurred, and that parents can learn about how their children express and cope with pain to provide instruction while participating in role-playing imagined scenarios (Craig et al. 2006). The authors then highlighted the complex and dynamic nature of the development of pain-related linguistic competence and thereby emphasized the critical role of caregivers. Research encourages the education of young children to develop a vocabulary for expressing both pain sensations and emotional responses, to potentially improve both the assessment and treatment of young children's pain (Franck et al. 2010).

Opportunities also exist to target assessments and treatments via an improved understanding of the linguistic competence of caregivers. One study found that parents have well-developed individualized approaches to recognize and respond to their children's communication of pain, despite some uncertainty reported when

children are unable to describe internal symptoms to their parent (Lioffi et al. 2012). To cater for variations in the linguistic competence of caregivers, evidence-based leaflets have been developed to clearly guide parents in helping their children during acute procedural pain and pain related to minor injuries and illnesses (Power et al. 2007), as well as chronic pain (Great Ormond Street Hospital for Children NHS Foundation Trust 2014). These leaflets use non-technical language and clearly define important and relevant terminology. With recent advances in targeted pain science education (Pate et al. 2020), similar resources are needed for parents to reconceptualize pain.

Does parental uncertainty in pain judgements mean that the concept of pain needs to be reformed to make pain judgments certain? In principle, this reform might mitigate or eliminate parent uncertainty or disagreement in judging pain in children. The concept of pain, perhaps like many psychological concepts, *is* uncertain in some applications, but this is not necessarily a shortcoming. This is because much human behavior, and our response to it, is diverse and unpredictable. Help-giving has costs, even to one's own child, so it is conditional on the genuineness of the claim for help, and human beings are alert to possible "cheating," exaggeration, suppression, or malingering. Consequently, our concept of pain allows uncertainty in pain judgments as an essential feature.

## 5 Clinical and Research Implications

Better understanding the meanings of pain in children leads to several implications for clinical practice and research. For clinicians, clarity around the terminology used for conceptual change learning is essential in pediatric clinical practice. To distinguish education about pain science, such as "pain represents a need to protect the person" (Moseley 2002, 2003) from education about treatment strategies (often called "psychoeducation"), many different terms have been proposed. Two of the more prominent terms are "explaining pain" (Moseley and Butler 2015) and "pain neuroscience education" (Louw et al. 2014). As of the end of 2019, an expert consensus pediatric review highlighted "pain science education" (Harrison et al. 2019), to emphasize that the education has a broader scope than just biology or neuroscience. This clarity enables better access to appropriate educational resources and helps a clinician to strategically time different educational components within a treatment program. For example, pain programs commonly begin with pain science education to create a foundation for education about pain treatment, even in online environments (The Hospital for Sick Children (SickKids) 2020). Further research into the specific components of educational curricula regarding the science of pain is important (Leake et al. 2019). Such research could be based on expert consensus regarding a child's concept of pain (Pate et al. 2018), and more broadly account for "extended social ecological contexts of pain and care provision" (Craig 2020).

Further to this, age-appropriate language in conversations by health professionals may facilitate the therapeutic alliance in clinical settings. For example, if a child uses

a particular word or phrase to describe their concept of pain, a patient-centered empathetic communication strategy (Linton et al. 2017) would be to incorporate that child's language in the discussion, rather than using technical terms used by adults. In addition, children's apparent lack of awareness regarding how sensory input and distraction can influence pain provides some support for educating children at an age-appropriate level about biological mechanisms underpinning pain.

For researchers, further investigations into the efficacy of pain science education, and the mechanisms underpinning the effects of such education, are important. Many questions remain unanswered at present:

- Are children amenable to discussions about pain science and the meaning of pain? Or, does the influence of parents override this potential?
- Does a child's experience have more of an impact on their concept of pain than the impact of their knowledge or emotions?
- How much do each of the influences on a child's concept of pain differ from one child to another? Do they differ in children below the age of 8 years, adolescents, adults, or non-English speaking populations?
- How much do these influences change over time?

And, what are all of these influences? For example, intellectual and emotional intelligence, their general attitude, fears, social circumstances, and perspectives on "toughness" have all been suggested as possible influences (Pate et al. 2019).

The recently developed Concept of Pain Inventory (COPI) (Pate et al. 2020) can aid in individualizing pain science education by identifying "gaps" and misconceptions. Further to this tool, the helpfulness of using a variety of media (e.g., drawings, videos, and text) appears to relate more to a child's level of comfort with the medium or level of engagement, rather than their age (Pate et al. 2019). Some children may not require any formal pain science education, but rather benefit most from reassurance from a trusted adult with influence such as a parent, teacher, or health professional. Because a child's concept of pain is not usually overtly communicated by the child, particularly undisclosed or difficult to express emotional components which affect communication (Hadjistavropoulos et al. 2011), vignettes and drawings in pain science education or assessments may benefit some children with pain.

## 6 Conclusion

The uniqueness of pain in childhood contributes to the uniqueness of the meanings of pain in children. The analysis in this chapter may benefit readers interested in pediatric conceptual change education by better understanding how children conceptualize pain. An important limitation to note is the need for significantly more research in this relatively "young" field before strong recommendations can be made. Future "meaning-based" research on children at different stages of cognitive development is an essential next step in guiding pain science education. Complex concepts are developing throughout childhood, and so pain science education for



children should also incorporate educational approaches where concepts are taught with gradually increasing complexity built on previous conceptual development.

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## Chapter 4

# “Ooh, You Got to Holler Sometime:” Pain Meaning and Experiences of Black Older Adults



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*I have pain in my leg. I put it to be arthritis. It hurt, but I try to work it over, and I take aspirins. Then [I] have a lot of cramps and it is so painful. Ooh, you got to holler sometime. It takes awhile to go away, and when it grabs you, it holds you. All you can do is just walk and scream before it go away. It goes away, but then that is painful. ~Jane [All participant names have been changed to protect anonymity (Robinson-Lane 2015)]*

**Abstract** Throughout the history of the USA, the Black pain experience has been widely ignored and diminished, by media, medicine, and science. Convergent evidence demonstrates that Black adults shoulder a disproportionate burden of chronic pain and related disability. A structural racism lens shows how conditions such as residential segregation, economic deprivation, experiences of discrimination, and inferior access to high-quality medical care contribute to persistent pain in Black adults, worsen its impact, and impede its effective management. In addition to the negative physical consequences of daily pain, the emotional, social, and spiritual distress caused by unmet pain needs can significantly diminish the quality of life. These factors collectively contribute to complex pain meanings that center around dependence and defeat and are countered through social engagement, spiritual coping, and meaningful activity. Consequently, despite reporting moderate to severe daily pain and an increased frequency of catastrophizing—that is, negative emotional responses to pain and perceived exaggeration—Black older adults often report high levels of adaptive coping as evidenced by continued engagement in activities.

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The following chapter examines the meaning of pain for Black older adults both within and outside of the medical establishment and in the context of implicit racial bias. The authors examine challenges of effective assessment and treatment, and identify strategies Black older adults engage in to effectively cope with pain and prevent what many fear—becoming dependent on others. Finally, we highlight the need for culturally responsive pain management interventions to effectively address the complex meanings ascribed to pain by Black older adults, including the need for accessible care that is developed in close collaboration with community members to build on existing strengths and resources. **Clinical Implications:** Culturally responsive care is critical for optimal pain management. This self-reflective practice recognizes the role of bias in care delivery and urges clinicians to empower diverse patients to acknowledge important values, beliefs, and practices related to pain management, and integrate them as appropriate into their treatment plans.

**Keywords** Racism · Adaptation · Psychological · Catastrophization · African Americans · Aged · Pain management · Chronic pain · Religion and psychology

## 1 Pain and the Black Older Adult

Living with persistent daily pain is the norm for approximately 2.6 million Black older adults in the USA (Molton and Terril 2014; Dahlhamer et al. 2018). As a multidimensional stressor, pain can affect every facet of a person's life from their ability to earn an income, socialize with others as they would like, or even to manage basic care for themselves. For many, managing chronic pain also means managing depression, anxiety, social isolation, grief, and long-term disability (Evans et al. 2019; Fine 2011). This constant physical and psychological distress can be spiritually demoralizing and lead to suffering, or a state of altered perception characterized predominately by a sense of defeat and lack of purpose (del Giglio 2020). However, despite being particularly at risk for despair and poor quality of life as a result of persistent pain, Black older adults are resilient. Many remain actively engaged within their communities in a variety of ways, including maintaining volunteer roles and caregiving responsibilities (Robinson-Lane 2020). As one research participant living with chronic headaches and arthritic joint pain noted, "Like my grandmother said, 'You ain't old until you're cold.' You keep on living, to the best of your ability" (Robinson-Lane 2015). However, living as a Black older adult in the US to the best of one's ability is perhaps easier said than done.

Black or African American persons represent 13.4% of the US population and 11% of adults aged 65 and older (US Census Bureau 2020). Predominantly the descendants of enslaved persons with ancestral roots in Africa, Black adults have a shared history of forced acculturation and racial oppression that distinguishes this group from other cultural groups and influences their behavior, values, lifestyles, and creative expressions (Palmer 2006). Prior to the US Civil War, medical experimentation (sans anesthesia) on enslaved persons was the norm. In part, this treatment was related to false beliefs about Black persons having thicker skin and decreased pain

perception. John Brown, an abolitionist (formerly known as Fed) who escaped slavery to England, recounted being experimented upon by famed physician Thomas Hamilton:

. . . [Hamilton] set to work to ascertain how deep my black skin went. This he did by applying blisters to my hands, legs and feet, which bear the scars to this day. He continued until he drew up the dark skin from between the upper and the under one. He used to blister me at intervals of about 2 weeks. He also tried other experiments upon me, which I cannot dwell upon. Altogether, and from first to last, I was in his hands, under treatment, for about 9 months, at the end of which period I had become so weak, that I as no longer able to work in the fields.<sup>1</sup>

In the book *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (Washington 2006), neurosurgeon Harry Bailey notes during a 1960s medical school talk, “[It was] cheaper to use N\_\_ than cats because they were everywhere and cheap experimental animals.” This de-personification of Black individuals was a primary justification for slavery and arguably has been maintained through today, particularly within pain management practice, where false beliefs about biological differences between races persist and Black adults continue to receive inequitable pain treatment, often having to treat and or advocate for themselves in order to achieve any measurable relief (Booker et al. 2019; Mack et al. 2018; Robinson-Lane and Vallerand 2018; Hoffman et al. 2016; Meghani et al. 2012; Washington 2006).

Through 1968, Jim Crow laws legalized racial segregation and prevented equitable access to healthcare services based on skin color. Hence, all Black adults over the age of 65 who were born and raised in the USA have lived through a period of lawful racial discrimination in health care. Though no longer legal, the effects of structural racism in the healthcare system have persisted, and many older Black adults have accumulated a lifetime of experiences with discriminatory and often inferior care, including for pain treatment, as noted above. Yet the pernicious effects of structural racism also affect the experience and meaning of pain itself, as described in the next section.

## 2 Structural Racism as a Context to Black Pain Experiences

Structural racism, also called systemic racism, is a systemic and institutional problem that reinforces policies and practices that perpetuate racial inequity. It encompasses a number of dimensions including, a dominant racial hierarchy, comprehensive White racial framing, and individual and collective discrimination (Feagin and Bennefield 2014). In the USA, structural racism has yielded laws, policies, and practices, both historical and present-day, which disadvantage and marginalize Black Americans. Manifestations of structural racism include, but are

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<sup>1</sup>Brown (1855, pp. 47–48).

not limited to residential segregation, economic and educational deprivation, toxic physical environments, and sustained psychosocial stress stemming from all of the above, as well as experiences of individual-level discrimination (Bailey et al. 2017). Unsurprisingly, when evaluated through systematic review, racism has been found to be persistently associated with negative health outcomes, such as depression, anxiety, post-traumatic stress disorder (PTSD) and poor overall health (Paradies et al. 2015). Compounding the health effects of the systemic racism that Black Americans confront in everyday life is the persistence of deep-rooted racism in medical care and public health institutions (Feagin and Bennefield 2014).

Feagin and Bennefield argue that most health and medical institutions retain a “White frame,” and they cite evidence of ongoing differential treatment and implicit bias, or attitudes and behaviors based on stereotypes or beliefs a person has that they are not consciously aware of. Preferential healthcare access, delivery, diagnoses, and treatment for White adults has been maintained at varying degrees and has contributed to large disparities in health outcomes between Black and White older adults. As a result, Black adults have suffered from disproportionate levels of disease and death. For instance, the average life expectancy for Black adults in the USA is the lowest of every race and ethnic group—71 years for males. This is 13 years younger than the average life expectancy of Latina women and 5 years younger than White men (Arias and Xu 2020).

For Black older adults, pain is also an expectation that comes with aging. As Naomi, a former nail salon owner with diabetic neuropathy, degenerative disc disease, and arthritis noted, “Everything that is wrong with you generates pain” (Robinson-Lane 2015). As much as 80% of the physical pain experienced by older adults is attributed to chronic diseases, such as chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF), cancer, osteoarthritis, rheumatoid arthritis, and peripheral neuropathies (Horgas et al. 2021; Walke et al. 2006; Davis and Srivastava 2003). Among older Black adults, experiences with racial discrimination are also positively associated with bodily pain (Burgess et al. 2009), and this relationship remains after statistically controlling for socioeconomic and health status. Differential healthcare treatment has resulted in mistrust of medical providers by Black adults.

### 3 Medical Mistrust

The historical racist perception, poor treatment, and overall mismanagement of chronic pain among Black older adults have led to high levels of provider mistrust, reliance on home remedies, use of over-the-counter medications, and spiritual coping for pain management (Robinson-Lane 2020; Booker et al. 2019; Robinson-Lane and Vallerand 2018). In discussing why she did not necessarily trust everything

prescribed by the doctor, and particularly pain medications, Monica,<sup>2</sup> a survivor of a pedestrian motor vehicle accident, noted:

*If [the doctor] had results, then they lose money, because they won't be making no money if they heal-- if everybody feel good, they wouldn't have no reason to go back to the doctor. So I think the doctor just pacifies you with their medicines. And they do all right, but there's nothing really working for the important part. ~ Monica*

Monica believed that older adults in particular were over-medicated by physicians and that the medications mostly served to pacify symptoms rather than cure disease or address the root causes of health concerns. Many of the Black older adults that were interviewed in a qualitative study examining pain management experiences (Robinson-Lane 2015), believed that doctors were most interested in making money or experimenting on patients. As Zora, another participant noted, “...These doctors use people. ‘cause these old people in they 70s, 80s, and 90s and stuff like that. And I feel sorry for them ‘cause they use them just to make money off ‘em” (Robinson-Lane 2015).

Mistrust of medical providers began long before the often-discussed US government sponsored Tuskegee Study, which took place from 1932 to 1972 (Gray 2003). Here, Black research participants who had community-acquired syphilis were prevented from receiving penicillin, an effective syphilis treatment, and instead allowed to experience significant disease-related complications, including death, so researchers could study the long-term effects of untreated syphilis. One of the “benefits” of study participation, as promoted by the researchers, was free healthcare. This study began only 69 years following the Emancipation Proclamation that freed enslaved people in 1863.

The long history of mistreatment based on skin color that Black Americans have experienced has perhaps led to vastly different conceptualizations of what it means to experience pain and who one may trust for relief. The continued inferior treatment of Black patients by medical providers is amply documented in the literature, as recently comprehensively reviewed by Morales and Yong (2021). Relative to non-Hispanic White persons, across clinical settings, and amongst both cancer and non-cancer pain, Black pain is treated less aggressively. Morales and Yong’s review also cites evidence that Black patients are more closely scrutinized for opioid medication misuse. This finding is echoed in qualitative work in which Black pain patients report experiences in which they had to contend with racialized stereotypes about opioid addiction (Kempner 2017). Racism has undoubtedly shaped the chronic pain experience for Black adults.

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<sup>2</sup>Robinson-Lane (2015). All participant names have been changed to protect anonymity. The participants have given their consent to the publication of their stories.



## 4 Chronic Pain Dimensions and Linkages to Structural Racism

Racism is regarded as a fundamental cause of adverse physical and mental health outcomes and health inequities (Williams et al. 2019). Correspondingly, racism should be considered a fundamental cause of chronic pain for Black older adults. In contrast to acute pain, chronic pain is a health condition in its own right, with biological, psychological, and social dimensions (Gatchel et al. 2007). These dimensions are each affected by structural racism.

For example, the biological aspects of pain are influenced by Black adults' disproportionate risk of injury, chronic illness and multimorbidity, which are all associated with the presence of persistent pain and pain severity. In writing about ecosocial racism, Krieger (2012) notes that people literally embody stress exposures arising from their societal and ecological context. Psychological factors that generate or exacerbate pain include sustained stress and socially inflicted trauma, such as the experience of racism. Both untreated and undertreated pain exacerbate psychological distress, namely, symptoms of depression and anxiety (Gatchel et al. 2007). Further, and perhaps unsurprisingly, pain catastrophizing, or experiencing heightened feelings of helplessness, repetitive negative thoughts, and a magnification of pain threat value, is prevalent amongst Black adults with chronic pain (Fabian et al. 2011). Social risk factors for pain include disproportionate bereavement (Umberson 2017), mass incarceration (Brinkley-Rubinstein and Cloud 2020), and the public health crisis of police violence towards Black Americans (Fleming et al. 2021). All of these factors converge and exacerbate one another, resulting in a strikingly disproportionate burden of severe and disabling pain (Morales and Yong 2021).

Further, in considering the overall effects of chronic pain and various "isms" on Black older adults, the concepts of intersectionality and double jeopardy—that is, the consequences of holding simultaneous marginalized identities, such as being Black and older (Bierman and Lee 2018; Carreon and Noymer 2011; Crenshaw 1989)—should be considered and may partially explain pain-related disparities that disadvantage older Black adults. Racism, ageism, and sexism experienced by Black older adults are compounding stressors that affect psychological outcomes such as depression (Lyons et al. 2018; Burgess et al. 2009; Thomas et al. 2008), likely contribute to overall psychological distress, and may exacerbate pain.

## 5 Spiritual Coping as a Culturally Mediated Pain Resource

One way of adapting to the reality of an unreliable and biased medical care system is to turn to culturally mediated resources and self-care practices for pain management. Culture, or learned patterns of behavior, beliefs, and values, are what allow individuals to cope with the problems that arise, particularly health-related problems, over the life course (Robinson-Lane and Booker 2017). For Black older adults, these

culturally mediated resources and self-care practices include frequent use of complementary and alternative therapies for pain management and engagement of religious coping strategies, such as prayer and meditation. James, a cancer survivor living with severe chronic pain and related disability following a worksite injury, had a daily meditative practice and spoke about his faith as follows:

*My faith played an important part—in the healing I believe. Not that I believe; I know my faith carried me through. Because I had resigned myself ... Okay here it is. I'm going out this way. I probably would be dead. So I know that there is strength in faith.*—James.<sup>3</sup>

For many generations, religion has played a central role in Black American culture and communities by facilitating important social connections amongst members and providing meaning and purpose to lives that are often in distress. Within the Christian faith in particular, pain is viewed as an opportunity to draw closer to God and receive eternal salvation. The New International Bible translation notes:

*But as for me, afflicted and in pain—may your salvation, God, protect me. I will praise God's name in song and glorify him with thanksgiving. (Psalm 69: 29–30)*

*For it is commendable if someone bears up under the pain of unjust suffering because they are conscious of God. (1 Peter 2:19)*

*For I consider that the sufferings of this present time are not worth comparing with the glory that is to be revealed to us. (Romans 8:18)*

*If we endure, we will also reign with him. (2 Timothy 2:12)*

In his book, *Man's Search for Meaning*, (2006) Viktor Frankl, a Holocaust survivor, notes that suffering and stress are inevitable parts of the human experience. Frankl argues that the goal is not necessarily to try to have a life that is free from suffering, but rather to have a freely chosen and worthwhile goal to pursue through the trials that life brings. Although the practice of ancestral religions was forbidden amongst Black enslaved persons in the US and Christianity was an expected part of acculturation, for many Black Americans, religion afforded hope. Religion, and particularly Christianity, offered the opportunity to dedicate one's life to God and good works in this life in exchange for paradise in the next. Unfortunately, these dreams of lands of milk and honey<sup>4</sup> often become disrupted with despair for persons dealing with intractable pain.

## 6 Chronic Pain and Depression

Chronic depression is a common chronic pain comorbidity. The relationship between pain and depression is well documented both in community-dwelling older adults (Baker et al. 2008; Magni et al. 1990; Williamson and Schulz 1992),

<sup>3</sup>Robinson-Lane (2015). All participant names have been changed to protect anonymity. The participants have given their consent to the publication of their stories.

<sup>4</sup>Numbers 14:8.

and those in institutional facilities (Cohen-Mansfield and Marx 1993; Parmelee et al. 1991). Depression symptoms can affect the perception of pain, amplify its intensity, and affect the willingness to engage in adaptive pain management practices (Woo 2010; Baker et al. 2008). A pain-depression loop is then created that exacerbates symptoms of both conditions as one becomes more deeply entrenched in the cycle. In a study by Bierman and Lee, the pain-depression association was noted as being stronger for Black older adults relative to White adults. Further, Black older adults with severe chronic pain experienced significantly higher levels of depressive symptoms than those without pain (Bierman and Lee 2018). Particularly among older Black women, depressive symptoms have been positively associated with pain intensity (Baker et al. 2008). Current work has demonstrated that despite generally higher levels of reported disability, Black older adults, and particularly women, have lower than expected incidence of depression, anxiety, and other measures of poor mental health (Daly et al. 2021; Robinson-Lane 2020; Wyman et al. 2015). Interestingly, Black women are more likely to be religious as compared to White adults (Mohamed et al. 2021), and therefore are more likely to engage in spiritual coping, which may improve their mental health. A recent study by Dunn and Robinson-Lane (2020) found three themes reported amongst older adults who engaged in spiritual coping practices: (1) enhanced physical, psychological, and social well-being; (2) increased resilience; and (3) self-transcendence, or the highest state of growth and development in later life, where individuals develop the capacity to know who they are, find greater meaning in life, and achieve new dimensions of connectedness with others.

Religiosity is generally a prerequisite for spiritual coping. Spiritual coping is the engagement of spiritual rituals or practices based on a person's relationship with God, Transcendent, and/ or others, in order to control and overcome stressful situations, suffering, or illness (Cabaco et al. 2018). Such coping is an important part of the Black religious experience, and can be categorized as either adaptive (positive) or maladaptive (negative). When adaptive spiritual coping is taking place, the individual is able to effectively manage illness-related stress as evidenced by feelings of connectivity to God/ Transcendent, and/or others, and has a positive world view. Maladaptive spiritual coping, on the other hand, is evident by spiritual struggle (Gall and Guirguis-Younger 2013). In an older adult sample of mostly Black adults (74%), maladaptive, or negative religious coping was found to be predictive of anxiety, worry, and depression (O'Brien et al. 2018). While pain was not measured in that particular sample, a Swedish chronic pain study found that pain interference predicted the use of spiritual coping strategies such as prayer, and that prayer was predictive of depression (Andesson 2008).

## 7 Pain Catastrophizing, Mood, and Coping

It might be surmised then, that when pain is severe enough to significantly impede physical functioning, social engagement, sleep, life enjoyment and other commonly measured areas of pain interference, that adaptive spiritual coping may become more challenging, and that pain catastrophizing is more likely. In general, pain catastrophizing is strongly associated with both pain intensity and pain interference in older adults (Racine et al. 2016; Ruscheweyh et al. 2011). It also contributes to poor pain adjustment (Sullivan et al. 2001). Black adults with severe chronic pain are also more likely to catastrophize than other racial and ethnic groups (Fabian et al. 2011). However, while the concept of “catastrophizing” implies an unwarranted focus and unnecessarily pessimistic view of pain, given the anticipated disability trajectory of Black older adults with chronic pain, perhaps the pain-related fear and threat value inherent in catastrophizing are not unrealistic.

The complex interplay between mood and pain warrants further investigation in Black older adults, given the dearth of the empirical literature. In non-Black samples, psychological indicators of distress, such as anxiety and depression, mediate the effect of pain intensity on pain catastrophizing (Dong et al. 2020). Interestingly, Black adults are more likely to respond to pain with depression than anxiety, a finding interpreted as a consequence of the draining, or physically and emotionally exhausting, component of pain (Bierman and Lee 2018). Indeed, depression may play a more important role in pain intensity (Baker et al. 2008), and the experience of pain for older Black adults than once believed. However, cultural variances in the expression of depressive symptoms may lead to under-diagnosis.

In a recent study by Robinson-Lane (2020) aimed at understanding the coping strategies used by Black older adults to manage persistent pain, the ability to maintain a positive mindset was noted as a prominent recurrent theme amongst participants. Esther,<sup>5</sup> a research participant and artist with an unspecified chronic health condition that has caused muscle spasms and debilitating pain throughout her life since she was a child, who was also currently managing arthritis and severe carpal tunnel syndrome, spoke frankly about being depressed as a result of pain. When asked about the ways in which pain affected her, she noted:

*Depression ... I'm just depressed that I can't do the things like I used to do; just get up and go, and come back home and do whatever I've got to do. Now, if I'm having trouble with my joints or whatever, I can't get up and run and do what I have to do and come back.*

Interestingly, Esther had no medical diagnosis of depression and had previously spoken rather nonchalantly about making adaptations in her artwork to accommodate her increasingly disabled hands. She had moved from working with typical clay to a homemade paper clay that was easier to manipulate. She most often made jewelry that she frequently wore as conversation starters and gave as gifts to new

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<sup>5</sup>Robinson-Lane (2015). All participant names have been changed to protect anonymity. The participants have given their consent to the publication of their stories.

friends. As she considered whether or not pain had deeply affected her as an artist, she noted:

*I don't worry about it anymore. At first, it was depressing. Now I find, "I'm 74 years. I've accomplished quite a bit...I've been having pain over three quarters of my life. I don't think there's too much they can do...I've learned to live with it.*

Similarly, Abraham,<sup>6</sup> another research participant and former carpenter, who was managing persistent back pain and chronic arthritis in both knees, made the revelation that he believed his history of chronic headaches resolved when he stopped worrying all the time. He noted:

*I can't remember when I had the last headache. I don't know, I just don't recall having one for so many years, it's unbelievable. I think that's because I just quit worrying about anything, I just say the hell with all of it.*

When asked if there was a particular incident that occurred or how he arrived at this worry-free approach to life, he responded:

*No, I just decided, whatever it is, it isn't worth it. If I can take care of it I will. If I can't I won't. But I'm not going to worry about it . . . Nothing monumental occurred. It's just that I woke up one morning and I decided I'm not worrying about anything more, or I'm not going to let anything worry me . . . I haven't since then.*

Unsurprisingly, both of these participants identified with religious denominations associated with Christian faith. This worry-free approach to life is supported by Christian belief and scripture:

*Do not be anxious about anything, but in every situation, by prayer and petition, with thanksgiving, present your requests to God. And the peace of God, which transcends all understanding, will guard your hearts and your minds in Christ Jesus. (Philippians 4:6–7)*

## 8 Living with Pain

As one may begin to see, the relationships between pain, disability, and spirituality, are heavily intertwined for many Black older adults. There is a growing body of literature on the experience of chronic pain among Black Americans, including how it is perceived and managed. Booker et al. (2019) conducted in-depth interviews with Black adults over age 50 to better understand their experience living with osteoarthritis, and discovered an overarching theme of “bearing the pain.” Bearing the pain comprised three primary actions: adjusting to pain (including accepting osteoarthritis and “not claiming” it; with the latter being a protective mechanism with a spiritual meaning, rather than denial), sharing pain with others (including careful decision about when and with whom to share), and trusting God as a healer. These themes were echoed in qualitative work by Robinson-Lane (2020).

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<sup>6</sup>Robinson-Lane (2015). All participant names have been changed to protect anonymity. The participants have given their consent to the publication of their stories.

Having persistent pain often means not being able to work and perhaps becoming dependent upon others. Experiencing increasing pain intensity and interference, despite religiosity, may also lead to spiritual suffering. The meaning ascribed to the pain experienced by Black older adults along with their interpretation of that experience may affect psychological and mood outcomes. Factors likely to influence the personal meaning assigned to pain include: (1) the cognitive appraisal of pain; that is, whether the experience of pain is perceived and interpreted as threatening (e.g., see Lazarus & Folkman’s model of stress and coping, Lazarus and Folkman 1984); and (2) interpretation of the source and controllability of pain.

In addition, health-related locus of control, which reflects an individual’s orientation towards whether their health is a by-product of their actions versus circumstances out of their control, represents one avenue of investigating the meaning of pain and its relationship to psychological outcome. The Health Locus of Control scale (Fletcher and Scaffa 2018; Levenson 1974; Wallston and Wallston 1982) is an instrument that measures this construct by assessing three independent dimensions of controllability over health: *Internal* (one’s behavior directly influences health), *External-powerful* (the actions of others, such as physicians and healthcare providers influence health), and *External-chance* (fate or luck influences health).

Theoretically, one may anticipate that individuals with chronic pain who maintain an internal locus of control would be less emotionally distressed than those who believe they have no personal control over their pain (Seville and Robinson 2000). However, among older Black women, higher internal health-related locus of control is associated with greater pain intensity, a factor the authors hypothesize may be related to self-blame for the inability to manage the pain condition (Baker et al. 2008). Additionally, when considering Black older adults, who are more likely to engage in faith-based and religious practices involving a relationship with an external higher being (Chatters et al. 2009), the link between religiosity, locus of control, and emotional/health outcomes becomes complex. The literature remains quite mixed, possibly due to the fact that a combination of both internal and external loci are needed in a flexible manner to manage pain and emotional distress, and this may especially be the case for Black older adults who engage in spiritual coping (Clark et al. 2017). Exploration of cognitive appraisal and locus of control represents an important next step in unpacking how the meaning attributed to pain relates to psychological outcomes in older Black adults.

## 9 Improving Pain Management in Black Older Adults

Black adults have been persistently underrepresented in pain research (Booker et al. 2019), a fact that has constrained knowledge of optimal ways to alleviate pain in this population. For example, there have been few attempts to test models of culturally relevant pain care for Black adults, although in recent years, this literature has been growing (e.g., Allen et al. 2019). When considering the clinical treatment of pain, a strict biomedical approach fails to account for the complex, multidimensional

experience that is pain, thereby reducing pain to pathological changes resulting from an underlying medical etiology, discoverable by the clinician. Conversely, a biopsychosocial approach, which considers the relationship between biology, psychological processes, and social-environmental factors, is more appropriate for conceptualizing and managing pain for older Black Americans, as this accounts for the stressors unique to being a Black older adult, among other contextualizing factors such as socioeconomic status, and neighborhood/lived environment (Burgess et al. 2009). Further, as noted by the previous discussion, religiosity, and other measures of spiritual coping should be incorporated into pain assessment strategies. In addition, culturally responsive pain management approaches should be engaged to prioritize the integration of self-management strategies preferred by the community.

A key component of culturally responsive care is provider self-assessment of bias, in which providers are encouraged to think deeply about their own values and beliefs and consider how these perspectives may influence care decisions. At the organizational level, equity assessments may be conducted to evaluate curricula, policies, procedures, and organizational outcomes for the presence of disparities and bias. Standardized treatment protocols and consideration of how social determinants of health, such as income, education, and residence, may affect treatment access and related decisions, can improve equitable pain care across populations. Finally, institutions should consider how diverse perspectives are integrated throughout the organization and amplified—particularly the voices of the most marginalized. With these key principles in mind, and provided the feedback from Black older adults with persistent pain, the authors recommend the development of culturally responsive pain management programs, especially programs that promote pain self-management practice.

## 10 Future Research and Practice Directions

Data from research by the authors in 2017–2019 reveals preferences and practices for pain self-management in a sample of Black older adults. These data were collected as part of a pilot study of the feasibility of using wearable activity trackers to promote physical activity for chronic pain self-management among Black older adults in Detroit, Michigan (Janevic et al. 2020). As part of a baseline survey ( $n = 51$ ), we assessed participants' use of non-pharmacological methods for managing their chronic pain. These items included a broad array of self-management techniques, including religious and spiritual practices, given their importance as noted above. We also conducted a series of focus groups with a total of 41 participants. Participants were age 60 and over with chronic musculoskeletal pain. The sample was almost exclusively Black, predominantly female, and approximately 9 out of 10 had arthritis. The mean pain level upon study enrollment was close to 6/10 (on a 0 to 10 scale, where 0 = no pain at all, and 10 = worst imaginable pain).

**Table 4.1** Common self-management techniques (survey data) with illustrative quotes (focus group data)

Technique	Using now (%)	Quote
Praying or reading the Bible	77	“Because, that’s my friend, is prayer. And I can always go to Him day, the night, morning, any time. So, I throw everything in the universe, and it’ll be handled.”
Exercise or physical activity	77	“I might do maybe two or three hustle dances. But I try to always keep myself moving, you know I just don’t sit. Even though I have problems and limitations I know that if you just don’t do anything it’s not going to get better, it’s going to get worse.”
Herbal remedies/supplements	53	“Every morning, I get me a tablespoon full of apple cider vinegar and a glass of water, and I drink that. And that usually helps. If it don’t, I just deal with it.”
Imagery, relaxation, meditation	40	“Meditation, you have to work with yourself mentally. And I learned how to some times just relax. It was a meditation of the mind, breathing, remind you breath, just relax. And mentally talk to yourself and encourage yourself cause you don’t want to be in pain.”

Table 4.1 shows the four most common self-management techniques endorsed in the survey for current use: praying/Bible reading, engaging in physical activity, herbal remedies or supplements, and using relaxation techniques. Other techniques currently being used by fewer than 10% of the sample included: support groups (8%), acupressure (4%), magnets or copper bracelets (2%), marijuana (2%),<sup>7</sup> and biofeedback (0%). Other self-care treatments mentioned in focus groups included rubbing alcohol, heating pad, water flushes, and yoga.

While these data are from a small sample, findings are congruent with much of the above discussion regarding how Black older adults live with, and manage, longstanding pain. This includes a significant practice of spiritual coping, as well as maintaining a positive mindset and active life. One notable theme that emerged from the focus groups was reluctance on the part of respondents to take opioid pain medications. Sometimes this is related to implied dissatisfaction with encounters with the medical care system:

*And this lady told me you’re going to feel like a champ now. However, I don’t like to take medications. I’m afraid of getting stuck on it.*

*The V.A. hospital, they want you to start with physical therapy and everything else before they shoot you with pain pills and stuff. When you go to your primary doctor on the outside, first thing he wants is just give me a pain pill.*

More often, however, the hesitancy was related to a preference for being self-reliant and believing that self-care was both safer and more effective:

*I become immune to pain medicines real fast, so it didn’t stop the pain so I stopped taking the pills, and so I found heat and exercising.*

<sup>7</sup>Marijuana use is legal in the state where the study took place.



*I don't want no pain meds because the pain pills, you lose so much quality of life living like that. Your mind doesn't work, it takes away a whole lot of things with you.*

These findings have been used to support the development of a non-pharmacologically centered pain intervention led by community health workers.

## **10.1 Community Health Worker-Led Pain Interventions**

Self-management strategies that improve mood and have positive downstream effects on pain in older White adults, such as physical exercise, mindfulness, and music therapy, have been less studied as interventions for Black older adults (Reid et al. 2008), and warrant greater attention. In an attempt to test a new model of culturally responsive pain self-management support, Janevic, Robinson-Lane, and colleagues are developing community health worker-led interventions for Black older adults living with chronic pain.

Community health workers (CHWs) are an untapped part of the pain care workforce. CHWs are not licensed professionals, but rather are lay “natural helpers” with formal training for specific health care-related tasks, including supporting health behavior change, addressing social determinants of health (SDOH), and providing linkages to formal health care services when needed (Perry et al. 2014). CHWs have an advantage over other providers when it comes to teaching pain coping skills in that they typically share a community identity with the clients they serve (Rosenthal et al. 2010). Therefore, beliefs about pain and pain management are culturally congruent, yielding a high level of credibility and mutual trust. In other words, CHWs provide a comfortable, safe environment to discuss factors affecting pain management, and can deliver culturally-appropriate, patient-centered pain self-management support.

Janevic, Robinson-Lane and colleagues have tested two CHW-led interventions to support pain care among African American older adults in community-based settings: STEPS 2 (Seniors using Technology to Engage in Pain Self-Management), in which CHWs teach cognitive-behavioral pain self-management skills to older adults with the support of mobile health tools (Janevic et al. 2021a), and Positive STEPS (Janevic et al. 2021b), in which cognitive-behavioral skills are supplemented with positive affect-inducing activities (consistent with cultural preferences for leveraging a positive mindset to deal with pain; Robinson-Lane 2020). In both STEPS 2 and Positive STEPS, participants are introduced to specific pain management skills via expert-delivered videos on a user-friendly website. Then, CHWs engage with participants over a series of 7 weekly, structured phone calls, helping them apply these skills to everyday life, set behavioral goals, and address any obstacles to pain management, connecting participants to external resources when needed to address obstacles to pain management; e.g., finding accessible places to exercise, getting help with caregiving, or dealing with health insurance issues.

Findings from both the STEPS 2 and Positive STEPS pilots indicate that the interventions were successful at reducing pain interference over a 2-month period,

and participants reported reduced pain and improved functioning. In both studies, participants were very responsive to the CHWs, and found them to be motivating, encouraging, understanding, and relatable. Many participants felt that it was precisely this support that allowed them to get better control of their pain and to improve their day-to-day functioning and quality of life. Future scaled programs should continue to engage CHWs as self-management resource liaisons within community-based pain management programs. Another promising pain management treatment strategy for Black older adults is Cognitive-Behavioral Therapy.

## ***10.2 Cognitive-Behavioral Therapy***

Cognitive-Behavioral Therapy (CBT) is a recommended non-pharmacological treatment approach to managing depression and stress-related contributors to pain (Keefe et al. 2013). Unfortunately, the accessibility of CBT and other psychologically oriented interventions for Black older adults experiencing comorbid depression and pain is lacking (Ehde et al. 2014). There are few trained providers that work in communities with large Black populations and even fewer culturally tailored CBT programs that embed the language, values, traditions, and practices, of the community served. Further, and perhaps most importantly, there is general under recognition of depression in Black older adults, and the failure of clinical providers to subsequently initiate treatment. The diagnostic accuracy of mental health conditions in Black adults is poor, and Black older adults with depression are less likely to receive the correct diagnosis (Gallo et al. 1998). While the literature on depression prevalence initially suggested lower rates of depression in Black older adults, more recent evidence actually indicates higher or equivalent incidence and prevalence rates relative to White adults (Pickett et al. 2013; Harralson 2002).

Symptom presentation may differ across race, and it takes a culturally attuned provider to assess how pain and depression manifest in Black older adults, and to offer appropriate diagnoses and culturally congruent treatment. Black older adults are more likely to be diagnosed with psychosis or a related disorder (e.g., schizophrenia) as opposed to an affective or mood disorder such as Major Depressive Disorder (Ahmed and Kramer 2006; Baker 1995; Coleman and Baker 1994). In addition to lacking cultural awareness, poor psychometric properties of assessment instruments and culturally biased diagnostic tools likely contribute to the under recognition of mood and pain disorders in older Black adults. The underlying assumption that self-report instruments or semi-structured instruments measure the same constructs, especially when a majority of instruments were developed and validated in White samples, is faulty and may further contribute to observed disparities (de Williams et al. 2000).

Lastly, just as with pain treatment, mood disorders are less likely to be adequately treated among Black adults. Black adults are less likely to receive depression treatment within 6 months of diagnosis (Gallo et al. 2005). In general, Black Americans receive care in mental health settings at about half of the rate of White

adults (Lasser et al. 2002), and have inadequate access to depression treatment in spite of more recent contacts within the healthcare system (Alegría et al. 2008).

Persistent pain is a multidimensional experience of which physical discomfort is only one component. As a stressor, pain can easily consume a person as it interferes with their ability to optimally function both physically and socially. The resulting suffering can diminish hope and cause doubts to one's faith or sense of connectivity and purposefulness. For the Black older adult, living with chronic pain is an inevitable part of aging that may also result in depression. Current pain management approaches typically rely on analgesic medication management alone, and do not address other important dimensions of the pain experience. Further, many of the important pain treatment traditions and approaches that have been bringing comfort to generations, such as movement, rest, prayer, and heat are not actively incorporated into pain management plans, and thereby do not acknowledge their current cultural value regardless of current perceived clinical benefits.

Sustainable and culturally informed pain management practice is person and community centered. An ideal pain management practice is able to effectively provide wholistic care—that is, care for the whole person and supporting their pain management goals. In recognizing that provider mistrust continues to be a concern, and the need for maintenance independence is high, clinicians can facilitate trusting relationships and restore power imbalances by offering balanced information and accessible choices about pain management options. Clinicians can also follow-up to determine treatment effectiveness. Excellent pain management has not been the norm for the average Black older adult. It is our hope that culturally responsive wholistic pain care, care that recognizes and supports the unique contributions individual bring to the management of their own physical-psycho-social-spiritual-health, and that is sensitive to the meanings of lived pain experiences, becomes the standard for all persons with pain in the future.

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# Chapter 5

## Exploring the Meaning of Chronic Low Back Pain as a Life of “Living Death” in Rural Nigeria



Chinonso Nwamaka Igwesi-Chidobe

**Abstract Background.** Chronic low back pain (CLBP) experience, personal meanings, expression, and impact are influenced by sociocultural factors. Qualitative evidence indicates that people living with CLBP in rural Nigeria viewed it as a life of “living death”. This book chapter considers in more detail the meaning of a life of “living death” in this vulnerable group. **Methods.** Thirty purposively selected adults were interviewed individually and face-to-face with questions that explored their back pain beliefs and coping strategies. Following data saturation, data were thematically analysed using the framework approach. **Results.** Five themes and thirteen subthemes explained the overall experiences of people living with CLBP in rural Nigeria in a previously published study. These themes and subthemes included:

Themes	Subthemes
“Social construction of back pain as a disease of hard labour and deprivation”	“Back pain associated with the ageing process” “Back pain having a seasonal presentation”
“CLBP impacts on the family and mental health”	“impact on gender roles” “A life of “living death””
“Coping strategies driven by beliefs”	“Showing weakness appears unacceptable” “Drugs are the legitimate form of treatment” “Active life-style modification only a preventive strategy”

(continued)

This book chapter is informed by the author’s PhD thesis (Igwesi-Chidobe CN. Development and preliminary evaluation of a self-management programme for people with non-specific chronic low back pain in rural Nigeria. Dissertation, King’s College London, 2017), and a previously published article in the journal *Disability and Rehabilitation* entitled, “‘A life of living death’: the experiences of people living with chronic low back pain in rural Nigeria” (Igwesi-Chidobe CN, Kitchen S, Sorinola IO, Godfrey EL, 2017;39(8):779–790). The contributions of Dr. Emma Godfrey, Professor Isaac Sorinola, and Professor Sheila Kitchen, co-authors in the journal article, which stimulated interest in this book chapter, are duly acknowledged.

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(continued)

Themes	Subthemes
“The role of spirituality”	“Spiritual causal beliefs for back pain” “Spirit-body dualism” “Pain acceptance and support through spirituality”
“Dissatisfaction with health care”	“Dissatisfaction with conventional health care” “Dissatisfaction with available alternative health care” “Expectations still focused on cure”

Living with CLBP in rural Nigeria meant a life of “living death” expressed as life characterised by unbroken misery and hopelessness using multiple characterisations as detailed in this chapter. Personal meanings of CLBP as a life of “living death” was associated with feelings of hopelessness, severe depression—described using the physical symptom of “tiredness”, and suicidal ideation. **Conclusions.** The meanings CLBP has for people in rural Nigeria influence its impact, coping strategies, and clinical outcomes. This should be a focus of evidence-based interventions.

**Keywords** Chronic low back pain · Experience · Meanings · Pain experience and expression · Living death · Rural dwellers · Nigeria · Africa

## 1 Introduction

### 1.1 Background

A critical review of the literature had revealed that there was no available research describing the lived experiences of people living with chronic low back pain (CLBP) in rural Nigeria, its impact or the biopsychosocial factors associated with CLBP in this context. Rural Nigerian dwellers (about half of the Nigerian population) is a group of interest because they are regarded as a vulnerable population due to their high levels of poverty and illiteracy, combined with limited health facilities/services and social amenities. These factors combined with informal and manually driven work such as subsistence farming, carrying heavy building materials, and home activities such as fetching water, are likely to make the impact of CLBP more devastating in this context. Research in other countries, most of which were high income, had revealed the lived experiences of people with CLBP and the associated factors. However, the importance and impact of these factors were likely to be context specific. Exploratory qualitative studies are the best place to start when little is known about a population or condition (Moore et al. 2015; Craig et al. 2008); and was the approach chosen for this study.

Evidence-based guidelines for the management of CLBP advocate a client-centred approach adopting the biopsychosocial model (Oliveira et al. 2018; Koes et al. 2010; NICE 2009). Patients’ views are central to this model, which acknowledges biomedical, psychological, and social factors in supporting active self-

management of CLBP (Turk and Monarch 2018, MacNeela et al. 2015; Bunzli et al. 2013). For instance, negative beliefs about CLBP have been linked to CLBP disability (Lin et al. 2013). The views of these patients are their opinions about CLBP, which is often reflective of their feelings. These feelings are in turn underpinned by the personal meaning CLBP holds for them; that is the significance, the implication, or what CLBP represents in the lives of people living in rural Nigeria.

There are often wide variations in pain responses and the associations between pain, distress, and disability, which imply that relationships may not be linear or causal but multidimensional and variable (Corbett et al. 2007; Smith and Osborn 2007). Pain experience and expression are influenced by cultural factors, and the way pain is perceived and understood may vary in different cultures due to divergent health beliefs (Ojua et al. 2013; Snelgrove and Lioffi 2013). These pain expressions are “interpretations” or “perceived meanings,” which means the “significance”, the “implication”, or what pain “represents” in the lives of people. The “perceived meanings” of pain in turn influence pain beliefs—pain beliefs that are believed, accepted, considered to be true, or held as an opinion in different populations and contexts. For example, people of African ancestry are said to report higher levels of pain unpleasantness, emotional response to pain and pain behaviour, in response to similar levels of pain intensity than other ethnic groups (Reimann et al. 2012; Peacock and Patel 2008). However, other studies have reported little influence of ethnicity on pain experience, after controlling for pain duration, economic, educational and social factors (Tait and Chibnall 2014; Shavers et al. 2010). Furthermore, the Africans in these studies were African Americans and so may not represent African patients in Africa. The possible influence of acculturation and adjustment, with possible adverse influence on mental health, was not considered in these studies (Organista et al. 2003; Riley III et al. 2002). Moreover, these studies were quantitative cross-sectional surveys, and lacked the in-depth experiential accounts of qualitative investigation.

Pain is a subjective experience and difficult to quantify. Therefore, qualitative research, which enables the exploration of people’s subjective experiences, is essential (Crowe et al. 2010; Osborn and Rodham 2010). Qualitative research can explore the nature of the relationship between painful bodily experiences and self-concept (Snelgrove and Lioffi 2009). Qualitative studies enable the investigation of the meaningfulness of specific experiences—“phenomena”. For instance, phenomenology, a form of qualitative research, focuses on the study of an individual’s lived experiences within the world. Qualitative research is well suited for examining unique events and providing explanatory factors, providing contextual understandings, investigating complex phenomena such as the biopsychosocial paradigm, and giving voice to those whose views are rarely heard (Curry et al. 2009). Qualitative research is the best way to begin to study an area with little previous research as it provides information about contextual factors that might greatly alter the meanings of the findings of exclusively quantitative methods (Guba and Lincoln 1994). Qualitative research provides insights into issues that are highly relevant to a specific

group of people, which has important implications for planning, developing, and evaluating evidence-based interventions (Liddle et al. 2007).

Existing self-management programmes for CLBP had been developed in high-income countries to target the biopsychosocial factors in these contexts (Oliveira et al. 2012). Evidence for these factors and the ensuing interventions were informed by qualitative studies in these countries (MacNeela et al. 2015; Froud et al. 2014; Bunzli et al. 2013; Snelgrove and Lioffi 2013). Prior to this study, no research had examined the lived experience of people living with CLBP in rural Nigeria. Four syntheses of over sixty qualitative studies (MacNeela et al. 2015; Froud et al. 2014; Bunzli et al. 2013; Snelgrove and Lioffi 2013) explored CLBP in predominantly high-income countries, except for three studies conducted in Israel (Borkan et al. 1995), Iran (Tavafian et al. 2008) and South Africa (Wade 2003). The South African study involved only Caucasian adults. Consequently, the first qualitative study on the lived experiences of people with CLBP in rural Nigeria was conducted (Igwesi-Chidobe et al. 2017). This study informed the development of an evidence-informed intervention for people living with CLBP in rural Nigeria (Igwesi-Chidobe et al. 2020) via the exploration of the biopsychosocial factors linked to the perception, experience, and expression of CLBP-related disability. Furthermore, the results from Igwesi-Chidobe et al. (2017) informed this book chapter, which focuses in more depth, on the meaning of one of the subthemes in that study—CLBP as “a life of “living death”” in rural Nigeria.

This book chapter is reported according to the consolidated criteria for reporting qualitative research (COREQ) (Tong et al. 2007).

## ***1.2 Aims of the Study***

To explore in detail the meaning of CLBP as a life of “living death” in rural Nigeria.

## ***1.3 Methodological Considerations***

Section 1.3 is retrieved from the author’s PhD thesis (Igwesi-Chidobe CN. Development and preliminary evaluation of a self-management programme for people with non-specific chronic low back pain in rural Nigeria. Dissertation, King’s College London, 2017).

### **1.3.1 Qualitative Research Foundations**

Qualitative research entails systematically collecting, organising, and interpreting textual material that originated from discourse or observation, for exploring the meanings of social phenomena in the natural context in which they were experienced

by individuals (“lived experience”); sometimes, as these phenomena were being experienced by the persons (Malterud 2001). Qualitative research is a naturalistic paradigm that describes observed and/or described/narrated lived experience. Its characteristics include contextualisation (understanding the context from where data were obtained); understanding (linking individuals’ accounts with theories that account for them); pluralism (limited generalisability, as settings may be unique and researcher’s knowledge may be a constraint on what can be known); and expression (specific methods of communication of findings) (Sutton 1993). As opposed to quantitative research that answers the question of how many, qualitative research answers questions of what, why, and how.

Qualitative research paradigms are the worldview—a framework of methods, beliefs, and values within which the research occurs. They guide the researcher in the choices of qualitative research methods to employ, and the ontological and epistemological assumptions to be taken. An etic paradigm is an “outsider” view of a phenomenon, completely different from that of an emic-“insider” view (Coyle 1998; Guba and Lincoln 1994). Qualitative research takes an emic stance because it is characterised by results that emerge from the participant’s own lived perspective; it is idiographic because knowledge generated from it can only be ascribed to a few people. Quantitative approaches, on the other hand, are etic in nature because findings are determined by the researcher, and nomothetic because they can be generalised to large groups of people (Morrow 2007; Coyle 1998).

Qualitative research is inductive because it starts with research questions rather than hypotheses. Induction is a bottom-up approach to knowledge building because it occurs through world observations that form the foundations for theories and hypotheses. In contrast, deduction entails a top-down approach that starts with hypotheses or a priori theories that are tested against observations in order to confirm or refute them. However, pure induction or deduction may not be possible as qualitative research questions, analyses, and interpretations, may be influenced by known facts or the literature in the researcher’s field. Furthermore, theories or hypotheses that form the starting point of quantitative inquiry may have been generated through induction (Ritchie et al. 2013).

Validity in qualitative research is assured through clinical relevance, triangulation of methods and findings, respondent validation, detailing data collection methods and analysis, reflexivity and attention to negative cases, and transferability within the limits of sampling (Malterud 2001). Offering an insight into the emotional and experiential aspects of an illness, such as the meaning of illness to patients and their families, and the attitude and behaviour of patients, their families and clinicians, which may not be exposed through quantitative research, are ways that qualitative inquiry can provide clinical relevance. Respondent validation occurs when qualitative results are confirmed by the participants from which the qualitative data were obtained. Triangulation entails corroboration of qualitative results from multiple information sources (e.g., observation and interviewing), researchers (e.g., independent members of a research team) and known theories (Giacomini and Cook 2000). Triangulation investigates and maximises the credibility and transferability of qualitative research and depends on the researcher’s ability and efforts. In contrast,

quantitative research depends more on the psychometric soundness (validity, reliability, clinical utility) of outcome measures. This explains why reflexivity involving the exposure of the researcher's presuppositions, experiences, and biases is crucial in qualitative research (Golafshani 2003).

### 1.3.2 Reflexivity and the Role of the Researcher in Qualitative Research

In qualitative research, the researcher's background, experience, and stance are explicit parts of knowledge, rather than being viewed as obstacles as in quantitative research methods (Flick 2018). Reflexivity is central to qualitative research inquiry enabling researchers to expose their presuppositions, choices, experiences, and actions during the research process (Ortlipp 2008). Acknowledging subjectivity in relation to the researcher and the participants assures validity in qualitative research (Coyle 1998). Bias only arises when the effect of the researcher is ignored (Charmaz 2004), as preconceptions are not regarded as bias, unless the researcher fails to mention them (Malterud 2001).

Reflexivity enables the understanding of both the phenomenon being studied and the research process, facilitating the researcher in building a sense of what is happening both in the field and in the researcher's mind (Watt 2007). Identifying the researcher's social positioning in relation to study participants provides the reader with an understanding of the relative power between the investigator and participants, and sheds light on how the researcher views the participants and the phenomenon of interest (Coyle 1998). A researcher's background will affect what they choose to investigate, methods judged most adequate, results considered most appropriate, and conclusions and how they are communicated (Malterud 2001). Reflexivity can also be maintained by looking at the data, or its interpretation, for competing conclusions, while bracketing the researcher's internalised views of reality (Charmaz 2004). Reflexivity was maintained during study design, data collection, data analysis and interpretation, and writing up this study.

### 1.3.3 The Researcher's Orientation

It is believed that in the social world, research results are influenced by the relationship between the researcher and the researched participants. To improve validity, qualitative researchers are nudged towards "empathic neutrality", which encourages the declaration of assumptions, biases, and values, while maintaining neutrality and non-judgmental approach (Ritchie et al. 2013).

The author's backgrounds are physiotherapy and public Health. Clinical training emphasised functional movement and its anatomical, physiological and biochemical explanations. Although, the author had an earlier biomechanical orientation towards CLBP based on initial training, she has currently embraced a "biopsychosocial approach" to managing CLBP informed by clinical experience, postgraduate training and research. As a public health professional, the author's training emphasised

recognising and addressing health inequality. Qualitative research is highlighted as an important pathway for addressing health inequality as it gives voice to vulnerable or special groups of people whose views are rarely heard.

## **2 Methods**

### **2.1 Design**

Qualitative study involving in-depth semi-structured face-to-face individual interviews.

### **2.2 Ethical Considerations**

Ethical clearance was provided by King’s College London (Ref: BDM/12/13-123) and the University of Nigeria Teaching Hospital (Ref: UNTH/CSA/329/Vol.5).

### **2.3 Study Setting**

Interviews took place in participants’ homes. Participants were living in Umuatugboma village in Akegbugwu, in Nkanu West local government area of Enugu State, at the time of data collection. This is a typical rural setting in Nigeria, where subsistence farming is the most common occupation.

### **2.4 Participant Recruitment**

Participants were recruited via a village-wide announcement that provided information regarding the study. Interested adults with CLBP met with the author at an agreed local community centre, where they were screened to determine eligibility and further details regarding the study were provided. Eligible participants then provided informed consent by signing or thumb printing on the consent form after indicating that they understood the study details. Study participants were selected using purposive sampling using socio-demographic characteristics such as gender, age, and occupation to ensure diversity of views.

Inclusion criteria were:

- CLBP of neuromusculoskeletal origin (by ruling out CLBP due to specific pathologies; malignancy, spinal fracture, infection, inflammation, or cauda equina syndrome) (Oliveira et al. 2018).
- Pain that has lasted for more than 12 weeks (Balagué et al. 2012).
- Impaired capacity to give informed consent or participate in the interview.
- Pregnancy.

## **2.5 Procedure**

An interview guide, informed by the Leventhal's self-regulatory model of illness cognitions (Leventhal et al. 1980, 1992) asked questions regarding peoples' experiences and perceptions of living with CLBP in rural Nigeria, the coping strategies they adopted in managing their back pain, and their expectations from current and future treatment. The initial interview guide was written in English, then cross-culturally adapted into the native Igbo language using evidence-based guidelines (Chen and Boore 2010), as detailed in the previously published qualitative study (Igwesi-Chidobe et al. 2017).

Participants' pain location was determined using a body chart, and their current pain intensity was measured using a visual analogue scale (VAS). All interviews were conducted in the native Igbo language, and participants responded in the same language, except for two participants who preferred to respond in English.

Each completed interview was preliminarily analysed to inform a subsequent interview. Interviews lasted for between 40 and 80 min, and were audio-recorded verbatim. Completion of data collection was informed by data saturation. Pictures, field notes, and a reflective diary were used to augment audio data.

## **2.6 The Framework Approach to Qualitative Research**

This section is retrieved from the author's PhD thesis (Igwesi-Chidobe CN. Development and preliminary evaluation of a self-management programme for people with non-specific chronic low back pain in rural Nigeria. Dissertation, King's College London, 2017). The framework approach is a thematic analysis approach originally developed for large scale applied policy research (Ritchie et al. 2013). Its use has now extended into other areas, including health research (Gale et al. 2013). The approach is a data management and analysis approach as it is not aligned with any particular epistemological, philosophical, or theoretical approach (Ritchie et al. 2013). It is not a research paradigm such as grounded theory, phenomenology, or ethnography; rather, it has an eclectic approach that allows it to draw from different approaches such as ethnography, phenomenology, ethnomethodology, symbolic interactionism, grounded theory, constructionism, and critical theory. The ontological assumption of the approach is subtle realism, the belief that

an external reality exists independent of peoples’ perceptions but can only be known through peoples’ perceptions and constructions (Ritchie et al. 2013). Subtle realism appears as a pragmatic compromise between realist and idealist extremes due to its lack of conformity to any specific philosophical position (Seale 1999).

The framework approach sits on an inductive-deductive continuum depending on specific research objectives or questions. For instance, a deductive approach may be used when analysis is based on a pre-existing theory, while an inductive approach allows for unexpected socially sensitive or culturally specific responses that might not have been predicted by the researcher a priori. Interpretation then moves beyond participants’ responses to draw from both the researcher’s interpretations and existing theories, while maintaining reflexivity.

The framework approach was developed to address common criticisms of qualitative data analysis relating to rigour, clarity, and transparency (Ward et al. 2013). Its defining features include the framework matrix, which allows analysis by case and code, enabling a systematic reduction of data; and the provision of clear steps to follow that makes it especially useful for large data sets in multidisciplinary research teams with varying levels of experience. Being amenable to large data sets and novice qualitative researchers are important advantages of this approach. The approach consists of five steps: familiarisation, constructing an initial thematic framework, indexing and sorting, reviewing data extracts in the framework matrices, and abstraction and interpretation (Ritchie et al. 2013). One or more of these stages may be omitted depending on the research question, the depth of analysis required, and the available time and resources.

## 2.7 *Qualitative Data Management and Analysis*

The author (a native Igbo speaker, and bilingual in English and Igbo) transcribed the audio-recorded interviews verbatim in the language in which they were conducted. Igbo transcripts were then translated into English by the author using evidence-based guidelines as previously described (Igwe-Chidobe et al. 2017), and all data were subsequently anonymised. The Framework approach was used to manage the data (transcripts), after which thematic analysis was conducted. Although qualitative data is better analysed in the source language to minimise changes in meaning (Smith et al. 2008), analysis of the translated transcripts enabled the involvement of a multidisciplinary team who were native English speakers. Detailed steps were undertaken to ensure that there was no loss in meaning due to translation, and thematic data analysis methods using the Framework approach were rigorous enough to ensure the trustworthiness of analysis and results. NVivo (version 10, QSR international, Melbourne, Australia) was used to complete the data management and analysis. These have been detailed in the previously published qualitative study (Igwe-Chidobe et al. 2017). The final stage of the data analysis involved the abstraction and interpretation of the final framework matrices with



which the final narrative accounts were produced. The final themes were developed from categories and a bidirectional audit trail was documented.

### 3 Results

#### 3.1 Participants

Participant characteristics are illustrated in Table 5.1, as previously described (Igwesi-Chidobe et al. 2017). Most of the participants found it difficult to comprehend the VAS (adapted Igbo version), possibly due to low literacy levels. Therefore, pain intensity could not be ascertained, suggesting that numeric pain rating scales may be better for studies in this population.

#### 3.2 Analytical Themes

Five themes and thirteen subthemes were generated, as illustrated in Table 5.2, and as previously described in Igwesi-Chidobe et al. (2017).

Detailed explanation of these themes and subthemes are provided in the previous journal publication (Igwesi-Chidobe et al. 2017), which informed this book chapter. This book chapter focuses on, and considers in more detail, the meaning of the subtheme—a life of “living death” in this group of vulnerable adults living with CLBP in rural Nigeria.

##### 3.2.1 The Meanings and Characterisations of CLBP as a Life of “Living Death” in Rural Nigeria

CLBP meant a life of “living death” for people living with CLBP in rural Nigeria, explained as a life defined by unbroken misery and hopelessness. Participants characterised a life of “living death” using the categories depicted in Table 5.3.

**Category 1** Participants felt that having multiple illnesses, persistent pain, multiple pain sites, or not understanding why they are having chronic pain, characterises a life of “living in death”. Some participants believed that these aggravated their CLBP.

*What caused it [CLBP] is farm work and suffering. You are ill, you are rolling on the ground . . . all over your body problems . . . this back pain is worse very recently, but before the last 3 years, it was only hurting slightly . . . (Participant 11)*

*I will accept anything that will make this back pain leave me. Is there anyone that enjoys death? . . . (Participant 5)*

*Because it [CLBP] hurts me. Is there anyone who likes death in his life? (Participant 9)*

**Table 5.1** Socio-demographic characteristics of the participants

	Frequency ( <i>n</i> )	Frequency (%)
Age (years)		
30–39	8	26.7
40–49	11	36.7
50–59	4	13.3
60–69	7	23.3
Sex		
Male	15	50.0
Female	15	50.0
Main occupation		
Manual workers	14	46.7
Non-manual workers	3	10.0
Traders	7	23.3
Civil servants/retired civil servants	6	20
Religion (Christian denomination)		
Protestant Pentecostal	18	60.0
Catholic	8	26.7
Methodist	3	10.0
Anglican	1	3.3
Marital status		
Married	26	86.7
Widowed	3	10.0
Single	1	3.3
Educational level completed		
Primary	11	36.7
Tertiary	7	23.3
Secondary	6	20.0
Literacy (ability to read and write)		
Illiterate (inability to read and write)	13	43.3
English	9	30.0
English and Igbo	8	26.7
Co-morbid conditions		
Hypertension	4	13.3
Diabetes	1	3.3
Knee osteoarthritis	1	3.3

Some other participants believed that the above issues might transcend from being associated with a life of “living death” to being associated with actual death.

*. . . one day the person will get up and you will hear the sound “kpum”, and the person dies, people will say the person is dead due to lack of knowledge of which is which. We are in back pain; we are in chest pain, body pains, rheumatism pains. These are the problems we have today . . . (Participant 4)*

**Table 5.2** Analytical themes. *CLBP* chronic low back pain

Themes	Social construction of back pain as a disease of hard labour and deprivation	CLBP impacts on the family and mental health	Coping strategies were driven by beliefs	The role of spirituality	Dissatisfaction with health care
Subthemes	Back pain is associated with the ageing process	Impact on gender roles	Showing weakness appears unacceptable	Spiritual beliefs represent causal explanations for back pain	Dissatisfaction with conventional health care
	Back pain had a seasonal presentation	A life of “living death”	Drugs are regarded as the legitimate form of treatment	Spirit-body dualism	Dissatisfaction with available alternative health care
			Active life-style modification is seen as only a preventive strategy	Pain acceptance and support through spirituality	Expectations still focused on “cure”

**Table 5.3** Meanings and characterisations of *CLBP* as a life of “living death”. *CLBP* chronic low back pain

Category 1	Category 2	Category 3	Category 4
Having multiple morbidity is “living in death”	Complete functional dependence is a life of “living death”	Hunger results from inability to work and kills or leads to death	Idleness is “waiting for death”
“Living in death” is lack of knowledge combined with having multiple pain sites or multiple morbidity	Complete functional dependence on others means lack of give, and take or reciprocation and is a life of “living death”	Death is inability to look for what to eat	Idleness is “living in death”
	Death wished on them by those being depended on	Death is hunger without hope	Staying or remaining in a place is “waiting for death”
		Death is dying of hunger	Death is idleness

Some participants also felt that having back pain led to pain in other sites, which was understood as the disease spreading throughout their body.

**Category 2** Participants felt that complete functional dependence on others will lead to a one-sided relationship with lack of reciprocation, which might lead to those they were completely depending on wishing them death to reduce their burden. The perception of others (being depended on) wishing them death was understood as a life of “living death”.

*When you are able to get your own, you get and eat, get and give to the person you are living with, you know that the person will be happy, and you will be happy too. Rather than the person cooking and giving you morning, afternoon, and night . . . sometimes you feel very sad . . . the person giving you the food all the time will even prefer that you die. Her children have not seen food to eat, then morning, afternoon, night, she feeds you . . . (groans and sighs) . . . (Participant 11)*

Relatives were sometimes perceived to have abandoned those with CLBP due to this complete dependence.

*. . . I don't know what else to do. Who helps me? [tears in the eyes]. All the people that could help me . . . out, out . . . I can't see any of them . . . (Participant 11)*

A few participants began to wish for actual death.

*. . . (sighs) . . . if someone can decide by herself when it is time for the person to go, I would have said it was time for me to go and see my maker at that time . . . (Participant 1)*

*. . . God don't allow my life to be like that . . . let Him make me strong . . . rather than living a life without rest, let Him [God] take my life (Participant 11)*

**Category 3** Participants had the perception that functional limitation from CLBP results in an inability to work, or look for daily bread, which they associated with having “hunger without hope”. This can lead to a life of “living death”, or actual death from prolonged hunger.

*Whoever doesn't work, hunger will kill that person (Participant 11)*

Inability to hustle for daily bread due to CLBP was perceived as a sign of ill-health and “living death”.

*If it is someone that is healthy, you get up and look for what to eat. Will someone that is unhealthy get up? That is how it affects me the most. It is better that when someone is alive, that the person has good health to enable him to look for what to eat (Participant 5)*

Some participants wished for actual death before the death that could result from hunger.

*Rather than not being able to feed myself. . .let Him [God] take my life (Participant 11)*

Hunger without hope was perceived as a life devoid of aspirations, and a life of living in bondage and death.

*. . . God should have mercy on us and release us from bondage. Anybody that is alive, knows what he has in mind and desire, has hope that good things will come to her. Let God have mercy on us . . . and release us from bondage..and lack of hope (Participant 5)*

*Hunger that has hope does not kill (Participant 6)*

**Category 4** Staying in a place and idleness were perceived by participants as synonymous with death, waiting for, or “living in death”. Mobility, or its lack thereof, was associated with “living in death”.

*The person is unable to get up from bed, cannot get up from sitting to standing, cannot eat when food is placed in the person’s mouth, cannot lift anything up . . . (Participant 1)*

*. . . It is better when someone is alive . . . Someone without good health will only stare at everything. He is unable to do anything . . . (Participant 5)*

Being idle and unable to engage in occupational activities due to pain was seen as a sign that a person is waiting for death. This was also linked to death from severe poverty and hunger resulting from inability to work. Some participants made efforts to resist or fight this life of living death.

*Anyone who is idle is waiting for death. Sit down idly today, sit down idly tomorrow, and the day after. That’s not life . . . (Participant 11)*

*. . . a man must do his best in this world because one will not sit in one place and wait for death. You will be struggling to see if you can defeat the sickness. So I try . . . myself and it are really fighting . . . (Participant 14)*

*. . . I try my best to do some things in spite of the pain. Because a living person cannot be idle. The person will die of hunger. I still do my farm work. Whatever my mates are doing, I try my best. I do farm work . . . but my body will be hurting . . . (Participant 8)*

In conclusion, and as detailed in Igwesi-Chidobe et al. (2017), participants felt incapacitated to address the factors that they associated with this life of “living death”. This understanding led to them having feelings of hopelessness and severe depression, which they described using the Igbo word for “tiredness”, as there was no direct Igbo translation for “depression”. Sometimes, “tiredness” signified that participants were tired of continuing to live in this world. This led to suicidal ideation, and a few participants preferring actual death to a life of “living death”. This was particularly pronounced in CLBP-induced functionally dependent people (Igwesi-Chidobe et al. 2017).

### ***3.3 The Role of the Perception of CLBP as a Life of “Living Death” in the Previously Developed Model of Chronic Low Back Pain in Rural Nigeria***

As detailed in Igwesi-Chidobe et al. (2017), Fig. 5.1 illustrates the theoretical model of CLBP in rural Nigeria. This book chapter focuses on the contribution of the perception of CLBP as a life of “living death” to this CLBP model.

The perception of CLBP as a life of “living death” only had negative contributions to the CLBP model in rural Nigeria. This perception was linked with negative CLBP beliefs with participants believing that multiple pain sites or multiple morbidity meant that the disease was spreading throughout their bodies. For the females,

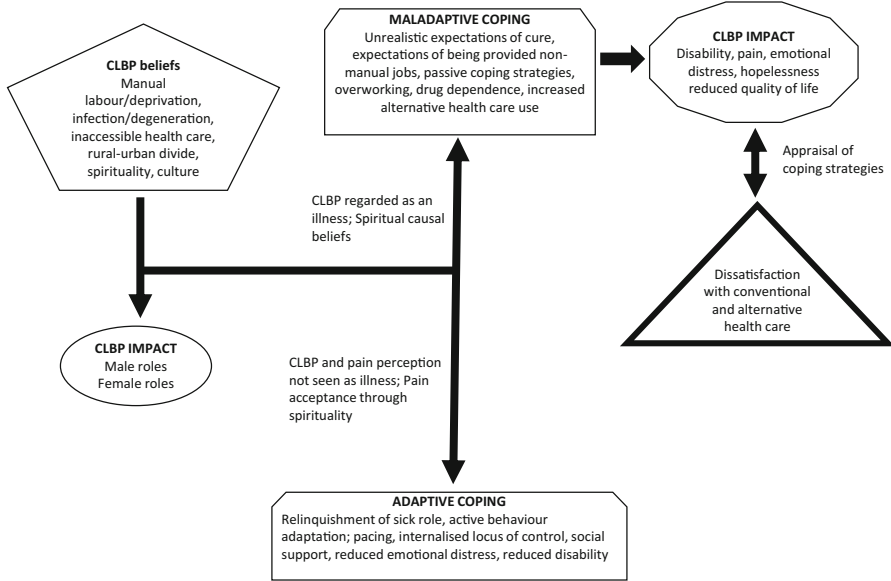


Fig. 5.1 CLBP model in rural Nigeria (Igwezi-Chidobe et al. 2017). CLBP chronic low back pain

this might be associated with the beliefs that CLBP is caused by infection. For the males, inability to work, or idleness due to CLBP, might have led to the expectation of death from hunger.

Perception of CLBP as a life of “living death” led to negative CLBP impacts on male and female gender roles. For instance, participants believing that multiple pain sites or multiple morbidity was from the disease-causing CLBP spreading throughout their bodies. The female participants appeared to believe that CLBP resulted from the spreading of infection and caused infertility. They therefore believed that CLBP prevented them from fulfilling their expected gender role of conception. For the males, the inability to work and the resulting idleness due to CLBP led to feelings of emasculation due to their perceived inability to fulfil the expected gender role of family provision.

Perception of CLBP as a life of “living death” led to the use of maladaptive coping strategies. Women who associated their CLBP with infection spreading throughout their bodies had unrealistic expectations of cure, adopted passive coping strategies, including drug dependence, and attended multiple conventional and alternative health care facilities. For men, the inability to work due to CLBP was linked to unrealistic expectations that the Nigerian government provides them with new non-manual jobs. These men also adopted passive coping strategies, including drug dependence.

When no cure of their CLBP was forthcoming and there was no provision of new jobs that were not manually driven, participants became hopeless, emotionally distressed, reported increased pain intensity and disability, and reduced quality of

life. Subsequently, participants appraised the success of the coping strategies they had adopted, which were associated with their perception of CLBP as a life of “living death”. They were consequently dissatisfied with both conventional and alternative health care, as well as the Nigerian government.

## 4 Discussion

### 4.1 *Summary and Interpretation of Findings*

A complex process is involved in giving meaning to any pain experience. The experiencing person is the subject, and has a bidirectional relationship with pain as the object. That is, pain sensation influences the meaning of pain experience and vice versa. The effects of this relationship on the experiencing person in turn has a bidirectional relationship with personal situation (cognitions, emotions, culture, pain beliefs, life history, and environment) and others’ experiences (notions and experiences of others). That is, the meaning of pain experience is affected by personal situation, as indicated above, and others’ experiences and vice versa (Ojala 2015).

The results of this study suggested that complex biopsychosocial factors influenced CLBP beliefs and the impact of CLBP in this context. As detailed in the previously published journal article (Igwesi-Chidobe et al. 2017), there were disparate unhelpful beliefs about CLBP, wide-ranging impacts, multiple coping strategies, and dissatisfaction with conventional and alternative healthcare. These findings suggest a mixture of biomedical, psychological, sociocultural, and economic factors influencing the experience of CLBP in rural Nigeria. A salient finding was the perception of CLBP as a life of “living death” in rural Nigeria. There is very limited research in this area with which to compare these findings, but similar psychosocial and physical factors were highlighted in a qualitative study conducted in rural Botswana (Hondras et al. 2016). There is very limited research in this area with which to compare these findings, but the psychosocial factors described included beliefs about CLBP being a disease of hard labour and deprivation, similarly reported in rural Botswana (Hondras et al. 2016).

Spirituality was linked to the perception of CLBP as a life of “living death” in rural Nigeria. This was expressed in two ways. Participants were expecting God to deliver them from living in bondage, living in death, living in extreme difficulty, and hopelessness due to CLBP, which might be linked with strong beliefs in the “divine healing” of physical illness. Some other participants preferred God taking their lives rather than continuing to live the difficult and hopeless life associated with CLBP in rural Nigeria. In Africa, the spiritual explanation of illness is common. There is often the attribution of misfortune such as ill-health to “closely related enemies” or “spiritual forces”, a sign of discord between man and God or punishment from God. In South Africa, patients with CLBP were expecting a pain-free after life following expected death (Wade 2003). As suicide is considered sinful, it is unlikely

that the suicidal ideation due to CLBP in this population would lead to actual suicide attempts. Spirituality associated with the perception of CLBP as a life of “living death” was maladaptive. In contrast, spirituality was sometimes associated with pain acceptance, and appeared to be adaptive for CLBP in this population, as shown in the previous publication (Igwe-Chidobe et al. 2017). Acceptance of chronic pain is an adaptive pain coping strategy associated with less pain, disability, depression, and anxiety (McCracken and Eccleston 2003).

The hopelessness and helplessness associated with the perception of CLBP as a life of “living death” led to participants feeling severely depressed, which they expressed using bodily symptoms of “tiredness”. There was therefore an apparent link between a “life of living death” and “tiredness”. When this was combined with the lack of an Igbo word for “depression”, it appeared that the language and culture in this population led to catastrophising and the use of somatisation in the expression of emotions, known to reinforce pain and discomfort (Ma-Kellams 2014).

The perception of CLBP as a life of “living death” was linked to gender roles in this population. The male participants felt emasculated and unable to fulfil their traditional gender role of family provision. Female participants were distressed that CLBP was causing infertility, and making them unable to fulfil their gender role of having children. Having specific gender roles has been linked to stress in people with CLBP (Tavafian et al. 2008). Hence, any compromise in the ability to perform the expected gender roles, particularly for an “invisible illness” such as CLBP, may be viewed negatively by others who might not support the people living with CLBP (MacNeela et al. 2015; Froud et al. 2014; Bunzli et al. 2013; Snelgrove and Liossi 2013). This often results in people living with CLBP having anger and guilt towards others (Vroman et al. 2009). Mutual support between spouses reduces the negative impact of CLBP (Hooper and Ong 2005), although this was not apparent in this vulnerable population.

In a bid to fight against the perception of idleness resulting from CLBP, which could lead to death from hunger, participants often exceeded their capacity as a way of fighting the CLBP. This was shown to be “escaping from the self” in the previous publication (Igwe-Chidobe et al. 2017), and has been illustrated in other studies where patients with CLBP sometimes exceeded their functional capacities in an attempt to fight back against pain (De Souza and Frank 2011). Participants perceived functional dependence on others as a life of “living death”; and this was associated with shame and distress. This might be related to the concept of “escaping from others” reported in the previous publication (Igwe-Chidobe et al. 2017), which might mean that participants are ashamed of their CLBP-related incapacitation when others are present. This has been linked to an “assault on the self” in a different study (Bunzli et al. 2013), described as a traumatising challenge to personal identity (MacNeela et al. 2015). These perceptions might lead to maladaptive coping strategies aimed at minimising exposure to situations that could reveal personal limitations to others. Social isolation and depression might therefore result from these perceptions and coping strategies.

Drug dependence appeared to be associated with the perception of CLBP as a life of “living death”. Women who believed that their CLBP was associated with



infection and infertility had unrealistic expectations of cure and depended on drugs. Unrealistic expectations of “cure” can be linked to the biomedical model of CLBP (Main and George 2011). Men who believed they were unable to continue in their manually driven jobs, had unrealistic expectations that the government would provide new non-manual jobs for them. They depended daily on analgesic drugs to cope. In contrast, medication use is often adopted reluctantly by patients in high-income countries (Coole et al. 2010), due to concerns about dependency, side effects, and impact on the “self” (De Souza and Frank 2007). The perception of CLBP as a life of “living death” was linked to participants living in rural Nigeria. This negative perception of the Nigerian rural-urban disparity is similar to findings in rural Western Australia (Briggs et al. 2012).

Participants’ expectations of cure resulted in dissatisfaction with health care services when this was not achieved, which has also been reported in high-income countries (Liddle et al. 2007). When a “cure” was not achieved, first using conventional healthcare, participants in this study sought alternative health care. Patients having an active involvement in CLBP management is associated with better satisfaction with treatment and less interest in searching for a cure (Liddle et al. 2007).

The perception of CLBP as a life of “living death” was associated with biomechanical factors. The male participants’ expectation that the Nigerian government would provide them with new non-manual jobs could be linked to their perception that their inability to work due to CLBP was related to the manual nature of their jobs. This is similar to reports in rural Botswana (Hondras et al. 2016). However, this perception could also be related to fear-avoidance beliefs (Rainville et al. 2011). In rural Botswana, this understanding was often expressed as a mechanical injury, or habitual work-related tasks (Hondras et al. 2016). Studies in other countries, such as Iran, have reported poor knowledge of correct posture and lifting techniques (Tavafian et al. 2008). Biomechanical understanding of CLBP has been associated with an increase in fear-avoidance beliefs, anxiety, pain intensity, pain catastrophising, hypervigilance, maladaptive illness perceptions and disability (Rainville et al. 2011).

The rigorous systematic data collection and analysis, detailed description of the methods and the orientation of the researcher, reflexivity and respondent validation, and the findings of this study being substantiated by a multidisciplinary team are some of the strengths of this study. Participants involved in this study are not representative of multicultural Nigeria or Africa; therefore, further research should explore the meaning of CLBP pain in other African contexts. Another limitation of this study is that a phenomenological investigation would have enabled a deeper understanding of the “meanings of pain” or “meanings of a life of living death” with respect to each individual in this study, in contrast to the thematic method of analysis utilised in this study. Phenomenological analysis aims to describe human experiences and the meaning of these experiences, such as pain. In phenomenology, every experience is personal, with emphasis on the individuality of an experience (Ojala 2015).

## 5 Conclusions

This first qualitative study of people living with CLBP in a vulnerable, rural African community has uncovered a significant burden that requires further research. Phenomenological and mixed-method studies are needed to further investigate the “meanings of pain” or the “meanings of a life of living death” in several rural African groups with different types of chronic pain. The findings of these studies can inform evidence-based patient-centred interventions for pain management in these contexts.

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## Chapter 6

# ***Painworld: A Phenomenological View of Veteran Experiences of Living with Chronic Pain***



**Sedona L. Koenders**

*Do you have chronic pain? Because if you don't have chronic pain, you won't understand.—Veteran Study Participant*

**Abstract** In the USA, military veterans experience chronic pain almost twice as much as the civilian population. The impact chronic pain has on the lives and lived experiences of veterans is striking. Ethnographic research allows for researchers to gain insights into the meanings of their lived experience of chronic pain. Between 2017 and 2019, at the height of the “opioid epidemic,” I performed an ethnographic study at a Veterans Affairs (VA) medical center in New England that consisted of qualitative semi-structured interviews with veterans who lived with chronic pain, as well as VA staff engaged in chronic pain care. I also engaged in participant observation and took extensive field notes throughout this time. The context of the opioid epidemic era additionally shaped the world these veterans lived in due to shifts in treatment approaches and perceptions of chronic pain both in healthcare settings and socially. In analyzing my observations in the VA space and illness narratives of older, white, male military veterans who live with chronic pain, I formed a pain-centered phenomenological concept of a *painworld*. The *painworld* shares several characteristics with the chronic pain lifeworld—namely that both are formed naturally, historically conditioned, intersubjective, and dynamic—and allows for a novel way to capture how pain (and pain care) alters the lives and daily lived experiences of this subset of the veteran population.

**Keywords** Chronic pain · Phenomenology · Veteran(s) · Lifeworld · Illness narrative(s)

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## 1 Introduction

Pain could be described as an experience that hurts, is unpleasant, and invokes suffering of varying degrees. But in attempting to describe a particular painful feeling to a parent, a friend, or a physician, how often do we struggle to find the right words to express that feeling? There are qualifying terms that we may invoke at the request of those who must medicalize our subjective experience in order to assign a diagnostic term, initiating us into the biomedical institution for further analysis and treatment. We may be prodded with options for what term is the best option to describe the pain our body is communicating to us. Does your pain feel sharp? Or is it an ache? Or stabbing? Or tight? Or twisting? Maybe you pick one or two of the terms. And then there is the seemingly ubiquitous pain scale. Some variation of: On a scale of 1–10, with 1 being no pain and 10 being intolerable excruciating pain, how do you feel right now? Or the visual version with cartoon faces allowing you to choose between options ranging from happy to clearly distressed. These tools attempt to objectively measure levels of pain, with the caveat that each person's ranking decisions are entirely subjective (de Williams et al. 2000).

Many people typically arrive at the need to identify and describe their pain only as acute injuries or illnesses arise. However, for chronic pain sufferers, attempting to communicate distress and physical feelings to others is an ongoing and often frustrating issue, for both the individual experiencing chronic pain and whoever they are conversing with. As inherently social beings, we want to be able to make someone else understand us, but perhaps complex human experiences, such as pain, could be better understood when looking at the person globally and using terminology that allows for flux based on a variety of factors. This would likely not be the best option when needing to identify the pain of a sudden broken leg, but for an individual living with widespread chronic pain lasting for years, such an approach may be needed to understand their lived experience and improve their quality of life. In this chapter, I suggest a way to do just that based on my experiences working with veterans who lived with severe chronic pain.

Military veterans with chronic pain form a special subset of the population due to the increased presence of severe and/or traumatic injuries associated with military service that lead to chronic pain. Other common illnesses and sociodemographic factors among veterans that contribute to their vulnerability as a patient population include:

- Mental illness
- Post-traumatic stress disorder
- Service-related disabilities
- Unemployment
- Homelessness
- Difficulties associated with reintegration into civilian life

Those who join the military often come from backgrounds of low socioeconomic status, adding a history prior to enlisting in the military that may have had an impact

on their physical and mental health early on in life. Veterans overall are underserved as a population due to difficulty accessing health care at the VA. Access challenges include issues such as long wait times to get appointments to see a provider, challenges navigating VA benefits, living in a rural area or a long distance from a VA facility, and more. These factors can all further impact veterans' ability to receive health care, proper treatment, and effective management of chronic pain and comorbid health conditions.

As an applied medical anthropologist who went into an environment in which I was aware the population I was interested in talking to was familiar with the need to effectively communicate with their VA healthcare providers, I also anticipated there were frustrations involved in that process. These frustrations were potentially due to the assumption people may have that another person's chronic pain is either not real, or not as bad as they say it is. This misunderstanding or inability to understand seemingly invisible illness has been well documented (Carroll et al. 2020; Palacios-Ceña et al. 2020; Pilkington et al. 2020; Crowley and Murphy 2018). I also had some personal experiences with chronic pain and attempting to properly address and alleviate that pain via biomedicine. As a young, relatively healthy, white woman, I knew my experience would likely differ immensely from that of predominantly older, white, male military veterans. Therefore, I went into my work mindfully attempting to set aside my personal experiences, but I also wanted to learn about the experiences of these veterans who had been struggling with chronic pain (something I comparatively only had a glimpse at) for such extended periods of time. To investigate that subjective experience, I decided to utilize a phenomenological and modified grounded theory approach. These methods were selected because they allow for the individual's lived experiences to be at the forefront of the work, and any resulting theories are *grounded* in the data gathered from participants.

Phenomenology, an anthropological method to conduct both data collection and theoretical analysis, is used to examine the ways people live and experience the world (Schutz 1972). Anthropologists and philosophers have used phenomenology to examine a large variety of human life and interactions. Within this theoretical framework, Edmund Husserl formed the foundational concept of *Lebenswelt*, the "lifeworld" (Desjarlais and Throop 2011; Ekebergh 2007). The lifeworld forms naturally and is shaped by social interactions and history, shifting over time—core characteristics we will return to later in this chapter. Many other scholars have also applied the lifeworld concept to their own scholarly work. Byron Good discussed chronic pain as threatening to "unmake the [life]world, and in turn to subvert the self" (Good 1993, p. 126). Jürgen Habermas used it as complementary to his theory of communicative action and proposed society was both a system and a lifeworld (Habermas 1985). Germond and Cochrane then took Habermas's communicative action and the lifeworld to create their theory of "healthworld" (Germond and Cochrane 2010). The healthworld encompassed different behaviors, perceptions, and influences related to health, but was also created as a way to study society. The lifeworld parallels other anthropological concepts, such as Bourdieu's "habitus" (Bourdieu 2013) describing the embodiment of society-shaped habits, and



Foucault’s “normalization” that occurs through power and discipline (Foucault 1976).

When analyzing the human experience of chronic pain, Arthur Kleinman’s (1988) foundational framework for eliciting illness narratives offers one way to discuss interview data. In his ethnographic work, he focused heavily on chronic conditions, including pain, and saw the value of storytelling of lived experiences as a way to communicate one’s understanding of their symptoms as shaped by society and culture. Kleinman explained chronic pain as an individual experience, an illness viewed upon by the clinical gaze, and a form of suffering that threatens productivity and is questioned by others. He said, “Chronic pain involves one of the most common processes in the human experience of illness worldwide,” and that he was “convinced that ultimately what the practitioner does best is to organize care around the phenomenological appreciation of the illness experience and its psychological and social consequences for the patient” (Kleinman 1988, p. 57, 250). This perspective is key to understanding the lived experience, how patients understand their own pain, and the lifeworld that forms for them.

Drawing on a year of participant observation and semi-structured interviews, this chapter examines how veterans experience living with chronic pain and how they communicated their stories to me. Since chronic pain is twice as prevalent among veterans than non-veterans in the USA (Sandbrink 2017), I expected it would largely frame the life and health of veterans. This proved to be true to an even greater degree than I anticipated throughout my participant observation, interactions, and research. As veterans who were participants in my fieldwork recounted their illness narratives, I learned how chronic pain became truly central to their lifeworlds. The remainder of this chapter will present my findings and relay how veterans described and managed their illness. Through the analysis of this work, I argue that a pain-centered life, or identity, exemplifies a different kind of lifeworld, which I came to interpret as a “*painworld*” inhabited by many of my participants. The *painworld* shares several characteristics with the chronic pain lifeworld—namely that both are formed naturally, are historically conditioned, are intersubjective, and are dynamic.

## 2 Ethnographic Exploration at a New England VA Medical Center

To explore veteran experiences of living with and managing chronic pain when receiving health care from a Veteran Affairs (VA) medical center, I performed an ethnographic study at a VA in New England from late 2017 through the spring of 2019. In this chapter, I refer to my VA fieldwork site as the Spacious Green VA (SGVA). The study consisted of qualitative, in-depth, semi-structured interviews with eight veterans who lived with chronic pain, and seven VA staff engaged in chronic pain care. Semi-structured interview guides differed between the two groups (veteran patients and VA staff), and each guide remained unchanged throughout the

duration of the study. These interviews were all audio-recorded after completion of informed consent and Health Insurance Portability and Accountability Act (HIPAA) forms, as applicable, and held in physical settings of the participants' choosing at the SGVA. My research was approved by the Institutional Review Board (IRB) at Boston University's School of Medicine and by the Department of Veterans Affairs (VA) IRB. All participant names have been changed to protect anonymity. The participants gave their consent to the publication of their stories.

Veteran participants were recruited using purposive sampling from among the larger patient population at the SGVA and all self-identified as having chronic pain. Due to time constraints within the interview portion of my study timeline, I completed as many interviews as possible, keeping in mind the level of data saturation in regard to chronic pain illness narratives. Once I began hearing similar chronic pain stories from participants, I stopped actively recruiting. I chose to allow for the chronic pain selection criteria to be self-defined, rather than formally and officially diagnosed, to make sure the veteran experience was at the forefront, but also to protect patient privacy during the recruitment process and eligibility determination. Recruitment of veterans was facilitated by opportunities to recruit in person when invited to do so due to strict limitations on recruitment protocols at the SGVA facility. As a without compensation (WOC) research associate, I did not have a clinical role at the SGVA and, therefore, was unable to identify and recruit veterans directly. For this reason, staff who were key informants were essential to my ability to find opportunities to recruit via the necessary convenience sampling and reach veteran participants for interviews. These interviews addressed daily life and a variety of health concerns, but focused on participants' experiences of chronic pain and how it was managed both at home and within the SGVA. Interviews with VA staff focused more on their experiences working with veterans who had chronic pain. As semi-structured interview guides, not all questions were asked of all participants, since not all questions were relevant for everyone. The participants guided the conversation, with myself as the interviewer asking specific questions and prompting for elaboration as applicable to keep the interview focused on the relevant topics. Interview length lasted from approximately 12 min to an hour (with most falling somewhere in the middle), based on how much the participant chose to elaborate in their responses to my questions. Participating veterans all identified as white and (cis) male, and were between 55 and 75 years of age. They had all served in the military during, or right after, the Vietnam War (Table 6.1).

VA staff participants were recruited via internal VA email notices of the need for participants and also through convenience sampling since I already knew many staff members involved in pain care. My intention was that interviews with VA staff who engaged in, or had knowledge about, chronic pain care of veteran patients would provide different perspectives of chronic pain management at the SGVA. These staff members did, in fact, represent a variety of credentials, training, and levels of experience with both veterans and chronic pain management (Table 6.2).

In conducting data analysis by hand, I transcribed and then coded these interviews using a modified grounded theory (mGT) approach to analyze themes emerging from them, and to identify and compare themes between participants. The mGT

**Table 6.1** Veteran participants

Veteran participants <sup>a</sup>	Age range (years)	Military service		Health conditions of note			
		Military branch	War era	Chronic pain	Arthritis	PTSD	Depression
Greg	70–75	Navy	Vietnam War	X	X	X	
Joe	55–59	Army	Post-Vietnam, Cold War	X	X	X	X
Bob <sup>b</sup>	70–75	Army	Vietnam War	X	X	~	
Phil	65–69	Army	Vietnam War	X	X		X
Jim <sup>b</sup>	65–69	Army	Vietnam War—Operation Enduring Freedom	X	X	~	~
Matt	55–59	Marines	Post-Vietnam, Cold War	X	X	X	X
Sam	70–75	Air Force	Vietnam War	X	X	~	~
Ben	65–69	Army	Vietnam War	X	X	X	X

~Indicates participant unease with the diagnosis. See text for qualification

PTSD: post-traumatic stress disorder

<sup>a</sup>Names to represent participants are all pseudonyms

<sup>b</sup>Are also VA staff, working as Peer Specialists, who are veterans in recovery from mental illness or a substance use disorder that provide support to other veterans experiencing similar illnesses

**Table 6.2** Spacious Green Veteran Affairs (SGVA) staff participants

SGVA staff participants <sup>a</sup>	Job title
Jack <sup>b</sup>	Peer specialist
Barb	Registered nurse (RN)
Mia	Psychologist
Sue	Clinical pharmacy specialist
Anne	Psychologist
Janet <sup>b</sup>	Nurse practitioner (NP)
Grace	Psychiatrist

<sup>a</sup>Names to represent participants are all pseudonyms

<sup>b</sup>Are also veterans

methodology allowed for flexible data analysis aimed at forming a theoretical explanation of the data by using comparative analysis and triangulation. Therefore, I compared the interview transcripts and codes between veteran participants, but also between veterans and VA staff. Recurring similarities between interviews formed my themes and then contributed key concepts to form a theory to identify and explain those themes.

Throughout my time at the SGVA, I also engaged in participant observation and took extensive fieldnotes. My ethnographic fieldwork consisted of learning about the medical center itself, interacting with and observing a variety of VA staff and physical spaces, and observing and participating in VA Pain Team meetings, in

which providers and other consulting staff discussed patient cases related to chronic pain and opioid use. I included my own participant observation in my comparative analysis to triangulate my three main data sources: veteran interviews, VA staff interviews, and participant observation (including field notes). Triangulation is a standard technique within mGT to enhance the trustworthiness of data.

### **3 Common Veteran Illnesses and Experiences**

The eight veterans who participated in the study all had self-reported chronic pain, which six of them attributed to events that had occurred several decades earlier, either during military service or worsened by such service. They all also reported having arthritis; seven said they had post-traumatic stress disorder (PTSD); six said they suffered from depression (one of which reported as previous depression). The prominence of these specific health conditions among veterans is consistent with existing literature, which shows all four conditions disproportionately affect veterans when compared to their non-veteran counterparts (Olenick et al. 2015). Depression and PTSD have additionally been found to be the most prevalent mental illnesses among the veteran population (Trivedi et al. 2015). Arthritis is diagnosed heavily within the VHA (Dominick et al. 2006), and is ultimately a condition that causes pain to varying degrees. The four conditions of depression, PTSD, arthritis (or arthritic pain), and chronic pain are also frequently referenced as occurring together, in a comorbid manner, supporting similar findings among other studies and relevant literature (Olenick et al. 2015).

As noted in Table 6.1, three of the veterans felt unsure about these diagnoses, especially PTSD and depression. This may have been due to stigma associated with mental illness, but some reported they felt “uneasy” about the diagnoses, because their symptoms did not look like those of some of their peers. For example, when discussing PTSD, I received responses such as: “they [SGVA providers] call it anxiety,” “depends who you talk to,” and “that’s what they say.” Similarly, one veteran said his provider told him that he had depression even though he did not think so. Only one provided a straightforward “no” answer when I asked if he had depression; of the seven veteran participants that reported “yes,” three were vague, describing having depression “sometimes” or only “a little.”

#### ***3.1 The Beginning of the Chronic Pain Illness Narrative***

The ways veterans told me (as well as their providers) about their pain and experiences formed their illness narratives. By sharing these stories, they were able to verbalize their lived experiences to others. Since my interviews focused on chronic pain, the narrative often began with the question, “When and how did your chronic pain start?” After years of telling their stories in the hope that someone could help,

the main events they associated with their pain were often relatively clear, considering for most it could have been decades since their onset of pain. For example, “Greg” told me the following when asked when and how his pain began:

*Oh forever . . . I hurt myself when I joined the navy, like day one . . . I checked in the next day with a sore back . . . but I nursed it all through my four years . . . and you know, I’m living with it. I’m learning to live with it . . . it’s been fifty years. (Greg)*

Greg was a large, strong man, in his seventies. He wore a hat that displayed his veteran status. As I sat across from him, he routinely stretched out his legs and changed his posture to try to avoid worsening his pain by staying in one position for too long. He told me about his life with a forceful voice and a smile, often shrugging his broad shoulders and laughing in acceptance of his situation (fieldnotes). Greg also told me how veterans joked about their pain, but that the military mentality was to *suck it up*.

“Bob” and “Joe” also rather nonchalantly described an event or period of time during military service that they associated with the start of their chronic pain. Out of the eight veterans I interviewed, six of them attributed the onset (or exacerbation) of their chronic pain to their military service. In this way, their experience as soldiers followed them physically through life. Their bodies held on to the memory of injury and firmly rooted the associated pain as part of their adult life.

*I have radiopathy [likely radiculopathy or sciatica] or whatever in my legs. I’ve got chronic damage to my spine that I received years ago. I had to jump out of a chopper about 35 feet with a full rucksack and so I got some damage. (Bob)*

*Probably goes back to basic training when I got hurt. But I was just brought up in a way that you worked through whatever was there. You know, unless it’s a broken bone or whatever, keep going. (Joe)*

As my interview with Joe progressed, he went from being uneasy and guarded to more comfortable talking about his pain. In relaying his story, he laid out the increases in physical struggles he experienced over time. However, his tone became somber when he reached one particular point in this story: when he learned he would have to stop working. He leaned closer, putting his elbows and forearms down on the table. He then looked down at his hands, occasionally looking back up as he told me:

*When they first told me I was gunna be stopping [work], the way it was put to me made me feel like I was a lump on a log. I was, I was useless. It did a number on me for a while. (Joe)*

Over time, Joe told me, due to the pain, he adjusted how he performed needed tasks throughout the day. At this point in the interview, I saw vulnerability and the toll Joe’s chronic pain problems had taken on him mentally and emotionally. He explained that he had to pace himself and just deal with each day as it comes. This “slowing down,” “pacing oneself,” or “knowing one’s limitations” was frequently mentioned among veterans as ways they had to change once chronic pain became too much to ignore. In fact, six of the eight veteran participants used slight variations of these particular phrases. The remaining two did not directly use the same terms, but provided examples that were consistent with the idea, such as tiring easily from a variety of normal daily activities. This proactive slowing down to allow for longer durations of activity additionally correlated to being mindful of how they extended

themselves physically, so that they would be able to make the most out of the day. Another phrase that came up in support of this intentional approach was *I have to take it one day at a time*.

### **3.2 Finding Support Among “The Guys”**

Throughout my fieldwork, I saw many veterans at the SGVA often interacting with one another in a manner that was both jovial and respectful. Joe specifically told me how he talked to *the guys* and had some good friends who helped him out a lot (fieldnotes). Receiving support from fellow veterans was a theme that emerged when discussing chronic illnesses, navigating the VA system, and life in general. All veteran participants went to at least one group session, which was run by a psychologist who specialized in pain management. I knew this psychologist, and at one point during my fieldwork, she invited me to attend one of these weekly sessions. Unsure of what to expect, when I arrived, I found a large group of veterans of varying ages waiting outside a relatively small conference room. When it was approaching time for the session to begin, they piled into the room, finding seats wherever they could. An oval conference table was in the middle of the room, with fifteen chairs packed around it. Additional chairs were brought in to fill in any and all additional space in the room. By the time everyone was settled inside, sharing stories and exchanging jokes, a few additional attendees found chairs elsewhere and squeezed them into the doorway while booming voices and laughter filled the room. When everyone quieted down to allow the psychologist to begin leading the session, I found myself sitting in a room literally overflowing with male veterans of varying ages and from different military branches, who all had their eyes closed as they were calmly guided through a mindfulness exercise. A few minutes later, these same men were taking turns describing what they experienced and felt when they tried to imagine lying in a grassy field as their pain floated away on clouds in the sky. The conversations that followed were open and honest, encouraging the attendees to describe how they felt during the exercise. Toward the end of the hour, the session came to an end, everyone squeezed past chairs and into the hallway, and returned to their raucous conversations with both established friends and new acquaintances.

Some of these group session attendees eventually became interview participants. It was during the interviews that my observations of the comradery and supportive relationships between veterans that become clear during the group sessions were further exemplified.

*We can talk to each other about stuff. ‘Cuz we’re all going through the same stuff.* (Joe)

For example, a story was relayed to me about a group of these veterans who went to a baseball game together. They joked about one of them being a bad driver and discussed highlights of the game. But they also mentioned losing one of their friends in the stadium and having to disperse in an attempt to find him. A fun social outing quickly turned into many buddies being worried about their friend because he had

trouble walking due to pain. The concerns swirled about whether he just went to the bathroom, or if he fell somewhere and potentially hurt himself. They ended up finding the missing friend, and he was fine, but that instant switch to needing to find and support a fellow friend and veteran who was struggling with a chronic painful injury was just one example of the comradery between these men. They worried about each other. They supported each other. And they felt understood by one another. During interviews, others also told me about going to a variety of events together, calling each other when they were frustrated or in pain, and attending formal and informal group events held at the SGVA.

### 3.3 *Reaching Acceptance of a Pain-Full Life*

With many chronic illnesses, there is a point where the affected individual reaches a point of acceptance regarding their illness (Karekla et al. 2019; da Silva et al. 2018). Bob and the other five veterans who had suffered from chronic pain for many years voiced acceptance that it was never going away. It is not entirely clear where this “acceptance” originated for each of them, but it was also brought up in staff interviews and throughout my participant observation at the SGVA. The difference in how staff talked about this idea was that they would describe to me how it was *important* (while often difficult) to get their patients to accept their chronic pain as something that was just part of their life. There were things that could be done to increase one’s functionality, but the expectations of achieving a pain-free life were considered unrealistic. Whether veterans I spoke with reached this conclusion on their own or through the influence of their healthcare providers was not something I actively probed on during interviews, but rather was discovered during my analysis and as I coded my interviews with both patients and staff. Bob, in particular, seemed to have reached a Zen-like level of acceptance.

*My mantra is . . . a body that rests tends to stay in rest, and a body in motion tends to stay in motion . . . You know, nothing ever goes away. Chronic pain is chronic pain, but as I’ve learned in mindfulness, pain times resistance increases suffering, and pain times acceptance reduces suffering. (Bob)*

However, Bob’s view was not at all universal among participants. Some seemed more defeated in their acceptance, while others clearly struggled with reaching that point and were constantly questioning their own pain. A contrasting example was seen with “Phil,” who began experiencing chronic pain in his sixties when he started having issues with his hip, unlike most of the others who were many years into their chronic pain-filled lives. He was having a very difficult time understanding why this had started and how he could make adjustments in his daily life to avoid it. As we sat in an empty consult office to talk, he attempted to reason through it with me:

*Well, (chuckles) I used to be the Energizer Bunny . . . I would sleep maybe five or six hours a night and I’d be up and I’d be flying all day . . . But um, I just feel really tired all the time. And everything that I do now is a big effort . . . I’ll get home at one or two in the afternoon, and there’s a lot of times I just feel so tired that I don’t want*

*to eat anything and I just want to sleep. I don't understand that . . . I know these things need to be done, but I'm just having a very difficult time getting the stuff done. And that's something else I don't understand either. It seems I've gone from the Energizer Bunny to a slow turtle, but I want to get back up to that point. (Phil)*

Even though the onset of Phil's pain was more recent, it was severe and significantly affected his ability to do the things he needed to do. While he found sitting on extra cushions in his car and practicing mindfulness helped, he was beginning to accept that he would have to have a hip replacement. As he discussed the procedure with me, he hemmed and hawed, knowing he probably could not avoid it much longer and realizing the other options he had tried to address it simply were not sufficient. One of the main reasons Phil did not want to have surgery was because he would be unable to work during his recovery. He was the only veteran I spoke with who was still working (not retired and/or on disability). He found joy in working, but it seemed his pain would soon take that away from him. Phil was not sure what he would do each day or to pay the bills once he lost the ability to work, but he also voiced concerns that he would go into a deep depression if he was not able to be active.

Depression was something seven veterans said they lived with (or were told they had), including Phil. This high prevalence of depression among chronic pain sufferers could be correlated due to the impact pain had on their lives and their ability to do things that they enjoy. The physical and emotional aspects of pain are also difficult to distinguish, potentially worsening one another. For example, this was seen previously in Joe's description of how he felt "useless" and "like a lump on a log" when he had to stop working due to his physical limitations, which led into his depression and also frustration. Unfortunately, the extent of my work did not examine full medical histories and did not allow for multiple interviews, so I cannot be sure the strength of the correlation between depression and chronic pain, or whether chronic pain was typically experienced as a precursor to depression. The comorbidity of PTSD also adds another layer of potentially worsening of symptoms between these three chronic illnesses. I would like to further explore these relationships among veteran populations in the future.

Through the examples explored thus far, we saw that Greg, Joe, and Bob's understanding of their chronic pain and its cause were shaped by their history—particularly their military service. Over time, their experience and understanding shifted, based on their lives and social interactions (including those with medical providers), ultimately leading to acceptance of the chronicity of their pain. Phil's world had also undergone change since the time of his military service, but pain did not play a part in an alteration to his lived experience until much more recently. While these excerpts from my interviews only show a portion of veterans' experiences and illness narratives, they provide insights into the experiences that veterans who have chronic pain share—forming the basis for a different world where pain is at the center of all experience.



## 4 Formation of a Painworld Among Veterans

In analyzing my interviews with veterans, SGVA staff, and my own fieldnotes and observations, I came to the realization that while my participants had developed and repeated their illness narratives many times due to the chronic nature of their pain, there were distinct commonalities between how veterans talked about their chronic pain. Together, their illness narratives and lived experiences produced what I call a “painworld.” The painworld is rooted in the phenomenological concept of lifeworld, but specifically revolves around chronic pain. Additionally, both concepts share the characteristics of being historically conditioned, intersubjective, dynamic, and naturally occurring. These components are noted in a very intentional manner as they are key pieces of both the lifeworld and painworld as theoretical concepts, and are, therefore, important to the bigger picture of what the painworld represents. It includes not only the lived experience and the impact of pain on daily life, but also the different ways veterans interact with the VA healthcare system and try to manage it in their daily lives (to be discussed further in the next section of this chapter). Many veterans spoke of adjustments they made in their daily life to ensure a greater degree of functionality and productivity, including keeping work or activities at eye level, utilizing smart phones for alerts when it was time to take medications, and staying as physically active as their bodies would allow. The focus and prioritization of addressing and self-managing pain among this population is consistent with themes found by researchers who also performed interviews with VHA patients (Richardson et al. 2016).

While there were many commonalities throughout interviews, veterans’ painworlds were not at all identical, reinforcing the idea that this is a dynamic concept influenced by many factors. Each person’s experience largely depended on when and how their pain started. This was the catalyst that initiated their own personal painworld. For example, those who had experienced chronic pain for decades had a common discourse around acceptance of it as a permanent part of their life. In contrast, those who started experiencing chronic pain more recently (in the last five years or so) had greater difficulty accepting and understanding it.

*We joke about it, but all of us [veterans] have physical pain and, you know, some have mental pain. (Greg)*

These veterans interacted with each other, providing support and advice for managing pain and navigating VA care. This communication between peers also shaped the painworld, because it had the potential to alter how one viewed their pain and the methods available to treat it.

### 4.1 VA Pain Care: Biomedicine Meets Complementary and Integrative Health Care

The Veterans Health Administration (VHA) itself is a very large national healthcare system in the USA, formed on the basis of biomedicine. The extensive prescription

**Table 6.3** Five most prominent non-pharmaceutical pain management options

Non-pharmaceutical pain management approach	Number of interviews	Percent of interviews
Mindfulness	8	100
Aquatherapy/Swim Therapy	7	87.5
Physical Therapy	5	62.5
Yoga	4	50.0
Acupuncture	3	37.5

of medications (particularly opioids) has been observed throughout the last twenty years in biomedical settings in the USA, but also notable within the VHA (Office of Public and Intergovernmental Affairs 2020; Childress 2016). However, as the opioid “epidemic” raged on throughout the first decade of the twenty-first century and exploded into the second decade, the VHA was flying under the radar as a trailblazer for implementing complementary and integrative health options as alternatives to invasive procedures and pharmaceuticals. Throughout my fieldwork and interviews, I heard mention of a total of fourteen different non-invasive and non-pharmaceutical treatment options veterans had access to through the SGVA, specifically to help lessen their chronic pain.

During interviews, veteran participants mentioned five non-pharmaceutical approaches the most positively and the most frequently (Table 6.3). The most popular option was, by far, mindfulness. Veterans discussed practicing guided mindfulness at the SGVA and also maintaining their own practice (to varying degrees) on their own at home. Aquatherapy, or swim therapy, another approach many veterans viewed positively, helped with their pain, and was enjoyable. Unfortunately, aquatherapy (guided through a class format or done alone in a pool) was not as accessible as some wished. None of the veterans mentioned having access to a pool outside of the SGVA, and many mentioned the bureaucratic difficulties associated with the SGVA pool, which was often closed. Additionally, physical therapy, yoga, and acupuncture were discussed positively by some, and less enthusiastically by others, but were still methods found to be helpful in alleviating pain.

Over the last 10 years or so, providers have increasingly used complementary and integrative methods (Mattocks et al. 2020), rather than prescribing pharmaceuticals—especially opioids. This change was evident among my participants as well. Out of eight veterans, only two were taking opioids to manage pain. Throughout the interviews, providers noted this switch, as well as increased acceptance of integrative modalities among their veteran patients in recent years. Noting the risks associated with opioids (such as dependence, addiction/substance use disorders, and overdose), “Anne” explained how providers needed to be cautious with pain medications. This vigilance was also important to maintain the balance that Anne and Mia mentioned when trying to manage pain and maintain a high quality of life.

*It’s all about balance between making sure pain is well managed and that veterans feel that they’re empowered to use tools to keep it at a level that they still have a high quality of life, while also being really cautious about medications that might have really dangerous side effects. (Anne)*

*I think from the patients' side though, there's also been a shift of people are hearing in the news people are dying and the risks and dangers involved that they weren't aware of . . . they're more willing to consider other options . . . 10, 15 years ago there was much more resistance. (Mia)*

While Anne shared her concerns regarding treating pain in the midst of the knowledge surrounding opioid use, Mia said patients have also acknowledged the risks in recent years due to the media coverage. The increasingly cautious approach coupled with the growing concerns among patients were correlated with the increase in non-pharmaceutical treatments, but stigma was associated with opioid use, as Mia previously alluded to. Provider participants often opted to use the language of “active” versus “passive” when talking about integrative and pharmaceutical approaches. For example, “Barb,” a nurse, explained the desire to provide more active treatment methods, rather than passive:

*I think my main concern is making sure the patient is an active participant. I think for so long we've been in the paternalistic cycle of we just prescribe and the patient just takes [what we prescribe] . . . we're shifting now and we're really encouraging patients to take an active role. (Barb)*

The comments Barb made about encouraging active patient roles came up during other interviews and provide an example of how intersubjectivity between providers and patients alters the experience of living with chronic pain. This idea of having the patient play a part in their own treatment was connected to the desired opioid de-prescribing, but as Barb mentioned, this active approach also challenged the traditional paternalistic medical institution. The expected process of going to a biomedical doctor and receiving a prescription, therefore, was considered more carefully while integrative methods seemed to offer a safer alternative. By utilizing active modalities, veterans also gained agency and more control over their experience with pain, its treatment, and ultimately their own painworld.

This adoption among veteran participants was also clear (as addressed in a previous section), displaying societal conditions that could shift the painworld by altering the intersubjective understandings of how pain is viewed. Despite the siloed nature of different services and the confusing organization of a bureaucratic healthcare system, veteran participants told me about a large variety of services they had been offered within SGVA, and that they had tried, in an attempt to better manage their pain. Many spoke enthusiastically about practicing yoga, aquatherapy, physical therapy, mindfulness, and receiving acupuncture, to help with their chronic pain. For example, there were yoga classes available, which had been adapted for those who had chronic pain and/or problems with their joints. A veteran, whom I call “Sam,” told me about his experience trying this type of yoga:

*I did a research study for yoga . . . it's modified yoga, so most of it was done standing or using a chair instead of getting down on the floor . . . I am a firm believer in yoga now. I was misconceived as to what yoga was. [Now] if I don't do my stretching exercises for two days, by the third day I am feeling it. (Sam)*

The slow-moving and less strenuous nature of these modified classes allowed veterans to utilize yoga in a way that was easy to do in a class setting or at home. Four of the eight veteran participants spoke of using yoga to manage their pain.

Another method veteran participants used was aquatherapy. This often consisted of doing different exercises in a pool, including swimming and walking in the water. Being submerged in water allows there to be less weight and stress put on the joints and the body. Seven veterans said aquatherapy or swimming helped to lessen their pain and allowed them to be more active, including “Bob” and “Matt.”

*So, I started going to this [aquatherapy] class here to learn how to swim better using my feet. . .but slowly over the period of a year and a half, all of a sudden, I kept getting to the point where I could swim. So, I started to swim constantly, plus doing a regimen of exercises in the pool. . .I go in the pool and practice balancing. . .and that's improved. (Bob)*

*Swimming helps, ya know, if I'm in a pool or something that helps take some of the pressure off. (Matt)*

While these are only a few examples of the services veterans used at the SGVA to help with their pain, they provide illustrations of the active modalities providers spoke of. By learning how to do modified yoga exercises or pool exercises, veterans were able to take action and manage their pain on their own—rather than passively taking opioid medications. This type of approach grew as a response to the current prevalence of opioid use disorder and related overdoses. As the preferred treatment approaches changed to be more active and integrative, veterans gained more control over their treatment, improved their functionality, and positively shaped their own painworld.

## **4.2 Improving Patient–Provider–Peer Communication**

The way health care was provided at the SGVA displayed the complicated nature of a highly structured and siloed institution. While the complex details of this bureaucratic system surpass the scope of this chapter, the structure made communication difficult—both between patients and providers, and different providers and SGVA departments (Koenders 2019). Veterans helped each other navigate the VA system either informally as friends or more formally through the role of Peer Specialists. This role consisted of SGVA employees or volunteers who were veterans and helped patients access services, but also advocated for them in clinical and more administrative settings.

While Peer Specialists offered a unique connection and helped improve access to proper services, there were only a handful at the SGVA at the time of my fieldwork. Therefore, the traditional provider–patient dyad was still prominent within clinical appointments that did not involve an interdisciplinary team. Based on my participant observation and interviews with both staff and patients, when an interdisciplinary team or Peer Specialist was involved with a specific patient case, the patient’s story appeared to hold more weight during the discussion of a treatment plan. When it came to chronic pain treatment, some staff participants had concerns that other

providers at the SGVA could improve on their clinical communication with these patients.

*I think I would like to see my mental health colleagues and people outside of primary care being more actively involved with understanding the experience of pain and wanting to play a role. (Grace, psychiatrist)*

*The healthcare system has a ways to go still in terms of being compassionate about how we treat patients with pain. As much as we on the [pain] team try hard to not stigmatize what's happened and be open to hearing veterans' stories, it's not unheard of, regrettably, that they do get treated not in compassionate ways. (Mia, psychologist)*

Both Grace and Mia believed providers needed to be more compassionate and take the time to listen to veterans and really learn about their pain. However, Mia also mentioned the stigma that can occur when treating this particular patient population. Staff with views like Mia and Grace emphasized that communication and empathy were important when addressing a stigmatized condition that is also an extremely subjective experience because of the immense difficulty understanding, explaining, and diagnosing such an illness. Several staff acknowledged this complexity by explaining the need to address each veteran patient on a case-by-case basis. While Grace and Mia both worked on interdisciplinary teams to treat many of their patients who had pain, other providers that were not involved in such teams may not have been able to connect with these patients as well, or learn more than the basic symptoms.

When treating veterans with chronic pain, providers at the SGVA could request assistance from multiple services, including three separate “pain clinics,” offering a variety of interdisciplinary services. However, despite the fact that there were both opioid and non-opioid medication treatment options for pain, as well as over a dozen non-pharmaceutical approaches available, the existence of the different options and how to connect patients to them did not appear to be well understood among SGVA staff overall. The common reference to separate clinical entities as “pain clinics” added provider confusion about the available services and how to access them, further complicating communication about such services. Staff participants also told me how providers for different treatments did not communicate or coordinate well, creating more inconsistency. The chaotic nature of how interdisciplinary pain management care was provided at this VA was the antithesis of the deeply structured nature of military culture and also contributed to the painworld.

While veterans often found workarounds to access the care they needed, it was not easy to do so. Dedicated SGVA staff helped when they could, as did Peer Specialists and veteran friends. By staff advocating for patients, and patient advocating for themselves, a variety of pain management options could be made available with the hope that a modality that had low potential to cause harm (unlike long-term opioid use) would be effective at improving that veteran's quality of life, creating a more positive version of their painworld.

## 5 Conclusion

In conducting the analysis of veterans' illness narratives and lived pain experiences through qualitative interviews and participant observation, it became clear that the lifeworlds of these veterans with chronic pain were so pain-centered that their lives ultimately encompassed what I have called a "painworld." This painworld formed naturally as chronicity formed, was shaped by history, particularly that of the Vietnam War, the "opioid epidemic," and intersubjectivity (through interactions with other veterans and SGVA staff), and was constantly shifting due to the dynamic nature of bodily experience and the aforementioned characteristics. It was also influenced by pain care at the VA where the participants received health care, the bureaucratic structure and provision of care, and social interactions within that setting. While there were many services available for pain management within the SGVA, their organization (or lack of) made it difficult for providers to truly implement patient-centered care for those suffering from a deeply subjective chronic illness. The interactions involved in getting access to the needed care additionally shaped the painworld through the ways people navigated bureaucratic barriers.

The study provided a unique understanding of the lived experiences of veterans who have chronic pain and has contributed new terminology to describing the all-encompassing nature of chronic pain as an illness, but also a way of life. However, the study itself and the results are still a window into a particular moment in time. In the era of widespread opioid use disorder in the USA, anthropologists can further examine non-opioid pain management methods and the experiences of those who suffer from chronic pain. It is important to research the experiences of an illness disproportionately prevalent among the veteran population; however, it is only a subset of experiences of those living with chronic pain at the height of an "opioid epidemic." I specifically examined the experiences of older (55–75 years of age), white, male veterans with chronic pain who all served in the military during, or immediately after, the Vietnam War. Many veterans fit this category, but their experiences may differ for veterans who are younger and/or women. Chronic pain for veterans who are not older white males may be experienced differently and require different treatment approaches. Future studies should focus on other cohorts of the veteran population to ensure better pain management at the VA for all veterans, for example, building upon the work led by Mary Driscoll and Diana Higgins examining chronic pain differences between male veterans and the consistently growing cohort of female veterans (Driscoll et al. 2015, 2017; Higgins et al. 2017).

Additionally, while all participants had chronic pain, only one was taking opioid medications to assist in managing it. Due to the addictive potential of opioid medications, it is also important that similar studies be performed to gain a better understanding of the experiences of veterans with chronic pain who have struggled with substance use, particularly related to managing their pain. This could include prescription opioids, but also other substances, such as illicit drugs and alcohol. I anticipate those who have struggled with substance use will have different illness

narratives and experience a different painworld, compared to my participants. It is important to understand the differences between these groups because they could require different health care and pain management.

This chapter has explored how the experiences of veterans with chronic pain who receive care within the VA healthcare system illuminated and provided the basis for the painworld concept. Veteran participants also had additional medical conditions, which may have exacerbated their pain. These comorbid conditions, and the fact that most veterans reported that their pain originated several decades ago (before or during their military service), made the nature of their experiences particularly complex. The complicated nature of treating pain and managing it on a daily basis has become increasingly difficult to address in recent years as concerns surrounding opioid medication have grown, resulting in a push toward non-pharmaceutical methods. As veterans accept their chronic pain status and providers implement more integrative options, there is potential to thoroughly assess much needed safer pain management methods. Hopefully, this research will encourage other researchers and healthcare practitioners to further explore how veterans experience chronic pain and other chronic conditions. It is also my hope that by considering different ways to frame and talk about pain, such as through the painworld concept, we may allow for more flexibility that looks at the bigger picture of chronic pain sufferers' lived experiences, rather than the limited options currently utilized for biomedical assessment and diagnosis.

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## Chapter 7

# “It’s Just One of Them Things You’ve Got to Try and Manage”: Meanings of Pain for People with Brain Injury



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**Abstract** Long-term pain is a common comorbidity for people with acquired brain injury. This chapter explores what it is like to live with those two conditions, focusing on the meaning for the individual. The meaning of pain plays a part in determining people’s emotional reactions and behavioral choices, and it is central for the process of psychosocial adjustment to a life with functional, social, participatory, and emotional challenges. Meaning is also closely linked to the identity changes that typically happen once people are faced with the challenge of living with long-term conditions. The field of positive psychology has contributed valuable insights into this process and the roles of benefit-finding, resilience, and post-traumatic growth are discussed. Two significantly different case stories are used as an illustration of life with acquired brain injury and long-term pain. One case, Julie, illustrates the process of adaptation and the other case, Mark, illustrates the challenge of dealing with pain issues when insight and pain perception has been changed by a frontal lobe injury. In both cases, the meaning of pain is integral to the meaning of brain injury. Neither Julie nor Mark consider themselves to have long-term pain; they live with

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the long-term impact of their brain injury, where pain is just one aspect. In fact, Mark's altered pain perception causes him to claim that he feels no pain, yet it is nevertheless a challenge for him. The chapter concludes with clinical recommendations, calling for access to systematic, psychosocial rehabilitation that includes meaning-based approaches. A holistic rehabilitation model is proposed, suggesting that traditional medical and rehabilitation approaches need to happen within the context of psychosocial adjustment and rehabilitation, rather than expecting psychosocial adjustment to happen by itself, as a "by-product" of medical, physical, cognitive, and occupational interventions.

**Keywords** Chronic pain · Long-term pain · Acquired brain injury · Meaning · Purpose · Identity · Psychosocial adjustment and rehabilitation · Positive psychology · Resilience and benefit-finding · Post-traumatic growth

## 1 Long-Term Pain in People with Brain Injury

With the advances in trauma medicine more and more people survive even severe head and brain injuries (acquired brain injury or ABI), which means an increase of people living with the long-term effects of such injuries (Holtslag et al. 2007). In rehabilitation settings, there is typically a focus on physical, cognitive, and social function; however, pain is a commonly overlooked problem for brain injury survivors (Dawson et al. 2007; Williams and Evans 2003). Survivors may be poor at monitoring and reporting their sensory experiences, and functional issues tend to be more observable and therefore more noticeable for others, whether relatives or clinicians. For the individual, this means added discomfort and distress, especially if the pain is not managed properly. Consequences of living with long-term pain, which may be overlooked due to other functional problems, can be severe. The pain may interfere in rehabilitation efforts (Wu and Graham 2016) and, as for anyone without an ABI, it can lead to anxiety and depression. Efforts to cope with these complex issues may lead some to drug and alcohol misuse (Williams and Evans 2003), which will further jeopardize rehabilitation and psychosocial adjustment to a life with functional challenges and long-term pain.

This chapter aims to look at what it might be like to live with ABI and chronic, long-term pain. In line with other chapters in this compendium, we will focus on the meaning of this for individuals, who daily try to live with two such debilitating conditions. As there is limited evidence to draw on in this area, we have enlisted the help of a lived experience ambassador and two people, who were willing to share their story. Together we want to make the case for using meaning and sense-making as central to helping people, who find themselves needing to adapt to a life with both ABI and long-term pain.

## 2 Meaning: Our Communication Highway

Although pain medicine is a rapidly developing clinical discipline, medical explanations about pain are often unsatisfactory. The problem seems to be with meaning: some people with pain do not find meaning in clinical discussions of pain, and clinicians typically are not looking for it (van Rysewyk 2016, 2019). For patients with pain, biomedical information can be perceived as lacking meaning in relation to their personal experience (van Rysewyk 2016, 2019). By contrast, some patients view personal narratives and stories about pain, clinical encounters and therapies, cautionary tales, and common-sense experience, as offering meaningful and actionable information (Frank 2004). No biomedical explanation of pain, however useful it might be to a pain clinician, could describe the personal meaning or burden of pain to the individual. Traditionally, scientific research has had much to say about the physical nature of pain, but much less about pain experience. It seems that one limitation in the ability of clinicians to effectively treat pain or pain-related suffering is an incomplete appreciation of the meaning of “pain experience” (van Rysewyk 2016, 2019).

While there is no consensus on the meaning of “meaning,” perhaps its most basic denotation is association (Baumeister and Landau 2018). For example, learning the use of a word (“chair”) in connection with an external object (*this* chair) is a form of association. The child learner discriminates behaviorally objects within her environment without recognizing that her behavior is normatively guided by adults. This normatively shaped behavior is indispensable in learning subsequent higher cognitive competencies and more sophisticated associations (Baumeister and Landau 2018). When learning the word “pain,” a child acquires a representational means of telling “what is happening,” which develops into exploring and negotiating complex meanings of pain through interpersonal interactions (Wittgenstein 1953). Meanings build slowly over time, are context-dependent, and culturally determined (Baumeister and Landau 2018). In clinical settings involving pain, a major challenge is to establish the biologically determined associations that contribute to health outcomes in patients. But this biomedical approach does not seek or address other associations that may have been formed by the person experiencing pain.

Language is arguably humankind’s premier tool for using meaning. In Bayer et al. (1991), participants were instructed that they would receive electrical stimulation at increasing intensities through electrodes placed on their temples, and they were required to report the level of pain they experienced. The stimulus intensity was signaled by an intensity gauge that each participant could view and by a tone whose pitch increased in increments that were parallel with the gauge readings. Although no stimulus was actually delivered—the electrodes were not connected to a power source—up to 50% of participants reported pain at the electrode site, and up to 25% requested pain medication. This striking finding demonstrates that meanings conveyed through linguistic manipulation in a social setting can produce pain experience, even in the absence of noxious stimulation to the body’s periphery.

In Barrell and Price (1977), 22 university students were asked to report on their experiences during a stress condition that consisted in “waiting out” the prospect of pain stimulated by an electric shock. Attitudes toward stress were studied in a prior pilot study in which a phenomenological analysis was made of participant self-reports. “Confronters” attempted to understand the situation and prepared for the prospective stressor. By contrast, “avoiders” focused on the non-stressful situation and avoided the stressor for as long as possible. A questionnaire was developed based on these different attitudes. Trapezius electromyograms (EMG) and heart rate (dependent variables) were recorded in the stress and non-stress conditions. The questionnaire responses revealed 10 participant “confronters,” 11 “avoiders,” and 1 with mixed attitudes, during the stress condition. Confronters had significant increases in EMG activity but not heart rate in the stress condition; avoiders showed the opposite pattern of response. These responses related to experiential differences in belief, intent, attention, and coping strategy between “confronters” and “avoiders”: “confronters” accepted the anticipated pain, gathered additional information about it, and showed elevated somatomotor activity, whereas “avoiders” denied the reality of prospective pain, had no interest in learning more about the situation, were anxious, and had increased heart rate. The two attitudes could not have been predicted by the environmental setting, or by the stimulus conditions of the experiment, because both were the same across all study participants. The large differences observed in the psychological and biological responses between “confronters” versus “avoiders” were understood only when the meanings of each attitude were known.

As meaning can produce pain, can pain produce meaning? When the child can tell it is in pain, it can both register pain as a private experience and give it a role in human activity and in the organization of human reactions. Thus, the experience the child is having is articulated with other experiences to which concepts can be applied. The presence of pain immediately raises certain possibilities about the *meaning* of the pain: “What has caused the pain?” “How long did it last?” “Is it sharp or dull, burning, boring, aching, stinging, throbbing, or nagging?” “Where do you feel the pain?” When the child can tell that it is in pain, then the child has taken its first step toward telling all these other things about it. The child has articulated its experience of pain in a system of meanings by which human beings make intelligent, informed responses about what is happening. This articulation conveys the meanings of the pain in terms that the child can think about, and relate to other experiences, meanings, and action. It also allows the child to tell others, and to secure their help in understanding and dealing with the pain. Since the brain is the biological substrate of human function, an ABI may cause any one, or more, of a range of functional disabilities. Therefore, a relevant question is whether the ability to understand the role of pain in human reactions, or the ability to articulate pain in a system of meanings, as described above, is different in people with ABI and chronic pain?

### 3 Meaning of Pain in ABI: Who Knows?

Whereas long-term pain in ABI is sometimes overlooked in clinical practice, there is nevertheless research and emerging evidence of acute pain in ABI, including some clinical management recommendations (Andrews et al. 2018; Arbour et al. 2014). Research and evidence into long-term pain in ABI is less advanced, but it seems to be receiving more attention in recent research (Khoury and Benavides 2018; Nampiarampil 2008). However, when the authors looked for research evidence relating to the meaning of pain in ABI, it was virtually non-existent. This left us with the issue of how to write a chapter on meanings of pain in ABI, without being able to draw on an existing knowledge base. To address this issue, we have chosen to define and present the most pertinent issues in ABI and long-term pain that are likely to interact and then review literature that can inform a discussion around what we need to research in the future. In addition, we have interviewed two people with ABI and long-term pain to get some initial impressions of how they make sense of their dual conditions. From those interviews, we were able to present two significantly different case stories that have informed this chapter. Finally, one author (GH) on the team is himself a survivor living with ABI and long-term pain. He has helped guide our focus in this chapter. However, we will start by looking at the background, including definitions and some epidemiological evidence.

### 4 Acquired Brain Injury

Acquired brain injury (ABI) is damage to the brain that occurs after birth. It includes all types of incidents that result in lasting organic damage to the brain: traumatic brain injury (TBI) (e.g., road traffic accidents, concussion, or assault), medical incidents (e.g., stroke, epilepsy, brain surgery), toxic injury (e.g., alcohol or chemically related damage), or lack of oxygen to the brain (e.g., choking, cardiac arrest, near drowning). Long-term pain is more prevalent in people who have suffered TBI. Long-term headaches after TBI are very common, with preexisting headache syndromes becoming worse after TBI (Nampiarampil 2008). However, other types of long-term pain are also common after trauma; for instance, musculoskeletal pain such as joint pain, inflammation, and pain from exertional overuse is common (Schoneboom et al. 2016).

Typically, in clinical practice, and for the purpose of this chapter, degenerative brain conditions (e.g., dementias or progressive neurological conditions) are not included in the definition of ABI, although long-term pain can be an issue in these conditions as well (Scherder et al. 2009).

People who survive brain injury of one type or another will often be left with varying levels of impairment, depending on the severity of the organic damage occurred. The Glasgow Outcome Scale (GOS) (Jennett and Bond 1975) defines 5 severity levels:

1. Dead
2. Persistent vegetative state, characterized by the patient being awake, but not aware
3. Severely disabled, where the patient is conscious, but dependent
4. Moderately disabled, where the patient is independent, but disabled
5. Good recovery, where the patient recovers well, but may have minor sequelae

Natural recovery combined with rehabilitation efforts can do much to alleviate the impairments people are left with after the acute phase; however, the more severe the incident, the higher levels of impairment survivors are typically left to cope with (Pozzato et al. 2019).

Incidence and prevalence estimates vary substantially, and estimates are more often produced for TBI only, rather than for ABI, which covers a much more extensive range of events and conditions that might lead to brain injury. The latest research (Dewan et al. 2018) gives a worldwide incident estimate for TBI of 69 million people per year. This is approximately 0.8% of the world's population suffering a TBI year on year, or between 800 and 1300 people per 100,000, depending on the region. For the majority, the severity level will be mild (81%) or moderate (11%), leaving 8% with high levels of impairment. This estimate varies considerably from region to region, with the USA and Canada having the highest incident levels (approx. 1.3%) in the world. Another meta-analysis (Nguyen et al. 2016) estimated incidence of TBI worldwide to 295 people per 100,000, which is a significantly lower estimate; however, this study also found significant differences between countries. The two studies employed different methodologies, which may be part of the reason for the large difference. Other issues impacting on incident estimates include lack of standardization in clinical data collection and reporting as well as differences in definitions of TBI (Roozenbeek et al. 2013).

As mentioned, these estimates only concern TBI. To obtain a fuller picture of the extent of ABI, which includes both TBI, medical and toxic incidents, we also need to look at other incident rates. To take but one example, stroke is a major cause of ABI worldwide, and according to the World Health Organization (WHO) (2020), 15 million people suffer a stroke every year. Of those, around five million (<0.1% of the population) are left permanently disabled. Another global study from 2010 suggests an incidence figure of 16.9 million people or 258 people per 100,000 (Feigin et al. 2014). Here, we see less discrepancy between the two estimates than in the TBI estimates above, presumably because stroke is a more clearly defined event and the course of treatment similar across countries.

Combining the figures for TBI and stroke, we get a wide estimate of 553 (295 TBI + 258 stroke) to 1558 (1300 TBI + 258 stroke) people per 100,000 or up to 86 million people acquiring a brain injury every year, not including a wide range of other causes of brain injury. If we consider that many of those, who acquire a brain injury every year in one way or another, may live a full life span with their disabilities, then we see a rapidly accumulating number (a rising prevalence) of people living with mild (the majority) to severe disabilities. A large proportion of

these people will also have to face long-term pain. Pain is a universal experience, and yet, it is a complex issue.

## 5 Pain

When the International Association for the Study of Pain (IASP) was formed in 1975, it was faced with the challenge of establishing definitions that needed to accommodate the significant advances in the scientific basis of nociception and pain and to be pragmatic for people experiencing pain and their clinicians.<sup>1</sup> In 1979, the IASP approved a definition of pain that coupled the sensory and emotional dimensions of the experience, and recognized the association between tissue injury and pain:

*An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.* (Merskey 1979)

This definition, which aimed to provide a universal characterization of the human experience of pain, was intended for use by clinicians, although this was not made clear until 1986. However, from its inception, it heralded a growing recognition that pain is a subject worthy of study in its own right. It has been described as concise, flexible, and accurate, and therefore clinically workable (Morris 2003), and has gained wide acceptance as being authoritative (Jensen and Gebhart 2008), including being adopted by the World Health Organization. A Note on Usage appended to the definition was intended to counteract the mistaken belief in “imaginary” pain, which differed in some way from the pain of “real injury or disease” (Merskey 2005). No longer was it necessary for a clinician to tie the experience to a stimulus: “Activity induced in the nociceptor and nociceptive pathways by a noxious stimulus is not pain. . .,” but nociception. Nociception, the neurophysiological process of encoding noxious stimuli, does not imply pain as a consequence of encoding.

The 1979 definition of pain was updated in 2020:

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<sup>1</sup> Prior to the IASP definition of pain, Sternbach (1968) proposed that “pain” denotes “(i) a personal, private sensation of hurt, (ii) a harmful stimulus which signals current or impending tissue damage, and (iii) a pattern of responses which operate to protect the organism from harm.” This proposal confuses a stimulus (“harmful”), a sensation (“hurt”), and a function (“to protect the organism”). Mountcastle (1974) proposed that pain was “that sensory experience evoked by stimuli that injure or threaten to destroy tissue, defined introspectively by every man as that which hurts.” This definition is circular—“pain is that which hurts”—and linked the experience to an alarming stimulus (“threaten to destroy”). Merskey (2005) also linked pain to tissue damage but, in contrast to Sternbach and Mountcastle, he proposed that the link between pain and actual or potential tissue damage could be identified by association as “An unpleasant experience which we primarily associate with tissue damage or describe in terms of such damage, or both.” Merskey was the first modern pain theorist to view pain as an experience. His definition emphasized “the relationship of pain with the experience of damage to the body and, without making any assumption as to causes, it provides a framework whereby the statements of patients who describe bodily experiences like burning, aching, stabbing, etc., can be assessed, investigated and compared.”

*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 2020)

The association of pain with tissue damage, identified in the 1979 definition, is complemented in the updated 2020 definition with the observation that pain can resemble those experiences which occur during tissue damage or during stimulation that would result in tissue damage if it were maintained over time. If a person reports their experience as burning, pricking, or stinging, or distressing, these qualities could resemble those that reliably occur when nociceptive stimuli are applied to bodily tissue. The updated 2020 definition is a statement of association and similarity, and these sensory and emotional qualities can occur without any tissue damage and without an association with tissue damage in personal experience. However, such an association can and often does exist.

## 6 Pain in Acquired Brain Injury

A systematic review (Nampiaparampil 2008) investigating the prevalence of long-term pain after TBI in veterans and civilian populations estimated that between 43% and 64% of people with TBI live with long-term pain, with some indications that prevalence was higher in civilian populations. Long-term pain was found to be more prevalent in mild TBI, compared with moderate and severe TBI. It was suggested that this might be due to difficulties processing and/or expressing symptoms in the latter group. The review further concluded that long-term pain is independent of psychological disorders like depression and PTSD, although some associations were found.

Another review (Khoury and Benavides 2018) also found systematic reports that long-term pain was more common in mild TBI. However, they further reported in another study (Seal et al. 2017) that in veterans with TBI the risk of developing long-term pain was higher in moderate to severe TBI, with the presence of PTSD and depression adding to that risk.

Perhaps unsurprisingly, the most common long-term pain condition in TBI is posttraumatic headache (PTH) (Nampiaparampil 2008). A wide estimate suggests that between 30% and 90% of people develop PTH after TBI, with a significant number of people having to live with this headache disorder for up to and beyond one-year post-injury (Moye and Pradhan 2017). However, particularly for TBI, around 40% also have injuries to other parts of the body, which may lead to long-term musculoskeletal pain (Khoury and Benavides 2018).

The brain is involved in all human function, so depending on the site of the injury, any type of disability may result from an ABI, for instance, mobility issues, cognitive and sensory impairments, fatigue, emotional lability, personality changes, and behavioral issues. For the individual, such disabilities may have a significant impact on their life, whether vocationally, on their ability to live independently, on their relationships, or in numerous other ways (Headway 2020). Consequently, it is



likely that living with ABI will impact on an individual’s ability and capacity to cope with and manage long-term pain.

When a person acquires a long-term condition, it will typically come with symptomatic and/or functional challenges that the person must adapt to. This involves learning to overcome the challenges and find alternative ways of doing certain things (Hammond and Hirst-Winthrop 2018). In the case of long-term pain, it could involve learning to do certain activities in a different way, what pain medication to take and when to take it, and how to keep as fit as possible through appropriate exercise (Main et al. 2008). Learning happens in many ways, both formally and informally, and people have varying capacity for learning. This becomes especially true in ABI, where the main “instrument of learning,” the brain, has been injured and impaired in some way. Furthermore, these brain-based impairments may come with other functional challenges and more issues to adapt to. The question is how these impairments and need for learning interact in the process of adaptation to living with both conditions.

We start with the formal learning process, which is what happens when the individual attends hospital, gets advice, or receives formal rehabilitation, including relevant education. Whether an individual is offered rehabilitation of their long-term pain or the brain injury may depend on the relative severity of each condition, or maybe even be determined by which services are available, rather than by what the individual’s needs dictate. This latter issue was the focus of a declaration published by the International Pain Summit of the International Association for the Study of Pain (2011). They declared pain management a human right on the background that in most of the world there is a “failure to recognize that chronic pain is a serious chronic health problem requiring access to management akin to other chronic diseases” (p. 29). A multinational commentary claimed that comprehensive multidisciplinary pain management is cost-efficient and clinically effective, but not widely available (Kress et al. 2015). Nevertheless, in Western countries there are offers of pain management available, increasingly delivered at primary care level. According to Johnson et al. (2013), this comes with the challenge that general practitioners in Europe receive an average of 10 h training in pain management, which means that their knowledge is not comprehensive. Breivik et al. (2006) estimated that around 19% of adult Europeans suffer moderate to severe long-term pain, that very few have access to pain specialists, and that around half receive inadequate pain management. To highlight just one issue: due to lack of specialized knowledge in prescribers, use of opioids for pain management is common for people with ABI and long-term pain. However, this is not recommended for people with ABI due to issues of cognitive effects, exacerbation of mental health issues, and substance use disorders, which are common in ABI (Bertenthal et al. 2018). If specialized or comprehensive pain management is hard to find for people with long-term pain without ABI, it is likely to be even rarer to find specialized pain management, where there is also expertise in how to support acquisition of pain management knowledge and strategies, in cases where the individual also has acquired ABI impairments, in particular, cognitive and behavioral challenges.

Formal rehabilitation of long-term pain involves learning self-management strategies such as planning, prioritizing, and pacing of activities, relaxation techniques, appropriate fitness exercises, and management of medication (Faculty of Pain Medicine 2016). This may be done on an individual basis or in groups. For group work there is a set program, and the learning consists typically of formal education with an added element of experiential learning, e.g., by being with other people in the same situation as oneself. This element of learning can be particularly potent in helping people find meaning and belonging in their new situation. However, what happens to someone with an ABI, who may have a degree of memory impairment, which typically causes difficulties with learning? They may still be able to learn, but it will normally take them longer and require more repetition of what needs to be learned (Judd 2012). This is a particular issue within groups, where the pace is set for people without significant cognitive impairments. However, exclusion from group work would also exclude them from the experience of being in a group of people, who can understand what it is like to live with long-term pain. This is a particularly potent aspect of rehabilitation, which is supportive of the psychological adjustment process, especially if close family members are involved as well (Lemmens et al. 2005). Behavioral learning is more effective for people with ABI (Judd 2012), but that is more demanding of resources as behavioral groups require a higher staff–patient ratio. In the current situation with ever-increasing numbers of people living with one or more chronic conditions and the ensuing increased demand on health economic resources (Department of Health 2012), it is hard to imagine that any health service will be able to increase the level of specialization.

On the other hand, if a person with ABI and long-term pain receives their rehabilitation in a brain injury setting, it is unlikely that they will also receive specialist pain management support, as these are traditionally two separate services. In specialist brain injury rehabilitation, there is typically a focus on cognitive and vocational rehabilitation with a focus on reintegration into the individual’s personal context (Judd 2012). Take the example of cognitive rehabilitation, where the person is taught strategies to alleviate functional problems stemming from issues of perception or reduced capacity for attention, memory, and learning. It is hard work to learn when the brain has lost some capacity for learning. It is also difficult to concentrate and learn if one has a headache. It is hard to imagine what it is like to attempt learning new cognitive strategies with a pounding headache!

With limited access to specialist rehabilitation and interacting barriers to formal learning, informal learning may be the main adaptation process for many people with ABI and long-term pain. Informal learning is first and foremost experiential, which has aspects of both embodiment and cognitive learning. An essential element of that is self-reflection, which can be thought of as a critical inquiry into one’s own experience with the aim of meaning-making (Jordi 2011). If we experience symptoms or functional difficulties, the first thing we do is trying to make sense of it. If we cannot make sense of the experience, we are in a poor position to do something about the problem.

The issue with experiential learning and learning through reflection (without guidance) is the risk of maladaptive learning. A typical example in long-term pain

is pain catastrophizing and fear avoidance. Acute pain is a warning signal that compels us to avoid the pain; for instance, if we get burnt on a hot pan, we unconsciously withdraw our hand. However, in long-term pain, there is no direct noxious stimulus to withdraw from, the pain experience is maintained by complex interactions between our cognitive, sensory, and affective systems (Wiech 2016; Garland 2012). If a person with long-term pain holds on to the belief that pain means a warning, signaling the need to withdraw, then they will have difficulties engaging in, for instance, physical exercises that may have the effect of either reducing the pain or increasing their fitness and ability to cope with the pain. In cases like this, pain-related fears may be the main determinant of disability, more than the pain itself (Quartana et al. 2009; Main et al. 2008). In other words, if the experiential learning—“it hurts when I move”—teaches the individual to avoid movement to avoid pain, then we have maladaptive learning, which leads to increased disability. Chaput et al. (2016) investigated the role of fear avoidance in mild TBI and found that pain catastrophizing correlated significantly with reported pain severity, post-concussion symptoms, psychological distress, and levels of functionality, leading to higher risk of post-concussive syndrome and long-term pain.

However, what if the pain experienced is very intense? That would surely make anyone withdraw, fear avoidance or not. ABI can affect any brain area, and certain kinds of thalamic damage may have the effect of causing the experience of excruciating pain. The thalamus is involved in perception of body sensations; it has reciprocal topographical connections with the cortex. The result of injury to these related brain areas can be that tactile experiences become extremely painful. Another result can be reduced sensory capacity, which can lead to chronic central pain (Krause et al. 2012; Ofek and Defrin 2007; Lezac et al. 2004). The opposite can also be the case: that the pain perception is reduced to a greater or lesser extent.

The effect of reduction or lack of pain perception is best described in the literature on congenital insensitivity to pain. If there is no pain, there is no warning and protection against injury. People who cannot perceive pain are prone to injury, often seen as an accumulation of wounds, bruises, broken bones, or other injuries, which may go unnoticed and unattended (MedlinePlus 2020; Nagasako et al. 2003). A person with normal pain perception can discriminate the conditions causing pain from the minor irritations that distress the person with congenital insensitivity to pain. We separate off certain conditions and experiences because they are painful, but the person with congenital insensitivity to pain tends to lump them together with things that others do not regard as painful in any literal sense. Thus, it is not clear whether the person with congenital insensitivity to pain really knows what the word “pain” means (or what a pain is).

Pain in ABI is an extensive and complex topic, so it has only been possible to touch on a few central aspects. However, common to anyone with either or both conditions is that they have to find a way to live with the symptoms and impairments, possibly for the rest of their lives. This requires psychosocial adjustment and it eventually leads to identity changes. Meaning is a central aspect of this journey.

## 7 Meaning, Identity, and Psychosocial Adjustment

Injury and illness of any kind can lead to long-term impairment, continuous health challenges, and disability. Common for anyone experiencing such issues is that they must face and adapt to various potential changes, typically functional issues, be it physiologically (e.g., mobility or symptomatic), cognitively (e.g., memory or perception), and/or emotionally (e.g., increased stress/anxiety or depression). However, we do not exist in isolation, so such issues will have wider implications on the person's relationships, lifestyle, life roles, and, consequently, their identity. Engel's (1982, 1997) biopsychosocial model made these interdependent aspects explicit; however, even decades on, the biomedical model is still dominant in health care around the world (Fava and Sonino 2008). As a result, we have an increasing section of the world's population living with the impact of long-term conditions in their daily lives, of whom a significant proportion have not adapted optimally to a life within the constraints imposed by their condition. Estimates of this issue vary. The World Health Organization (WHO) suggested that around half of those living with chronic conditions do not adhere to their long-term therapy (WHO 2003). Barker et al. (2018) looked at how engaged 9348 patients with long-term conditions were, using the Patient Activation Measure. They found that only 13% could be classed as "highly activated" and 46% were activated but lacking knowledge and confidence to manage their health well. The two least activated levels accounted for 41%, a group that most certainly would experience psychosocial adjustment difficulties. Consequently, these people are likely to have a poorer quality of life than they might have had and not be contributing to society as fully as they might otherwise have done. People with ABI, people with long-term pain, and those who live with both these conditions are included here. Psychosocial adjustment can be particularly challenging for people with ABI and, more often than not, their psychosocial adjustment needs are not met, not even when they receive multidisciplinary, coordinated rehabilitation (Glintborg and Hansen 2016, 2020). Fortunately, there is an increasing understanding of the necessity of working according to biopsychosocial principles, particularly in rehabilitation settings (Wade and Halligan 2017).

Research into psychosocial adjustment and rehabilitation from a biopsychosocial perspective has increased significantly in the past decade. Psychosocial approaches focus on helping people with their psychological adaptation to a life that accommodates what they need to do to function well and experience a good quality of life. This happens within their social context, and it is founded on their precondition personality and function (Hammond et al. 2019; Hammond and Hirst-Winthrop 2018). This means that each psychosocial adjustment journey is highly personal and entirely unique. Any psychosocial rehabilitation approach needs to take this personal perspective into account and that works best if we can use the ways people learn and change naturally. This means considering people's values, attitudes to life, and how they make sense of things; in other words, what it all means to them.

Hammond et al.’s (2019) Integrative Model of Adjustment to Chronic Conditions (IMACC) is an innovative theoretical model describing the process of psychosocial adjustment to long-term conditions. The model was developed through a grounded theory (Charmaz 2006; Glaser and Strauss 1967) study into the experiences of adjustment to type 2 diabetes (Hammond and Hirst-Winthrop 2018). It was found that the precondition personality has significant influence on the psychosocial adjustment process, both negatively and positively, and this includes personal identity with its values and personal meanings in life. People who struggle to adapt to a life with a long-term condition (poor psychosocial adjustment) will over time develop negative identity changes: for instance, loss of confidence and self-esteem. However, if they manage to negotiate the adjustment process successfully, we typically see adaptive changes to their identity, such as increased confidence in dealing with their condition, but also more widely, a change of their perceived roles in life and a self-worth more relating to who they are than to what they can, or rather can no longer, do. In other words, they find new meaning and purpose in life (Kılınç et al. 2020a, b). This process applies to all long-term conditions, including pain (van Rysewyk 2016, 2019); however, in the case of brain injury there can be added challenges.

Adjustment requires motivation, learning, reflection, and collaboration with others, all aspects that can be impaired in ABI. Frontal lobe injury may be particularly challenging to the psychosocial adjustment process, as it can lead to personality changes and impaired capacity for insight and cognitive processing. This in turn affects the capacity for reflection, awareness, and learning, making it difficult to learn appropriate management strategies (Judd 2012). As discussed above, when formal learning is difficult, then people rely on their natural way of learning, which is through meaning, reflection, common sense, and within meaningful relationships.

The importance of personal meaning was central to the findings in Kılınç et al. (2020b), a study looking into the lived experience of self-management in neurological conditions (including people living with long-term pain). An important element in moving forward with the adjustment process was found to be the attempt to find *meaning and purpose* in life. Without meaning and purpose, personal identity is fragmented and incoherent. This main theme was underpinned by five subthemes: *what is important to me, me and my condition, embracing my body, connecting with others, and taking charge*. A second main theme was *finding the new normal*, which emphasized the central role of continuous reflection in self-management. Reflection allowed the participants to understand and know their condition and the fluctuations of symptoms, leading to a better understanding of their capabilities and supporting the process of adjustment and adaptation.

This focus on reflection, understanding, and building a life with meaning and purpose is at the core of positive psychology, which takes a growth and development perspective as opposed to the pathological perspective prevalent in the biomedical model (Ghosh and Deb 2017; Seligman and Csikszentmihalyi 2000). In the following, we will take a closer look at a few key concepts in positive psychology.

## 8 Benefit-Finding, Post-Traumatic Growth, and Resilience

As mentioned above, rehabilitation practices and research are still influenced by rehabilitation's origin in physical medicine. However, the biopsychosocial model and research in post-traumatic growth and resilience challenge this concept.

Traditionally, research has focused on the negative consequences of ABI. While this is understandable, given that 6 months post-ABI, approximately one-third of survivors develop clinically relevant psychological distress (Glintborg and Hansen 2016; Bombardier et al. 2010; Hackett and Anderson 2005), the fact that a substantial proportion of people with ABI do not develop psychological distress means that positive and protective mechanisms are also worthy of consideration. Thus, the field of ABI would be enhanced by the incorporation of the relatively new concepts of "post-traumatic growth" (PTG) and resilience, not least because they offer psychologically grounded entrées into the area of spirituality and meaning in ABI survivors (and partners).

Over the past 13 years, more people are subscribing to the idea that positive growth may be possible after ABI, particularly when changes occur in relation to a person's sense of meaning, purpose, heightened spirituality, and enhanced relationships after brain injury (Tedeschi and Calhoun 2004).

Around the turn of the century a paradigm shift occurred in the stress and coping literature with the evolution of a positive psychology approach based on constructs such as adversarial growth and benefit-finding (Tennen and Affleck 2002). This shift had been building for more than 20 years, largely from the work on post-traumatic growth (Linley and Joseph 2004). There followed a growth in the research literature on benefit-finding in chronic illness and disability (Helgeson et al. 2006), and also among family caregivers (Cassidy et al. 2014; Cassidy 2013). Helgeson et al. (2006) identified 235 studies, over half of which had been carried out between 2001 and 2006, and covered a range of chronic illnesses, war, sexual assault, disasters, and having a chronically ill child. Their meta-analysis concluded that benefit-finding was related to lower levels of depression and more positive well-being, but it was also correlated with more intrusive thoughts and was not correlated with self-rated physical health (Helgeson et al. 2006, p. 810).

Individual studies, however, have shown clear links between benefit-finding and health. One of the first in the area was conducted by Affleck et al. (1987), with 287 men who had recently experienced their first heart attack. Over 50% of men reported benefits and those who did were significantly less likely to have a subsequent heart attack and exhibited lower morbidity rates 8 years later, controlling for age, socioeconomic status, and disease severity. Several other studies have revealed physiological benefits (McGregor and Antoni 2009; Bower et al. 1998). Bower et al. (2009) propose what could be described as a resource model of stress to explain the pathways from benefit-finding to health, turning the traditional deficit model of stress (Lazarus and Folkman 1984) on its head. They proposed that benefit-finding leads to increased psychological and social resources, through improving coping

strategies, thereby making the individual more resilient and less responsive to stressful demands.

There is a large and increasing literature on the emotional impact of ABI. This includes systematic accounts of the natural process(es) of psychological adjustment undergone by the survivor and friends and family and also the development of therapeutic approaches to optimize adjustment (Glintborg 2015, 2019; Glintborg and Hansen 2016; Bowen et al. 2010; McGrath and King 2004).

In addition to focusing on what goes wrong with people who become chronically symptomatic and function poorly after adversity, we have begun to question what goes right in people who negotiate potentially traumatic events with equanimity. What are the natural mechanisms that allow people to cope successfully with adversity? However, the concept has in time suffered from serious conceptual misunderstandings, e.g., treating resilience as a personality characteristic, as the absence of symptoms and full recovery, or as a general term to connote average levels of psychological adjustment. Resilience can be summarized as a mix of several factors:

1. Personal competencies such as optimism and the ability to adapt
2. Psychosocial factors in an individual’s family
3. Context-based factors such as a supportive school and workplace.

The study of resilience in individuals with ABI is in its infancy, but initial results already suggest that resilience contributes to positive rehabilitation outcomes (Bertisch et al. 2014). Research has indicated that most people who experience a traumatic event are resilient and “bounce back,” even though initially they may catastrophize when predicting their emotional reactions (Gilbert et al. 2004). In general, people are poor at predicting how long their emotional reactions will last: overprediction of distress is generally matched by a faster-than-anticipated return to baseline functioning. Although this response pattern has been documented in individuals without cognitive impairment (Gilbert et al. 2004), it has not been adequately examined among people with cognitive and emotional changes secondary to a neurologic injury, such as ABI.

Every ABI is unique: even though two individuals may suffer from the same type of brain injury, this traumatic event will have individual consequences, and they will adjust and cope with it in different ways. Based on interviews with adults, Larsen and Glintborg developed the ABI resilience model (Larsen and Glintborg 2018). This model is a further development of Herrman et al.’s resilience model (Herrman et al. 2011, p. 261), which presents an overview of factors that enhance or reduce homeostasis or resilience (see Fig. 7.1).

Larsen and Glintborg’s model provides an overview of risk factors and protective factors contributing to resilience after ABI. It is important to see individual characteristics and social factors as interactive. Thus, this model rests on a dynamic understanding of resilience. Resilience is seen as a multifaceted system with three possible outcomes: post-traumatic growth (PTG), resilience, or broken spirit/struggling/mental illness. This chapter offers resilience as an integrative perspective that can illuminate the traits and mechanisms underlying the sustainability of a good life and recovery from distress for individuals living with long-term pain after ABI.

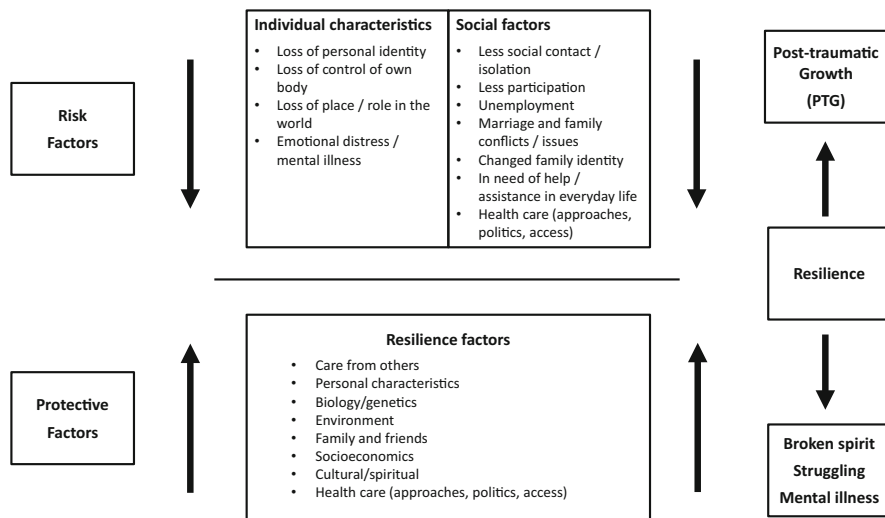


Fig. 7.1 ABI resilience model (Larsen and Glintborg 2018)

## 9 Asking Those in the Know

There is no doubt that living as well as possible with disabilities after ABI and long-term pain requires resilience and courage. For those of us, who are fortunate enough to not have such challenges, it is hard to imagine what it is like. It is therefore important to ask those in the know. Rather than conducting a full, systematic research project, we chose to focus on two case stories and employed a minimal analysis.

The data collection procedure for these case stories was conducted by author SK. Ethical approval was sought and given by a British university. Two participants, a man and a woman, were recruited using purposive sampling (Etikan et al. 2016) through voluntary sector support organizations. Recruitment through such organizations ensured that the participation was voluntary and that the participants had sufficient capacity and resilience to cope with the interview and the publication of their personal stories. Anonymity was ensured by not naming any personal details, including the exact age of the participants, neither at the time of interview nor at the time of their injury. Prior to data collection and interview, the participants were given information about the purpose of the study and they were informed about their right to withdraw their consent, should they regret their participation subsequently.

The data used in this chapter are from the individual interviews. However, to support participant recall and reflection, they were each asked to keep a reflective diary for 1 week prior to the interview. The diary consisted of specific sheets designed to aid reflection, for instance, “A day in my life,” “What pain feels like,” and “What pain means to me.” The diaries were used to prompt recall and guide



discussion. During the interview, participants were asked open questions about their experience and meaning of pain at various levels (e.g., sensory, existential, social, emotional), as well as how they cope with living with both pain and the effects of an ABI.

The interviews were transcribed staying true to the dialect and including laughter and pauses (not timed). No other details were recorded (Gardner 2001). During the initial reading of the transcripts, it became clear that each case story was significantly different. Authors LH and SK discussed the pros and cons of analyzing the two stories together. We eventually decided to analyze each story separately to avoid masking their uniqueness through joint analysis. Nevertheless, the main differences and similarities of the two cases will be discussed after the presentation of each case story.

Various phenomenological methods of analysis were considered, and Moustakas’ method (Yüksel and Yildirim 2015; Moustakas 1994) was chosen because it explicitly involves reworking the data from each dataset into a structured narrative. Moustakas considered data collection and subsequent analysis a joint work between participants and researchers, where participants provide a narrative that aims to express the meaning they ascribe to the phenomenon in question. Moustakas therefore considered participants to be co-researchers, and the participants were involved both before and after the interview, where the data used for the analysis were collected. The formal analysis was conducted by author LH and the researcher analysis followed the stages recommended by Moustakas, as detailed in Table 7.1.

In the following, each constructed case story is presented in its final form, followed by a discussion of key features of each case story and a comparison of similarities and differences that are relevant to our understanding of what it is like to live with ABI and long-term pain. The names of each participant are of course pseudonyms. The participants gave their consent to the publication of their stories.

## 10 Julie’s Story

### 10.1 *The Stroke: A Painful Journey*

At the time of interview, Julie was in her thirties. When she was in her late twenties, she suffered a stroke, which left her with presumed locked-in syndrome in the acute phase. She was paralyzed, only able to move her eyes, but conscious of her body and her surroundings.

Julie nevertheless recovered from her injuries, but was left with long-term pain: headaches, low back pain, abdominal pain, as well as spasticity, neck and shoulder pain, and muscle stiffness due to right hemiplegia. In addition, Julie reported having suffered gallbladder problems as a consequence of her stroke.

The impact on Julie and her life, in addition to the pain, included poor balance causing frequent falls, fatigue, and limited physical capacity for daily activities, for

**Table 7.1** Stages of analysis according to Moustakas' phenomenological analysis (Yüksel and Yildirim 2015; Moustakas 1994)

Stage	Research action in present study
1. Horizontalizing	The transcripts were read through and irrelevant data was removed. Note: due to the use of diaries, the discussions with the participants were highly focused, so only a small amount of data was eliminated.
2. Reduction of experiences to the invariant constituents	Each transcript was reduced separately, resulting in two different sets of themes, with each theme containing data representing only one meaning.
3. Thematic clustering to create core themes	Resulting in the main themes found in each of the below case stories.
4. Comparison of multiple data sources to validate the invariant constituents	Conducted by authors SK and GH by validating and comparing the coded data with the data contained in the diaries and the reflective notes made after each interview.
5. Construction of individual textural descriptions of participants	Each dataset was reworked into a narrative describing the key features of the participants' experiences, whilst staying close to the verbatim excerpts.
6. Construction of individual structural descriptions	A more in-depth interpretation of the material, considering how the experience occurred and what it might mean to the individual.
7. Construction of composite structural descriptions	Note: This was done using imaginative variation, which is a process of looking at the data from a range of perspectives with the aim of generating a deep and complex understanding of the phenomenon. Throughout this analysis the findings are structured and presented systematically. The perspectives used in this analysis included existential meaning, learning and change, relational connections, resilience, and coping.
8. Synthesising the texture and structure into an expression	Each case story was re-developed into a structured narrative comprising both the verbatim expressions from each participant as well as key interpretations. These final case stories were presented to each participant to ascertain their agreement of the content as well as final consent to use the constructed narratives for publication.

instance, limited use of her right hand and difficulty standing up for any length of time.

The way Julie makes sense of her brain injury and pain is intricately linked to her coping and management of her condition. In the early stages, she was in pain and crying "*all the time*." She was medicated for the pain, leaving her pain free much of the time, but it still seems to have been a painful experience. As Julie describes it:

*... when I first had my stroke, like I said, because I was completely paralysed, I couldn't talk and I was, all the time I was crying and they, I couldn't say to the nurses, "this is what's wrong". It would happen and a lot of the time I wasn't in pain, I don't, I can't explain why I was doing it but it seemed to me a lot of the time*

*that they would just give you morphine and it felt a lot like they were just doing it to shut me up. That’s how I felt. There wasn’t a lot of time spent trying to, like one on one, trying to . . . I understand communication’s hard with someone who can’t speak but the tools were there later on, like an alphabet chart using my eyes, that came later on but they didn’t even try it.*

After discharge Julie struggled from time to time with her gallbladder problems. A couple of times a year her gallbladder would get infected, causing levels of pain that left Julie feeling like she was going to die. The gallbladder was later removed, and that type of pain experience was no longer an issue. However, it seems to have been an experience, which later enabled Julie to put her remaining pains into perspective:

*. . . luckily I don’t get pain like that now. I wouldn’t say, I do suffer from pain, but I think it’s not a chronic... And you hear about other people and I feel really lucky that I don’t have to manage that constantly and I don’t have to take a lot of medication . . .*

Interestingly, Julie’s view is that her pain is not chronic, yet she does describe being in some form of pain or discomfort all the time:

*. . . there isn’t a time, like there’s always something going on, like there’s always, I’ve always got a pain somewhere, erm, you know. Doesn’t necessarily mean I’m having, like, you know like I said about my tummy, I’m having an attack of that, or something’s always aching or even just a dull ache where you can get on with it. There’s always some kind of pain somewhere.*

Nevertheless, when asked about what the pain means to her, Julie immediately answers: “*I feel very lucky.*” Again, the experience of having been paralyzed and unable to communicate allows Julie to put her current pain experiences into perspective. She is also comparing herself to others with chronic pain, whom she perceives to be in more pain, more of the time. This seems to help Julie cope as it is a perceived benefit.

However, her injury has left her with a life different to the one she had expected, and her limitations make her feel older than her age.

*. . . anytime I feel pain I just feel older than what I am. [. . .] everything is more effortful. And I just feel you know, I’m only [in my thirties] and like seeing how things are just so much harder and they hurt more and it’s kind of like, like I said, like getting up, you wouldn’t expect that to be painful but it, like, it is. And it just makes me feel like older [. . .] you feel like you see your friends and your peers, even my mam and dad, you know, doing things and you think “oh god, I can’t do that and I’m only half their age” . . .*

## **10.2 Learning to Live with It: Get Tuned into Your Own Body**

Julie described the process of learning to live with her brain injury and long-term pain. Her initial experience was one of expecting to be able to do what she was used to doing, only to discover that her body could not do what she wanted. Experiences

like that would leave her “wiped out” for a few days. Julie’s way of learning was through “*trial and error*” and often learning what she could NOT do by going through an uncomfortable experience.

*You maybe try and do things and think, “oh God, that was really uncomfortable”. Like I went to like a day festival. I didn’t take my wheelchair. I was being stubborn and thought I could manage this. And there were limited places to sit down obviously. I can’t get on the floor. I can get down, but I can’t get back up. And I learnt from experience like that, it was uncomfortable, it made me, it ruined the day cos I was in pain. And it was just like, you know, “I can manage this if I’m in my wheelchair”.*

On the other hand, trying to do things she used to do eventually helped her find out what she could do and how to do them. This “experimental approach” shows Julie’s personal competences; she was motivated and determined to learn and adapt, and this promoted her resilience. Her personal approach was combined with collaborative support from health professionals, which seemed central to that process.

*Things are gonna be hard or more difficult to do and they might take more planning, but I think as you learn and you learn to adapt to these, you learn what things you can do.*

*It’s like with physio they have different methods, so it’s not just a standard physiotherapy. They’ll try techniques, they will try and you just pick up new things and you learn things from different.. like your occupation therapists they would maybe be telling you different way to kind of, like do an everyday task but if you say, “this is hurting” then they will maybe suggest an adaptation that manages it . . .*

As part of learning to live with the effects of her stroke, Julie needed to inform herself. For instance, she found information online and, through that, realized that every stroke is different and, maybe more importantly, people’s experiences of brain injury and pain vary.

*. . . every brain injury is different and the way people experience pain is different.*

To Julie, the consequence of this is also that you have to find your own way to a new way of functioning.

*Everyone’s different but for yourself you know, I think you get tuned into your own body.*

### **10.3 It Is All a Bit of Trial and Error**

Talking about her pain and “tuning into her body,” Julie described how she has learned that certain sensations and pain are a forewarning of worse to come. This allows her to take steps to manage her pain before it flares up.

*I’ll kind of get a little niggling pain and I know. It’s as if your body’s like telling you, like, or something will happen now.*

*More like with my shoulders, as well, I get a tingling like, it feels like pins and needles, and then I know that my shoulder’s gonna be aching. It seems as if I get a kind of like prewarning. It doesn’t just suddenly come on. Something will happen and I’ll think, “right, this is”, you know.*

She has also learned that some pain comes as a result of what she does and how she does it.

*My shoulder tends to ache more if I’m sat doing work, sat in my chair, like posture and I’ll think, right, it will start and I’ll think right, I need to kind of take a break and have, like do something else for a bit.*

Other pains are different and do not serve as a prewarning that helps her manage. Her restless legs she cannot do much about as they happen when she is in bed. However, the pain and discomfort are predictable, and they do not interfere with her activities, which seems to help from a psychological point of view.

*But more with the restless legs, only tends to happen when I’m in bed so that won’t make any difference.*

However, it is not only the pain that needs to be managed. Because the impact of the stroke has left her disabled, there is a need to manage her activities, what she is doing, how she is doing it and whether she needs to wait until she feels more able to be active.

*It’s [studying] just one of them things you’ve got to try and manage. I mean, a lot, like, obviously since my stroke I, I suffer a lot more with fatigue and it is like about managing your time. And it could like, with experience, when it first happened, like, “oh I can do this, do that” and then like your body’s just, you can’t do it. Like you’ll be ok at the time and then the next few days I’ll be absolutely wiped out and it’s kind of like, you can’t keep up with it.*

*And I just have to try and manage it the best I can, you know. It’s not the end of the world if I’m doing something and I need to take a break or I’m having you know, one of these attacks in my stomach and just go, you know, I just think I need to find another time when I can do it. I have to plan a lot more but that’s not, I think that comes into kind of all areas of my life. Not just about managing the pain, about managing everything.*

Recovery after activity and generally resting is an important element of Julie’s management strategies, but that is not always easy, when pain and discomfort keep her from falling asleep. However, she seems to find mindful breathing a useful way of managing her pain and get some relief and she acknowledges that sometimes she needs to just stay with the pain until it eases. This demonstrates Julie’s positive approach and ability to cope and self-soothe, even when the pain is really bad.

*Generally, if I try and have a rest and have a sleep I generally, I feel ok.*

*This [restless legs] happens every night and the period of time it goes on for, you know, cos my sleep, I’m not, I struggle with getting to sleep and you know, this kind of seems like it exaggerates it more if I’m . . . It’s like a vicious circle, you’re trying to get to sleep but you’ve got this and the more it goes on, the more you can’t get to sleep.*

*But something as simple as just breathing, controlling your breathing, you know. It is uncomfortable cos you do have, like it’ll take different time for different areas but if you just sit with it and breathe through it, eventually it will go.*

*. . . trying to just, acknowledge it’s there and it’s happening and I think you’ve just got to be with it.*

## **10.4 Do Not Let It Stop You!**

The meaning of pain and living with pain seems reflected in the attitudes that Julie expresses. Personal attitudes are easily challenged, when the body changes from a healthy one to one with limitations and pain. Julie's independence was challenged, and she found herself with no other choice than asking for help when needed.

*I think that's one of the things I had to come to terms with and learn to adapt, cos I was very . . . erm . . . you know if I wanted something doing, I'd do it myself and just get on with it and I didn't like asking for help. But when, depending on your injury, your brain injury, sometimes you have to do these things.*

On the other hand, her need for independence seems to be motivating for her. She is keen to find solutions and she has a "get on with it" attitude. Other aspects seem to be refusing to let the pain win and trying to stay positive. When the pain is bad, Julie reminds herself that it is "not going to last forever."

*I think I've just learnt, just try and get on with it the best I can.*

*You've got to try and manage it and not let it stop you doing things. [. . .] You can't give in to it.*

Julie seems to have developed a new attitude that is central to coping with her physical limitations and pain. Her view on the future has changed because she has recognized that the limitations reach further than her daily living. Consequently, she is focusing more on the here and now and less on what the future brings. However, this change of attitude has not come easily to her.

*You know, that was one thing that I struggled a lot with was like thinking about the future and worrying about things and I've kind of just learnt to just take one day at a time, you know.*

## **10.5 Adjusting to a New Identity**

Like mentioned above, accepting the use of a wheelchair was a challenge to Julie. It is like she did not want to be associated with the image of being in a wheelchair, or not wanting to stand out and draw attention to herself. It could also be adding to the discomfort of feeling older than her age.

*. . . ever since I've had my stroke, I've had a huge thing about, I don't like to be seen in it [the wheelchair]. And I've really struggled, like that's caused problems.*

It is also important to Julie to be seen to cope and to not come across as negative. She is aware that her friends would accept and support her regardless, but she seems determined to keep the independent and coping part of her identity and only compromise, when it is necessary.

*I understand what it's like when you're having a conversation with someone and someone is very pessimistic and they're always complaining about something or, and it is, just, think it brings you down, you know. And I'm very aware of people can be like that and I don't be like that and I don't want to come across as that as well. I*

*think all of my close friends are aware of it and they probably wouldn’t even bat an eyelid if I was going like that, if I was saying, “oh, this is hurting, that is hurting”, and whatever but me personally, I don’t want to come across like that.*

*It’s, all like, about making things easier for yourself. I think that’s one of the things I had to come to terms with and learn to adapt, cos I was very . . . erm . . . you know if I wanted something doing I’d do it myself and just get on with it and I didn’t like asking for help.*

## **10.6 They Are Close Friends, It Is Not a Big Deal**

Julie reported having good relationships with her close friends, whom she trusted to be supportive and understanding. This seemed particularly important to her in terms of being able to balance her social life within the constraints of her condition.

*To be quite honest, like, my close friends know and they, cos I can just cancel things and say, “look, I’m having this, this is happening, I can’t come”. And it’s not, like for my close friends, I wouldn’t say like they expect it but they kind of know, I’ve explained it to them and it’s not so much of a big deal, you know.*

Nevertheless, the unpredictability of her pain sometimes forces Julie to cancel planned events, making her feel that she is letting her friends down. Julie expressed feelings of guilt and feeling responsible for helping her friends having a good time. Her sense of responsibility compels her to try and manage the situation, she has left her friends in, maybe as a compensation for not having succeeded in managing her pain well enough to be able to be reliable socially.

*. . . its always like I’ll text, “I’m really sorry”, you know. Like I understand I can’t help it but I just feel guilty that I’ve had to cancel. Cos, well in the past when it’s happened it’ll be things that were planned, you know, for a while. It’s not just a spur of the moment thing, it’ll be a plan, and then I’ll feel like I’m, like it’s last minute and I’ve left them in the lurch cos they’ve been planning it as well. And I’ll try and like, “oh, can so and so go” and like make plans, you know, and not just say, “I can’t come, that’s it” kind of thing. It makes me feel . . . awful, really. Just . . .*

## **10.7 More than Just a Therapeutic Relationship**

Living with disability and pain also means developing long-term relationships with health professionals. Julie seems to have had good experiences with this, including good continuity of care with communication between her and her therapists—and among the healthcare professionals—being central to good progress and the experience overall.

*Like obviously they have their MDT meetings when you’re in hospital, they all do work together but it’s just things that you pick up, you know, now you’re not in*

*hospital. It's just nice and a lot of the time, these professionals, they all know each other and it's just nice that you kind of work together and they all acknowledge what everyone brings to the table.*

Julie also reported the importance of trust and a personal element to the professional relationships. She seems aware of the value of an equal, collaborative relationship, where there is trust and an absence of judgment.

*And I think you've kind of got to build up a trust with, you know with the brain injury I'm lucky that the group I've worked with, like the physio I see now is the physio I've seen since I first had my stroke, so he's been with me throughout. And it's quite personal. I think you've got to have like, everything you tell them. I know before my stroke I wouldn't like going to the doctors, I'd feel judged, I just didn't like going and I'd avoid going at all costs. I think I'd have to be pretty much at death's door to go. But I think now, I've had a lot of the same health professionals and they kind of understand and you don't feel, like I don't feel that judged now. I can go and they'll, it's nice they'll remember things and they've got that, it's more personal. They kind of seem to remember you as a person and what's happened and what's going on and it's just that personal touch, it makes it easier.*

*I would say it even goes a bit further than a therapeutic relationship. Not a friend but it's more, it's more.*

## **10.8 The Pain Is My Brain Injury**

For Julie there is no differentiation between the various effects of the brain injury, whether the physical impact of the hemiplegia, the different types of pain she gets, or any cognitive issues she might be experiencing (she does in fact not mention anything about such issues). For Julie it seems that it is all one big thing that she needs to get her head around.

*... as a consequence of the brain injury, it's all, like the physical difficulties that cause me the pain, so I kind of manage together.*

*I don't know, I think it's just learning things, erm, that kind of work for you. Like management. You've got to ... like for me it's rest.*

Julie's story takes us through a process of adaptation and learning from the early days of paralysis and isolation to a point of living a daily life with pain, discomfort, and constraints, but nevertheless a life that works for Julie. She has learned through trial and error, but also through forging trusting and collaborative relationships with the rehabilitation professionals, who worked with her along the way. She has a level of control through management of her activities and pain, which allows her to engage socially with close friends, who are not judging her. The journey has shaped her identity in a way, which shows resilience and post-traumatic growth. She is determined to stay positive and find the benefits by putting things into perspective.



## 11 Mark’s Story

### 11.1 *The Accident Leading to Brain Injury*

At the time of interview Mark was in his thirties. Around 10 years earlier, he had had an accident on his mountain bike. He had hit a rock and fell face first to the ground. As a result, he acquired a significant brain injury, predominantly affecting his frontal and occipital lobes as a result of the brain being pushed backward and then forward by the force of the impact.

Mark’s ensuing impairments included hemianopia, with loss of the right field of vision, and he was left with very limited reading abilities. The impact of this was loss of his driving license and being unable to do the kind of occupation he had hoped to do. Prior to his injury Mark was studying for a PhD. Now Mark reported having no occupation.

Mark was less explicit about his frontal lobe injuries; however, from his description he seemed to have some executive dysfunction with attention deficits and impaired awareness leading to risk-taking behaviors. Crucially for this chapter, Mark’s pain perception seems to have been affected by the injury, because Mark expressed an inability to feel pain or only feel acute pain without being too bothered by it.

### 11.2 *If It Does Not Hurt You, It Is Not Pain*

Mark was able to report on a range of incidents, when he was likely to have experienced pain, at least if he had not had his brain injury. In fact, prior to his injury he was able to feel and to react to pain in normal ways, so Mark did have a concept of pain. However, talking about his pain post-injury, he explained it was a mere “*mental*” or cognitive recognition that he had injured himself in some way.

*For me it’s more of a mental thing because if it doesn’t actually physically hurt you, you can’t accept it as pain, you know.*

Mark seems to have learnt this mental recognition of pain and injury from people around him. He mentioned his daughter as someone central to this understanding. Another way of recognizing pain for Mark would be if he was bleeding.

*My girl does lots of things that make me realise I should be responding in a different way to like pain and stuff.*

*I cut myself, hold my hand above my head until it stops bleeding and then get a covering and carry on.*

However, it does seem to be possible for Mark to detect pain on occasions when it is acute.

*So, unless the pain is kind of, instant and acute, I won’t notice. It’s subtle change that doesn’t really make much difference.*

### ***11.3 I Do Not Let It Stop Me***

Mark's limited capacity to perceive pain seems to have had an impact on his behavior. Mark reported being accident prone due to the loss of the right side of his vision; however, there was also an element of not considering risk or the potential consequences of doing certain things, such as cycling.

*I used to feel pain, but I don't let it physically stop me doing something. I don't respond to it. I think if you've got pain, you get over it, you know.*

*So, I still cycle a lot, but I've had quite a few accidents, because I can only see half the world, I do have accidents. Yeah, again...once I cycled into a lamppost...you might bleed, it doesn't matter.*

Mark reported that he would ignore not only pain, but any other physical discomfort as well. Looking closer at Mark's tendency to ignore the potential risks, there is an element of priority in his choices, in spite of having a level of awareness and understanding of risk. Nevertheless, he acknowledges that it is a "terrifying" experience to cycle, so the choice is probably not "fully informed" before Mark sets off. The likelihood is that he only thinks of the risk once he is on his way and then feels the lack of perception and control. Mark reported feeling upset about having lost his driving license and, hence, his ability to go where he wants, when he wants. This seems to be the underlying and meaningful driver for his behavior. The question is whether Mark does feel pain at some level, but his determination to live has helped him learn to ignore pain, unless it is a severe "breakthrough" pain.

*... if 'm going out to something or my friend and me want to meet up and I've got a cold or something, I will deliberately ignore it and go out because things aren't organised very often and because I've had my driving licence revoked and I can't really get anywhere, well I can't afford the taxi.*

*I went to the hospital for an eye test. [...] it said make sure you get somebody to give you a lift because they put the drops in your eyes and the pupils expand and stuff. But again, I cycled to the hospital and I cycled back and I was terrified. [...] I take unnecessary risks regularly.*

*I mean with a severe ear infection cycling [like I did] I was an absolute mess. I couldn't hear at all. My right ear just shut down completely and I thought, you know, the body still works so use it. Obviously dangerous, you know, cycling with half a bloody vision, half an ear not working, it's terrifying but I thought if it's not physically stopping me doing anything, I'll do it. I've got to accept when I've got an illness, accept it. But I don't like to, cos I can't drive now, when people organise things, I want to go to them.*

I don't call it serious unless it stops you physically doing something.

Seeing friends and participating in activities is important to Mark, and with all the losses the brain injury has caused him, he is determined to not lose that as well. However, it seems even more essential for him to maintain a level of independence and keep as active a role in his family as he can. His determination and the strong

drive for independence contributes to psychological resilience and a level of post-traumatic growth.

*[Before,] I wouldn't have let it [the pain] stop me completely but I would have been a lot more hesitant. But again, I could drive and that changes everything because I could actually go somewhere. Ok, now my girlfriend could go to the shop and stuff but I don't want to rely on her. I don't want to rely on her at all for anything. The car's hurt me so much now. I want to, you know, unless I physically can't do something, I'll do it.*

## 11.4 You Only Live Once

The meaning of pain and brain injury for Mark seemed to be very existential. He was basically saying it should be ignored and not allowed to get in the way of living.

*The thing is, you live once and I want to live it to the max still. I want to do something; I want to do it now because you could be dead tomorrow.*

Mark's family seems to have been central to helping Mark change his perspective and accept his life as it is. Talking about how his girlfriend and daughter have helped him realize his lack of pain perception, he expressed an experience of happiness and acceptance. Having this level of support from close relationships has contributed to his resilience and adaptation to his condition.

*. . . it's good because I finally accepted. Basically, it's made me accept my, my disability.*

*I'm very glad. I'm much, much, I'm very happy with it. Because before I wasn't accepting it, if people say I'm fine, I'm fine. But now I'm accepting, ok, this brain injury really has affected how I see everything . . .*

However, even though Mark claimed to have accepted his disability and not feel physical pain, he did report having negative emotional reactions to accidents and injury. His loss of vision and a limited attention span would often be the cause of accidents, but he would blame himself, as if he were at fault. It seems like the acceptance he is expressing is more a recognition that his brain injury has changed him and that he needs the feedback from others to know how to be. His frontal lobe injury probably prevents him from having a more internal insight and he is likely to have difficulty concentrating, so even if he has a learned awareness of the issues that comes with the hemianopia, it is hard for him to be mindful all the time. He nevertheless experiences that his body is causing accidents, and as the body is his, it must be his fault. He seems to be thinking like it is his old, healthy self causing accidents, rather than accepting that it is a consequence of his brain injury.

*I know people say you should look all the time, but you can't be every single hour, you do have moments where you turn off a bit and that's where I do silly things.*

*I'll always berate myself because it's always the bloody vision that does this you know, because I can't see the right, so I blame myself.*

*Now I've twice played football with these people and with others I've had an accident. Once, the guy was leaning backwards, I could hardly see him at all, he ran*

*bang into my nose, my nose bled. But again, I view it as completely my fault. Even though I was in pain and stuff, it was completely my fault. I should have been paying attention.*

Overall, Mark's strong drive to live as independently as possible and to do things that are meaningful for him are psychologically protective, helping him to be positive and resilient. Socially, his family is a key resource for him, both in terms of increasing his awareness of the problems he is facing and providing him with an important role in life.

In fact, this is just half the story, because Mark's propensity to ignore the risks may be largely due to the frontal lobe injury having changed his pain and risk perception as well as his capacity for planning ahead and ability for inhibition of impulses. Therefore, from a psychosocial adjustment point of view, his expressed acceptance of the injury is incomplete. To be fully adjusted from an objective point of view, he would also need to accept that he cannot cycle anymore, as he puts himself at risk of further serious injury or death. However, this is also an example of the power of meaning — it is more meaningful to him to participate in life and be with his friends than to protect himself. So maybe it is a better adjustment to live life dangerously?!

## **12 What Have We Learned from Julie and Mark?**

One of our questions above concerned how ABI and long-term pain interacts in people, who live with both conditions. Whereas there undoubtedly are clinically relevant interactions, an insight we get from the case stories is that, in the lived experience, the two are not clearly differentiated. Although Julie and Mark tell very different stories in terms of their pain experience, they both give the impression that it is all “one package” to be managed. Julie directly says that her pain IS her brain injury, because the various difficulties she is experiencing, including her pain, all stem from the stroke incident. In fact, neither Mark nor Julie consider themselves as living with long-term pain: Mark, because he does not acknowledge the pain; Julie, because it is not there all the time, and she has a level of control over it. Maybe it is not unusual that they do not differentiate their ABI and pain. Someone with, for instance, inflammatory bowel disease (IBD) will most likely consider the IBD to be the condition they have to deal with and the pain just one among several symptoms.

However, whereas Julie and Mark seem to experience ONE condition, from a health service perspective they have (at least) two different conditions, and therefore come under the term “multimorbidity.” The increase in long-term multimorbidity worldwide presents not only a major health economic challenge but, more importantly, it challenges the organization of our health services (Soley-Bori et al. 2020). It begs the question how to develop health structures that can accommodate people with multiple long-term conditions, who present with a range of symptoms and functional challenges that are likely to interact, but are experienced as a whole by the person, who is trying to live with the impact of their conditions.

Another similarity between Mark and Julie is the will to “move on,” to not let the pain and other issues stop a meaningful life. Both are stories of resilience and post-traumatic growth; they both express acceptance and even feeling happy, or lucky. This is not to say that life is easy for any of them; but it is the overall meaning they convey about where they are in their lives. For Julie, there seems to be an element of perspective in her attitude; having experienced a period of locked-in syndrome; just being able to live a relatively normal life is a benefit. Mark’s reaction seems similar; he expresses intense appetite for life, as if this is his “second chance.” These are examples of benefit-finding, which has been shown to be important for resilience and adaptation to living with chronic conditions (Bertisch et al. 2014).

However, whereas Julie conveys a detailed view of her coping that gives an impression of good psychosocial adjustment and a meaningful way of living life within the constraints of her condition, Mark’s story leaves us with questions. Firstly, does Mark have long-term pain? Not in the simple diagnostic sense of chronic pain, which is pain that persists beyond 3 months. However, Mark does have a long-term problem with pain because the hemianopia causes him to have frequent accidents, and not feeling (or perceiving or acknowledging?) the pain reduces his fear of pain (and thereby self-protection mechanisms) and possibly also his self-care post-injury. Does Mark actually feel pain? Or, like congenitally analgesic patients, has he learnt a set of prudent responses to minimize tissue injury, which do not amount to an experience of pain *per se*? It seems that there is doubt about the meaning of the word “pain” as uttered by Mark: whether he has a concept of pain. What is the basis of our suspicion about Mark’s capacity to experience pain?

One consideration is that, despite Mark’s avowals of personal pain, he shows no, or little, reaction to pain. He says he feels immediate pain, but he does not seem to do much that we normally regard as inseparable from feeling that way, even though he does sustain certain acute injuries, and he takes measures to deal with them. In the situation like Mark’s where an individual’s self-ascriptions of pain do not lead to agreement in pain judgments, we must determine whether the person understands what counts as pain; it is possible that he is just making a mistake about what his present state should be called (this occurs in some patients with advanced cancer-related pain). The conclusion we arrive at will depend on the person’s application of the term “pain” in different situations, and the role the person gives the concept in a range of thoughts.

It is unclear what Mark *feels*, but focusing on that aspect alone leads to an incomplete understanding of pain, since it is clear that feeling pain has intrinsic connection to reacting in certain ways. In the same way, when we examine the neurological instruments used to document consciousness in patients, such as the Glasgow Coma Scale, we use signs of cognitive engagement with the world and attend closely to the manifestations of cognitive attunement to the environment. Thus, given Mark’s personal account, there is no doubt that his pain perception is altered in some way. Is it that, which enables him to ignore any pain he might experience, or is it his appetite for life and fear of missing out that makes him ignore the risks of cycling with only half a field of vision?

Frontal lobe injury often leads to impairment of the working memory (Smith et al. 2015), and this seems to be the case for Mark. Working memory is essential for complex planning, risk assessment, and decision making, and we get the impression that Mark's planning is relatively simple. He wants to be with his friends; he is not allowed to drive a car anymore, so he uses the bicycle. This is an excellent example of the power of meaning. It is meaningful for Mark to keep in touch with his friends, so that is what he does. That it involves a terrifying bike ride is "by the by" and only a temporary inconvenience in the here and now, while he is on the bike. There seems to be no advance fear of the ride and limited rumination over what could have happened afterward. On the other hand, when he causes injury or upset in others, then he blames himself and gets angry and upset. He is taking personal responsibility for something that is caused by his disability. We do not know whether Mark has had rehabilitation interventions for self-management of his hemianopia. It is possible to learn to compensate for the problems. Mark may have had an intervention at an early stage before he developed his awareness of the consequences of his impairment and, hence, would have been able to engage with the strategies with motivation and intent. In other words, he may have had an intervention at a point in his recovery, when the learning did not have sufficient meaning for him.

In any case, from a psychosocial adjustment point of view, at least seen from the outside, Mark does not seem to have adapted to his condition. He does not have appropriate strategies for keeping in touch with his friends without putting himself and others in danger of accidents. In this case, good psychosocial adjustment would see a greater level of cognitive engagement between Mark and his environment: he would, for example, negotiate with his friends and express his needs, leading to, for instance, an agreement that his friends pick him up, when they want to spend time together. Nevertheless, Mark expresses acceptance and even happiness.

This begs two questions: Who is optimal psychosocial adjustment optimal for—the individual or society? What is optimal psychosocial adjustment—that which is meaningful, that which is functional, or both? If Mark were to accept his limitations and stay at home, not seeing his friends, that would most likely leave him unhappy and maybe even depressed. In reality, good psychosocial adjustment is about reasonable compromises and making the best of a bad situation.

For both Julie and Mark, an important source of meaning has been their close relationships. Julie talks about trusting her close friends to not judge her and to be there for her, even if she occasionally lets them down, when the pain gets too bad. For Mark it is his close family, without whom he might not have realized that he is supposed to feel pain when he injures himself. We do not know whether the awareness he has developed through feedback from others has helped him modify his behavior and make him less accident-prone. His attitude of not letting it stop him doing anything suggests that there may be limited change. However, Mark expresses the importance of going shopping as a way of helping his family. This could be Mark holding on to having a positive role within his family and holding on to a part of his pre-injury identity. Role-based goal setting has been found to be more meaningful than function-based rehabilitation. The life roles and community participation goals motivate the individual, but the result is still improvement of function (Dungey et al.

2020; Pick et al. 2020). This is consistent with the findings in Kılınç et al. (2020a, b) where meaning and purpose in life was seen as central to self-management in long-term neurological conditions. A sense of purpose supports personal growth and increases self-knowledge. It typically involves seeking relevant challenges and experiencing achievement, which is important for the development of resilience, benefit-finding, and post-traumatic growth.

Looking at Julie’s story, it could almost be any other typical story about persistent pain and pain management. The interviews were questions about pain to people with ABI and, although we did have some questions about the interactions between pain and ABI, we may have unintentionally caused bias in Julie’s story. However, as she considered her condition to be ABI and not long-term pain, the question regarding interactions was not meaningful to her. Nevertheless, the focus on pain is likely to have influenced the way Julie chose to express her experiences. The result is that we get limited information about whether Julie’s way of experiencing and adjusting to living with her long-term pain is any different from people who do not have ABI.

Julie’s story raises several questions. Firstly, Julie does not mention any cognitive challenges, e.g., short-term memory problems and difficulties learning, which are typical problems in ABI. Any such issues may not be pronounced for her, but it is important to understand the ways in which this might be a barrier to learning self-management of pain and disabilities. Julie does mention that it has taken her “a long time” to learn; however, that is not necessarily unusual or specific to people with ABI.

Further to that, Julie mentions working with physiotherapists and occupational therapists, but not in which context. It is most likely to be as part of a physical and functional rehabilitation program after her stroke, and not in any pain management context. She mentions learning to do things differently, if they cause her pain, with the help from these health professionals. Julie seems to have learned what she needed to learn to put her life back together and get back to doing some of the things that are important to her. However, the way she describes her own learning experience is “trial and error,” and this has the feel of experiential learning, which is our “natural way” of learning. As discussed in the introduction, the issue with that is that experimenting and learning from experience sometimes lead people to develop strategies that maintain the problems rather than leading to optimal function. We cannot see if this is the case with Julie, although the way she expresses her coping and management seems quite typical and reasonably sensible. Julie’s learning experience is “self-centered,” as you would expect, and not concerned with who taught her what and which domain each problem belongs to. As clinicians we are trained to think systematically and in discrete domains (cognition, neurology, physiology, psychology, etc.); for Julie it seems to center around what she can/cannot do (“agency”), how she can compensate, and what it all means for her identity and relationships.

The question is, therefore, how do clinicians best guide and strengthen this experiential learning in a way that optimizes an experience of “holistic learning,” which encompasses all functions and domains at the same time? Clinicians each have their core competencies, but to be effective and efficient we need to be able to

work simultaneously on all domains. Multidisciplinary teams were designed to do this but, as specialist services get reduced and generalist services in the communities become the main source of support for people with long-term conditions, clinicians ideally all need to be interdisciplinary, at least to an extent. However, the typical health structure in Western Societies rarely supports this. It is “easier” to send people round to various services than integrating the service provision in a way that is tailored to people’s needs. Providing holistic and coordinated care for people with multimorbidities is a major challenge.

### 13 Clinical Recommendations and Future Research

We do not have the answer to the question of how we can develop health services that can accommodate multimorbidity. However, psychosocial adjustment to long-term conditions is a psychological process that happens independently of which condition(s) people suffer from. A clear recommendation is therefore to provide access to psychosocial rehabilitation support and interventions, where necessary, across conditions. The consequences of poor psychosocial adjustment are costly (Barker et al. 2018), and if we can reduce the number of people struggling to accommodate their health and social needs, then there is not only financial savings to gain. Much more importantly, more people will be able to achieve a better quality of life and, most likely, be able to contribute more socially and financially to their community. Central to such psychosocial rehabilitation efforts is working with what is meaningful for the individual. This includes working with individual values, meanings, identities (Glintborg 2019; Glintborg and Hansen 2016; van Rysewyk 2016), and relationships (Hammond et al. 2019), as well as strategies to help people find benefit, develop resilience, and foster post-traumatic growth (Larsen and Glintborg 2018; van Rysewyk 2016).

In addition to cross-condition offers of support for psychosocial adjustment, we also recommend that all health professionals are trained in psychosocial rehabilitation approaches. Psychosocial adjustment has been part of their work for as long as there have been rehabilitation services, but the approach has been based on experience, intuition, and tools mostly developed for mental health interventions. These elements are all relevant, but probably not sufficient. Although work has been done to develop systematic, structured approaches to psychosocial rehabilitation in long-term physical conditions, none have been based on a theoretical understanding of the process of adaptation and change specific to long-term conditions (Dekker and de Groot 2018). It requires an integrated biopsychosocial approach that accommodates the functional approach from traditional rehabilitation as well as the wider psychosocial process of adjustment (Hammond et al. 2019; Hammond and Hirst-Winthrop 2018), and meaning-based work, as described above. Training in these approaches should be offered in a systematic and integrated way both within professional educational courses for new health professionals and also as continuous professional development courses for established health professionals. This is particularly



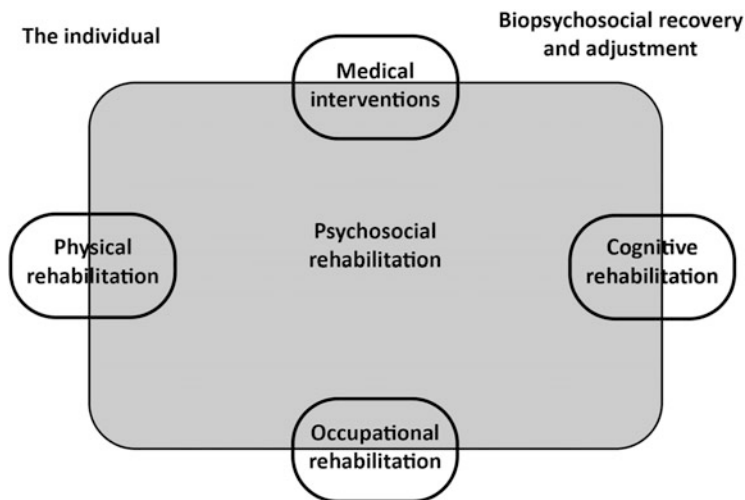
important for health professionals working as generalists in community rehabilitation contexts with limited access to specialist services. If we want to reduce the cost of poor adjustment for both society and people with long-term conditions, we need to get better at psychosocial rehabilitation as quickly as possible and across the board.

As mentioned, effective interventions need to be based on a sound theoretical understanding of the normal process of psychosocial adjustment. We previously touched on the issues of the vast numbers of people with long-term conditions, who do not adjust optimally (Barker et al. 2018). Looking at that issue from the opposite perspective, there are many who do achieve good levels of psychosocial adjustment without professional help specific to that process. The IMACC (Hammond et al. 2019; Hammond and Hirst-Winthrop 2018), mentioned above, is a theory of the normative psychosocial process, based on interviews with people about their experiences of adjusting to living with long-term conditions. The IMACC can also be used as an intervention tool by health professionals, and the strength of the model is that it provides a systematic way of identifying barriers to the normal progression of psychosocial adjustment. Furthermore, the IMACC is an integrative framework model with the potential to integrate existing theories and interventions already in use in psychosocial rehabilitation contexts.

However, whereas this presents a clinical and theoretical approach to helping people, it does not necessarily represent a picture of how people with long-term conditions think about their adaptation process. Kılınc et al.’s (2020a, b) self-management framework is directly based on people’s narrative of how they experience their process of adaptation. The framework was used to develop a reflective tool to support this process in people with long-term conditions. MyLifeTool (Kılınc et al. 2020a, b) is built on principles from positive psychology, which takes a growth and development perspective as opposed to the pathological perspective prevalent in the biomedical model. The tool is a reflective self-management tool that encourages engagement with self-management of any condition and problem-solving of challenges and barriers. The tool can be used by health professionals in group interventions or as an adjunct to their main intervention. As such, it has the potential to encourage continued self-management as well as preventing relapse and deterioration due to psychosocial issues.

If we want to make rehabilitation in acquired long-term conditions truly person-centered, then we must work from a basis of personal meaning, identity, values, life roles, and purpose. If we take our starting point within the psychosocial process of adjustment, and build the individual recovery and rehabilitation program within these personal frames, we are likely to see higher levels of motivation and, hence, better progress and achievement of higher levels of psychosocial adjustment. It is still possible to work systematically and in a structured way, but it requires turning the rehabilitation models “upside down.”

Traditionally, rehabilitation has focused on discrete functions “belonging” to different health professions, e.g., physical rehabilitation after a major road traffic accident in physiotherapy, occupational rehabilitation of daily living functions in occupational therapy, and, if required and if access is available and offered,



**Fig. 7.2** Proposed holistic rehabilitation model

cognitive rehabilitation in neuropsychology and/or coming to terms with life changes, anxieties, and identity challenges in psychology. Ideally, if we could do a comprehensive biopsychosocial assessment from the outset, including values, life roles, community participation, etc., as well as identifying the barriers that might get in the way of the biopsychosocial adjustment process, then we would have a basis for collaborative rehabilitation that is meaningful for the individual and their close relations. This could also reduce the issues of maladaptive learning due to a self-directed, experiential process with limited guidance. Nowhere would that be more meaningful than for people with multiple, long-term conditions like, as in the case of this chapter, people living with ABI and long-term pain. This alternative scenario is illustrated in Fig. 7.2: Medical and rehabilitation interventions are happening within the context of the individual's overall biopsychosocial recovery and rehabilitation process (the rectangular overall shape). This typically involves, depending on the specific condition, medical intervention, as well as physical, cognitive, and/or occupational rehabilitation. It should also involve formal, systematic support for psychosocial adjustment, which is a holistic process that needs to be accommodated across all levels of recovery and rehabilitation, and, in complex cases, involve formal psychosocial rehabilitation delivered by psychologists trained in rehabilitation psychology.

The dominant model of care in developed countries, stepped care, works on the principle of providing the most effective and least resource intense level of care and only stepping up to higher levels of care, where necessary. The model is evidence-based and cost-effective (Stoop et al. 2015). On the face of it, this seems incompatible with a delivery where the holistic psychosocial adjustment process is at the center of every individual encounter. However, this is already happening—health

professionals have always been working with individuals, who bring their biopsychosocial problems with them to any consultation and therapy session. What we need to do is raise the awareness of psychosocial adjustment challenges and better equip health professionals to recognize and support the psychosocial adjustment process. As mentioned above, there are now evidence-based tools available that could be adapted for training of and use by non-psychological health professionals. It would not take away the need for specialist knowledge and multidisciplinary specialized clinics, but it would improve the quality of care at the more generalist levels. It would most likely reduce the proportion of people with long-term conditions who struggle to reach a good level of adjustment and, consequently, reduce the health and social care costs for services impacted by the increasing prevalence of long-term conditions and multimorbidities.

More specifically, for the problem of long-term pain in ABI, there needs to be a greater awareness of this comorbidity issue and more training for healthcare professionals working with such individuals. Ideally, chronic pain services need to have at least one member of staff trained in how to support learning in people with ABI, and ABI services need to be able to deliver at least a basic level of pain management support. Alternatively, there needs to be a closer collaboration between chronic pain and ABI services, for instance, the possibility of developing a care plan, centered around the individual’s needs, and with collaborative intervention involving both services. In addition, both types of services need staff trained in psychosocial rehabilitation theory and methods. Looking abroad, we find that rehabilitation psychology has been growing as a field, especially in the USA, but rather less in Europe. Rehabilitation psychology is defined as “a specialty area within psychology that focuses on the study and application of psychological knowledge and skills on behalf of individuals with disabilities and chronic health conditions in order to maximize health and welfare, independence and choice, functional abilities, and social role participation across the lifespan” (American Psychological Association Division 22 2021). Psychological rehabilitation interventions should not only address clients’ psychosocial needs but also those of their families. Previous research (Glintborg and Hansen 2016, 2020) indicates such a gap in services, particularly a lack of psychological rehabilitation. Future research should look into the field of psychological rehabilitation that is currently in its infancy in Nordic rehabilitation, but seen in the USA and in some European countries such as Germany. This approach to the issue of rehabilitation might solve some of the current problems in addressing the psychosocial consequences of an ABI.

In addition to development of clinical services, future research needs to systematically investigate how pain affects learning and psychosocial adjustment in ABI, and vice versa. A better understanding of these interactions will allow further development and improvement of existing methods and tools that can support and enhance positive psychosocial adjustment and rehabilitation. A particular aspect that needs much more attention is how people living with ABI and long-term pain make sense of their condition and how they can be helped to create meaning and purpose in their lives. If comorbidity impacts on their ability to learn self-management in the

more traditional way through advice and formal learning, then we need to get better at using meaning-based learning to foster resilience and post-traumatic growth.

Finally, integrative methods specific to holistic biopsychosocial rehabilitation need to be continually tested and further developed, in terms of theoretical knowledge, effectiveness, and ease of use in clinical practice.

## 14 Conclusion

What is the meaning of pain for people with acquired brain injury? This is a complex question with many answers, some of which we have attempted in this chapter. Long-term conditions and multimorbidity are growing problems for health services around the world. However, for the individual, the experience of multimorbidity is a more or less unique collection of symptoms, functional challenges, and meanings. Managing such issues, when the support is spread over a range of health services, is likely to be a challenge in its own right. The added challenge for people with ABI and long-term pain is that one condition is likely to affect the other negatively, at least in terms of learning and developing good self-management strategies. Research shows the importance of adherence to medical advice for self-management and quality of life, so improvement of adherence rates and self-management is seen as a key strategy for reduction of health and social care costs. However, adherence cannot be improved unless we find a way to optimize psychosocial adjustment. Adherence needs to happen in the context of people's lives, and psychosocial adjustment is much more than just sticking to a self-management regimen. Living with a long-term condition, maybe for the rest of one's life, requires that it is accommodated within daily life, the social context, and, ultimately, one's identity. To achieve that accommodation, strategies and relevant health behaviors need to be meaningful and allow for development of purposeful activities and participation. This will in turn foster resilience and post-traumatic growth.

Changing health services dominated by the biomedical model seems a daunting prospect; however, the biopsychosocial model is gaining in influence, especially within rehabilitation services. Health professionals have been dealing with these issues for as long as rehabilitation has existed. Building awareness of psychosocial adjustment issues and providing methods and skills to support change processes seems to be the next step for rehabilitation services. This should be done by raising awareness of psychosocial adjustment and upskilling all health professionals working in rehabilitation settings. For people living with ABI and long-term pain, there are additional challenges, as there is limited knowledge of how the two conditions interact and affect one another. However, this question can be addressed with relevant research and findings integrated into the continually evolving methods that support holistic, biopsychosocial processes of recovery and rehabilitation.

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