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# **The Treatment of Pain in India: power and practice**

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MSc MA MB BChir Cantab FRCA FFPMRCA

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Degree of Doctor of Philosophy

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## **Abstract**

The World Health Organization describes over 80% of the world's population as living without adequate access to treatment for pain. Improvement initiatives focus largely on the field of palliative care and on increasing access to opioid medications. Predominantly, they are led from the global North while targeting healthcare provision in the global South. I propose that the limited improvement seen from these programmes is in part, attributable to their narrow clinical focus and to a lack of understanding of practice at the local level. Using India as a single case of study, the aim of this research project is to assess critically how medical practitioners, working within and outwith palliative care, treat patients in pain.

My research questions address the practice of pain management and clinicians' evaluations of this care, from the perspective that pain as a medical problem, is a professionally constructed phenomenon. In this cross-disciplinary research, I use mixed methods, combining qualitative and quantitative data, from interviews and surveys administered to clinicians, field observations in India and secondary analysis of a pre-existing oral history archive. I draw on theories of the policy process, postcolonialism and social constructionism. Through critically evaluating practice, I move beyond more familiar descriptions of care delivery and barriers to improvement, to understand how these issues are framed, formed and contested.

The study demonstrates salient features of the Indian healthcare system: scarce resources, multiple providers, weak regulation, and the dominant role of the private sector. The availability of treatments, including opioids and non-pharmacological therapies, is low and variable. The framing of pain as a problem requiring medical treatment is ubiquitous and there is consensus regarding the need to improve the delivery of clinical care. There is variation, however, in opinions about how this should be achieved, particularly with respect to the choice of treatment modality. Power is wielded by clinicians in the form of knowledge, and is negotiated with other medical professionals, politicians and patients.

In conclusion, although Indian clinicians' descriptions of individual practice recognise the unique local factors that impact on the delivery of pain management, their proposed strategies for improvement emphasise increasing the provision of medical treatments developed in the global North. There is, however, little acknowledgment of the assumptions and limitations of this western medical model when used to treat pain in India.

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## **Author's declaration**

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Name: Clare Roques

Signature:

A handwritten signature in black ink that reads "Clare Roques". The signature is written in a cursive style with a long, sweeping tail on the final letter.

## Introduction

Many high profile international bodies, including the World Health Organization describe untreated pain as a medical problem demanding increased provision of targeted healthcare services. A significant barrier to this is a gross imbalance in access to analgesic opioid medications such as morphine, between high and low- and middle-income countries. India is an example of a jurisdiction in which poor opioid access persists despite having been the focus of local and international initiatives. In general, these programmes appear to have a narrow clinical focus and fail to incorporate detailed critical appraisal of local medical practice, which, I propose, has contributed to their limited efficacy. It is this gap in the knowledge base, specifically related to clinical practice that I seek to address in this work.

In the thesis I present a cross-disciplinary research project on the medical treatment of pain. Using India as a single case of study, I describe through the eyes of clinicians how pain management is practised at a local level and explore how this relates to wider issues of global healthcare delivery. I incorporate the use of mixed methods and a variety of theoretical perspectives, including social constructionism, theories of the policy process, and postcolonialism, and draw on my training as both a practising medical specialist and a social scientist. The thesis is presented in five chapters: 1-Background, 2-Methodology and Methods, 3-Results, 4-Discussion and 5-Conclusions.

In Chapter 1, I introduce my research questions and describe how pain is conceptualised within western medicine. I begin with a historical perspective, explaining how technological advances and a burgeoning knowledge base led to the increased use of morphine and other techniques of providing analgesia (namely through injections called nerve blocks). Through the twentieth century, within western medicine, pain became classified into distinct types, acute or short term, chronic or long term and pain associated with terminal disease, reflected in the organisation of the profession. In the latter half of the century, dedicated pain clinics were set up and the specialty of palliative medicine created. I explain how controversy remains regarding both the knowledge base and the resulting practice and organisation of pain management within western medicine, and why these debates are so political with respect to the use of opioid analgesia.

The global picture of opioid access is hugely variable, with the majority of the world's population largely living in lower income regions (also known as the global South) unable

to access the medications, whilst use in North America is described, albeit controversially, as excessive. I demonstrate how the vast majority of work aiming to improve pain management at a global level by redressing this imbalance, emanates from the field of palliative care and the high-income countries of the global North. Consequently, much of this work does not address the treatment of pain outside of the palliative care setting or access to treatments other than opioids. Whilst the barriers to improving access to pain management both globally and in India are described remarkably consistently in the literature as a lack of education, poor medication availability and inappropriate policy provision, there is a paucity of critical appraisal of these topics. I describe the key published studies in this field and explain how my research adds to this knowledge base through in-depth analysis of practice from the perspective of clinicians, incorporating the management of all types of pain and treatment modalities in India.

In the final section of Chapter 1 I describe the theories that underpin my work, namely social constructionism, theories from the field of policy studies and postcolonialism. I explain how the treatment of pain can be considered to be a socially constructed entity, largely created by the medical profession. I consider the implications this professional construction has on clinical practice, with particular reference to the power wielded by clinicians. I then describe how policy theories, especially when viewed from a social constructionist perspective, can facilitate our understanding of the field of study and help to frame the results of my project. Crucial to these theories are descriptions of the role power plays in fuelling the dynamic stages of the policy process. Finally, I explain how postcolonial theory can inform the discussion of the processes when viewed from a wider global perspective. Specifically, postcolonial theory aims to critique the power dynamics that persist across the world today as a direct result of past European colonial rule.

In Chapter 2 I begin by explaining how the theoretical perspectives introduced in the opening chapter inform my methodology, specifically, my decision to use a combination of research methods, namely a survey, semi-structured interviews and the analysis of an oral history archive, and incorporating qualitative and quantitative data. I explain the current controversies in the literature related to the combining of research methods, and outline the strengths and weaknesses of each element. I demonstrate how the use of multiple methods is essential to this project, due to the nature of the research questions and ultimately because it adds rigour to the results. In the following section of the chapter I set out the

details of my research method, describing the processes of defining my research questions, creating my research tools (the survey and interview guide), collecting my data and analysing the results.

In Chapter 3 I present the study findings, combining the results from the different data sources and types and reporting them under topic headings. I begin by identifying the key issue from the results, namely that participants universally conceptualise pain as a medical problem. I then describe key findings related to the delivery of healthcare in India relating primarily to inadequate resources and diversity of provision. I then move on to topics related to the organisation of medicine and the treatment selection made by clinicians. Finally, I present data linked to how power is enacted by the medical profession, specifically in the form of knowledge and money.

In Chapter 4, I discuss each set of results presented in Chapter 3. I describe how my results confirm other research relating to the provision of healthcare in India particularly with respect to the diversity of provision and a lack of resources. I consider how these conditions that are particular to the Indian context affect the practice of pain management. I discuss how the treatment of pain is professionally constructed and how this leads to controversy related to the organisation and practice of clinical medicine. For example, the boundaries between the clinical remit of different professional groups are indistinct and the relative merits of particular treatment modalities are disputed.

The professional construction of pain management inevitably leads to concerns over how power is wielded by clinicians, and I discuss this concept in detail. I contend that in India power is enacted in many forms, most demonstrably as knowledge and money, manifesting in many areas of healthcare. For example, clinicians dispute knowledge as they debate the most appropriate treatment strategies, and compete for patients' custom and therefore money within the private healthcare system. In order to demonstrate these facets of contested power I discuss three specific areas of the policy process namely, agenda setting, policy formation and policy implementation. In each of these areas I explain with respect to my results how clinicians enact power and the effects this has on the provision of pain management to patients. I also discuss how power is negotiated at a global level, and in particular how the persistent dominance of the global North can adversely affect the lives of the underprivileged majority living in the global South. For example, through the

exportation to India, of a western medical model of treating pain that does not incorporate a clear acknowledgement of its underlying assumptions and limitations.

I conclude in Chapter 5 by summarising the key findings from my study and the wider implications they have on the provision of pain management at a global level. I discuss the current political struggles playing in different regions of the world with respect to the over and under use of opioids, and show how this relates to the professional construction of pain management. I consider the funding of healthcare and the potential conflicts of interest that arise within the medical profession particularly as the demand for pain treatments increases. Finally, I describe how important it is for organisations that are directing international healthcare improvement initiatives to appreciate the power imbalances that persist between the global North and South and crucially to fully acknowledge the limitations of western medicine in these contexts.

## **Chapter 1 – BACKGROUND**

### **1.1 Introduction**

I begin this opening chapter by introducing the aims and research questions of this study. I then present an overview of the medical practice of pain management. In Section 1.3, I give a brief description of the historical evolution of the treatment of pain within western medicine before explaining how pain is currently conceptualised and described within the wider context of global healthcare. I elaborate on the current key topics within this field, with particular reference to the highly publicised and political issue of the medical use of prescription opioid medications. I demonstrate some of the gaps in the current knowledge base and the need for cross-disciplinary research.

In the following section (1.4) I explain and justify my use of India as the location of the study, describing the pertinent features of the healthcare system with respect to the treatment of pain. I present the key published studies in this field, which largely focus on descriptions of the delivery of pain management within the field of palliative care. I explain how my research adds to this body of work, by considering individual clinicians' evaluations and normative positions, moving beyond simple descriptions of delivery of healthcare to address my research questions.

In the final section of this chapter (1.5), I describe the theoretical perspectives that underpin my cross-disciplinary work, beginning with social constructionism, moving on to key aspects of political theory and concluding with a description of postcolonialism.

### **1.2 Study Aims and Research Questions**

In a briefing note published in 2012, the World Health Organization (WHO) estimates “that 5.5 billion people [...] have inadequate access to treatment for moderate to severe pain”.<sup>1(p1)</sup> India serves as an example of one such country, with huge numbers of patients described as living without access to pain relief.<sup>2</sup> Despite numerous initiatives, largely targeting improved access to opioid medications for patients receiving palliative care,

progress has been limited.<sup>3</sup> I propose that key factors contributing to this limited progress are an overly narrow clinical focus and a lack of detailed understanding of practice at the local level, resulting in a disconnect between individuals' practice and improvement initiatives driven by international organisations.

Therefore, the aim of this research project is to assess critically how western medical practitioners in India, working within and outwith palliative care, treat patients in pain. The specific research questions are:

- 1) What types of painful conditions do clinicians treat, what treatments do they offer and how are these funded?
- 2) How do clinicians think pain *ought* to be treated, and how do they consider their own practice compares to this ideal?
- 3) How do clinicians conceptualise the barriers and assets to improving the treatment of pain?
- 4) What are the opinions and evaluations of clinicians regarding the wider provision of pain management across the country?
- 5) With respect to pain specialists, how is the medical profession organised and what impact does this have on the delivery of care?

## **1.3 Pain as a Medical Problem**

### **1.3.1 The Emergence of Medical Specialties**

The phenomenon of pain existed even before man evolved as a species and found means to describe it. Throughout history its complex nature has been subject to multiple, changing cultural interpretations.<sup>4</sup> It has been treated as a religious entity, deeply imbued with spiritual meaning, its tolerance considered a virtue.<sup>5</sup> It has been described in beneficial terms when considered a necessary component of rites of passage and initiation.<sup>5</sup> It has been used as a devastating tool to control and inflict suffering during organised torture.<sup>6</sup>

The advent of modern anaesthesia in the nineteenth century which enabled hitherto harrowing procedures, such as limb amputations, to be carried out as painless operations is

heralded as one of the greatest medical advances in modern times.<sup>7</sup> The invention and widespread use of anaesthesia marked a shift in focus, away from the description of pain as a universal experience demanding cultural interpretation and meaning, towards a reductionist model of pain as a physical problem to be fixed by medical intervention.<sup>8</sup> As David Morris writes in his book *The Culture of Pain*, “Today our culture has willingly, almost gratefully, handed over to medicine the job of explaining pain.”<sup>5(p19)</sup> Although opium (a naturally occurring opioid pain killer) had been used medicinally to treat pain for centuries,<sup>4</sup> the industrial production of morphine in 1820 and the advent of the hypodermic (or hollow) needle in 1855 significantly increased the medical use of opioids.<sup>9</sup>

At around the same time the medical profession began to conceptualise pain as falling into three different categories: acute or short-lived pain following injury, pain of cancer and other terminal disease, and chronic or long-term intractable pain conditions - each requiring different treatment strategies.<sup>9</sup> This classification of pain has remained central to the practice of pain management within western medicine and has shaped the organisation of pain related specialties.

In the first half of the twentieth century, fuelled by the awareness of the failure of particular chronic pain conditions to respond to treatment with opioid medications, there was a growing interest amongst the medical profession, in performing therapeutic medical procedures.<sup>10</sup> The aim of these physical techniques, known as ‘nerve blocks’ was to disrupt, either temporarily or permanently, the neural pathways that transmit pain signals to the brain. By the second half of the century, however, there was increasing acknowledgement of the complex nature of pain and the importance of understanding and treating its psychological as well as physical components, a seminal work in this field being Melzack and Wall’s *Gate Control Theory of Pain*.<sup>11</sup> This culminated in the first multidisciplinary pain clinics being founded in the USA by John Bonica and in the UK by Mark Swerdlow during the 1950s and 1960s.<sup>9</sup> The formation of the International Association for the Study of Pain (IASP) and its journal *Pain* soon followed.<sup>9,12</sup> Of note, pain medicine, a medical specialty dedicated to the treatment of chronic pain, is formally recognised in a few countries,<sup>13</sup> but in many, including the USA and the UK, it is considered a sub-specialty of anaesthesia.<sup>14,15</sup>

During the beginning of the twentieth century, concern grew around the risks of addiction to opioid medications that were increasingly being prescribed by the medical profession.<sup>16</sup> However, a marked change occurred specifically in the treatment of pain in patients suffering with terminal cancer, led in the UK by Cicely Saunders in the late 1950s. Her pioneering work, and the creation by other experts working with the World Health Organization (WHO) of an opioid based analgesic ladder in the 1980s as part of its Cancer Pain Relief Program, led to opioids becoming the mainstay of treatment for the pain of terminal cancer.<sup>17,18</sup> Furthermore, in the same manner as her colleagues working in the field of chronic pain who described the psychological components of pain, Cecily Saunders also wrote extensively on the need to address patients' psychological and spiritual suffering, coining the term 'total pain'.<sup>19</sup> Saunders founded the first modern hospice, dedicated to treating dying patients in London in 1967, a national society for clinicians specialising in the field of palliative care was founded in 1985, and since then increasing numbers of countries have formally recognised palliative medicine as a medical speciality in its own right.<sup>20</sup>

The treatment of severe acute pain following trauma, surgery and including childbirth, has also evolved over the last century, with doctors drawing on similar techniques to those used in chronic pain management, such as nerve blocks and epidural injections, and advanced systems for delivering opioids.<sup>21</sup> Since the 1990s, there has been a growth in the numbers of specialist acute pain teams within hospitals, largely led by doctors working within the specialty of anaesthesia.<sup>22</sup> Most episodes of acute pain following surgery or trauma, however, do not require specialist input from anaesthetists, and are dealt with by the clinical team overseeing the patient's care, such as surgeons.<sup>23</sup>

Whilst the structure of professional specialisation that has grown around the treatment of pain over the last century partly reflects the western medical classification of pain, there have been important changes, particularly within the field of palliative care that complicate this picture. Since the early days of the palliative care movement, there has been a close association between palliative care and the treatment of patients with cancer,<sup>20</sup> but over time the field has evolved and the remit of the speciality has gradually broadened. The most recent definition of palliative care conceptualised by the WHO describes it as encompassing all 'life-threatening illness'.<sup>24</sup> Although a definition has indeed been created by this organisation, its content is a still matter of debate.<sup>25</sup> Some have called for a

narrower remit, for palliative care to be restricted to use in cancer patients, others have called for all patients to be treated within a palliative care model, and others have gone still further describing palliative care as a philosophical model to transform healthcare systems.<sup>25</sup> While some members of the medical profession have questioned the need for palliative care to be a medical speciality in its own right since its inception,<sup>26</sup> the current trend of broadening the remit of palliative care to encompass more medical conditions and to treat patients within this model earlier in the course of their disease, reinforces the ideal that all clinicians should adopt the ethos of palliative care.<sup>27</sup> The trend also leads to an increasing overlap between the clinical remit of palliative care and chronic pain specialists.

Despite the growth of medical specialisations dedicated to the treatment of pain, and society's enthusiastic and increasing reliance on the use of this medical model, it is vital to note that pain is not, with the current knowledge base of western medicine, universally amenable to elimination.<sup>28</sup> The word 'pain' can indicate a vast range of causal factors including physical trauma such as a broken limb, an emotional event such as the death of a loved one, or a daily event such as hunger. Even leaving aside the second two examples and concentrating on pain that is secondary to some form of physical pathology or medically identifiable disease process, pain is an incredibly diverse phenomenon. The physical initiators are vastly wide ranging and different types of pain vary in how amenable they are to medical treatment. The western medical classification into acute pain, pain of terminal disease and chronic pain emphasises this variability. Specifically, acute short-lived pain, such as that following surgery or trauma is usually treated effectively within western medicine, often using opioid medications.<sup>29</sup> Similarly pain due to terminal diseases, that is, incurable conditions in their final fatal stages, such as (but not limited to) advanced cancer, is also frequently amenable to medical treatment and again opioids are a key tool in providing analgesia.<sup>30</sup> Of note, pain of terminal disease, whilst strictly speaking not transient, is none the less limited in its timescale due to the nature of the underlying disease process resulting in the death of the sufferer. In contrast, pain that is chronic, or long-standing and not caused by a terminal condition, examples of which include phantom limb pain (following amputation), chronic back pain, diabetic neuropathy (nerve pain) and arthritis, is much less amenable to western medical treatment. The vast majority of pharmacological therapies, including opioid medications, provide relief only for the minority.<sup>31</sup> While multidisciplinary pain clinics aim to help patients manage their pain, total relief or a cure is highly unlikely to be achieved. Indeed implicit in the very definition

of chronic pain as a long-standing condition, is its resistance to curative therapy. As Arthur Kleinman and colleagues explain, “Chronic pain is an important health issue that biomedicine has handled with an astonishing lack of success.”<sup>32(p6)</sup>

The conceptualisation of pain as a problem to be fixed within a medical framework underpins the early and highly influential work of the WHO carried out the 1980s in relation to the treatment of cancer pain.<sup>33</sup> Mirroring the expanding remit of palliative care, the WHO and other high profile organisations, most recently the Lancet,<sup>3</sup> describe pain of multiple aetiologies, as a global health concern of increasing proportion. I focus on these descriptions of the current state of medical pain management in the following section.

### 1.3.2 The Global Picture of Pain Management

In the aforementioned briefing note published in 2012, the WHO estimates that 5.5 billion people (over 80% of the world’s population) live without access to treatments for moderate to severe pain.<sup>1</sup> The organisation lists examples of painful conditions that are undertreated such as terminal cancer, end-stage HIV/AIDS, trauma and surgery, labour and chronic illnesses, and it cites the lack of access to opioid analgesics, including morphine as a particular obstacle. Due to the illicit use of morphine and other opioid analgesics, these medications are controlled under the United Nation’s (UN) *Single Convention on Narcotic Drugs* (SCND)<sup>34</sup> which is overseen by the International Narcotics Control Board.<sup>35</sup> However, despite an acknowledgement in the SCND preamble of the need to allow the use of opioids for medical purposes and the inclusion of morphine in the *WHO Model List of Essential Medicines*,<sup>36</sup> in many countries there is an imbalance with stringent legislation resulting in little or no access to their legitimate use. In an attempt to redress this imbalance, the WHO has created the Access to Controlled Medications Programme (ACMP)<sup>37</sup> of which the briefing note described above is a part. In this document, the WHO also describes access to controlled medications that are simultaneously considered to be ‘essential’ as a human right quoting another UN document, the *International Covenant on Economic, Social and Cultural Rights*.<sup>38</sup> This framing of pain and its treatment by different organisations, all working under the remit of the UN, is profoundly influential and consequently informs much of the work in this field. In the remainder of this section, I consider in more detail the published literature relating to the three prominent themes

raised by these organisations, namely the description of the need to treat pain within a medical framework, the availability of opioid medications and the related politico-legal issues.

Estimates of the scale of the need for improved pain relief emanate from estimates of global disease burden,<sup>39</sup> and include the prevalence of trauma, the need for surgical procedures, cancer, HIV/AIDS and indeed all chronic diseases.<sup>40-42</sup> Several epidemiological studies have been carried out to estimate the prevalence of chronic pain across the world,<sup>43-49</sup> and although results vary across countries, a prevalence of around 20% is common. When considering acute pain following surgery, one of the reasons that estimates of prevalence vary is because of the inclusion of estimates of the number of patients who could *potentially* benefit but currently do not have access to surgical procedures. These patients are said to account for 11-32% of the global burden of disease.<sup>42</sup> An estimated additional 143 million surgical procedures per year (including those needed to treat trauma) would need to be carried out to redress this imbalance.<sup>50</sup> Up to 50% of patients suffer severe pain following surgery and trauma<sup>51</sup> and an estimated 10% of the world's deaths are due to injuries.<sup>52</sup>

The need for pain relief in terminal disease is frequently described in conjunction with a need for palliative care.<sup>3,53</sup> Estimates of the scale of need therefore vary depending on the diseases included in this category. Some quote only the incidences of cancer, but increasingly all chronic or non-communicable diseases (NCDs) are included. Although not all of those suffering from these diseases may be in need of pain management and/or palliative care, mapping studies, such as the *Global Atlas of Palliative Care at the End of Life* (a publication by the WHO and the Worldwide Palliative Care Alliance) estimate that over 20 million people are in need of pain relief and palliative care, based on NCD prevalence.<sup>53</sup> The 2017 report of the Lancet Commission on Palliative Care and Pain Relief, which uses wider inclusion criteria, estimates that over 60 million people worldwide, over 50 million of whom are living in low and middle-income countries (LMICs), could benefit from palliative care.<sup>3</sup>

These descriptions of poor availability of pain management on a global level have a specific focus on improving access for the vast majority of the world's population that lives in LMICs. In terms of acute and chronic pain not associated with terminal disease

there are some examples of initiatives aiming to tackle this problem such as the IASP's Developing Countries Working Group, and their yearly advocacy projects entitled 'Global Year Against Pain',<sup>54,55</sup> and the World Federation of Societies of Anaesthesiologists educational projects.<sup>56</sup> Of note, however, the IASP's remit is to promote awareness of all types of pain including that caused by cancer. Other authors have also called for increased efforts to improve acute and chronic pain management in developing countries.<sup>23,40,42,49</sup> However, the vast majority of the work in this field has emerged from within the field of palliative care with many key programmes originating from organisations specifically targeting the treatment of pain in those who are dying of cancer.

Alongside the WHO, many global organisations focus on improving access to pain relief within the context of palliative care, such as: the International Association for Hospice and Palliative Care (IAHPC), the Worldwide Palliative Care Alliance (WPCA), the Pain and Policy Studies Group (PPSG) at the University of Wisconsin, and the Union for International Cancer Control. Both the need for palliative care and current levels of provision have been mapped at a global level,<sup>53,57</sup> and a world ranking index has even been produced.<sup>58</sup> A prominent theme included in this advocacy work is the need to improve access to opioid medications. The 2015 *Quality of Death Index*, produced by the Economist Intelligence Unit uses opioid availability as one of its ranking indicators<sup>58</sup> and the problem of opioid availability is highlighted in numerous other international projects including the Lancet Commission on Palliative Care and Pain Relief<sup>3</sup> and the Global Opioid Policy Initiative.<sup>59</sup> Furthermore, it has been noted that the availability of opioid medication for cancer pain relief and palliative care, correlates with each country's Human Development Index, although this factor is not the only predictor.<sup>60</sup> Other so called 'barriers' to improving palliative care at an international level include: a lack of policy as well as a lack of financial and material resources, poor awareness amongst the public and politicians, insufficient education and training, as well as other psychological, social and cultural barriers.<sup>53,61</sup>

As I noted previously there is far less published work surrounding the evaluation of the provision of treatment for pain outside of the remit of palliative care, and consequently less discussion of the barriers contributing to this lack of access. Similar categories of barriers are, however, described with respect to acute pain management, as are described in palliative care, such as: poor access to opioid medications, a lack of policy, scarce

resources particularly in rural areas, and inadequate education of patients and professionals.<sup>23,49,62</sup> Despite the expanding remit of palliative care, the treatment of chronic pain not related to terminal disease is, in global terms, even less widely researched and discussed. Nonetheless, a few authors have described barriers to improving the treatment of chronic pain, noting the importance of making available pharmacological treatments other than opioids and non-pharmacological therapies; in addition to addressing the familiar obstacles identified above, namely the lack of education, low availability of opioid medications and scarce resources.<sup>40,49,63,64</sup>

The increasing overlap in the remit of conditions that specialists working in palliative care and chronic pain management are treating, has strongly informed my research, which incorporates the critical evaluation of both these areas of practice. This overlap is especially pertinent with respect to opioid medications, the medical use of which I discuss in detail in the following section.

### **1.3.3 Opioid Medications**

In terms of global pain management improvement initiatives, as I outlined above, there is a huge focus, particularly from within the field of palliative care on improving access to opioid medications.

*The Single Convention on Narcotic Drugs, 1961*,<sup>34</sup> provides guidance for the legislation of the use of opioid medications by governments broadly overseen by the International Narcotics Control Board (INCB).<sup>65</sup> Individual countries are obliged to report their yearly consumption of such medications to the INCB. Based on this data, the INCB estimates that 92% of the world's morphine is consumed in countries where 17% of the world's population lives – essentially in high-income regions such as North America, Western Europe, Australia and New Zealand.<sup>66</sup> Studies have also demonstrated a strong link between national levels of opioid consumption and Human Development Index.<sup>60,67,68</sup> Despite multiple initiatives to improve this imbalanced access and recent increases in the total use of opioids across the world, these increases have largely been due to increased use in high-income countries.<sup>68</sup>

The reasons for the low use of opioids in low and middle-income countries has been extensively researched and discussed. Despite specific reference in the *Single Convention* preamble of the need to ensure access to controlled substances for medical use, in many countries an imbalance has resulted from overly stringent legislation aimed at controlling illicit use. Overly complex and restrictive legislation at national or a more local level has been cited as a key barrier to access.<sup>68-70</sup> Over stringent legislation is, however, not the only barrier to access. Reduced availability of medications is frequently a problem with many countries reporting an absolute absence of certain opioid medications, as well as variable supply within pharmacies and healthcare institutions.<sup>69</sup> Further problems include the paucity of resources within the healthcare system and difficulties for individual patients purchasing medication.<sup>68,71</sup> A lack of local financial resources is compounded by the reported increased costs of opioid medications in lower income countries.<sup>72</sup> Finally, there are many reports of problems related to a lack of knowledge, leading to clinicians and patients being reluctant to prescribe and take opioids due to fears of addiction and physical side effects.<sup>68,73</sup>

These key barriers to opioid access, namely poor availability, inappropriate policy and low levels of knowledge, have been described repeatedly since they were initially published in the WHO's document *Cancer Pain Relief* in 1996.<sup>30</sup> Numerous organisations are involved in addressing these barriers including several United Nations bodies besides the WHO,<sup>69</sup> the European Association for Palliative Care (EAPC), Help the Hospices, Human Rights Watch, the IAHP, the Open Society Foundation, the PPSG, the Union for International Cancer Control and the WPCA.<sup>59</sup> Their work has resulted in many highly publicised initiatives such as the Global Opioid Policy Initiative, the Access to Opioid Medication in Europe project and the Global Access to Pain Relief Initiative.<sup>59</sup> These operate alongside a plethora of national and local projects, and other initiatives carried out outside of the palliative care community. Despite this remarkable body of work which now includes a UN Sustainable Development Goal<sup>74</sup> and a Lancet Commission,<sup>3</sup> a lack of access to opioids remains an immense problem in low and middle-income countries.

Several issues are notable by their absence in many of these studies. For example, the focus on the treatment of acute pain is limited. Although the problem of the under treatment of acute pain is highlighted by some authors,<sup>23,40,49,75</sup> is specifically cited in the 2012 WHO briefing note<sup>1</sup> and is the subject of the IASP's 2017 advocacy initiative,

entitled ‘Global Year Against Pain After Surgery’,<sup>54</sup> these voices are in the minority. This is particularly noteworthy because, as I explained above, acute pain is generally considered to be very treatable within a western medical paradigm by using, alongside other modalities, opioid medications.<sup>76,77</sup> Furthermore, the incidence of undertreated acute pain is reported to be unacceptably and avoidably high.<sup>1,23,40,49</sup>

Similarly, there is little attention given to the problem of managing chronic, long-term pain that is not associated with terminal disease. I highlight this with particular reference to the expanding remit of palliative care because it is associated with another fundamental issue that is frequently absent in many of the discussions surrounding increasing access to opioids, namely, the contested nature of the use of opioid medications to treat chronic pain that is not caused by terminal illness.<sup>78,79</sup> While a minority of individuals may benefit, there is a lack of population-based evidence of long-term effectiveness and indeed evidence for the risk of harm, of the use of opioid medications in chronic pain not associated with terminal disease.<sup>31,80</sup> Furthermore, although highly contentious, the widely publicised problem of prescription opioid abuse in North America has been, at least in part, attributed to over zealous prescribing of opioids to treat chronic pain in patients who are not suffering from terminal disease.<sup>81</sup> Some consider this to be fuelled by calls from within the medical community to recognise pain as being ‘the fifth vital sign’, and as such, requiring routine measurement and recording by nursing staff, alongside patients’ pulse, blood pressure, temperature and respiratory rate.<sup>81</sup> This perception of many physicians that opioids are at risk of being over prescribed has led to the creation of national guidance in several countries in an attempt to limit their medical use in chronic pain,<sup>82,83</sup> and a call from the American Medical Association to cease recommending the assessment of pain as a vital sign.<sup>82,84</sup>

While there are concerns among some clinicians that the epidemic of opioid abuse in North America will be replicated across the world if availability is increased<sup>81</sup> this is not a universally held opinion. For example, despite the recent rise in prescriptions of opioids in the UK, this country has not seen the same rates of addiction and misuse as those of North America.<sup>79</sup> This has been attributed to differences in the culture and structure of their healthcare systems.<sup>85</sup> For example in the UK with its National Health Service one general practitioner monitors each patient’s care, by contrast in the USA a similar patient may have access to multiple independent prescribers. Furthermore, unlike in the UK, the

pharmaceutical industry markets directly to both patients and professionals in the USA where different combinations of opioid medication prescriptions are seen.<sup>79</sup> Even the International Narcotics Control Board states that increasing patients' access to opioids does not equate to an increase in abuse.<sup>66</sup>

When considering this debate in conjunction with the current global initiatives advocating for increased access to opioid medications from within a field of palliative care that has an expanding remit to treat all patients regardless of their underlying medical conditions, I propose that a number of concerns follow. For example, although current guidelines that recommend limiting the use of opioids in chronic pain are well publicised amongst specialists working in this field it is conceivable that those working in other fields such as palliative care will be less familiar with their content. There is therefore the potential for some patients with chronic pain not associated with terminal disease, if treated under the remit of palliative care, to receive opioid medications that are unlikely to provide them with pain relief and have the propensity to cause harm. In countries with low levels of healthcare infrastructure and multiple private healthcare providers, the chance of the failure of medical professionals to keep in contact with such patients to monitor for side effects or problematic use, including diversion of opioids to other individuals, are likely to be high. Furthermore, I propose that the failure of many initiatives to discuss the complexities of these issues in combination, may contribute to resistance from some medical professionals to increase the use of opioid medications where they are likely to be of benefit to patients.

Since the creation of the first multidisciplinary pain clinics as well as the hospice movement in the 1950s, the need to treat pain, regardless of its underlying cause, employing a holistic approach has been recognised.<sup>19</sup> Furthermore, the use of treatments besides opioids including interventional techniques such as nerve blocks are specifically described as being useful for the treatment of pain in low-resource settings.<sup>75,86-88</sup> Another potential weakness of the focus of global initiatives on opioid treatments is their failure to address low availabilities of other treatment modalities, which is especially pertinent when considering patients who are suffering from painful conditions that may not respond opioid medications. There is a paucity of data relating to the global provision of non-pharmacological treatment modalities including interventional procedures, although some work has been undertaken in relation to non-opioid pain relieving medications<sup>89</sup> often

through initiatives to improve access to the whole of the *WHO Model List of Essential Medicines*.<sup>36,90</sup>

### 1.3.4 Politico-legal Perspectives

A seminal meeting held in Geneva in 2004 marked the beginning of an increasingly prominent movement describing pain relief in terms of human rights. Conveners of the meeting, entitled a ‘Global Day Against Pain’, sponsored by the IASP, the WHO and European Federation of the IASP Chapters, boldly declared through the subtitle that ‘The Relief of Pain Should be a Human Right’.<sup>51</sup> Key features of this day included highlighting the prevalence of chronic pain, its effects on individuals and wider society, the need to engage public policy makers, to educate healthcare workers and to discover new treatments. In 2008 a declaration from the WPCA and the IAHPIC broadened this remit to incorporate access to palliative care in their *Joint Declaration and Statement of Commitment on Palliative Care and Pain Treatment as Human Rights*.<sup>91</sup> There is a noteworthy change in language here from talking of ‘pain relief’ to ‘pain treatment’ (my italics), the implication being an acknowledgment that not all pain can be relieved. As well as describing the scale of the problem of poorly treated pain, a need for improved education, national policy change and access to opioid medication is given particular recognition. The declaration also describes the specific legal arguments for describing access to pain treatment and palliative care within a human rights framework, quoting two key UN declarations, namely the 1948 *Universal Declaration of Human Rights*<sup>92</sup> and the 1966 *International Covenant on Economic, Cultural and Social Rights*,<sup>38</sup> that together describe the right to health and the right to freedom from torture.

In 2010, the IASP convened an International Pain Summit with representatives from numerous countries and organisations resulting in the publication the *Declaration of Montreal*.<sup>93</sup> This declaration again describes access to pain management as a human right, and includes a description of the need to treat acute pain, pain from terminal disease and chronic pain; and to address the issues of education, opioid access and policy reform. Other similar declarations urging for access to pain management to be considered a human right have followed such as the *Lisbon Challenge* from the EAPC,<sup>94</sup> and the *Morphine Manifesto* from Pallium India, the IAHPIC and the PPSG.<sup>95</sup> Access to pain management has

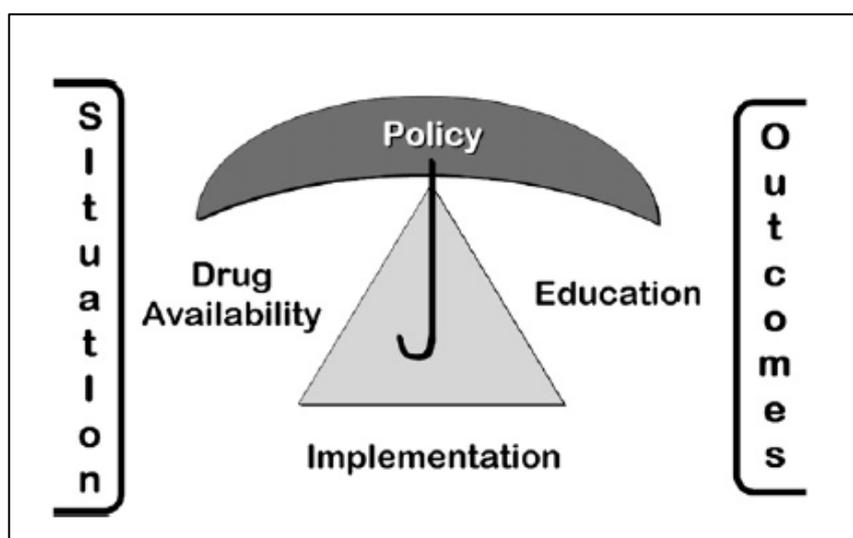
also featured as a resolution of the World Medical Association, and has been a feature of several UN initiatives including through the Human Rights Council, the UN Commission on Narcotics Drugs, a 2016 UN General Assembly Special Session and the WHO.<sup>96</sup> In 2009, the American based non-governmental organisation Human Rights Watch also championed the cause, by publishing its emotionally provocatively titled report “*Please, do not make us suffer anymore... ”Access to Pain Treatment as a Human Right.*”<sup>97</sup> Although little is known of their efficacy, there have been an increasing number of declarations across the world since the 1980s, now numbering more than 30, calling for improved access to palliative care, within which the most frequently highlighted issues are the need for more education, policy change and access to pain relief.<sup>98</sup>

A detailed critique of the use of a ‘rights based’ approach as an advocacy tool is beyond the remit of this thesis, however, I briefly outline two potential themes of debate. Firstly the medico-legal implications for professionals treating patients in pain can be controversial, particularly in the USA, with clinicians describing a tension between the obligations to treat pain and to comply with increasing professional guidance related to concerns about over-prescribing of opioid medications.<sup>99</sup> Secondly, and at a much more fundamental level is a critique of the use of human rights per se as a global advocacy tool. A prominent theorist here is Stephen Hopgood who argues in his 2013 text *The Endtimes of Human Rights*,<sup>100</sup> that the Human Rights movement (note the capitalisation) has become a western neoliberal tool of moral authority. He argues that although the underlying sentiment of an individual declaration that a particular issue should be considered a human right may be entirely laudable, embedding such declarations within the largely western dominated UN led Human Rights movement can act against local uptake of the declaration, particularly in certain situations or political regions. Tied up with this idea is the concern that the very action of describing an issue as a Human Right deems the issue to be of such moral certainty that it is placed beyond debate. Furthermore, Hopgood argues that rather than searching for a one-size-fits-all approach to issues of human rights in the form of UN sanctioned global declarations, we should be championing local solutions created by local citizens.

The description of the right to receive medical treatment for painful conditions reinforces the argument that pain is a medical problem to be fixed. Despite the shift from the earliest descriptions of pain *relief* being a human right, to access to pain *treatment*, implying

limitations to western medicine's ability to cure pain; in 2016, the WPCA's theme for its World Hospice and Palliative Care Day was 'Living and dying in pain: it doesn't have to happen'.<sup>101</sup> While, from within the field of palliative care, with a focus on treating pain from terminal diseases this advocacy sounds entirely laudable and rational, I argue that the generalised wording of the statement could be interpreted as implying that all pain, regardless of its cause, can be cured, which demonstrably is not the case.

Another recurring theme across the medical fields of both palliative care and chronic pain management is the framing of each of these areas of healthcare as public health issues. As early as 1990, the WHO described the need to improve cancer pain management within the field of palliative care as a global, public health concern.<sup>102</sup> The description by the WHO of how access to palliative care can be improved at a global level evolved to become the WHO Public Health Strategy for Palliative Care.<sup>103,104</sup> The final iteration published in 2007 by Stjernsward and colleagues (Figure 1-1) has become a widely cited model and again includes the three key themes of drug availability, education and policy, as well as the need to consider implementation strategies.



*Figure 1-1 WHO Public Health Model<sup>104</sup>  
(Permission to reproduce this diagram has been granted by Elsevier)*

Many others have described palliative care as a public health concern<sup>105-107</sup> and textbooks have been devoted to the topic.<sup>108,109</sup> Although frequently presented as a common sense, logical approach to the increasing prevalence of diseases, the combining of these two

spheres of medicine is complex. As I explained in the previous section of this chapter, the definition of palliative care is debated and there is a similar lack of clarity on the meaning around the term ‘public health’ within the palliative care literature.<sup>110</sup> In a recent study prompted by these issues, Dempers and Gott identify three key partially overlapping public health paradigms that are described within current palliative care literature, namely: a WHO model focussing on service provision and integration into national healthcare schemes, a health promotion approach, and a population based epidemiological approach.<sup>110</sup> Interestingly, despite the popularity of the WHO model, Dempers and Gott show that the health promotion approach which prioritises notions of social capital, community empowerment and a *de-medicalised* approach (my italics) is the most prominent paradigm in the literature.

There is also a call from within the medical profession to consider chronic pain that is not associated with terminal disease to be a public health issue,<sup>111</sup> although this is perhaps less prominently championed by high profile organisations than the corresponding descriptions of the public health approaches to palliative care. Authors highlight the high prevalence rates of chronic pain (of around 20%) as well as the costs to individuals and the wider society resulting from the incapacity of sufferers.<sup>111,112</sup> A key theme highlighted in these descriptions is the inherent complexity of this type of pain and the resulting deficiencies of the frequently used western, biomedical model which aims to cure causative disease rather than to prioritise symptomatic treatment.<sup>40</sup> Advocates of adopting a public health approach describe the need to look beyond increasing the availability of current models of healthcare delivery, including specific treatments such as opioid medications, to address the much more complex issues of socio-economic disadvantage that are associated with sufferers of chronic pain.<sup>111,113</sup>

Interestingly, mirroring these descriptions of pain as a public health topic are concerns surrounding the over use of treatments. Particularly in the USA, the scale of problematic misuse of opioid prescription medications has led to this phenomenon also being described as a public health issue.<sup>114</sup> A recurring theme in the descriptions of both the treatment of chronic pain and issues related to opioid over use as public health problems is the need to address healthcare policy.<sup>111,112,114</sup>

When considering global pain management initiatives, a significant amount of policy related work has focussed on the detail of modifying national level legislation to improve access to opioid medications, a key body of work being that of the PPSG at the University of Wisconsin and their policy fellowships.<sup>115-117</sup> This specific area, however, is an exception, with the wider issues around improving access to all aspects of pain management and treatments other than opioids being far less well described in terms of policy. In particular, despite the extensive literature from the wider field of healthcare policy exploring the complexities of policy creation and implementation, there is a paucity of cross-disciplinary research.

In this opening section I outlined the key assumptions in the field of global pain management that remain largely unexamined within this literature. Pain is framed as a problem that should be treated within a western medical model and access to this medical therapy is widely described as a human right. The need to increase awareness and education of the concept that pain is medically treatable is an important part of many advocacy projects. Education is also aimed at increasing others' knowledge of the use of treatment strategies particularly the use of opioid medications. The majority of advocacy work aimed at improving access to pain treatments has originated within the field of palliative care. While not surprising perhaps, due to the evocative nature of descriptions of patients dying in unnecessary pain, it is also problematic. Patients suffering with acute, short-term pain are often not included in these projects. The definition of palliative care is becoming more contested due to the speciality's evolving remit to encompass a widening range of medical conditions and to instigate palliative care at an earlier stage of patients' illnesses. The increasing overlap with medical specialties treating patients with chronic pain not associated with terminal disease, the frequent failure of medical science to reliably and consistently ameliorate this type of pain, and the debates surrounding current treatments strategies further complicate efforts to improve pain management at a global level. Similarly, the overly narrow, although understandable focus on increasing availability of one specific treatment, namely opioids, is problematic due to the highly publicised debates surrounding their use in the treatment of chronic pain not associated with terminal disease, and the need to address low levels of access to other therapies. Finally, altering and implementing healthcare policy are widely cited goals. The complexities of policy creation and implementation, however, as well as the contested nature of the issues above that inform these processes are rarely acknowledged. I argue that

the lack of appreciation of the assumptions being made and the debated nature of each of these issues, namely education, clinical treatment and policy, are at least partly responsible for the lack of progress. In the following section I discuss how these issues play out in the Indian context.

## **1.4 The Case of India**

India is an example of a country where pain management is described as particularly problematic.<sup>2</sup> Multiple advocacy projects aiming to improve pain management have been led by teams both within and outside the country,<sup>2,118</sup> it is the site of several WHO collaboration projects<sup>119,120</sup> and has been the subject of a Human Rights Watch campaign,<sup>121</sup> but progress has still been limited. Reflecting the global picture, most projects originate from within the palliative care community and largely focus on improving access to morphine. Furthermore, within India palliative care is a growing medical specialty, and the fields of chronic and acute pain management are expanding, but as these specialties find their feet in the competitive market that is the Indian healthcare system a unique set of complexities is arising.

### **1.4.1 Healthcare in India**

At the time of writing India is classified by the World Bank as a lower-middle-income country<sup>122</sup> with an estimated population of over 1.3 billion, 18% of the world's total population.<sup>123</sup> The immense size of the country with its vast regional socioeconomic and cultural diversity often leads to India being described as a continent rather than a single nation. India has a disproportionately high burden of disease for its population<sup>124</sup> and despite recent improvement, rates of malnutrition, maternal and child mortalities and infectious diseases remain high.<sup>124,125</sup> Further adding to the disease burden is a rising life expectancy and an increasing prevalence of non-communicable conditions such as heart disease, chronic lung disease, diabetes and cancer.<sup>125,126</sup> India's health ratings are the lowest of the comparable BRIC (Brazil, Russia, India and China) nations<sup>127</sup> and in some measures it is falling behind its neighbours Bangladesh and Nepal, despite recent economic growth.<sup>124</sup> Clearly, the issues related to healthcare delivery in such a context are

profoundly complex and a detailed description and analysis are beyond the scope of this thesis. I outline, however, some of the salient issues, namely resources in healthcare, plurality of service provision and regulation of practitioners.

Despite numerous government initiatives to improve healthcare provision in India, universal healthcare coverage is far from being realised.<sup>124</sup> Government provision of health services is grossly underfunded, with the latest available figures from the World Bank showing public expenditure on health remaining one of the lowest in the world at less than 1.5% of Gross Domestic Product.<sup>128</sup> Furthermore, the majority of healthcare is provided by the private sector, even to the poor and those living in rural areas.<sup>124,129</sup> Across the population, rates of healthcare insurance are very low, resulting in most individuals paying out-of-pocket for treatments<sup>129</sup> and pushing millions of Indian citizens into poverty each year.<sup>124</sup> Government insurance schemes aimed at addressing this problem have largely been targeted to those living in extreme poverty and have shown little impact.<sup>124,130</sup> The scarcity of financial resources within healthcare is echoed in the scarcity of human resources, with numbers of trained healthcare staff, including doctors, nurses and midwives reported to be around a quarter of that recommended by the WHO.<sup>131</sup> The lack of personnel is further exacerbated by the ‘brain drain’ of trained staff who choose to relocate to more affluent countries.<sup>131,132</sup> Compounding the scarcity of both financial resources and personnel is the unequal distribution of these entities across the country and between particular groups. The resulting inequities of service provision and outcome are profound and have been the subject of multiple studies and improvement initiatives. They include discrepancies between socioeconomic status, male and female populations, different castes, and between rural and urban areas.<sup>124,133</sup> Furthermore, each of India’s 29 states and 7 union territories, has its own jurisdiction over healthcare leading to gross inequality in the provision of healthcare, and reflected in health outcomes across the country.<sup>124,134</sup>

As well as significant variation in distribution of the limited resources, the actual clinical care that is delivered between different institutions varies enormously, with different providers in the same city simultaneously delivering corporate funded, state of the art interventions which attract increasing numbers of health tourists<sup>135</sup> while government clinics fail to cope with the number of patients attending for the most basic levels of care. There is also a huge range of healthcare on offer to patients. Alongside physicians trained in western medicine, known as allopathic doctors, large numbers of practitioners offer the

non-biomedical therapies of ayurveda, yoga, unani, homeopathy and amchi. Known collectively by the acronym AYUSH and often funded by the government, these practitioners make up an estimated 9% of the Indian healthcare workforce.<sup>131</sup> Complicated by a weak primary healthcare system<sup>124</sup> which would ideally help guide patients to the most appropriate specialist practitioner, the range of choice of healthcare providers presented to society is enormous.

Across the board, encompassing the fields of allopathic medicine and AYUSH, private and government funded institutions, at the levels of service delivery and university training, healthcare is weakly regulated.<sup>124,131</sup> In 2010 the president of the Medical Council of India (MCI) was arrested on bribery charges and the very existence of this body, designed to uphold high standards of education and training within allopathic medicine, is currently under question.<sup>136,137</sup> Reports of practitioners falsely claiming qualifications, high rates of absenteeism, poor quality services, irrational use of investigations and treatments, financial kickbacks for referral and other corrupt practices are widespread, and needless to say result in low levels of public trust in the medical profession.<sup>124,129,131,133,138</sup>

### **1.4.2 Pain Management and Palliative Care in India**

The first western style palliative care institutions were established in India in the 1980s and 90s, notably the Shanti Avedna Hospice in Mumbai, and the contrasting model of the Pain and Palliative Care Society (PPCS) in Calicut, Kerala.<sup>139</sup> Much of the early work in this field was driven by UK based charitable organisations which ran educational programmes for Indian clinicians both in India and in the UK.<sup>140</sup> Services began to expand and numbers grow and the Indian Association of Palliative Care (IAPC) was founded in 1994, with significant input from Jan Stjernsward, the then Chief of Cancer and Palliative Care at the WHO.<sup>141</sup> The IAPC although initially made up largely of anaesthetists with an interest in pain management has always had a strong emphasis on the need to address pain management from a multidisciplinary perspective and continues to embrace this philosophy. Its membership has grown to well over 1000 members, many of whom are not doctors.<sup>142</sup> Education in palliative care has also grown, culminating in the creation of the first MCI approved MD (post graduate medical training) programme in palliative medicine at Tata Memorial Hospital in 2012.<sup>143</sup>

In 2008, McDermott and colleagues published a report on the state of palliative care services in India as a part of the work of the International Observatory on End of Life Care, at Lancaster University, to map the level of palliative care delivery across the world.<sup>118</sup> The study identifies 138 hospice and palliative care institutions in 16 states and union territories, leaving 19 with no identifiable services. However, the vast majority of these services are located in one region, the southern state of Kerala, with most of the others concentrated in urban areas. The PPCS of Kerala, founded in the 1990s has seen phenomenal growth over the last quarter century and has evolved into a unique and widely celebrated palliative care service. It has been the driving force behind two WHO collaboration projects, one based at the Institute of Palliative Medicine in Calicut and the other at the Trivandrum Institute for Palliative Sciences led by MR Rajagopal,<sup>141</sup> and has led to the development of the Neighbourhood Networks in Palliative Care (NNPC) project.<sup>144</sup> The NNPC, run by Suresh Kumar, is a community led scheme, where patients identified by locally trained volunteers as being in need of care, are referred to medically trained practitioners.<sup>144</sup> Key to this model is the prominent role of the local community in channelling medical care through assessment of need. This is in clear contrast to a western medical model wherein professionals control and direct care according to clinical diagnosis. The NNPC, funded through community donations and government support, now runs over 200 clinics, has over 10,000 volunteers, and is estimated to provide care to over 60% of the state of Kerala. Patients are treated according to their need or suffering, regardless of their underlying medical condition.<sup>145</sup>

Despite the growth of services, increasing interest in the medical speciality of palliative care and pockets of outstanding care delivery such as in Kerala, many describe the provision of palliative care across the country as grossly inadequate with care only reaching an estimated 1% of the population.<sup>141</sup> A series of projects has aimed to map the global delivery of palliative care, classifying countries by their level of service provision, ranging from no known service provision (level 1) through to integration into main stream healthcare services (level 4).<sup>57,146</sup> The latest iteration classifies India as 3b with ‘Generalised palliative care provision; containing pockets of clinical and educational work but lacking widespread coverage’.<sup>146</sup> Furthermore, the Economist Intelligence Unit’s 2015 *Quality of Death Index*, ranks India 67 out of 80 countries surveyed.<sup>58</sup>

At around a similar time to the initiation of palliative care services in India, chronic pain clinics were also commencing.<sup>147</sup> There has been a growth in interest in India over the last 25 years in the medical profession's treatment of chronic pain alongside the growth of the field of palliative care. It is also important to note, however, that some palliative care organisations, a clear example being Kerala's NNPC programme, treat patients with pain and other symptoms that are not associated with terminal disease. This demonstrates the practical overlap that occurs at times between these two areas of medical specialisation in the Indian context. The Indian Society for Study of Pain (ISSP) was founded in 1984 and became recognised as a chapter of the IASP in 1987. Annual conferences have been held since its inception and the society now has 13 state chapters and 10 city branches.<sup>148</sup> In contrast to the IAPC, the ISSP has maintained an emphasis on leadership from within clinical medicine with at the time of writing, only doctors permitted to be full members of the organisation. In contrast to palliative medicine, pain medicine, despite calls from specialist practitioners is yet to achieve recognition as a specialty from the MCI in the form of a dedicated MD programme.<sup>149</sup>

The provision of pain management in India outside the remit of palliative care is scarcely documented and large-scale mapping projects and rankings such as those described above have not been published. However, a recent epidemiological study reports the prevalence of chronic pain (of any cause) in India as 13% resulting in significant disability, the commonest reported problems being joint pain and headache.<sup>48</sup> Pain is one of the commonest reasons for patients to seek medical advice<sup>150,151</sup> and according to the Institute for Health Metrics and Evaluation, back and neck pain is the second commonest cause of disability.<sup>125</sup> Although official numbers of pain clinics are not documented, provision is described as being far below that needed to treat all patients in need, particularly in government funded settings and outside large urban conurbations.<sup>152,153</sup> Short lived acute pain such as following surgery or trauma is also described as an undertreated problem,<sup>154,155</sup> with few specialist acute pain services reported to be in operation.<sup>156,157</sup>

The barriers that contribute to the low level of provision of pain treatments (whether within or outside of palliative care) are reported remarkably consistently. These barriers include a lack of resources, particularly in rural areas.<sup>118,156,157</sup> Education is also reported to be a fundamental problem. Specifically, there are low levels of understanding regarding the use of basic pain treatments,<sup>62,141,158</sup> and an absence of formalised, coordinated postgraduate

programmes and national clinical practice guidelines.<sup>119,159,160</sup> A need to improve policy is also noted but this is mostly described within the context of improving palliative care at a national level and even more specifically to improving access to opioid medications.<sup>2,141</sup> Despite enormous efforts to create a national policy for the provision of palliative care services in India, only fragmented implementation in certain states has occurred.<sup>141</sup>

Mirroring global initiatives, the vast amount of the work aimed at improving pain management in India has focused on improving access to opioid medications in palliative care. However, a notable few have described the need to increase opioid availability for the treatment of acute pain.<sup>156,157</sup> The low levels of availability of such medications in India have been highlighted in numerous high profile studies and initiatives including the Global Opioid Policy Initiative<sup>2</sup> and the Human Rights Watch report *Unbearable Pain: India's Obligation to Ensure Palliative Care*.<sup>121</sup> The problem of low availability of opioids in India is made all the more poignant by the country being a key exporter of medicinal opioids across the world.<sup>73</sup> Further complications occur with widespread reported problems of poor quality pharmaceutical preparations<sup>161</sup> as well as complaints about pharmaceutical companies encouraging the use of expensive formulations that are in practice put beyond use for the majority of the population.<sup>162</sup>

Other widely described barriers that contribute to the low levels of access to opioids in India can be considered under the familiar themes of education and policy. Fears of addiction, diversion and other side effects are common amongst the medical profession and the public, and many clinicians lack clinical experience in using such medications.<sup>73</sup> Legislation surrounding the use of opioids in India is particularly complex and is further impacted by different regulations operating in each state and union territory. The Narcotic Drugs and Psychotropic Substances (NDPS) Act introduced in the 1980s, with its highly bureaucratic policies and associated penalties including prison sentences for breaking its rules, is considered to be responsible for the steep decline in opioid consumption seen in the 1990s.<sup>2</sup> The government subsequently permitted a set of simplified rules but many states failed to adopt this new 'model rule'. Following years of advocacy work, the Indian government finally approved a modified NDPS Act placing legislation creation with central government in 2014.<sup>141</sup> How this will affect the use of opioids across the country remains to be seen.

To recap, as is the case across the world, particularly in low and middle-income countries, pain in India regardless of its cause is widely described as a medical problem that is grossly undertreated. Most of the efforts to increase the provision of pain management originate from the palliative care community and focus on increasing patients' access to opioid medications. Palliative medicine and pain medicine are medical specialities with a growing number of clinicians and care providers but both are in their relative infancy. There are examples of significant overlap in the medical conditions treated by chronic pain and palliative care specialists. Barriers to the improvement of pain management, alongside poor access to opioids, include a lack of resources, low levels of education, and inadequate policy. Many high profile organisations at a global level and within India have tried to address these barriers but success has either been limited or restricted to isolated examples. The underlying assumptions and limitations of this framing of pain as a medical problem, how this relates to barriers to progress, recommended improvement strategies, and their associated controversies, are rarely, if ever, discussed in the published literature.

In the following section I describe in more detail the key published studies relating to the provision of pain management in India and explain how my research compares, contrasts and ultimately enhances the evidence base in this field.

### **1.4.3 Key Studies**

As I outlined above the large scale international projects examining data in this field have largely focused on the provision of pain treatment within a palliative setting and on the availability of opioids. These include, reports from the International Observatory on End of Life Care (IOELC) at Lancaster University and Human Rights Watch (HRW), the work of the Global Opioid Policy Initiative (GOPI), a series of global mapping projects and the Economist Intelligence Unit's *Quality of Death Index*. Much smaller scale projects, conducted by the IASP and individual researchers, have attempted to describe some of the provision of pain management services beyond only the remit of palliative care. Their inclusion here, despite their small scale, in stark contrast to the palliative care reports, is a reflection of the paucity of research in this field. I now consider these studies in turn,

describing the basic methods used, their aims and outcomes, and limitations before comparing my own study to those already published.

All of the palliative care reports listed above, from the IOELC, HRW, GOPI, the *Global Atlas of Palliative Care at the End of Life* and the *Quality of Death Index* include data and descriptions of service provision in India as a part of global projects. In general, they are large, multi-centre projects with numerous contributors, authors and high profile funders. Furthermore, there is significant overlap in the data used to compile each of these reports with much cross referencing of data and use of the same sources. In contrast, the surveys published from the IASP and those detailing the provision of acute pain treatment are much smaller in scale and ambition, and present only primary survey data.

The IOELC's *India Country Report*<sup>118,163</sup> sets out a detailed picture of the provision of palliative care, incorporating data from multiple sources including demographic and epidemiological, published and grey literature, ethnographic field work and qualitative interviews. The report lists, state by state, the number and types of palliative care services identified, data of opioid consumption, as well as descriptive passages focusing on the perceived barriers to providing care, with particular examples of improvement initiatives. Central to this work is the use of oral history interviews from those working in the field of palliative care, many of whom are high profile pioneers in the field, but interviews with junior nurses and volunteers are also sources of data. It is important to note the emphasis given in this report to expert opinion.

I describe the IOELC's *India Country Report* in some detail because, together with the other country reports, it forms the basis of several key publications. In 2006, commissioned by Help the Hospices, and the National Hospice and Palliative Care Organization, the IOELC created a global map of the state of palliative care delivery.<sup>57</sup> In this map, a 4 level classification system is described with each country designated as having a particular level of palliative care development ranging from 1- 'no activity yet identified', through to 4 – 'approaching integration'. This global mapping project has continued with an updated dataset (supported by the WPCA) published in 2013.<sup>146</sup> This latest version of the classification system has been further refined to contain 6 categories, with classes 3 and 4 each subdivided. In this report, India is classed as 3b - having 'generalised provision'. The data has also been incorporated into the 2014 publication *Global Atlas of Palliative Care at*

*the End of Life* supported by the WHO,<sup>53</sup> with the key addition of estimates of the global need for palliative care derived from disease prevalence rates.

The Economist Intelligence Unit's 2015 *Quality of Death Index*,<sup>58</sup> commissioned by the Lien Foundation, ranks countries according to their provision of palliative care. Originally published in 2010 with 40 countries, the latest version now ranks 80 nations according to five categories: 'palliative and healthcare environment', 'human resources', 'affordability of care', 'quality of care' and 'community engagement'. It also estimates the need for palliative care using estimates of disease burdens and predictions of aging within each population. With comparable methodology to the IOELC based maps, the *Quality of Death Index* uses multiple data sources to compile the ranking scores, drawing on published research, widely available healthcare data and key informant expert interviews. The index leans heavily on the key concepts I outlined above, such as: the idea that pain is a medical problem, that education needs to be improved, that there is a need to assess healthcare policies in relation to palliative care and that access to opioid medications is considered the principal treatment strategy. It is perhaps not surprising therefore that the country ranked number one, the UK, is the very country where palliative care first originated, a country strongly associated with the model of palliative care that is lauded in the *Quality of Death Index*. Of note, one of the key markers in the quality of care section is the availability of opioid medications, which is ranked from 5 – 'freely available and accessible' to 0 – 'illegal'. Overall, India is ranked as 67 out of 80 countries and whilst there is some detail contained in the report including descriptions of successful projects such as those in Kerala, recent changes to the narcotics laws and interview extracts from key local experts, there is considerably less detail here than in the IOELC's report, with an emphasis on quantitative data and the use of a numerical weighting system to rank care.

A final report that I want to include in this section although rather different in its structure and methodology to those outlined above, but important in its role as an advocacy tool, is the HRW Report *Unbearable Pain: India's Obligation to Ensure Palliative Care*.<sup>121</sup> This extensive document published in 2009 describes in emotive terms a picture of grossly inadequate palliative care service provision for the vast majority of citizens in India. Not surprisingly, given the charity's name, Human Rights Watch, these deficits in healthcare are described in terms of human rights violations, namely the right to health, as well as the prohibition of torture and ill treatment. The report includes key recommendations to

influential groups including the Indian and state governments, the International Narcotics Control Board and the Medical Council of India. Again the report heralds the need to focus attention on policy, education and opioid drug availability, all of which are discussed in detail with specific recommendations for action. The report combines evidence from interviews with patients and key workers in the field of palliative care collected on field visits, with other more disparate data retrieved from desk based study. The research concentrates on four states and Delhi, chosen due to their varying levels of service provision as well as their location. A chapter is dedicated to patients' stories, with contrasting descriptions of personal experiences before and after access to treatment. There is a personal and emotive tone throughout the document, with several examples of patients in pain and unable to access treatment, describing suicide as their only viable option. Added to this are strong human rights declarations calling for urgent political action. In this sense, the report is constructed as a partisan advocacy tool rather than as an objective measure of the state of clinical care in India.

The HRW and IOELC reports, and the seminal mapping projects that have followed are impressive in their scope and act as valuable tools to inform improvement strategies and as advocacy tools. There are, however, limitations to each of these reports, which I outline below.

The use of rankings and categories to stratify levels of development of care delivery as used in the *Global Atlas of Palliative Care at the End of Life* and the *Quality of Death Index* are helpful tools to guide and measure change. They are widely cited, have received high profile media attention and serve as important advocacy tools. Despite the breadth and depth of data contained in these reports, however, they inevitably have limitations. There are simple methodological problems that arise when such descriptions of complex systems are reduced to categories or numerical ratings, which are inherently reductionist. This is demonstrated by the fact that although several studies have carried out ranking of palliative care delivery in European countries the ratings produced have been inconsistent.<sup>164</sup>

Furthermore, I argue that not only is it impractical to compare such disparate data sets in a quantitative fashion but that the concept is flawed at a more fundamental level. The description of service delivery at a country level, within a ranking system or as stratified categories of development, contains an implicit assumption that there is a single ideal trajectory of development that all countries should aspire to and ultimately could attain. As

I discuss in more detail with reference to the literature from postcolonial studies in the final section of this chapter, the idea that there is one single ideal is likely to be flawed as a model for guiding clinical service improvement at a global level. Furthermore, this ideal is very strongly informed by a western model of healthcare. Similarly the strong emphasis in the HRW report of framing access to treatment in terms of UN defined human rights contains a degree of western bias.

The specific methods of these studies also have limitations and are relatively poorly defined in the reports with little reference to, for example, the precise manner in which experts are identified and interviewed. There are potential problems here with the degree of geographical representation especially in a country as vast as India. With the plurality of healthcare delivery I already describe, there are inevitable problems with ensuring participants from all groups are represented. Whilst efforts have been made in these studies to incorporate a wide range of experts, interviewees and other data sources, it is difficult to be sure that all relevant healthcare groups are included. This inclusion of different groups is particularly difficult in low resource settings but ironically due to the complexities of healthcare delivery it is also likely to be more revealing and important.

Some authors have also critiqued the use of individual experts due to their bias in evaluating services.<sup>164</sup> Whilst I support the fact that asking individuals to report in detail on large geographical regions and sections of healthcare is problematic, for the reasons I outlined above, I would question the idea that the bias of experts should or indeed could be removed. I would argue that describing the removal of bias of experts is to misunderstand the practice of clinical medicine, to conceptualise it as a purely rational scientific process rather than the, at least partially, socially or more specifically, professionally constructed entity that it is. When considering healthcare delivery and improvement strategies in practice, medical expert opinion *is* western medicine, it is not something that can be removed in order to reveal an underlying scientific truth, and therefore it is these opinions themselves that should be the object of study rather than being treated as an unwanted contaminant of the scientific process. I will return to this issue and the concept of the socially constructed nature of medicine in more detail in the final section of this chapter.

The last key limitation I outline from this group of reports is the lack of clarity in definition of the sorts of painful medical conditions that are being treated under the remit of palliative

care. The IOELC report and associated maps do not clearly outline whether patients in the palliative care services are suffering from cancer, terminal diseases or any chronic condition. The diseases included in the estimates of need for palliative care are similarly unclear. The HRW report, with a clearly stated remit in its title to focus on palliative care, and a note that the paper is focusing on pain from life-limiting illness rather than acute or chronic pain not associated with terminal disease, includes a case report of a patient suffering with pain following a road traffic accident. As I have already outlined this lack of clarity is common, problematic and rarely acknowledged in these papers. Not only is there a lack of precision in the definitions of palliative care but also the use of opioids is described with little or no discussion of the controversies surrounding their use, particularly in the management of chronic pain not associated with terminal disease. For example the HRW report states “oral morphine is the drug of choice for chronic pain”<sup>121(p13)</sup> which is, as I demonstrated earlier, a highly debated statement within western medical practice. Furthermore, there is little or no mention of the lack of availability of other modes of treatment.

Each of the reports I described above specifically describes the problematically low availability of opioids in India and they all refer to usage data, compulsorily reported by each country to the International Narcotics Control Board. The PPSG at the University of Wisconsin collates this data into per capita data for each medication, and for each country and region.<sup>115</sup> This extensive data set with multiple, freely available, clearly accessible graphical representations is an impressive resource that is widely used as an advocacy tool and a means of monitoring change in usage over time. Indeed, the work of the PPSG is used in the reports described above. There are, however, limitations with this resource such as inaccuracies and time delays in the reporting of data. Furthermore, the data is collected for the use of all opioids regardless of their use. The data therefore includes opioids used in anaesthesia and drug dependence substitution therapy, as well as in pain management.<sup>165</sup> Within pain management the opioids will likely be used to treat acute and chronic pain as well as for patients suffering from terminal disease. As I explained above, however, opioid consumption and accessibility data is used as a marker of quality of palliative care delivery, as in the *Quality of Death Index*.

In an attempt to improve the understanding of the use of opioid medications in cancer pain, an ambitious study was published in 2013 entitled the Global Opioid Policy Initiative

(GOPI).<sup>59</sup> Following on from a study by the European Society for Medical Oncology and the European Association for Palliative Care, to assess the availability, accessibility and barriers to the use of opioid medications in Europe, a wider global study was set up as the GOPI, with the assistance of the PPSG, the WHO and the Union for International Cancer Control. Specifically, the GOPI project sets out to assess the formulary availability, cost and actual availability of opioids listed as ‘essential’ by the WHO and the IAHPC, as well as barriers to access. Several reports are published by geographical region, but India due to its size and complexity earned its own detailed report.<sup>2</sup> The study used a detailed survey tool delivered to two or more field reporters per country or state. Of note, it is not clear in the study report exactly how these reporters were identified, their professional role or their location of work. The resulting data is presented as a table of formulary availability for 24 of India’s states, ranging from ‘always’ available to ‘never.’ The familiar barriers of a lack of education and appropriate policy are also highlighted. This report and the GOPI as a whole provide a clear and extensive picture of opioid availability, but there are inevitably limitations with the work. The methodology defined in the published reports in terms of details of the participants and their selection is limited in detail. The use of small numbers of informants without clear information regarding their professional roles inevitably leads to questions of representation of the country as a whole. The aim of the study is to assess the use of opioids only for the treatment of cancer pain, consequently, again, the work fails to address the issues of opioid use in treating pain from other medical conditions<sup>166</sup> and indeed of the availability of other treatment modalities.

The studies I have outlined so far focus on the provision of pain treatment, specifically opioids, within palliative care or even more specifically for cancer pain. As I demonstrate, studies relating to the provision of pain management in India from a more general and inclusive perspective are far fewer in number and markedly smaller in scale and ambition. There are no widespread mapping projects of service provision for acute pain or chronic pain that is not associated with terminal disease, or of treatment availabilities other than opioids. There are, however, some small-scale surveys relating to the management of both acute and chronic pain, which I discuss in detail below. To be clear, their inclusion in this section alongside the global palliative care projects, reflects the lack of attention given to these areas of pain management.

The IASP carried out a survey, published in 2007, to assess training and education in pain management, and the facilities available for delivering care, in developing countries.<sup>62</sup> The survey of the IASP members yielded 9 responses from Indian members which were reported as pooled data with 8 responses from other countries in the Indian Subcontinent. The survey identifies low levels of education in pain management at all stages of medical training, from undergraduate to postgraduate. The survey also describes low levels of service provision for the treatment of all types of pain including acute, chronic non-cancer pain and cancer pain. 100% of the respondents from the Indian subcontinent considered pain control to be a problem. The low availability of opioids is also noted although interestingly the use of opioids for 'non-cancer pain' is also included in the survey, albeit in little detail. Again, the barriers are described in terms of education, policy and medication access. There are notably low numbers of respondents in the study as a whole, for each region and for some questions in particular. Again, as with the previous studies I have outlined, the respondents act as key informants, describing the state of pain management across their country or region as a whole, as well as describing specifics of their own place of work, which for some of the data raises questions of how representative it is. Nevertheless, the survey does address the treatment of pain regardless of its cause, and the use of opioids beyond palliative care, providing some valuable data in a very under-researched field.

Vijayan Ramani, a pain specialist from Kuala Lumpur, has described some summary findings from an 'informal' questionnaire within a IASP published article on acute pain management in developing countries.<sup>23</sup> Although the methods and results are only reported in very limited detail, data is published from several countries including India describing: acute pain as undertreated, low availability of opioids, low levels of education and low levels of resources.

A final survey included here relates to the provision of acute pain management in India. Carried out by P N Jain, a past-president of the ISSP, and published in 2015,<sup>156</sup> the survey of anaesthetists identifies low levels of the presence of specialist acute pain management teams, low levels of the use of opioids and infrequent availability of clinical protocols. Yet, again, the barriers are identified as educational, related to opioid access and inadequate resources. The study has a notably low return rate of just 0.04% but with 146 responses

and in a field of study that is scarcely represented elsewhere in the published literature it is a notable piece of work.

In this section, I have discussed the key studies, relating to the medical treatment of pain in India, outlining their strengths and limitations. I have showed their emphasis on conceptualising the treatment of pain as a medical problem and their repeated identification of the presence of barriers relating to treatment availability, education and policy, that are described as needing to be overcome. I have also demonstrated the markedly different degrees of attention that are given to addressing pain management depending on its cause. Specifically, the predominance in the literature and the scale of global advocacy projects addressing pain related to cancer and palliative care, and their treatment with opioid medications.

The methods I use in my research have been heavily informed by each of the studies and their limitations as discussed in this section. I expand on findings and address areas that are currently under or not represented in this literature. Specifically, I choose to study specialists working in all fields of pain management and in particular to include those working outside of palliative care. I also include evaluation of access to treatments other than opioids. I use in depth interviews from multiple key informants specifically identified to represent different areas of clinical and geographic practice, and incorporate with this data from a wider survey of practitioners. When addressing my specific research questions (set out in Section 1.2) I focus on asking in detail about the delivery of care at each individual's place of work where knowledge will likely be most clear and accurate. When considering the provision of pain management across the whole country, I include critical evaluation of participants' opinions in this field. I move beyond descriptions of the existence of barriers, to understand their assumptions and associated controversies by examining the evaluations and normative positions of individual clinicians. The comparative Table 1-1 summarises the key studies I described in this chapter alongside my own research, outlining each study's scope, aims and methods, and highlighting the innovative nature of this project. In the final section of this chapter I outline the theories that underpin this work.

<b>Project</b>	<b>Medical Scope</b>	<b>Aims</b>	<b>Methods</b>
<i>India Country Report, International Observatory on End of Life Care, 2008</i> <sup>118</sup>	Palliative Care	To quantify palliative care services operating in India To identify strengths and weaknesses in the state of development	Publicly available material (published and grey literature) Key informant interviews
<i>Unbearable Pain: India's Obligation to Ensure Palliative Care, Human Rights Watch, 2009</i> <sup>121</sup>	Palliative Care	To describe the availability of palliative care services in India within a human rights framework	Field visits Selected states (chosen for variability in pall care provision). Interviews – stakeholders (patients and professionals) Desk research on availability in other states
Global Opioid Policy Initiative, 2013 <sup>2</sup>	Cancer Pain	To describe the availability, accessibility and barriers to the use of opioids for cancer pain in India, and other regions	Survey to key informants
Mapping projects, <sup>57,146</sup> <i>Global Atlas of Palliative Care at the End of Life, WPCA &amp; WHO, 2014</i> <sup>53</sup>	Palliative Care	To map of availability of palliative care services, barriers to improvement and global need	Publicly available material (published and grey literature) Key informant interviews
<i>Quality of Death Index, Economist Intelligence Unit, 2015</i> <sup>58</sup>	Palliative Care	To describe availability of, quality of and need for palliative care Country ranking	Publicly available material (published and grey literature) Key informant interviews
<i>Education and Training for Pain Management in Developing Countries, IASP, 2007</i> <sup>62</sup>	All Pain Management	To assess education, training and facilities for pain management in developing countries	Survey to IASP members
Informal survey on the status of acute pain management, Vijayan, 2011 <sup>23</sup>	Acute Pain Management	To assess acute pain provision of services and education/training in India and other countries	Survey – details unclear
<i>Acute Pain Services in India: A glimpse of the current scenario, Jain, 2015</i> <sup>156</sup>	Acute Pain Management	To assess the presence of acute pain services in India	Survey of anaesthetists' own practice in India
This study	All Pain Management	To critically appraise individual clinicians' practice of pain management, their evaluations and normative positions.	Key informant interviews, and survey of clinicians treating pain in India Field visits and oral history archive

*Table 1-1 Comparative Table of Studies Detailing Service Provision of Pain Management and Palliative Care in India*

## **1.5 Theoretical Perspectives in the Study**

As I demonstrated above, pain is conceptualised by the medical profession as a clinical problem to be fixed. Not only is this approach debated both within medicine and across society in general, but the nature of best clinical practice within medicine is also the subject of controversy. In this section, I explain some of the key ideas relating to the social and professional construction of health, illness and medical knowledge, and how they relate to the subject at hand. I describe principal aspects of theories relating to power and the policy process that have informed this work. I conclude with a description of the dominance of western models in relation to improving healthcare at a global level, drawing on some of the main themes in postcolonial studies.

### **1.5.1 Social Constructionism**

The fundamental concept of social constructionism suggests that reality is created by the actions and interpretations of society's members. As Elder-Vass explains, social constructionism argues that "the ways in which we collectively think and communicate about the world affect the way the world is".<sup>167(p4)</sup> He goes on to explain that a key attribute of a socially constructed entity is that, given an alternative set of social circumstances it could or indeed would be structured differently. This is in contrast to an objectivist perspective wherein entities are considered to exist independently of any socially constructed reality. Whilst some argue that these two ontological and their associated epistemological positions are incompatible, others describe social constructionists as positioned on a spectrum that includes radical and moderate orientations. Radical social constructionists argue that reality only exists as a socially created phenomenon but more moderate social constructionists, a group in which I include myself, consider the world to consist of an underlying reality that is then socially modified.<sup>168</sup> Roy Bhaskar, through his philosophical theory called critical realism,<sup>169</sup> embraces this concept by conceptualising the world as consisting of multiple, 'laminated' realities.<sup>170</sup> He also describes the fundamental importance of understanding the generative mechanisms that create an observed phenomenon.<sup>169</sup>

Incorporating a social constructionist view can be used to understand multiple areas of healthcare including the meaning of illness within a culture, what constitutes normality or abnormality, individuals' and society's responses to illness and the creation of medical knowledge.<sup>168,171,172</sup> When considering this research project, although particular entities such as healthcare workers, medications and other physical treatments exist as objective realities, the manner in which they act or are used is highly dependent on the social context in which they operate. Furthermore, critically evaluating the context in which healthcare is delivered is particularly pertinent when researching the use of western medicine in non-western countries, where the sociocultural environment is different to that in which the medical technologies were initially devised and implemented.<sup>171</sup> Furthermore, the conceptualisation of entities as being at least in part socially constructed, leads to important considerations of the power individual actors hold in society, and the role they play in healthcare and wider political processes.<sup>173</sup> Specifically, with respect to this project, a critical evaluation of the power wielded by doctors and their primary role in the construction and application of medical knowledge is particularly relevant. As I outline below, this role has been the subject of considerable scholarship throughout the twentieth century.<sup>174</sup>

Functionalists, such as Talcott Parsons, describe doctors as highly skilled individuals and therefore holders of significant amounts of power through their ownership and application of specialist, professional knowledge.<sup>175</sup> Crucially, they are considered to use this power only in a benevolent manner. Deborah Lupton explains how functionalists consider the medical profession to be a "moral guardian of society".<sup>174(p4)</sup> This is exemplified through descriptions of patients as 'malingerers' who exaggerate or fabricate illness for personal gain. This functionalist approach is criticised, however, for ignoring the potential conflicts of interest that arise between doctor and patient, and for placing doctors on an artificially high pedestal of morality.<sup>174</sup>

In contrast to the functionalist approach, authors such as Eliot Freidson, Erving Goffman and Ivan Illich describe the negative effects that can result from the power wielded by the medical profession. Freidson in his *Profession of Medicine: A Study of the Sociology of Applied Knowledge*,<sup>176</sup> first published in 1970, describes a 'professional construction of illness'. In doing so, he moves away from considering medicine as a benign, benevolent profession, and instead describes doctors as self-serving, and the creators of diseases

necessitating medical treatment. He describes in detail how illness is constructed as doctors define the boundaries of normality, stating “it is medicine’s view of illness that is officially sanctioned and, on occasion administratively imposed on the layman”.<sup>176(p206)</sup> Similarly, in Goffman’s *Asylums*,<sup>177</sup> first published in 1961, he describes how a medical model constructed for use in other areas of healthcare is implemented, despite being a poor fit, in psychiatric medicine. He explains how diagnostic labelling is used to describe behaviour patterns, stating, “in practice these categories become magical ways of making a single unity out of the nature of the patient – an entity that is subject to psychiatric servicing.”<sup>177(p326)</sup> In this example, doctors are defining what constitutes a disease, prescribing treatment, and in some cases incarcerating patients against their will in medical institutions.

This notion of a professional construction of illness is particularly apt when considering chronic pain. Despite this condition’s resistance to medical treatment, there is, through it being labelled as an illness, an implication that treatment is required by a physician. As declared by Freidson, “The jurisdiction that medicine has established extends far wider than its demonstrable capacity to “cure”.”<sup>176(p251)</sup> He goes on to explain how the profession “seeks to discover illness of which laymen may not even be aware.”<sup>176(p252)</sup> and thereby to attract patients. Similarly, Ivan Illich writes, “Man has not only evolved with the ability to *suffer* his pain, but also with the skills to manage it”.<sup>178(p144)</sup> He goes on to describe the many methods used to treat pain before the relatively recent dominance of the medical profession, such as massage, acupuncture and opium.

This perspective, sometimes described as a political economy approach<sup>174</sup> also moves beyond the doctor–patient encounter to incorporate consideration of the wider societal effects of the power wielded by the medical profession. For example, doctors seek to influence the political field through their professional organisations.<sup>176</sup> and in doing so increase the amount of economic resource devoted to the delivery of healthcare.<sup>174</sup> This contributes to the so called ‘medicalisation’ of conditions, including pain, that are, transformed from being considered a normal part of the human condition into treatable illnesses.<sup>179</sup> This increasing medicalisation seen in recent decades and described with respect to many other conditions such as childbirth, sexuality and death,<sup>180</sup> is attributed to multiple factors including the pharmaceutical industry, medical insurance companies, the medical profession, governments and the wider society.<sup>179,181</sup> It is interesting to note at this

point, that there remains a call, albeit debated, within the medical profession for chronic pain to be classified as a disease,<sup>182,183</sup> and within several countries, including India, for pain medicine to be formally recognised as a medical speciality in its own right.<sup>13,149,184</sup>

Freidson also talks about the variations in opinion and different schools of thought within the medical profession. Whilst he acknowledges that this is to some extent obvious, he also states that they “by their very existence, call into question the stability and objectivity of the corpus of medical knowledge.”<sup>176(p263)</sup> It is interesting then to consider this perspective alongside the current debates within the field of chronic pain surrounding the definition of the condition itself. For example, the very presence of the IASP’s taxonomy<sup>185</sup> which includes a list of definitions including of the phenomenon of pain itself, and of a dedicated working group continually revising and updating the terminology. Within the taxonomy, the distinction between acute and chronic pain is noted to be difficult to define with precision, beyond the notion that one is short-lived while the other persists. Chronic pain is described in a number of ways including: pain that exists beyond the time of tissue healing following an injury, pain that exists for a quantified length of time, and pain that is not relieved with particular treatment strategies.<sup>186</sup> The authors acknowledge that no one simple definition will suit all scenarios. Similarly, despite a WHO initiative to develop clinical practice guidelines for the treatment of acute and chronic pain, none have been published at the time of writing. There is, however, a description of the degree of difficulty in reaching consensus simply on the number of guidelines that should be written.<sup>187</sup> Definitions of palliative care are also disputed, vary across the globe and continue to evolve.<sup>25</sup>

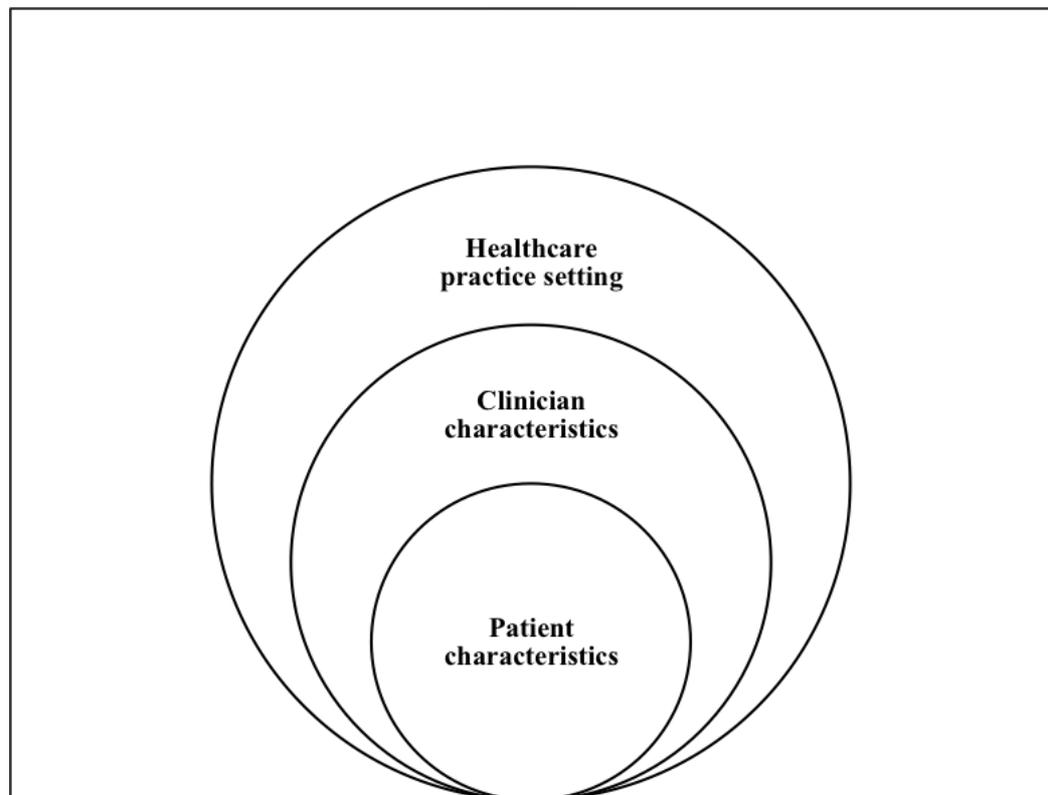
The political economy perspective as a model for understanding healthcare is also challenged from a social constructionist perspective, perhaps most notably by the French philosopher Michel Foucault.<sup>174</sup> Foucault, in *The Birth of the Clinic*<sup>188</sup> first published in French in 1963, specifically talks of how medical knowledge is created and then used by the medical profession to exert power. For example, he describes how a patient’s experience of suffering is transformed into an object of inquiry or examination, “to look in order to know, to show in order to teach, is not this a tacit form of violence, all the more abusive for its silence, upon a sick body that demands to be comforted, not displayed?”<sup>188(p102)</sup> Crucially, however, he explains how knowledge and the resulting power it enables is the product of *relationships*, and is therefore dynamic and changes with

the socio-cultural environment.<sup>174</sup> When considering clinical medicine, knowledge is therefore inextricably linked to the patient's experience, rather than situated entirely with the medical profession. For example, David Armstrong explains how Foucault conceptualises the voice of the patient as "an artefact of socio-medical perception."<sup>189(p743)</sup> This version of reality as presented by the patient is then further reinterpreted by the doctor so that the "field and gaze are mutually self-supporting."<sup>189(p743)</sup> This analysis is compatible with Bhaskar's critical realism and his laminated conceptualisation of reality.

I have explained above how the medicalisation of the problem of pain can be considered to be a profession construction. However, pain cannot be seen. It is a personal experience of the individual sufferer that is therefore inevitably modulated by the social milieu. Only the individual experiencing it can appreciate its nature in its entirety. Consequently, when a patient is seeking medical advice for the treatment of pain, there is an imperative to communicate the precise nature of this symptom to the clinician. Inevitably this exchange will result to some degree in the doctor re-interpreting and transforming the symptom, and even potentially under estimating a patient's pain.<sup>173</sup> In this sense, in line with Foucault's perspective the treatment of pain is not solely a *professional* construction, but rather a dynamic social relationship influenced by many members of society - a *social* construction. It remains important, however, to acknowledge the particularly potent power differential between patient and doctor with the medical description and evaluation of the sufferer's pain ultimately resting in the hands of the clinician. In this research project I am specifically considering this perspective of practicing clinicians and therefore focus on the professionally constructed aspects of the treatment of pain. However, I also acknowledge the influences of other individuals and the wider social context by critically evaluating these phenomena from a social constructionist perspective.

The practical relevance of this theoretical philosophical perspective can be demonstrated by considering the process of medical decision-making. Variation in treatment selection between doctors is widely reported, and occurs within<sup>190</sup> and between countries.<sup>191,192</sup> The treatment of pain is no exception, with social and demographic variables reported to affect the treatments received by patients.<sup>193,194</sup> Multiple factors are described as affecting the process of medical decision-making including: characteristics of the patient such as age, gender and personality; characteristics of the clinician such as specialty training, seniority, class and ethnicity; and characteristics of the practice setting such as its funding and

size.<sup>192,195-198</sup> Clinicians therefore draw on knowledge received from multiple sources beyond the purely scientific. This includes experiential knowledge from previous clinical work, social knowledge from their own cultural background and the knowledge of the patient themselves.<sup>199</sup> My research is specifically focused on the critical appraisal of clinicians' normative positions and evaluative judgements, which are created by, and in turn influence, their wider social context. Figure 1-2 summarises these factors that relate to medical decision-making, incorporating wider society, the healthcare system and the individual actors.



*Figure 1-2 Social Context of Medical Decision Making*

A specific example that demonstrates the importance of understanding how clinicians construct, interpret and ultimately utilise knowledge is the case of evidence based medicine, or EBM. Fuelled by an expansion in medical research, EBM was heralded as a 'new paradigm' within the practice of medicine 25 years ago.<sup>200</sup> The idea behind the movement is to collate rationally derived data from scientific studies to guide the use of medical treatments, thereby improving outcomes for patients by ensuring they receive the treatments that are most likely to be effective and reducing harm by cutting the use of

ineffective therapies.<sup>201</sup> EBM has given rise to hugely influential projects such as the Cochrane Collaboration, and it informs clinical practice guidance and healthcare policy. Since its emergence in the 1990s, however, there has been a critique of the use of EBM in clinical practice due to concerns over how appropriate it is to use evidence derived from scientifically constructed, artificial scenarios, when treating patients in real life situations that are inevitably complex and socially situated.<sup>202,203</sup> Rather than call for an alternative paradigm to EBM, however, there is increasing recognition of the value of incorporating the science of EBM with other types of knowledge such as experiential and social<sup>202,204</sup> and to use cross disciplinary research to fully appreciate the value of EBM.<sup>203</sup> Greenhalgh explains the need to move away from the notion that knowledge can be simply ‘translated’ into practice, and consider a more critical approach incorporating concepts from the social sciences such as notions of how knowledge is ‘created’, ‘constructed’ or ‘embodied’.<sup>205</sup>

EBM is also widely used to inform healthcare policy.<sup>206</sup> The policy process which can be, albeit simplistically, considered as a series of stages starting with agenda setting, moving to policy creation and ending with policy implementation, shares many characteristics with the creation and use of scientific knowledge through clinical practice guidelines. Appreciating the importance of issues such as the professional construction of knowledge, complex social networks and power hierarchies are key to understanding these processes. To this end I now turn to describe some of the elements of policy theory that I draw on throughout this thesis.

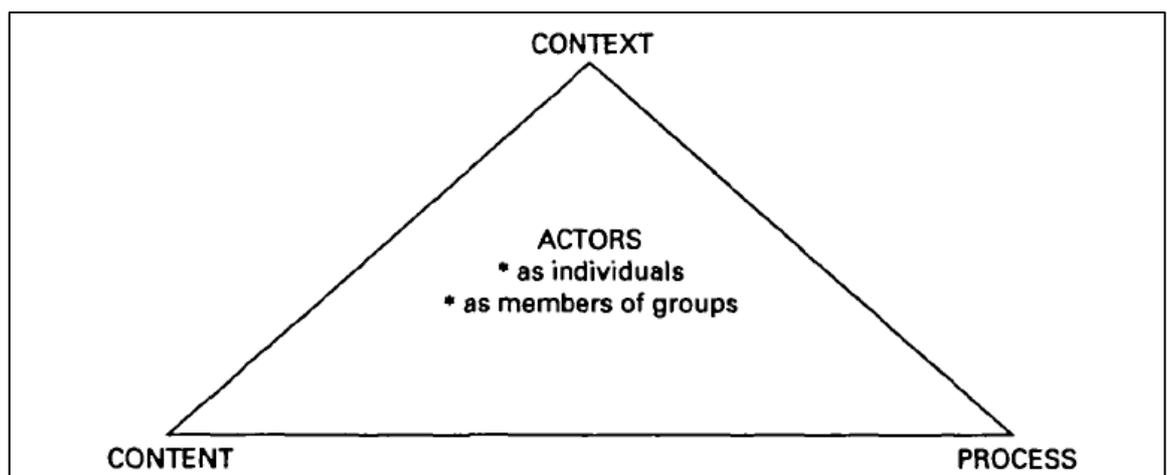
### **1.5.2 Policy Theory**

As I demonstrated in the earlier sections of this chapter, the need to address healthcare policy in order to improve access to pain management and palliative care is frequently cited. The same authors, however, make minimal reference to the extensive literature base from policy studies.<sup>53</sup> Similarly, there is, in general, a lack of detail in descriptions of how policies should be amended and implemented, although there are notable exceptions such as the work of the PPSG and its International Pain Policy Fellowship programme.<sup>207</sup>

Clearly, the scope of policy theory is vast with multiple journals, books and indeed entire university faculties devoted to the discipline. My aim here is to give an overview of some of the complexities of how policies may be created and implemented, and demonstrate

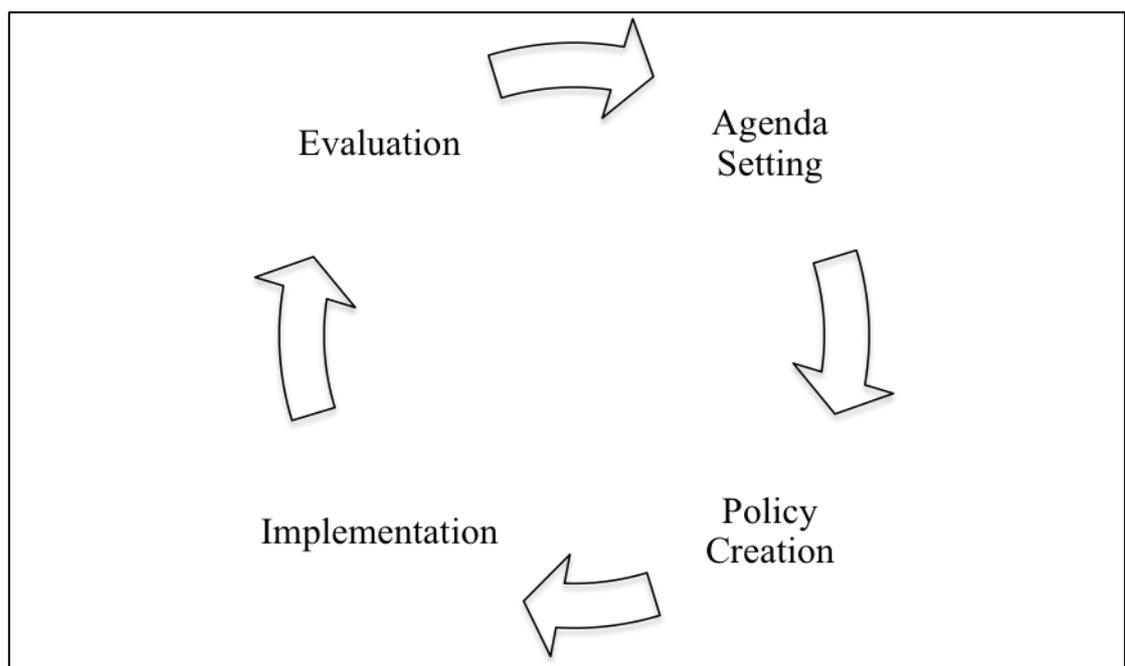
why there is the need to appreciate these complexities in order to gain a better understanding of the medical treatment of pain within a global setting. There are multiple definitions of the term ‘policy’ but for the purposes of this discussion, I will consider policy as a set of aims, objectives and strategies set out by figures of responsibility.<sup>208</sup> Within the context of the Indian healthcare system therefore this will include many levels of authority and responsibility, from local clinical institutions (public or privately funded), professional bodies such as the IAPC and ISSP, regulatory organisations such as the Medical Council of India, as well as state and national government. Consequently written policies will range from national government strategic documents to local clinical practice guidance.

In response to the tendency to focus only on the content of policy, Walt and Gilson<sup>209</sup> constructed a framework to aid understanding of the wider role of policy within healthcare. They describe four key interrelated elements, namely the policy content, the policy process, the policy context and the multiple actors involved. These actors are also collectively often described in terms of networks or communities reflecting the numerous participants and their dynamic interconnectivity.<sup>210</sup> Walt and Gilson’s policy triangle<sup>209</sup> demonstrating these interrelated elements is shown in Figure 1-3. To be clear, this is a simplistic diagram of a highly complex system, but the aim of the triangle is to guide analysis of health policy by ensuring that the key elements of the process are considered.



*Figure 1-3 Walt and Gilson's Triangle for Health Policy Analysis<sup>209</sup>  
(Permission to reproduce this diagram has been granted by Oxford University Press)*

By studying each of these elements and crucially their dynamic interactions, a deeper understanding of a particular policy can be gained. So, when considering for example the creation of national guidelines for the treatment of pain in India, the content of what should be included in the guideline will be affected by the local healthcare context such as the availability of medications or equipment, the proximity of rural populations to institutions, or the ability to fund treatments. Many actors will be involved in the negotiated process that is the writing of the policy. There will be power differentials between different clinicians relating to their professional hierarchy both as individuals and as representatives of professional societies such as the ISSP or IAPC. They will have different opinions as to what constitutes best practice and, as explained in the previous chapter section, they will draw on multiple knowledge types beyond the scientific such as social and experiential. Other actors may also be involved, directly or indirectly, such as the pharmaceutical industry, international non-governmental organisations, politicians and patients. Finally, the process of creating the policy needs to be considered, what is the topic of focus and why has that been prioritised, who are the authors, how are different opinions of these actors negotiated, how will the policy be used and implemented?



*Figure 1-4 Stages of the Policy Cycle*

Another useful aid to analysis of the policy process is its conceptualisation as a series of stages of a cycle. There are many such frameworks published in the literature such as that

described by Barker<sup>211</sup> which outline the constituent elements of this cycle such as, agenda setting, the creation of policy, implementation of policy and evaluation. An example of a simplified visual representation of this process is depicted in Figure 1-4.

Early descriptions of the process of creating and implementing policy favoured a rational, positivist model. Describing decision-making and actions as logical predictable processes. Torgersen calls this a time when it was assumed that “knowledge would replace politics.”<sup>212(p34)</sup> The stages approach or policy cycle in Figure 1-4 can indeed be considered an example of one such rational model.

In more recent years, driven in part by a philosophical shift in the social sciences towards postpositive and moderate social constructionist perspectives that demand an appreciation of the particular social context in which individuals function, multiple alternative theories have been proposed.<sup>213-216</sup> A detailed description of these theories is beyond the scope of this thesis but examples include incrementalism, wherein small changes occur repeatedly as a response to the complex inputs from the wider political environment<sup>208</sup> or punctuated equilibrium, wherein, particular sets of circumstances can lead to sudden profound changes within the policy system.<sup>217</sup> These newer theories have largely displaced the stages cycle approach as a causal theory of the policy process due to the over simplification and description of events as linearly ordered.<sup>210,218</sup> Nonetheless, in the same manner as the policy triangle is a useful tool to aid analysis of policy, the stages approach is frequently used as a framework to aid discussion. I will indeed follow this by referring to three stages of the policy process, namely agenda setting, policy formation and implementation, with respect to the particular case of pain management in India. However, it is vital to appreciate that these stages are neither distinct nor isolated, nor are they related to each other in a predictable chronological fashion. Rather they are interwoven as complex and dynamic processes with multiple cycles of feedback and modification.

Central to any discussion of the policy process, regardless of the particular theoretical approach being invoked, is the concept of power - who holds it, how is it negotiated, and how is it enacted? Power is ubiquitous within society and can be thought of as the fuel of the policy process.<sup>211</sup> Unequal distributions of power result in one individual or group being able to exert control over another. This control can be enacted in multiple ways but can be usefully conceptualised within three different dimensions.<sup>208</sup> Firstly, an individual

that has a higher ranking related to a particular attribute such as money, professional status, knowledge or physical prowess, when compared to another individual, will be able to exert control.<sup>219</sup> An example would be a senior doctor demanding a medical student to carry out a particular task. The second dimension occurs when the holder of power creates a structure that inherently removes choice and therefore power from those who are less powerful.<sup>220</sup> An example would be the creation of a political system in which only certain groups are allowed to vote in an election. Power is exerted in this fashion within healthcare when members of the medical profession take the lead in deciding which diseases will be prioritised in advocacy projects or which treatments will be included in clinical practice guidelines. The final and most covert form of power enactment occurs when the more powerful actors create an environment in which those holding less power are made to agree with the distribution of power and the resulting pattern of control.<sup>221</sup> They become unknowingly complicit in maintaining and reinforcing the status quo, and their own powerless position. An example would be the marketing of particular medical treatments to patients on the sole premise that they will benefit the patient. If during this process, the full extent of the likely risks is not fully explained to the patient, it would be only the clinician who gains from the interaction either financially or professionally. The patient would be unknowingly complicit in this reinforcement of the unequal distribution of power.

Moving on to consider how these theories of power enactment relate to society as a whole, I describe two examples: pluralism and elitism.<sup>211</sup> From a pluralist perspective everyone holds an equal stake in society and is in a position to wield power, for example through the process of democratic political elections. The government then acts in response to the demands of the electorate. In contrast, elitism dictates that just a few elite members of society such as politicians or members of the medical profession hold power. Whilst there are criticisms of each of these theories and neither truly represents society<sup>208,211</sup> both can be drawn upon to aid the analysis of the policy process in particular individual circumstances.<sup>210</sup> For example, although the medical profession within Indian society is profoundly powerful, patients also exert power when they choose to take their custom to a particular practitioner or choose to not take a prescribed medication. It is therefore necessary to examine the potential power that all actors in a particular situation may hold and to consider all the ways in which power is enacted, the importance of which is made clear in the policy triangle of Walt and Gilson (Figure 1-3).

In general, there is a paucity of research in low and middle-income countries related to the analysis of health policy and much of the work that is done relies on theory and frameworks originating from high-income countries.<sup>229</sup> Nonetheless, whilst acknowledging that more work is needed in this area, these frameworks have been used in low and middle-income countries with a degree of success.<sup>229</sup> This thesis is not designed to be an analysis of policy, but I am aiming to demonstrate, with reference to work from the field of policy analysis, that it is important to understand aspects of the policy process in context, rather than simply to declare the need to create or change policy. So, with reference to the topic of this thesis it is useful to consider the elements of the policy triangle and look at different stages of the policy process, its context and the networks of actors involved. I now elaborate on each of three stages of the policy process (agenda setting, policy formation and implementation) with specific reference to the treatment of pain in India, considering the key elements of the policy triangle and the complexities of power distribution.

Beginning with agenda setting, that is, how or why an issue receives political attention, the actors are numerous and include members of the medical profession, patients and their families, Indian charitable organisations, professional societies, the pharmaceutical and medical devices companies, state and national government, corporate healthcare and international organisations such as the WHO, the International Association for the Study of Pain, the Worldwide Palliative Care Alliance and Human Rights Watch. Each of these actors holds different degrees of power and tools of influence, and each has a different set of personal interests. This list of actors is not intended to be exhaustive, but rather demonstrates the size and disparate nature of the networks involved.

When considering the context in which these issues are being raised, the wider political environment is highly influential. For example, the structure of jurisdiction in India with each state creating its own health policies results in an environment where multiple different groups need to be lobbied in turn in order raise an issue such as improving the availability of opioids at a national level.

The actual characteristics of the issue being raised as well as how it is framed, that is, how it is conceptualised and publically presented,<sup>230</sup> are also important.<sup>231</sup> For example, when considering the characteristics of the issue of providing pain relief, an alternative cause that is in competition for scarce resources, such as providing universal health coverage, or

detecting cancer, may be deemed more worthy. The manner in which the issue is framed, however, is also key to whether or not it receives priority. For example, In India, as I demonstrated earlier in this chapter, within the field of palliative care, access to pain management is often framed as a human right. Low levels of access are described as a widespread problem that could potentially be fixed very cheaply within a western medical framework through increasing the availability of opioids, if only due effort was directed to the cause. As I also explained this medicalisation of pain, however, is only one of several frames present within society and more specifically, there are a range of views on what the most appropriate treatment strategies are, besides increasing the use of opioid medications.

Moving on to policy formation, which is again an ill-defined stage in the policy process. A variable number of processes may occur during policy formation in which ideas and evidence are assessed, and policy is formulated by multiple actors into repeatedly revised versions until a degree of consensus is reached.<sup>232</sup> Due to the relevance to this thesis I will consider in a more detail here the specific act of the use of evidence based medicine (EBM) in policy formation to create clinical practice guidelines and other evidence based policies.

EBM began to gain popularity within western medicine at the end of the last century<sup>233,234</sup> in response to an observed variation in clinical decision making and a burgeoning published scientific literature. By compiling data objectively from the increasing number of published studies, the aim of the EBM movement is to improve quality and minimise costs by treating patients only with the most effective treatments. As I introduced in the previous section, while this rational aim is entirely laudable, its simplistic approach is becoming increasingly debated and critiqued.<sup>203</sup> Critics argue that EBM only considers the use of treatments in a subset of individuals functioning in specific experimental conditions who are not therefore representative of patients in general living as a population in the 'real world'.<sup>235</sup> Furthermore, while the aim of EBM is to direct treatment selection for clinicians, it fails to take into account other factors that affect this decision making process discussed above, such as the characteristics of the patient, the healthcare environment and other forms of clinician knowledge whether it be social, political or experiential.<sup>205</sup>

Moving on from the complexities of using EBM to guide individual patient treatment, there is also a significant body of work describing the use of EBM in generating wider-

reaching clinical practice guidelines. These may be created at a local level within a small medical clinic, across a healthcare system such as those published by the UK government body the National Institute for Health and Care Excellence, or internationally by the WHO. The premise of clinical practice guidelines is to make best use of EBM but the creation of each guideline is inherently influenced by characteristics of its authors.<sup>236</sup> Guideline authors have been shown to draw on other types of knowledge besides scientific - such as experiential and to be influenced by wider political issues.<sup>237,238</sup> It therefore follows that far from being objectively created tools to streamline rational healthcare delivery, clinical practice guidelines should be considered as complex, contested and at least partially socially constructed entities.<sup>238</sup> Furthermore, despite the guideline creation process itself frequently being described as involving a particular set of actions or as following set criteria, whether this process actually occurs in practice is less certain.<sup>239</sup>

The use of the results of scientific studies to create public healthcare policy for use at a population level shares many similarities to the use of EBM to create clinical practice guidelines. For example, some argue that rational scientific quantitative data, the use of which is frequently prioritised over qualitative studies, is not a good fit for the complex 'messy' world of the policy process.<sup>204</sup> It has also been noted that what is needed is a deeper understanding of how EBM is used to inform policy rather than an increase in the scientific base of EBM.<sup>206</sup> Analysis of the factors involved in the system of incorporation of EBM into healthcare policy, including clinical practice guidelines is a complex field<sup>238,240</sup> and a framework to improve our understanding of this process has been created by Dobrow and colleagues.<sup>241</sup> They describe a 'context-based evidence-based' conceptual framework consisting of three stages - introduction, interpretation and application of evidence, each of which is affected by multiple internal and external contextual factors. Internal factors include the purpose of the policy, the actors involved and the creation process. External factors include the characteristics of the medical condition, qualities of the healthcare system and the wider political environment.

Of note, there are many examples of the content of EBM and its use in the creation of clinical practice guidelines, causing conflict between professional groups. For example, within the medical profession itself, clinicians can resent the power EBM gives to academic colleagues,<sup>242</sup> and managers who use guidelines to ration treatments may be perceived as taking control away from physicians.<sup>243</sup> A clear example of the political

nature of the process of guideline creation occurred recently in the UK, when the publication of national guidance on the treatment of back pain, and controversy regarding its content, led to the forced resignation of the president of the British Pain Society who had helped compile the work.<sup>244</sup> More specifically there are concerns regarding the frequency with which published studies are funded by organisations such as pharmaceutical and devices companies that have a financial interest in their results,<sup>203</sup> and in financial conflicts of interest of guideline authors.<sup>203,245</sup>

The final stage of the policy process I consider here is that of implementation. Again theories abound but are largely dominated by the contrasting ideas of processes being either top-down or bottom-up.<sup>229</sup> In a top-down system, compatible with rational theories of the policy process, once created, a policy is widely supported across society and is seamlessly implemented by compliant able citizens (such as civil servants and healthcare professionals), resulting in the desired favourable outcome.<sup>208</sup> In contrast, a bottom-up approach describes the fundamental role that the implementers play and how they are ultimately in possession of power. Lipsky's seminal work in this field where he coins the term 'street-level bureaucrats'<sup>246</sup> describes how frontline staff such as doctors and nurses, despite being bound by certain rules, do indeed hold a significant degree of autonomy when determining their day-to-day practice. Despite Lipsky's theory being several decades old, it is still considered widely relevant within healthcare settings in both high and low-income environments.<sup>247,248</sup> That said, neither a top-down nor a bottom-up approach alone will provide an adequate explanation for any given policy implementation scenario but by referring to elements of both theories a deeper understanding of the complexities will be gleaned.<sup>210</sup>

A final note here with particular reference to this thesis is the need to appreciate the many influences that impact the manner in which clinicians enact power as professionals. On the one hand, doctors have a high degree of autonomy and resulting power, conferred to them through, for example high levels of specialised knowledge that are obfuscating to others. Their professional status may also ensure they are held in particularly high regard within society.<sup>249</sup> Conversely, they are also simultaneously bound by a particular combination of guidelines and rules from their local employer as well as higher regulating authorities.

In this section, I set out the profound and wide reaching influence that both individual practitioners and the medical profession as a whole, have on the healthcare policy process - at the stages of agenda setting, policy formation and implementation. I now turn my attention to consider some of the wider global influences on the practice of pain management in India, drawing on theories from postcolonialism.

### 1.5.3 Postcolonial Perspectives

In this section, I demonstrate some examples of how power is distributed unequally between different countries or regions of the world with respect to healthcare improvement initiatives. I explain how postcolonial theory can inform a more balanced approach to research and ultimately practice.

Numerous high profile organisations working at the global level to improve access to pain management are, despite being named as international, in fact western-based organisations: examples include the International Association for the Study of Pain based the USA, the International Association for Hospice and Palliative Care based in the USA, the Worldwide Palliative Care Alliance based in the UK, the World Institute of Pain based in the USA and the Union for International Cancer Control based in Switzerland. As I have demonstrated, these and many other western based organisation such as the Pain and Policy Studies Group at the University of Wisconsin, and Human Rights Watch have been profoundly involved in influencing improvement initiatives related to pain management in India, particularly relating to improving access to opioids for the treatment of pain within palliative care. Furthermore, several European clinicians are described as being pioneers of the palliative care movement in India.<sup>141</sup> Classification systems of the development of palliative care such as those included in the *Global Atlas of Palliative Care at the End of Life* and the *Quality of Death Index*, report western countries with their particular model of healthcare as ranking highly. The majority of research publications in this field also emanate from the west.<sup>250</sup> Furthermore, the problems of poor access to pain relief are much more prevalent in low and middle-income countries.<sup>60,72</sup>

At a more general level, I have also explained earlier in this chapter how the description of a problem in terms of human rights, an idea frequently coined to describe access to pain management, can be considered to originate from a western perspective. A critique has

been levelled at the field of global health becoming increasingly medicalised, conceptualising health related issues as problems requiring technical western medical solutions.<sup>251</sup> The WHO, considered by some to have an inherent western bias,<sup>252</sup> clearly holds enormous degrees of power in global health, but many other organisations may also be wielding power in a less obvious manner such as the pharmaceutical industries and charitable organisations. Shiffman describes some of these organisations<sup>253</sup> and talks in particular of two new, very prominent, western based players in this field, the Institute for Health Metrics and Evaluation (IHME) and the Lancet, that he describes as rivalling the WHO. Although the aims of these organisations maybe laudable, he describes the need to question and understand their motivations and remit. For example, the IHME is funded by the Gates Foundation which puts considerable power in the hands of this organisation, and the Lancet as a world renowned peer reviewed journal may be seen as a purely rational unbiased voice and thereby placed beyond critique but will inevitably privilege the views of some individuals over others.

Postcolonial theory is based on the concept that the dominance of European countries that controlled vast swaths of the world during the colonial era of the 16<sup>th</sup> to 20<sup>th</sup> centuries still persists despite the end of direct colonisation. The political and economic power of the European countries and those that their descendant populations now preside over such as the USA, Canada, Australia and New Zealand, is sustained and reinforced by a structure heavily weighted to favour this power differential.<sup>254</sup> Various terminologies are used to describe these two regions, such as ‘western’ and ‘non-western’, ‘first’ and ‘third world’, ‘developed’ and ‘developing’ or the ‘global North’ and ‘South’. Each of these has their own limitations, ‘first’ or ‘third’, and ‘developing’ imply rank and include normative connotations about how things ought best to be done, and similar value laden judgements are attached to the word ‘western’.<sup>255</sup> So although imperfect and indeed geographically inaccurate, from herein I will use the terms ‘global North’ to indicate the more wealthy ex-colonising populations and ‘global South’ to indicate those living in disadvantaged, low and middle-income circumstances.<sup>255</sup> However, due to particularly widespread usage, including in the study results, I will continue to use the term ‘western medicine’ to describe specific models and techniques of healthcare delivery that have originated in this part of the world.

Postcolonial theorists describe the actions of the global North as maintaining the unequal distribution of wealth between the two regions, for example through economic policies of organisations such as the World Bank and the International Monetary Fund,<sup>255</sup> and similar criticisms have been made in the field of global health.<sup>252</sup> Power is also wielded in other ways, however, such as through the dominance of the European powers in the writing of history during the colonial era. For example, despite considerable contributions to scientific knowledge, including in the field of medicine, from the colonised populations these are either not acknowledged at all or only described through the eyes of the colonial system.<sup>256</sup>

A seminal postcolonial text is Dipesh Chakrabarty's *Provincializing Europe: Postcolonial Thought and Historical Difference*.<sup>257</sup> In this work, first published in 2000, Chakrabarty explains how detrimental the use of the terms 'developing' and 'developed' are to those included under the 'developing' umbrella. He talks of how the wording assumes that each country will progress along a fixed trajectory of development, one that is already described in the histories of the developed nations, that is, the countries of the global North. However, he challenges the idea that any one country will follow the same trajectory as another. In part, this is due to the structures created by the North, which inherently places countries in the South at an economic disadvantage, but also due to the unique nature of any country's path in history. Furthermore, by describing countries as developing they are assumed to be striving towards a set of goals and aspirations that are defined by the countries of the North. He describes this state as being confined to the waiting room of history, aspiring to an ideal that can never be achieved and resulting in feelings of inadequacy and failure. He also critiques the idea of simply transferring ideas from the North to the South without significant translation. However, he also proposes an alternative model of multiple futures, where each individual country progresses along their own unique path, and ideas and technologies are translated for use between nations.

Chakrabarty's theories are highly relevant to this thesis, indeed the concept of using a paradigm where multiple futures exist rather than one single ideal has already been described in the academic literature with respect to the field of global palliative care development.<sup>258</sup> Furthermore, in the earlier sections of this chapter I outlined how the sociocultural environment affects the conceptualisation of pain, its expression and treatment, and of how the particular local context informs all areas of the healthcare policy

process. I argue therefore that it is imperative to consider improvement strategies at a local level rather than simply extrapolating from work that originates from the global North, and indeed that implies there ultimately exists a universal model to suit all.

#### 1.5.4 Power and Gender

No description of power would be complete without an acknowledgement of the role of gender, although I did not attempt to analyse this dimension in my study. From its inception the medical profession has been a male dominated, patriarchal system. As Rosemary Pringle writes, feminists often consider the profession to have “snatched healing out of the hands of women”<sup>222(p1)</sup> who had previously owned this role. The first women to be added to the British Medical Register was Elizabeth Blackwell in 1849<sup>222</sup> although notably her training had occurred outside of the UK. She was followed by Elizabeth Garrett Anderson in 1856 who had forged her own path of training in Britain.<sup>223</sup> These early female pioneers endured great hostility from their male counterparts during this era – a struggle tightly linked to the rise of women in other professions and the suffrage movement.<sup>222</sup> As Virginia Woolf wrote of the period, until 1919 marriage had been “the one great profession” available to women.<sup>224(p13)</sup> Of note, discussions of gender do not feature in the early sociological writings related to medicine from key authors I have discussed such as Freidson and Parsons.<sup>222</sup>

In India, The particularly strict societal gender segregation that existed in the 19<sup>th</sup> century meant that women were unable to be examined by male physicians. Ironically, in order to serve the female population, women were permitted into medical schools in India ahead of the UK and before the all male tradition had been established.<sup>225</sup> However, these early recruits were limited in their areas of practice – working only in women and child health.<sup>225</sup>

The number of women entering the medical profession increased enormously over the last century.<sup>223</sup> However, in contrast to the ‘first-wave’ of feminism related to the suffrage movement and the *presence* of women in professions, attention more recently has focused on so called ‘second wave’ feminism – related to discussion of professional *status*.<sup>222</sup> As Pringle writes, “Women clear one set of hurdles only to find they are faced with another”.<sup>222(p222)</sup> Despite a significant rise in the number of women practising medicine,

they have tended to work in lower paid specialties and taken on less high-status roles when compared to their male colleagues.<sup>226</sup> This discrepancy is reflected in the persistent gender pay gap recently reported in the UK.<sup>227</sup> Similarly, in India, although the situation is noted to be changing, it is compounded by the lower status of women in society in general, and women in medicine still work in lower status roles and lower paid fields.<sup>225</sup> Furthermore, as I have described elsewhere, women in India persistently have poorer access to healthcare than men.<sup>133</sup>

Interestingly, palliative medicine, especially when compared to surgical specialties, and certainly in the UK, is a particularly female dominated specialty.<sup>222,228</sup> In line with this observation, some feminist writers have argued that women are viewed by society as more holistic, caring practitioners, when compared to their male counterparts who are more attracted to higher status, surgical specialties where problems are cured with technical fixes.<sup>222</sup> It is interesting then to consider how these gender roles might affect the practice of pain management in India. If, for example, the masculine stereotype is reflected in the technical solutions to pain treatment in the form of interventional procedures, is the rising power of the feminine voice (of palliative medicine) a threat to male status?

## **1.6 Summary**

I have described in this chapter how pain is widely described by high-profile medical and advocacy organisations as a global health problem that ought to be addressed through the improved provision of western medical treatments, and the limited impact that many improvement projects have had. I have also demonstrated, however, that many elements of pain management as practised within western medicine are professionally constructed, and how this leads to areas of contention. Examples are seen in the debates surrounding the use of opioid medications and the clinical remit of the medical specialty of palliative care. Variations in local practice across the world add complexity to this picture. Many research projects and high profile initiatives have focused on improving global pain management by targeting improved access to opioid medications within the field of palliative care, and there is a strong tendency for these projects to be led by the wealthier countries in the global North, despite their remit being to improve healthcare in the global South. This

leads to a disparity between improvement initiatives and local clinical practice, which I argue limits their efficacy.

I have explained why I chose India as the location for this project in which I am aiming to assess local clinical practice. I have demonstrated the need to expand on the current evidence base, which is largely descriptive and narrow in its focus. I have described how my research project adds to the published literature through appraising medical care that lies outside the remit of palliative care and consideration of the use of treatments besides opioids. My study is also innovative in nature as I situate a critical evaluation of the normative positions and evaluative judgements of clinicians alongside descriptions of practice.

The need to conceptualise illness and healthcare as complex phenomena influenced by and inextricable from the socio-cultural environment is well described.<sup>259</sup> Many have talked of the need to look beyond the reductionist models upon which western medicine is based and which conceptualise medical science as a quest to discover a universal truth.<sup>260,261</sup> Despite these contributions there remains a paucity of truly cross-disciplinary collaboration in healthcare research, demonstrated in the academic literature.<sup>262</sup> In this chapter, I have introduced the theoretical perspectives that inform this research study in its entirety, namely social constructionism, policy theory and postcolonialism. By examining the professionally constructed nature of medicine, the complexities of the policy process and global distributions of power I have described why the treatment of pain at a global level and specifically within India should be considered within a cross-disciplinary framework.

In the following chapter I describe my research methods in detail, demonstrating how theories from the fields of social and political science have informed this part of the research process.

## **Chapter 2 - METHODOLOGY AND METHODS**

### **2.1 Introduction**

The overarching aim of this research is to understand how pain is treated in India through building up a map or landscape of this field of medical practice from the perspective of practitioners themselves. In contrast to the majority of published research related to improving pain management at a global level, I seek to incorporate the views of clinicians working across all areas of pain management, including and beyond the remit of palliative care, and to consider the medical use of a wide range of treatment modalities, including and beyond opioid medications. I argue that this terrain, that is in part professionally constructed, can only be mapped out with a degree of completeness by using more than one research tool and data type.

I therefore choose to answer my research questions, as laid out in the introductory chapter, through the use of multiple methods incorporating both open and closed questions from semi-structured interviews and written surveys, created and analysed in conjunction with field notes gathered throughout the duration of the study. As I explain in detail in this chapter, the vast majority of the data was collected from attendees at two national conferences of the professional societies of the Indian Society for Study of Pain (ISSP) and the Indian Association of Palliative Care (IAPC).

In the following section of this chapter (2.2) I explain the methodology of the study, beginning with a discussion of the use of mixed methods research and its theoretical underpinnings, before considering interviews and surveys as research tools in their own right. In Section 2.3, I then detail the specific methods of data collection and analysis used in this project.

### **2.2 Methodological Considerations**

In the opening chapter, I demonstrated the professionally constructed dimensions of the medical treatment of pain, the extension of social constructionism into policy theories and

their relevance to this study, and the importance from a postcolonial viewpoint of directly seeking the perspective of individuals living in the global South. Therefore, in this study, the aim of which is to critically assess the practice of individual clinicians treating pain in India, I argue that drawing on multiple theories and the use of multiple methods is paramount.

### 2.2.1 Combining Research Methods

The use of more than one method of data collection and analysis has increased over recent years within the social sciences<sup>263</sup> but needless to say this has not occurred without a degree of controversy. In this section I outline some of the key topics of debate, the potential advantages of using multiple methods and data types, and how and why I have chosen to use these techniques.

Much of the debate in this field has focused on the specific issue of mixing the use of quantitative and qualitative data.<sup>264</sup> Controversies include contention over theoretical ideas as well as the practical use of such methods. Traditionally qualitative and quantitative data represent opposite ends of the research spectrum and associated philosophical positions. Quantitative data is associated with a positivist or postpositivist paradigm,<sup>265</sup> within which researchers seek out an objective answer to a question, albeit with, within the postpositivist paradigm, the acknowledgment that a degree of bias is inevitable.<sup>212</sup> The aim of research is to test a pre-defined hypothesis using a deductive process. In contrast, qualitative data traditionally belongs within a constructionist worldview wherein there is no such thing as an objective truth but only various interpretations of reality. Research within this paradigm is inductive, with the aim of discovering new theories and concepts from the data itself.<sup>266</sup> Purists therefore argue that the incompatibility of these associated philosophical worldviews or ontological and epistemological positions make the use of research involving both quantitative and qualitative data untenable.<sup>267</sup>

However, on a more practical level, the association between data type, and ontological and epistemological positions is not absolute. For example, quantitative data such as counting the frequency of phrases used in media articles can be used to deepen the understanding of a socially constructed phenomenon.<sup>263</sup> Some argue therefore that although the paradigms themselves are incommensurable, within each paradigm multiple methods and data types

can still be used. Other proponents working with qualitative and quantitative data, consider their approach to be a distinct field called ‘mixed methods research’ or MMR and conceptualise it as a methodological movement in its own right.<sup>268</sup> Some even describe the presence of an alternative philosophical paradigm called pragmatism to support the use of mixed methods techniques.<sup>269</sup> Pragmatism as a philosophical model is described in various ways but is essentially concerned with actions and their context rather than with predetermined situations.<sup>265</sup> However, others contest the existence of or even the need for an alternative MMR paradigm and describe how researchers should instead draw on the multiple paradigms already in widespread use.

Positivism and constructionism themselves are often considered to represent two ends of a paradigm spectrum,<sup>266</sup> upon which others such as postpositivism and critical approaches (such as feminism and postcolonialism) are positioned. An argument then follows that whilst it may not be feasible to combine the use of strongly positivist and strongly constructionist paradigms, it may well be possible and indeed necessary, to draw on multiple paradigms that lie in close proximity on the spectrum, for example constructionism and critical theory, or positivism and postpositivism.<sup>266</sup> This mixing of methods and paradigms, switching and comparing as the particular research demands, is sometimes referred to as the technique of ‘bricolage’.<sup>267,270</sup> The ‘bricoleur’, originating in this context from the work of the anthropologist Levi-Strauss,<sup>271</sup> far from being the unskilled ‘jack of all trades’ that its name may suggest, is in fact able to tap into multiple paradigms and theories thereby working in a fashion more reflective of the complex social environment in which we research. Similar to this is a technique called ‘crystallization’, an approach to research which also embraces the idea that philosophical paradigms lie on an arts-science spectrum.<sup>272</sup> The approach calls for the use of multiple lenses, or facets of the crystal, drawn from artistic representations and scientific approaches in order to enhance understanding of our complex social world.<sup>267</sup>

There are many reasons why multiple methods and data types may be an advantage within a research project. In general terms, by using multiple approaches the strengths of each can be exploited whilst the weaknesses are offset. Similarly, qualitative data can be used to add depth whilst quantitative data can add breadth. More specifically, different tools and data may be needed to answer different components of a research question. One method can also be used to create the data collection tool for another, such as interview data used to

create questions of a survey. Furthermore, two data sets can be compared to each other to triangulate or corroborate results and each can be used to add depth or breadth to the other.<sup>263</sup> When considering these practical issues of carrying out research, those from the field of MMR call for a clear structure to the integration of each data type. They talk of specific designs with their own nomenclature such as ‘convergent parallel’, ‘explanatory sequential’ or ‘exploratory sequential’.<sup>265</sup> Others criticise this approach as being too fixed to the positivist tradition and argue for a more pragmatic approach, that can be closely fitted to each individual research project making use of all available data collection tools,<sup>267</sup> akin to the method of bricolage outlined above.

Ultimately our aim is to seek rigour in the research process and hence maximise the quality of the research. I argue that quality will not be enhanced by the choice of a particular tool *per se*, which contains inherent rigour, but rather by using whichever combination of tools is most appropriate to the particular research scenario, in a rigorous manner.<sup>273</sup> The focus can then move to issues of validity, reliability and generalisability,<sup>274</sup> or as these concepts are often referred to with respect to qualitative data: truth value, consistency and applicability.<sup>275</sup>

Reliability or consistency, is the degree to which results will be replicated if repeated.<sup>276</sup> Although with any socially situated research, the dynamic nature of the processes being studied makes it impossible to completely replicate findings,<sup>263</sup> strategies to increase consistency include keeping and making explicit a meticulous log of the entire research process and the decisions taken during planning, data collection and analysis; using electronic tools to collect data such as audio recordings, and using computer software for collation and analysis.<sup>274,275</sup> Validity or truthfulness, is concerned with the accuracy of the research findings.<sup>276</sup> Whilst acknowledging, that from a constructionist perspective multiple versions of reality exist, the truthfulness of the realities presented in the research will be enhanced through clear referencing of underlying philosophical positions and theory, triangulation or corroboration of findings, inclusion of thick rich descriptions and detailed accounts of reflexivity.<sup>275</sup> Broadly speaking, findings from studies in which statistical probability sampling is not employed cannot be definitively applied or results generalised at the population level.<sup>263</sup> However, this is not to say that the results of such studies cannot be applied to other scenarios. For example, in a case study, findings can be generalised in the sense that they add to our understanding of theory, a concept known as

‘theoretical generalisation’.<sup>277</sup> Strategies to enhance methodological rigour in this dimension include the incorporation of detailed descriptions of the research context.<sup>275</sup>

### 2.2.2 The Use of Interviews and Surveys

Interviews are widely used to collect research data. The method includes a huge range of specific data collection methods from unplanned conversations in ethnographies to highly structured interview processes eliciting quantitative data.<sup>278</sup> The process itself can take place in many environments such as face to face, by telephone, online or as a written exercise.<sup>263</sup> Needless to say there are pros and cons to each of these techniques, all of which can be equally valid depending on the research questions and setting. The ethnographic interview allows the participants to direct the content and flow of the conversation in a relatively unrestricted manner but the serendipitous nature of this process means that large parts of the data may not be directly relevant to the research questions.<sup>278</sup> In contrast, a structured interview requires the interviewee to read questions verbatim and often offers the participant only certain fixed responses.<sup>279</sup> Whilst this ensures consistency it does not allow for individual expression. Between these two poles lies semi-structured interviewing where the interviewee follows an interview guide outlining the topics of discussion.<sup>279</sup> This allows a degree of flexibility for the respondents who answer questions in their own words but ensures the key areas of interest in the particular research project are covered.<sup>278</sup>

Semi-structured interviewing elicits qualitative data as thick, rich descriptions of areas of interest and is therefore suited for use within an interpretive or constructionist framework.<sup>280</sup> The interviewer can build up a rapport with the research participants enabling a depth of understanding of key issues and concepts. This relationship requires specific attention be paid to reflexivity to appreciate and understand the inherent bias contained within this process.<sup>274</sup> The subjective, qualitative data that emerges from these interviews is analysed to uncover themes, concepts and theories, as opposed to generating numerical, quantitative data.<sup>279</sup> This process is, however, time consuming and relatively onerous both for the participants and the researcher which limits in practical terms, the number of interviews that are carried out.<sup>278</sup> The relatively small numbers means that research is focused on gaining a deeper understanding of concepts and their context rather than revealing numerical data that is statistically representative of populations.<sup>263</sup>

When considering the use of structured questioning, again there are a wide variety of methods of delivery, which may be face to face or self-administered.<sup>278</sup> Due to the structured nature of these collection tools, they generally include large samples of participants, thereby increasing the generalisability of results and in some cases allowing for statistical extrapolation to wider populations.<sup>263</sup> There can be problems, however, with low rates of return of self-completed data collection tools.<sup>281</sup> If self-administered there will be less reactivity or influence of the researcher in the process but the researcher cannot prompt or probe the participant if they have a particular query.<sup>278</sup> Furthermore, it can be difficult to ensure the respondents have fully understood each question or indeed have even completed a written questionnaire themselves.<sup>278</sup>

Structured questions may be open or closed and data collection tools may contain a mixture of the two. The use of closed questions allows for a standardisation of results, which can be analysed and compared quantitatively. Closed questions with fixed category answer options, however, force respondents to choose from a list compiled by the researcher, which may not adequately describe the respondents' opinions. In contrast, open questions will elicit more nuanced data but require increased effort from the respondent and often require more time consuming analysis.<sup>263</sup>

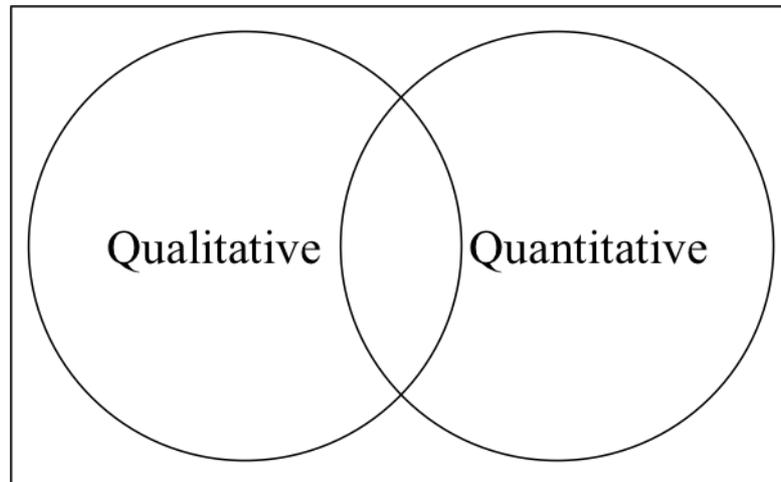
The word 'questionnaire' indicates the use of structured questions (as opposed to semi- or un-structured approaches),<sup>278</sup> but there is variation amongst researchers in the precise interpretation of the term. For example, in some instances a questionnaire is simply a collected set of questions<sup>263</sup> whereas in others it is a highly refined, standardised tool specifically for use with quantitative data and probability sampling.<sup>282</sup> In contrast, the term 'survey' whilst also not used entirely consistently<sup>263</sup> is generally a more inclusive term, encapsulating the use of various data collection methods such as questionnaires or fully structured interviews.<sup>278</sup> To be clear, for pragmatic reasons, which I discuss in more detail below, the questionnaire I have used in this study is not a standardised tool and was administered to a convenience (rather than a probability) sample. Whilst some researchers would therefore deem it to be more appropriately referred to as a survey, where I specifically describe my use of the tool and the data collected from it, I will use the term 'questionnaire'.

It is important to acknowledge that with any of these research methods there is a sampling bias in favour of those who are confident and at ease with the specific process of data collection and indeed with the use of the spoken or written language.<sup>278</sup> There is an inherent power differential between the researcher, who chooses the topics and methods, and the participant who is asked to give up their time and knowledge.<sup>263</sup> As I explained above the collection of interpretive data is by its very nature a product of the characteristics of both the participant and researcher. It is therefore imperative that this bias is recorded and understood as fully as possible in order to interpret the research findings.<sup>275</sup> Field notes accompanying data collection and reflexive research journals logging the researcher's values, biases and decisions are therefore important parts of the research process.<sup>274</sup> The analysis of this data in conjunction with the raw results from the data collection tools is imperative in order to maximise the quality of the research.<sup>263</sup>

### 2.2.3 My Use of Multiple Methods

As I outlined at the beginning of the chapter, the theoretical perspectives that underpin this study support my use of multiple research methods. Furthermore, I argue that my specific research questions, which include recording the medical conditions clinicians treat and the therapeutic modalities they use, and how they *evaluate* this practice and wider issues of healthcare provision across the country, are *only* answerable by using more than one data type. For example, when I ask about the availability of medications and what treatments are offered, these are essentially closed questions requiring quantitative analysis. In contrast, questions related to individuals' ideas such as their normative position and evaluation, require in depth answers to open questions that are subsequently analysed as qualitative data. Similarly, when considering presentation of the results, I have used a mixture of both quantitative and qualitative techniques for data from each of the methods of collection. For some questions this is the only logical approach such as using graphs to show the duration of each interview or the frequency with which participants have particular treatments available. In contrast, participants' views on how pain should be conceptualised and regarded by fellow practitioners and government bodies clearly requires qualitative analysis, presentation and discussion. I have also added some quantitative analysis to some qualitative data to condense some findings for additional clarity. Figure 2-1 shows a Venn diagram representation of this use of qualitative and

quantitative data. Each contributes alone to answering some specific questions but other questions are answered by using both types of data.



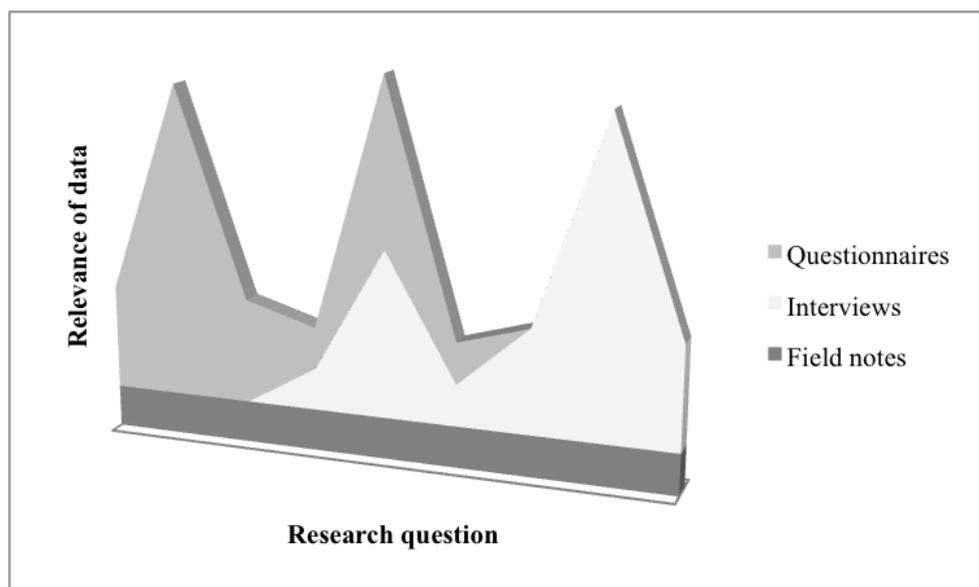
*Figure 2-1 Representation of my use of Qualitative and Quantitative Data*

Similarly there are specific reasons for choosing to use different data collection tools. For example, the question on the availability of specific treatments involved asking about the use of 43 different therapies which would have been very cumbersome to ask in an interview. Whilst I acknowledge there are limitations with the use of a survey, which I address in more depth later, I consider it to be the most appropriate method in this context. Likewise, detailed discussion of physicians' normative positions, personal influences and relationships with other society groups are only realistically explored through in depth dialogue, such as in interviews.

As I describe below, the interviews directly informed the creation of my questionnaire. Early on in the study I aimed to carry out a survey with the main focus being to increase the breadth of responses to the questions asked in the interviews. Having collected a significant proportion of the interview data, however, I realised that the survey could be used to gain collect more detailed quantitative data regarding treatment availability, not simply to add breadth. Furthermore, the actual components of the questions related to treatment availability, that is, the specific treatments I asked about, were populated from my early analysis of the interview data.

Not only is the use of both collection tools necessary, I also argue that it increases the quality of the data I collected. A few advocates of multiple methods justify its use by

suggesting that using more than one technique can offset the inherent weaknesses of each method.<sup>283</sup> However, a more widely cited reason is to exploit the strengths of each data type to produce a more complete picture of the phenomenon of study.<sup>263</sup> With reference to this study, the broad aim of the questions in the interviews is to ascertain detailed information regarding evaluative judgements of the participants while the surveys are largely concerned with data relating to service provision such as treatment availability. I did in fact ask both interviewees and survey participants to talk about both the areas of service provision and evaluation, albeit in varying detail. This led me to be able to draw upon the strengths of each of these methods of data collection. For example, the survey is useful to increase the breadth of data relating to evaluation as well as adding depth to questions related to treatment availability. Likewise, the interviews add depth to the evaluative questions of some of the questions thereby adding the ability to corroborate some responses.



*Figure 2-2 Representation of the Contribution of each Method of Data Collection to a Range of Research Questions*

Mutual corroboration, whereby results from one method are confirmed or not by another method, is known as ‘triangulation’ and is described as a tool to enhance the validity of research.<sup>263</sup> While I did not specifically set out to formally triangulate across the qualitative and quantitative data in this project, I incorporated a degree of cross checking between the questionnaire and interview responses. For example, having inductively created a structure of categories and themes from interviews I used these deductively to

compare to the relevant responses in the questionnaires. Furthermore, alongside all of the methods outlined here I collected detailed field notes which I consider to both inform, and to have been informed, by the research process. These notes along with my research journal are a crucial part of the reflexive component of this study. Figure 2-2 represents how the different methods of data collection I used each have their own strengths but work together in a complementary fashion. Whilst Figure 2-1 represents the overlap in the questions answered by the qualitative and quantitative data, Figure 2-2 also incorporates the idea that the strengths of each data type can be additive. So for a given research question, a more complete answer may be acquired by using multiple data types. However, for other questions the use of all data types may be either inappropriate or unfeasible.

In summary, I used multiple methods for several reasons: to create my data collection tools, to provide a sense of completeness in answering my overarching research questions, to answer the different types of specific questions within this topic and to incorporate a wide breadth of participants whilst including in depth analysis of certain areas; each of which ultimately enhances the rigor of my research.

## **2.3 The Research Process**

### **2.3.1 Overview**

The process of formulating my research questions, choosing and planning my research methods in detail, collecting the data, and collating my findings, began in 2012. This work included a literature search, analysing an oral history archive and four trips to India – each during the month of February, from 2013 to 2016. I describe this largely inductive process in detail below, but in summary, I carried out a planning exercise to assess the feasibility of the study in 2013, collected interview data in 2014 and 2015, questionnaire data in 2015, and presented preliminary findings from the questionnaire data in 2016. During the field trips to India as well as attending the ISSP and IAPC conferences, I visited a total of 14 clinical institutions across the country, in the states of Maharashtra, Karnataka, Odisha, West Bengal and Tamil Nadu. These were a mixture of corporate hospitals, independent private clinics, charitably funded organisations and government institutions. Throughout this process I kept a research journal describing my work and personal reflections, and a

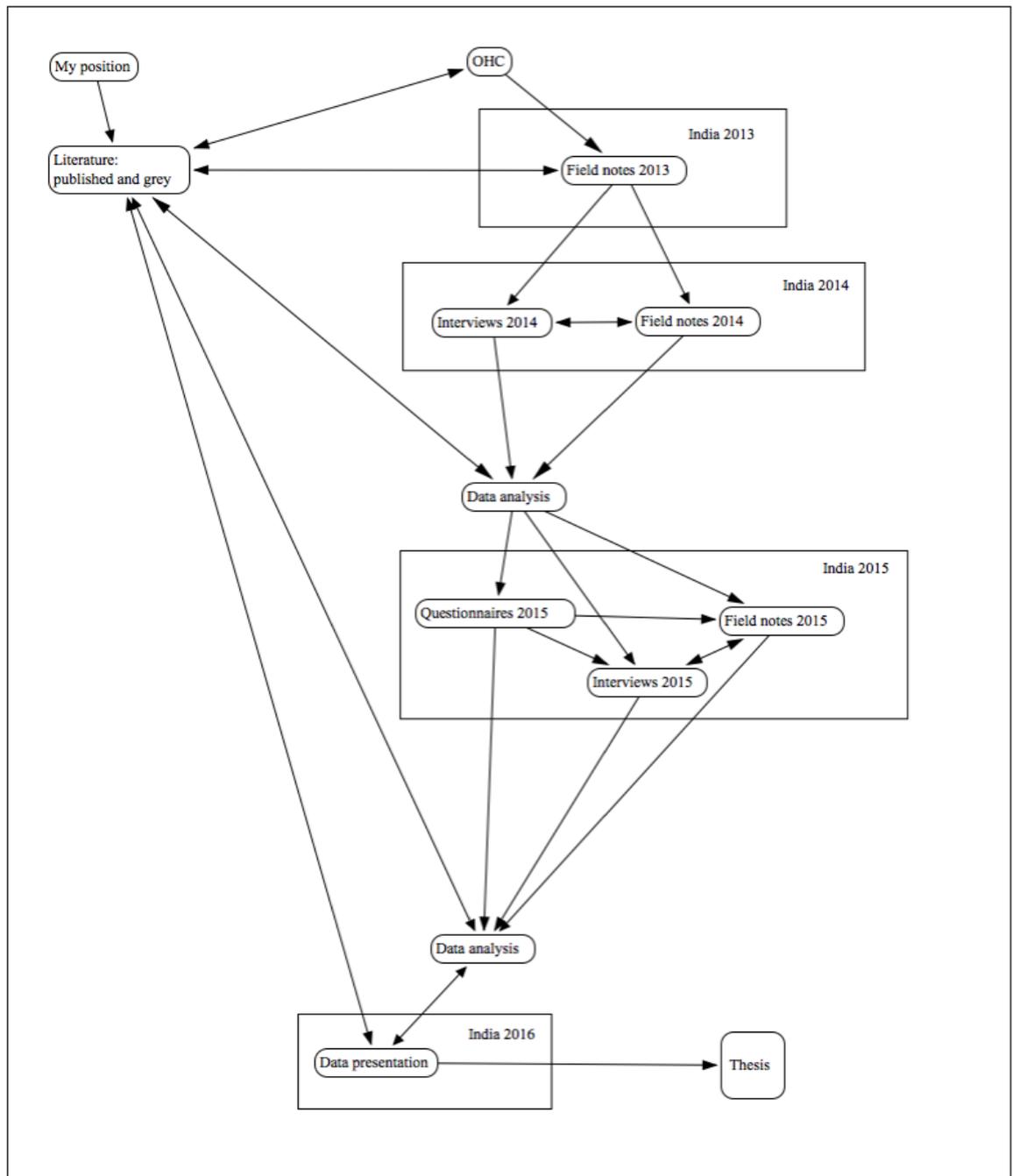
detailed technical log of the steps taken within my research process. A summary of these field trips and the data collected is shown in Table 2-1.

Year	Conference Location		Number of hospital visits	Data collected
	ISSP	IAPC		
2013	Nagpur, Maharashtra	Bangalore, Karnataka	4	Planning
2014	Navi Mumbai, Maharashtra	Bhubaneswar, Odisha	8	28 interviews
2015	Chennai, Tamil Nadu	Hyderabad, Andhra Pradesh	2	5 interviews 95 questionnaires
2016	Indore, Madhya Pradesh	Pune, Maharashtra	0	Preliminary results presented

*Table 2-1 Chronological Summary of Field Trip Data Collection*

Given the scope of the research questions spanning several academic disciplines and multiple fields of medicine, a systematic literature review was not feasible. However, in order to ensure I had reviewed the key published texts I undertook online literature searches of multiple databases including Embase, CINAHL, Medline, PsychARTICLES, Psychology and Behavioral Sciences Collection, PsychINFO, SocINDEX with Full Text and Anthropology Plus, using key words including ‘pain and India’ and ‘pain and human right’. I also hand searched key journals including *The Lancet*, *WHO Bulletin*, *Social Science and Medicine*, *Pain*, *Palliative Medicine*, *Indian Journal of Palliative Care* and *Indian Journal of Anaesthesia*, and relevant grey literature.

During the research I continually referred to earlier stages of the process, such as reading background literature (including updating online searches) and my journal and field notes, in order to reflect and refine both my research questions and my findings. For example, at the start of my work I was particularly interested in the fact that access to pain relief is frequently described as a human right,<sup>93,121</sup> but as my work progressed this became less central to my enquiry. This process is summarised in Figure 2-3.



*Figure 2-3 Summary of my Research Process*

### 2.3.2 Data Collection Planning: India Field Trip and the Oral History Collection

My initial interest in this topic of research stemmed from my own career working as a consultant in anaesthesia and pain management in the UK's National Health Service and from my experiences of teaching pain management overseas. It was a relatively simple

process therefore to establish contact with clinicians who worked or had worked in pain management in India through UK colleagues, previous overseas trips and contacts at the University of Glasgow. I established that the two major professional societies representing the related medical fields of pain management and palliative care, the ISSP and IAPC, each hold yearly three day national conferences on consecutive weekends in February. Having received encouraging feedback from discussion of my early research plans with Indian practitioners I decided to attend the two conferences in February 2013 to establish what detailed research was likely to be practical.

In February 2013 I attended the ISSP conference in the city of Nagpur, Maharashtra and the IAPC conference in Bangalore, Karnataka. During the conferences I was able to talk extensively with a wide range of professionals including those on the executive committees of each of the societies. Those I met were very encouraging about my research and offered to both participate in and to facilitate the process. I also visited four hospitals in these regions to observe some elements of practice in pain management in the corporate and public sectors. Of note at the ISSP meeting I was often the only overseas delegate present and my interest in the work of the other conference attendees appeared to be particularly novel. This was in contrast to the IAPC conference, which was attended by a large number of overseas delegates and faculty, with several representatives from high profile international organisations. A field note entry dated 8<sup>th</sup> February 2013 whilst I was attending the IAPC conference reads:

“At ISSP everyone immediately wanted to know why I was there - they were very surprised to see me. Here it's very different.”

As well as visiting India, during this planning phase I reviewed relevant literature with an emphasis on analysing comparable studies focused on the mapping of palliative care and pain management services in India, and on opioid availability. I was particularly interested in the observation that numerous projects studying the practice of palliative care at a global level actually incorporate data related to treating patients in a wide variety of situations, crucially, situations that in the UK would not normally be considered to be within the remit of palliative care. I also had access to a data set called the *Oral History Collection*, which I was able to analyse in some detail in order to refine my research questions.

### 2.3.2.1 Oral History Collection

The *Oral History Collection* (OHC) has been compiled over a number of years from several different projects related to researching and documenting the growth and delivery of palliative care services across the world. Initially, a relatively small set of interviews was collected for the Hospice History Project based at Sheffield University in the 1990s detailing the growth of the hospice movement in the UK and culminating in the work *A Bit of Heaven for the Few*.<sup>284</sup> Subsequently, the scope of the archive was increased to incorporate a more international perspective. Following the creation of the International Observatory on End of Life Care at Lancaster University in 2003, the archive grew considerably, and now consists of 674 separate interviews, from over 700 interviewees, in 54 countries, spread over 6 continents, with material from subsequent studies still to be added. The recording medium of these interviews varies from audiocassettes, minidisc recordings and digital sound-files, reflecting the changing technologies of the past two decades. Some files also incorporate photographs of the subjects with summary life histories to give a more complete record of individuals and their work. Much of this data has then been incorporated into a database, charting not only the development of palliative care services, but also the creation of the OHC.

Within the OHC there are 67 interviews from 44 participants listed under the country heading of 'India', recorded between 2003 and 2005. These were collected by multiple interviewers, in various locations such as during national academic conferences and in clinical institutions. Consequently, some subjects were interviewed on more than one occasion and some interviews involved more than one interviewee. During the first stage of analysis of the archive I undertook some basic re-organising of the 67 interviews to incorporate a new numbering system specific to this work. I removed duplicates and corrected minor inconsistencies in the original database. I read all of the 66 available transcripts and wrote brief summary notes of the interview content with comments added to indicate areas I thought likely to be relevant to my research questions. I then listened to the primary audio data, completed and corrected where necessary the transcripts all of the 67 interviews and identified 44 that contained data relevant for more detailed analysis. A summary of this interview data is included in Appendix 1.

I then listened and re-listened to the interviews coding and re-coding for themes of interest and relevance, modifying the coding structure as I progressed. This coding of interviews

yielded data relating to the following themes, each of which specifically informed the subsequent questions included in my semi-structured interviews and questionnaires: the organisation of pain management as a medical specialty, specifically in relation to which medical conditions patients are suffering from, pain management's relationship to the medical specialty of anaesthesia and the effects this has on training, clinical practice and other professional responsibilities of practitioners including their personal finances; and the clinical practice of pain management specifically related to variations in the use of interventional techniques, such as nerve blocks. Inevitably, because this was secondary analysis of data, with the interview questions not specifically designed to answer the questions set out in my research project, some topics did not yield enough data for analysis but their brief presence in the OHC data none the less prompted me to inquire in more detail around these topics in my own data collection. These themes include: conflict between clinicians especially related to financial issues, other inter-professional tensions, perceptions of human rights related issues, motivations for choosing a particular career and the roles and aims of the ISSP in comparison to the IAPC.

Following this OHC analysis and my 2013 fieldtrip to India, I finalised my research questions and methods. These included collecting semi-structured audio-recorded interviews at the ISSP and IAPC conferences in 2014, and carrying out an online survey to the whole of the membership of each society. I gained approval for this work through the University of Glasgow's Ethics Committee of the School of Social Sciences. Although neither the ISSP nor the IAPC had a formal ethics committee able to grant approval, I had extensive discussions with executive members of both groups and provided them with my ethics committee approval letters from the University of Glasgow. They were universally encouraging of the work and gave me written approval to conduct my data collection.

### **2.3.3 Interview Data Collection**

#### **2.3.3.1 Creation of the Interview Guide**

Having established the plausibility of conducting interviews with ISSP and IAPC conference participants, I started the process of refining the wording of the questions in the interview guide. For example, I began to appreciate the complexity, variation and plurality of the healthcare system in India, which includes corporate run multi-speciality hospitals,

over-subscribed government hospitals and numerous unregulated privately run street side clinics. In a field note written in India, dated 5th February 2013, I wrote:

“Up and down the road I am staying on, are numerous clinics, hospitals, diagnostic centres - some with operating theatres [...] I'm amazed at the number of institutions out there (I wonder what regulation exists) and at the level of medical jargon on advertising hoardings.”

I also recognised an even more fundamental issue - that there is a difference of opinion as to whether untreated pain is indeed a *problem* at all. For example, I talked to an anaesthetist in a hospital treating patients in pain during and after surgery who explained why he did not use morphine. I wrote a field note dated 5<sup>th</sup> February 2013 saying:

“He said patients didn't really complain of pain and that giving morphine is very problematic because there is lots of bureaucracy/licences needed, risks of addiction and diversion, and risk of side effects on the ward due to limited monitoring.”

This is a crucial issue when interpreting my research because my participants are almost inevitably self-selected as individuals who consider untreated pain to be a problem. It is highly likely that there is a significant, but as yet un-quantified, cohort of healthcare workers, politicians, managers and members of the public who do not consider this to be the case and who are not included as participants in this study.

I also noticed a variation of practice within the medical profession. For example, although the anaesthetist in the quotation above described not having morphine available, an oncologist working in the same hospital explained that he did in fact use morphine. At the ISSP conference I noticed a particular focus on certain modes of pain management namely interventional treatments often called nerve blocks. Similarly, some of the participants in the OHC interviews talked of their use of these techniques. As I described in the opening chapter, however, the vast majority of work in the field of improving access to pain treatments at an international level has focused almost exclusively on the availability of opioid medications.

I also began to appreciate the enormous significance of money within the field of healthcare in India. Topics included clinicians' income, patients' ability to pay for treatments and even suggestions of corrupt practice. For example, one participant in an OHC interview remarked:

“It’s all 100% voluntary. We don’t have any paid work.” (OHC Interview 52)

In contrast, having been discussing pain management with an Indian doctor, I wrote in my PhD journal on 11<sup>th</sup> June 2012:

“She commented on how she has noted an increasing number of her Indian colleagues are interested in chronic pain as a specialty. She suggested they were wanting primarily to learn interventional techniques and that there was potentially money to be made in this area.”

These insights, together with my review of the published literature led to my focus within the interview schedule on gathering in depth information from practitioners regarding the specific treatments they offered, the medical conditions they treated and details of the institutions they worked in. I was particularly interested in understanding their normative positions and how these positions were informed. The interview guide used together with a plain language statement and consent forms are attached as Appendices 2-5, all of which were approved for use by the university ethics committee as explained above.

### 2.3.3.2 Interview Participant Sample

In 2014 I attended the ISSP and IAPC conferences in the cities of Navi Mumbai, Maharashtra, and Bhubaneswar, Odisha in order to conduct semi-structured interviews with clinicians working in pain management in India. I used purposive sampling to select participants to ensure that I included those working in a range of clinical settings. The areas I addressed were: funding of the institution (to include private, charity and government sectors), medical specialty (to include those working in settings that are not labelled as palliative care and as well as those that are), type of medical condition treated (to include those treating pain from all causes as well as those treating only certain condition such as cancer) and to cover multiple geographical areas of the country. I also targeted key informants who have a particular eminence and seniority within the field and I used a snowballing technique to identify further potential participants. While I describe this technique as purposive, there is also clearly a degree of convenience sampling. I chose to collect data at the national conferences due to the ability to meet and interview a large number of potential participants in a short period of time. During this first round of data collection I recorded 28 interviews.

Although I endeavoured to select a range of participants, there are disadvantages to this approach of sampling as I was unable to identify practitioners who did not attend the conferences, leading to difficulty in assessing the representativeness of my sample. While it is likely that a significant number of those with a strong interest in the field will attend the yearly national conference, there is a selection bias linked to aspects of the event such as the location of the conference, the costs and the education style of the programme, which practitioners may not choose to or be unable to engage with. Furthermore, I cannot be sure of the nature of the bias of the key gatekeepers to this process who initially introduced me to the participants. Membership of the professional societies, let alone attendance at the national conference, does not equate with practising pain management in India. Many professionals may regard themselves as specialists but for various reasons choose to not join the society. Still more are likely to be treating pain but not regarding themselves as specialists.

As had occurred in my visit of 2013, during each of the conferences I was invited to visit various hospitals and clinics, sometimes in order to record interviews but also to observe practice. In total I visited eight institutions including private independent clinics, corporate hospitals, charitably funded hospitals and government run organisations. I took detailed field notes during the conferences and these clinical visits to supplement my research data.

In 2015 I returned to India and again attended the two national conferences this time in the cities of Chennai, Tamil Nadu, and Hyderabad, Andhra Pradesh. Again I used purposive sampling to identify the key informants who I had not been able to interview in the preceding year. I recorded a further five interviews during this time and again was invited to visit clinical institutions; on this occasion I attended two. I recruited one participant at one of these clinical venues who had not attended the ISSP or IAPC conference but was introduced to me by a delegate.

### 2.3.3.3 Interview Recording

During the planning stage of the research I asked clinicians working in India whether they thought it most appropriate to conduct the interviews anonymously or with participants' names recorded. The responses I received were not consistent so I opted to give participants the choice. The interviews themselves were conducted 'on the record' with

names, occupations and places of work identified. However, during the consent process I gave participants the opportunity to have identifiable details removed from the transcript and any resulting publications. I chose this approach due to the nature of the interviews, with many participants expected to be high profile individuals, and therefore making it potentially difficult to completely conceal every participant's identity. I also stated that if I planned to use quotations with explicitly identifiable data I would send these to the participant for verification.

The interviews were recorded in various locations. During the conferences they were conducted in closed rooms with only the participant and me present, in public areas with a variety of potential delegates able to overhear or interrupt and with more than one actual participant present. Of the recordings held outside of the conferences the settings again varied with a range of people present. They were carried out in private offices, public areas such as the hospital canteen and a busy department, and one during a patient treatment session (with consent from the patient). The participants themselves chose each of these locations. Sometimes there was added benefit to this open process, for example during one interview in a hospital, the participant had arranged for all of their team members to be present so that they could ensure wide representation. However, there were also hindrances such as background noise and regular interruptions.

I used a checklist during the data collection to help ensure I stored and filed the data and accompanying paperwork. I made each of the recordings on a battery powered portable digital audio recorder as MP3 files at a resolution of 128kbps. As soon as practical after the recording I downloaded the audio files to a laptop computer and a memory stick where they were stored as password protected files. I listened to the files whilst I was still in India in order to ensure the data was useable. Each interview was then numbered in chronological order of collection and filed with notes related to each individual interview. On my return to the UK I emailed all the interview participants to thank them for their participation and to confirm their contact details.

During the period of data collection I added some annotations to the interview schedule of some additional prompts that I found useful during the process. The original interview guide (version 3a) is shown in Appendix 2, and the annotated guide (version 3b) is reproduced in Appendix 3.

Prior to the data collection in India, I carried out a pilot interview with a physician working in the UK who had previously worked in pain management in India. During this interview I trialled the interview schedule, my recording equipment and my interview skills. This interview was not used as part of the research data.

### **2.3.4 Survey Data Collection**

#### **2.3.4.1 Creation of the Questionnaire**

In order to enhance the interview data and to widen my study sample, I planned to carry out an online survey (using the web based tool SurveyMonkey) late in 2014, in order to ask questions from the whole of the membership of both the ISSP and the IAPC. The specific questions asked were to be informed partly from the interviews collected in 2014. As I outlined above I obtained permission to do this via the executive committee members of both societies and from the relevant research ethics committee at the University of Glasgow.

On compiling the first drafts of the questionnaire, my initial aim was to discover in particular what the individual participants' views and experiences of delivering pain management were rather than how they viewed the picture in their whole country, so that a more detailed and nuanced picture could then be created by the analysis of their combined responses. The questions, focused on the quality of pain treatment, what improvements could be made, what types of painful conditions were treated, what treatments were offered and some basic demographic questions. This first draft was sent as a pilot to the following sample groups: UK colleagues who had worked in India, Indian pain specialists whom I met during my first visit, and known experts in the international field. This was then updated several times to create a draft, which was submitted and approved by the University of Glasgow ethics committee in October 2013.

I took this draft out to India with me for my first data collection field trip in February 2014 where I also obtained feedback and comments from local specialists. As I had originally planned, this draft was then updated using data collected from the semi-structured interviews taken at the 2014 conferences. For example, on appreciating the wide variety of

professions represented at the IAPC conference, including many volunteers, I wrote in my field notes dated 15<sup>th</sup> February 2014:

“I will have to simplify some of the wording of the questions in the survey – I expect that the level of English spoken by IAPC members will be variable. I will also have to add a question asking about what the profession is of participants. I am beginning to see how the questionnaire will come together from this interview work.”

More specifically, there were two areas of the questionnaire that I updated considerably using information collated from this trip. Firstly, I became aware of the vast array of different medical establishments involved in delivering pain treatment. Secondly, I noted the considerable variation in treatments offered and decided to dedicate a large proportion of the questionnaire to asking about the availability of different therapies. In a field note written while observing a workshop held before the ISSP conference on 6<sup>th</sup> February 2014, I wrote:

“The focus was purely on interventions although several people I spoke to described the need to prioritise other treatments such as morphine availability and multidisciplinary (in the UK sense of the term) team work (although they noted that they were very much in the minority).”

On my return from the 2014 field trip I listened to all the interviews and took notes outlining some basic categories identified by the participants to help to begin compiling the survey. These were related specifically to the non-drug treatments available, the drugs available and the type of institution in which the participant worked. Much of the published debate surrounding the access to opioid medications is markedly tied in with the *WHO Model List of Essential Medications*,<sup>36</sup> stressing that although certain medications and formulations are listed by the WHO as ‘essential’, they are in practice, not available. The International Association for Hospice and Palliative Care (IAHPC) also publish a list of essential medicines for palliative care<sup>285</sup> which contains a more extensive list of drugs. I included medications from both of these lists (opioids and non-opioids) but also added medications that are easily available to me in the UK. Similarly, I compiled a list of non-medical treatments from both the interview responses and from published guidance including the *Guide to Pain Management in Low-Resource Settings*<sup>286</sup> published by the International Association for the Study of Pain, the IAHPC’s *List of Essential Practices in Palliative Care*<sup>287</sup> and UK specific publications. I also used a similar ‘scale of availability’ as was used in the Global Opioid Policy Initiative. This work resulted in a draft, which I

then piloted again with UK colleagues, Indian clinicians and other specialists in the international field.

I finalised a version of the questionnaire in October 2014, ready to be sent out, via email to the membership of both the ISSP and the IAPC. As I began to arrange this final distribution phase, however, I was told by the societies that a comprehensive email list of members did not actually exist. This called for a sudden change in my plans for this part of the data collection. It also reinforced my position in using a mixed methods or bricolage approach, making use of the particular tools that are available in a given context.

The questionnaire therefore evolved into a 'hard' paper format, which I planned to distribute to as many eligible participants as possible at the 2015 ISSP and IAPC meetings. I obtained revised ethics for this change of plan in November 2014 from the University of Glasgow and approval from the executive committees of the ISSP and IAPC. The final paper version of the questionnaire and its plain language statement are included in Appendices 6 and 7.

Despite my methodical process of creating the questionnaire there are still inherent limitations and weaknesses with the tool. The questionnaire contains a mixture of closed and open questions. When considering the closed questions, apart from the very straight forward opening questions related to profession, location and society membership, I asked respondents to choose a category of best fit for their answer. For example, asking: what proportion of time participants spend working in pain management, how frequently treatments are available and how they evaluate the quality of their service. This forces respondents to pick from a list chosen by me rather than one created by them. It does however make for easier collation and presentation of the data and a degree of comparison with other similar studies. However, these responses lack the thick description of open questions. In contrast, the open questions asking for example about how to bring about service change provide more complex data, albeit requiring time consuming qualitative analysis and presentation.

#### 2.3.4.2 Distribution and Collection of the Questionnaires

I took a small number of printed questionnaires to India in February 2015; due to airline luggage weight limits I printed the remainder in India. Although the survey itself was anonymous, I numbered each copy so that I could log the number distributed. The first conference I attended was the ISSP meeting held in Chennai. I originally tried to add a copy of the questionnaire to each delegate's conference bag, received on registration. However, it was not possible for practical reasons to reliably add the survey to each and every bag so I opted for the more labour intensive method of handing them out in person. I stood by the only entrance to the conference venue and tried to speak to every delegate after they had registered, explaining my work and the survey. I distributed as many as possible – the only inclusion criteria being that the participant practised pain management in India. This method, although extremely labour intensive enabled me to explain my work very personally and I suspect improved my rate of inclusion to the study. It meant that I met almost all the delegates, many of them familiar faces from previous trips. I asked delegates to return their completed questionnaires to a labelled box or in person to me at any time during the conference. Invaluably, I was also granted announcements during the conference lectures to remind delegates to pick up and complete the questionnaires.

My second site of data collection was the IAPC conference held in Hyderabad. I used a similar strategy of distribution by standing at the entrance to the main lecture theatre and attempting to speak to as many delegates as possible. The considerably larger numbers at this conference, however, and the relatively high percentage of delegates who did not fit my inclusion criteria meant that it was impossible for me to speak to everyone individually. Again, I was fortunate enough to have an announcement made during a well-attended plenary session publicising my study and reminding delegates to complete and return the questionnaires. An eminent colleague also generously assisted in distributing the questionnaires, which very helpfully increased the number of participants. There was nonetheless an inevitable difference in my methods of distribution and explanation at each conference.

### **2.3.5 Data Analysis and Presentation**

I analysed elements of the survey and interview data both individually and together. On returning to the UK I reviewed all of the completed questionnaires, numbered them from 1-95 and entered all of the data into a Microsoft Excel spread sheet for further analysis. In addition, I uploaded all of the answers to the open questions into the computer assisted qualitative data analysis software NVivo. Similarly, I transcribed all of the interview data and uploaded each transcript into NVivo.

#### **2.3.5.1 Quantitative Data**

I analysed the quantitative data from the questionnaires within Excel to produce a number of tables, graphs and charts. Most of the closed questions were easily collated and presented but as I worked through each question I created a log of my detailed methods, such as deviant cases, unclear responses and any assumptions I made. For example, when analysing the responses to a question asking what training respondents had received and how long it had lasted. I created categories of duration to present this answer graphically. Each of these assumptions is detailed in the following results chapter.

As I explained above, my sampling technique for the survey was largely convenience sampling with an added component of purposive sampling. This is therefore not a probability sample to be used to infer generalisable findings at a population level derived from statistical models. My aim in analysing and presenting this survey data is not to prove statistically valid relationships or causation, but to contribute to the map of how pain management is practised and to demonstrate some of the complexities and variations in practice. In some areas, such as treatment availability this data adds detail, and in others such as the description of assets and barriers to healthcare improvement, the data adds breadth.

I presented this preliminary quantitative, survey data at the ISSP and IAPC conferences in February 2016 in the cities of Indore, Uttar Pradesh, and Pune, Maharashtra; and at a University of Glasgow symposium in December 2015. This allowed me to add validity to my research results by discussing these data with participants, other healthcare workers in India, and expert peers in the UK and overseas.

Although the vast majority of the interview data was qualitative I did analyse and present a small amount of data quantitatively. Some of this was straightforward information such as the duration and location of the interviews. I also chose to represent the answers to some open questions in a quantitative manner as well as analysing them qualitatively.

Specifically I noted the number and type of institution worked in, the type(s) of medical conditions treated and the mode(s) of care given. I chose to do this in addition to qualitative analysis to complement the data and add some comparison between the data of the questionnaires and the interviews. There are however limitations with this approach with an over simplification of complex areas of enquiry.

### 2.3.5.2 Qualitative Data

Having uploaded all of the qualitative data into NVivo I began the process of coding. Starting with a selection of interviews I considered to be particularly pertinent, I read through the interview transcripts and my field notes and began selecting or coding any sections that contained information relevant to my research questions or that were of particular interest. I gradually created a set of themes or 'nodes'; and wrote memos connected to the transcripts, to the nodes and to my research diary detailing this process chronologically. By reading and re-reading, coding and re-coding, using a process of constant comparison to refine the nodes and to identify outliers I built up a hierarchical node tree.

Initially this process was a largely deductive process as I coded for themes related to some of the more specific research questions, often those included in both the interviews and surveys such as treatment availability and the types of medical condition treated. As I explained above, these themes are, broadly speaking, related to how pain management is delivered on a day-to-day basis and where possible I analysed and presented this data quantitatively.

In order to elicit more nuanced results, I then began coding data related to participants' evaluation of their work and of the practice of pain management across the country as a whole. This process was both deductive and inductive as I worked through some themes that were already well described in the literature such as a lack of resources, but also created themes for areas that were less well described, such as the existence and function

of specific medical specialties. Again, using a method of constant comparison I refined a hierarchical node structure related to participants' evaluations.

Finally, I created nodes relating to how these evaluations are formed, framed and contested. This process was largely an inductive process as the themes emerged as I coded and re-coded the data, rather than being defined at the start of the process. For example, early on I noticed the high prevalence of the use of the term 'awareness' in relation to improving the provision of pain management. As I worked with the data I began to see awareness as closely linked to ideas of knowledge creation, education and contested power. This led to the creation of the nodes reported in the final section of my results chapter.

During this process I created some nodes that turned out to be less relevant and less useful as the work progressed. For example, in an attempt to look at the various influences and normative positions of participants I coded some data with respect to its chronological reference. So I labelled information as 'past', 'present' and 'future'; depending on whether participants were talking about past influences, what currently happens and what should or could happen in the future. While these categories were useful to progress my understanding of the data, they did not turn out to be useful as final nodes in themselves to be presented.

Having created this node structure, I analysed the answers to the open questions of the questionnaire and my field notes and journal, within NVivo. This process enabled me to crosscheck my results by comparing and identifying outliers against my final node trees in a deductive process.

Of note, throughout this data analysis I used the computer software NVivo as a powerful system for filing and cross-referencing coded data. It enabled me to collate efficiently and to refine my coding process by keeping memos, nodes, and my journal cross-referenced. NVivo is not designed to carry out automated computer generated coding<sup>288</sup> and the actual selection and coding of the data was done by hand. Broadly speaking, in the results chapter I reported the qualitative data using the nodes I created in NVivo although some of the names have been modified or re-ordered to enhance clarity. To ensure completeness and to

provide a clear log of my work, where possible, I indicated within NVivo in which section of the results chapter each node's content is reported.

## **2.4 Summary**

The aim of my research, to assess critically the practice of medical practitioners working in pain management within the healthcare system of India, involves drawing on multiple social science theories including social constructionism, theories of the policy process and postcolonialism. I have demonstrated in this chapter how these theories directly informed my methodological approach of using mixed methods of data collection.

I have shown that my research questions, which incorporate both the assessment of specific details of clinical care delivery as well as the evaluative judgement of individual clinicians, demand the use of both quantitative and qualitative data.

I set out in detail my research methods that include the use of background reading of relevant literature, a review of an oral history archive, field notes from four visits to India, collection of interviews and surveys with healthcare workers in India, and journal entries; highlighting the strategies I employed to seek methodological rigour.

This research process, summarised in Figure 2-3 and Table 2-1, due to its iterative nature, resulted in constant modification of my understanding of the practice of pain management. In the early stages of the work, I followed a more inductive approach as new concepts emerged, but as I refined my results the process became more deductive and ultimately shaped the overall perspective and outcomes of the study.

## **Chapter 3 - RESULTS**

### **3.1 Introduction**

I outlined in the preceding chapters my strategy of using data collected from multiple sources in order to build up a detailed, multi-faceted picture of the practice of pain management in India. My key motivation for using multiple data sources is to create a more in-depth, rounded, and therefore representative depiction of the themes and phenomena involved. The results in this chapter are therefore presented in sections according to these themes, each of which contain data from multiple sources and combine qualitative and quantitative information.

In the first section (3.2), I present an overview of the primary data collected from questionnaires and interviews. In the remainder of the chapter I present key themes arising from these data. I begin by introducing the finding about how clinicians describe pain as a medical problem (Section 3.3). I then demonstrate the practical implications of this professional construction, firstly by presenting data relating to features of the Indian healthcare system in Section 3.4, and then by considering the organisation of the medical profession and clinicians' treatment selection in Sections 3.5 and 3.6 respectively.

In the final sections (3.7-3.9) I move on to present data related to how the participants' evaluations of these phenomena are framed, formed and contested, both locally and within a wider global context. In Section 3.7 I present results relating to descriptions of policy and governance. In Section 3.8 I consider data on clinicians' use of knowledge as a tool to enact power through their framing of arguments, and by seeking to persuade others to modify their thoughts and actions. Finally, in section 3.9 I summarise results describing the motivations of the individual participants and the dynamics of how power is contested between them and others.

## **3.2 Data Overview**

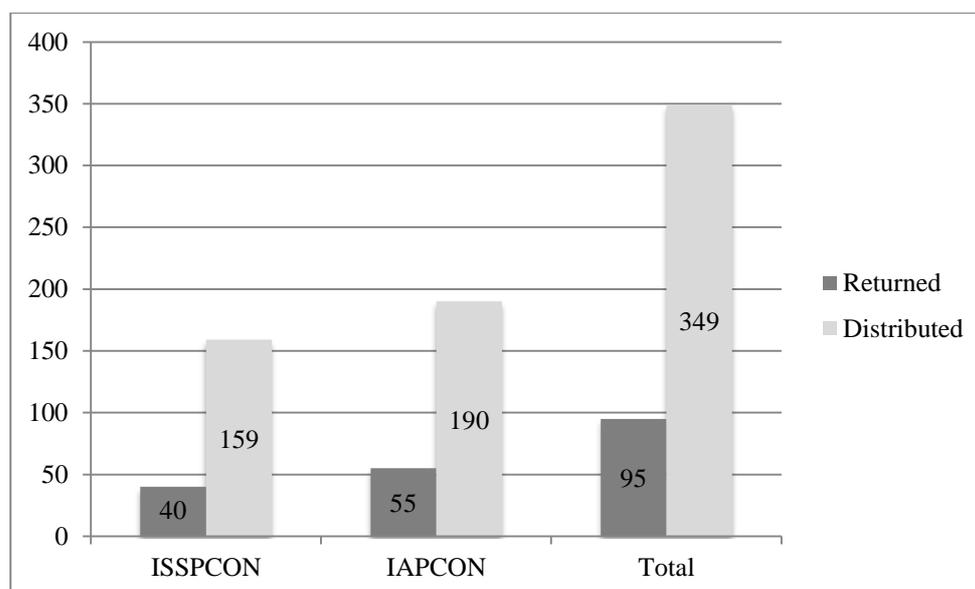
The questionnaire (Appendix 6) contains a mixture of closed and open questions and is divided up into five sections: questions about the participants (Questions 1-5), questions about their place of work (Questions 6-7), questions about the clinical care they provide on a daily basis (Questions 8-10), questions about treatment availability where they work (Questions 11-13) and questions about service quality (Questions 14-17). The audio recorded, semi-structured interviews follow an interview guide (Appendices 2 and 3) which covers similar topics: introductory questions related to how the participants came to work in their current post, questions related to how an ideal pain service would look, more specific questions related to the patients and medical conditions they manage and the particular treatments that they offer, and ending with questions relating to participants' appraisal of the state of pain management across the country of India as a whole. I also collected detailed field notes from each of my fieldtrips to India. Qualitative data from the open questions in the questionnaire, the interviews and the field notes were transcribed and analysed in NVivo using thematic analysis. Quantitative data, largely from the questionnaires, but supplemented with some content analysis data from the interviews was analysed in Microsoft Excel spread sheets to produce the tables and graphs presented here.

### **3.2.1 Questionnaires**

In February 2015, I attended the national conferences of the Indian Society for Study of Pain (ISSP) and of the Indian Association of Palliative Care (IAPC), known as ISSPCON and IAPCON respectively, in order to collect survey data from the conference participants. I asked only those participants who were currently working in India to complete the forms.

I have not been able to find out the exact numbers of registrants at the conferences who were eligible to take part in the research, however the conference organisers estimated the total number of registrants at ISSPCON to be 250, and at IAPCON to be 640 with 140 known to be from overseas. Overall I distributed 349 questionnaires and received 95 completed giving a total return rate of 27.2%. At ISSPCON I distributed 159, and received 40 completed (a return rate of 25.2%). At IAPCON I distributed 190, and received 55 completed (a return rate of 28.9%). These rates of return are summarised in Figure 3-1. On

my return to the UK, I numbered each completed questionnaire from 1-95 and entered the responses into a Microsoft Excel spread sheet.



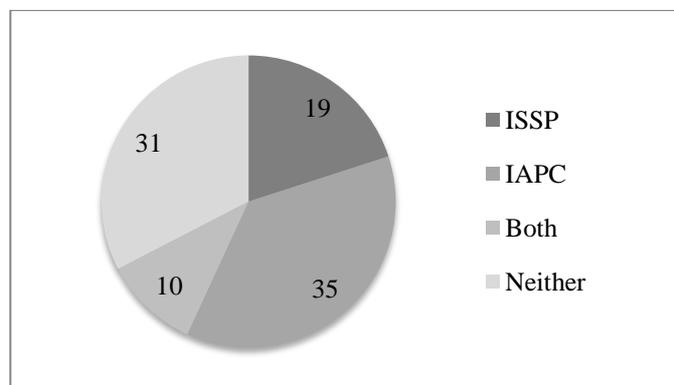
*Figure 3-1 Questionnaire Return Rates for each Conference*

The country of India is divided into states and union territories (UTs) and I asked survey respondents to name the state in which they work. At the beginning of my research there were 35 states and UTs but in 2014 the state of Telangana separated from the state of Andhra Pradesh making a total of 36. Because of the timing of this division, I counted the two states together. The states in which the respondents work are listed in Table 3-1. Of note, the states with the highest numbers of respondents are Andhra Pradesh (including Telangana), Kerala, Maharashtra and Tamil Nadu. The ISSP conference was held in the city of Chennai, Tamil Nadu, and the IAPC conference in Hyderabad, Telangana, which will likely contribute to the relatively high numbers of respondents for each of these states and lead to an over-representation from these areas. There are also other states with expected high numbers of respondents, notably Maharashtra at ISSPCON and Kerala at IAPCON. The state of Maharashtra contains Mumbai – India’s most populous city, although the state as a whole ranks second to Uttar Pradesh for total population.<sup>289</sup> Kerala is the state with by far the highest number of palliative care services recorded elsewhere.<sup>163,290</sup> Of note the questionnaire respondents represent only 15 States and UTs out of a total of 35. It is not possible to say from this data whether this reflects low levels of pain management provision in these unrepresented states.

State/Union Territory	ISSPCON	IAPCON	Combined
Andhra Pradesh (incl. Telangana)	1	15	16
Assam	1	3	4
Bihar	2	0	2
Chandigarh (UT)	1	0	1
Delhi (National Capital Territory)	0	3	3
Gujarat	0	1	1
Himachal Pradesh	1	0	1
Karnataka	4	6	10
Kerala	5	13	18
Maharashtra	11	6	17
Odisha	1	0	1
Puducherry (UT)	0	1	1
Tamil Nadu	9	3	12
Uttar Pradesh	1	2	4
West Bengal	3	1	3
Not stated	0	1	1
<b>Total</b>	<b>40</b>	<b>55</b>	<b>95</b>

*Table 3-1 State or Union Territory (UT) of Questionnaire Participants' Place of Work*

I asked questionnaire participants to indicate whether they are members of the ISSP the IAPC or both societies. The results for all participants are presented in Figure 3-2 and for each conference separately, in Figures 3-3 and 3-4. Overall more respondents are members of the IAPC than the ISSP, and some who are members of the IAPC alone, attended the ISSPCON. However no respondents at the IAPC conference are members of only the ISSP.



*Figure 3-2 Society Membership of all Questionnaire Participants (N=95)*

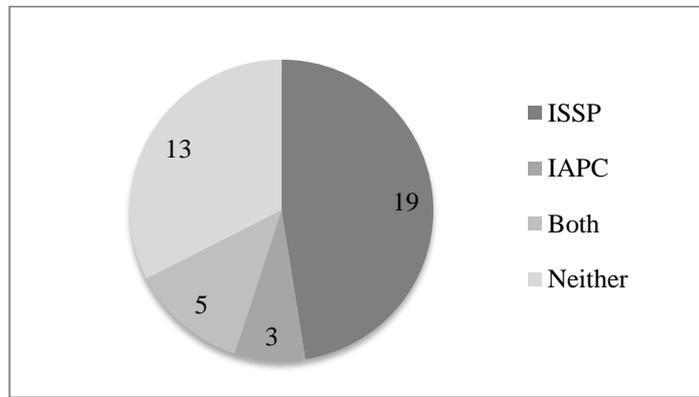


Figure 3-3 Society Membership of ISSPCON Questionnaire Participants (N=40)

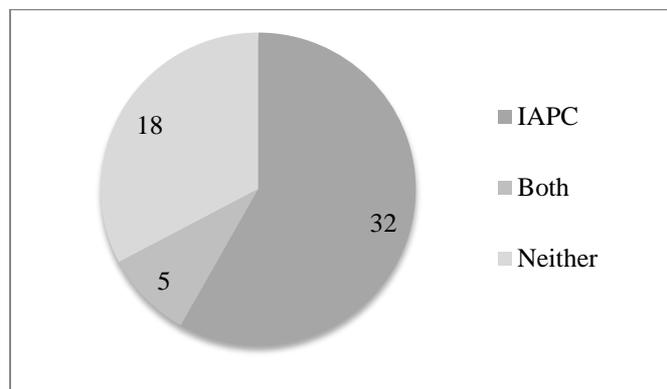


Figure 3-4 Society Membership of IAPCON Questionnaire Participants (N=55)

In the questionnaire I specifically asked respondents to indicate the proportion of their clinical time spent working in pain management. The results are depicted in Figure 3-5.

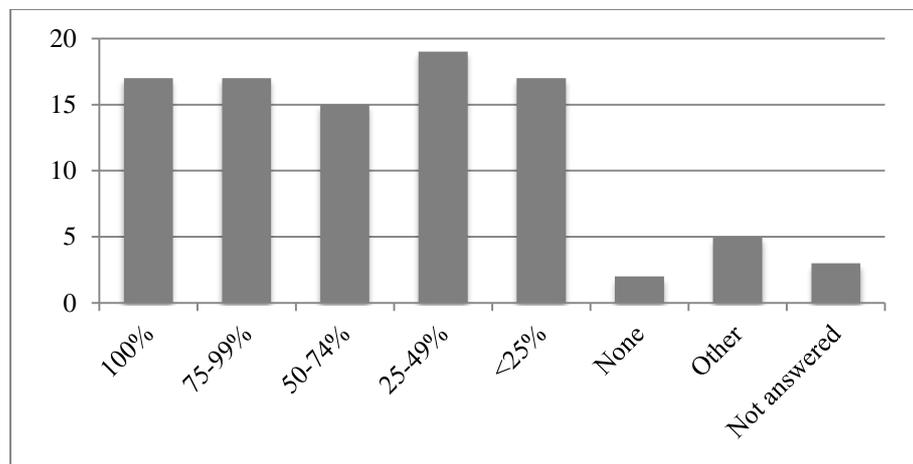


Figure 3-5 Proportion of Clinical Time Questionnaire Participants Spend Working in Pain Management (N=95)

Two respondents state that they spend no time working in pain, raising the question of whether their results should be included in the analysis of the other questions. However, one of these two responds to later questions stating the types of pain conditions they treat, implying that they do in fact work in pain management. The other respondent answers almost all the remaining questions with either “NA” or leaves them blank. One respondent writes in the free text area, “I am not directly involved in patient care”, but they also tick the ‘<25%’ as opposed to the ‘none’ box. The inclusion of this <25% option may actually mean that others who also tick this option do in fact work in pain management ‘none’ of the time. In retrospect the questionnaire may have been clearer if I had included a lower cut off to this category. Of the three who tick ‘other’, the following text is written “4 hours per week”, “We deal with the psychosocial side of PC – have a support group & Day Care. The doctors on the team deal with pain management.” And “All my free time after my regular work as a gynaecologist” [sic]. Two of those who leave the tick boxes blank write the following free text “When I have free time,” and “Used to work 75-99%. Now more of management of the centre.”

### 3.2.2 Interview Data

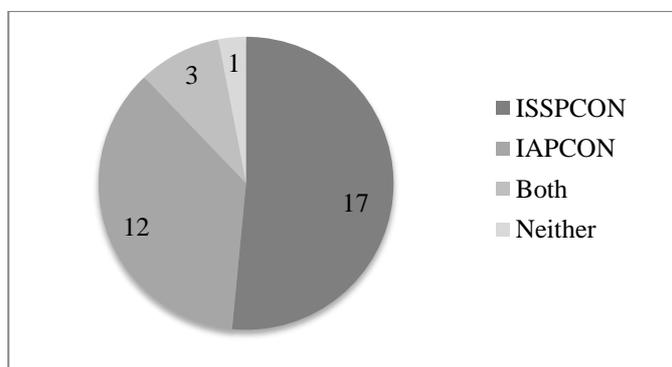
I collected 28 audio-recorded interviews in 2014 and another 5 in 2015. 10 of these 33 interview participants are female. The majority of the interviews were recorded at the ISSP and IAPC conferences in the cities of Navi Mumbai, Bhubaneswar, Chennai and Hyderabad but some participants opted to carry out the interviews at their place of work. Table 3-2 shows the state or union territory of the interview participants’ place of work.

As with the questionnaires, there is a high representation from the states close to where the conferences were held, namely Maharashtra and West Bengal (a neighbouring state to Odisha). Furthermore, three of the five most populous cities in India – Mumbai, Kolkata and Bangalore,<sup>289</sup> are situated in the states of Maharashtra, West Bengal and Karnataka respectively. These are the three states with the most participants in my sample, which may simply reflect the higher number of practitioners working in pain management.

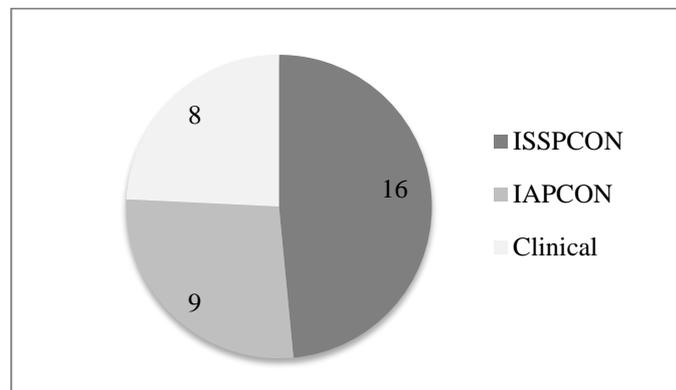
State/Union Territory	No. of Participants
Andhra Pradesh (incl. Telangana)	3
Chandigarh (UT)	1
Delhi (National Capital Territory)	1
Gujarat	2
Karnataka	4
Kerala	3
Maharashtra	8
Odisha	1
Punjab	1
Tamil Nadu	3
Uttar Pradesh	1
Uttarakhand	1
West Bengal	4
<b>Total</b>	<b>33</b>

*Table 3-2 State or Union Territory (UT) of Interview Participants' Place of Work*

The majority of the 33 interviews were recorded with individual participants. However, two consecutive recordings were carried out with each participant listening to the other, one was carried out with a whole clinical team present and one in front of a (consenting) patient. I met all of the participants at the ISSP and IAPC conferences except for one who was introduced to me through another conference delegate. I carried out the interviews either there and then or during subsequent visits to their place of work. Figures 3-6 and 3-7 show the numbers of participants met at each conference and where the interviews were recorded.



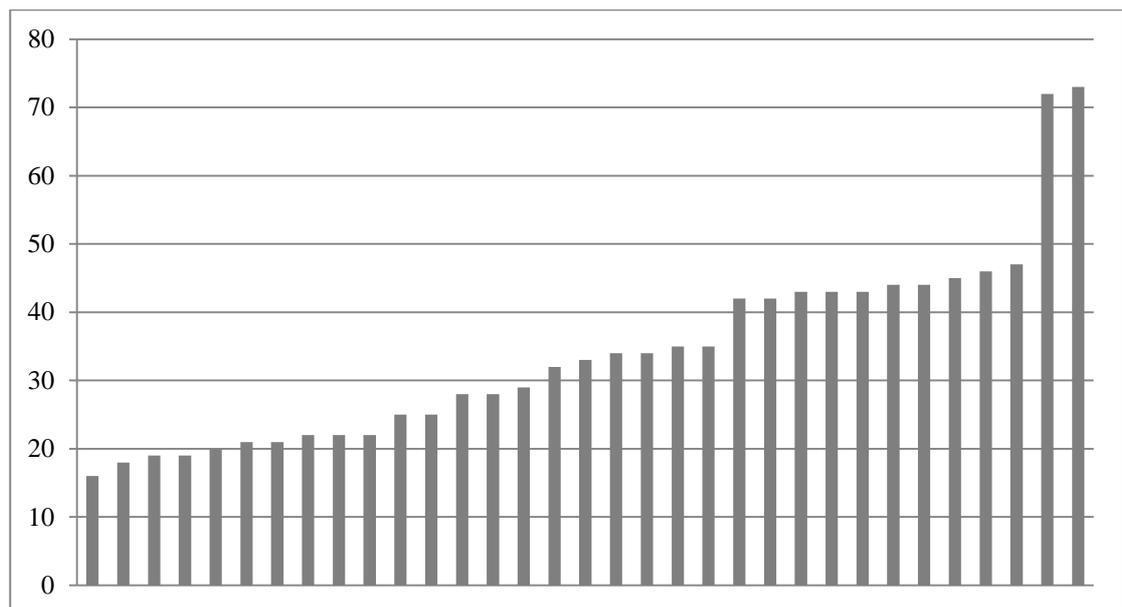
*Figure 3-6 Conference Attended by Interview Participants (N=33)*



*Figure 3-7 Location of Interview Recordings (N=33)*

Of note, the preponderance of participants attending the ISSP conference is intentional, reflecting my aim of ensuring that participants working in pain management outside of the field of palliative care are included in the study.

The interviews range in length from 16 to 73 minutes giving a total duration of 19 hours and 41 minutes of recorded data. Figure 3-8 shows the duration of the interviews arranged here in size order with each column representing one interview.



*Figure 3-8 Length of Interviews in Minutes (N=33)*

Table 3-3 is the final coding tree of nodes or themes resulting from the combined analysis of the qualitative data from the interviews, questionnaires and field notes. Where possible I

1 <sup>st</sup> Order	2 <sup>nd</sup> Order	3 <sup>rd</sup> Order	4 <sup>th</sup> Order	5 <sup>th</sup> Order
Evaluation	Philosophical position (3.3)	Humanitarian goal		
		Patients' acceptance of pain		
	Healthcare system	Resources (3.4.1)	Service finances	
			Buildings	
			Trained personnel	In-house More locations
		Patient finances		
		Plurality of healthcare (3.4.2)	Uniform practice	
	A medical specialty (3.5)	Conditions treated		
	Treatment selection (3.6)	Pharmacological		
		Non-pharmacological	Ultrasound	
		Holistic approach		
		Religion and spirituality		
	Policy and governance (3.7)	Bureaucracy		
Authority priorities				
Rules of medical organisations				
Knowledge exchange (3.8)	By – strategies	Higher education		
		In-house teaching		
		Writing books		
		Research to increase knowledge		
		Professional bodies		
		Patient consultation		
		Reputation (word of mouth)		
		Marketing		
		Public programmes		
		Reaching politicians and managers		
	For – target audience	Clinicians		
		Lay people		
		Managers or government		
		Companies		
	In order to – aims/achievements	Increase practitioner numbers		For the poor or rural
		Increase referral number and speed		
		Improve function of medical specialty		
		Improve access to specific treatments		
		Increase funding for awareness		
	As therapy			
	Of – issues/successes	Pain as a problem		Fundamental need
		Pain prevalence		
		Denial of terminal cancer		
Negative consequences of untreated pain				
Existence of specialty				
Treatment options				
Personal motivation (3.9.1)	Suffering patients			
	Painful experience			
	Blocks			
	Holistic approach			
	A good life			
	Autonomy or status			
	Colleagues' attitude			
	Pioneers			
	Self-taught			
	Inspirational teacher or place			
Power contestation (3.9.2)	Top-down			
	Competition			
	Corruption and trust			
	Collaboration			
	Global-local			
Money				

Table 3-3 Qualitative Data Coding Tree

indicate in this table the chapter section in which the themes (and their subsets) are reported. However, some of the topics such as ‘pain as a problem’ or ‘money’ are integral to the whole thesis and therefore their reporting is included in many topics and in many sections of the chapter, rather than in one discrete location.

### **3.3 Pain as a Problem**

All of the interview participants talk of the need to implement changes to improve pain management either where they work or in the country as a whole. Before discussing these desired changes in more detail I want to comment on the fundamental assumption described by participants that pain is a problem to be fixed. This is distinct from descriptions related to the prioritisation of the treatment of pain - whether governments and managers decide to provide medical pain services, whether a clinician considers a patient’s pain to be significant enough to warrant investigation or treatment, or whether a patient chooses to spend their money seeking medical advice, all of which I consider in more depth later. Here I concentrate on the actual conceptualisation that pain is a problem to be tackled within the healthcare system.

Participants describe the need to treat pain as a fundamental humanitarian goal, their aim being to relieve the suffering of others. Some describe this in terms of human rights, for example:

“I very strongly believe the pain relief is a human right.” (Interview 15)

Furthermore, there is an acknowledgment that potential patients do not share this view that pain is a medical problem and are instead very accepting of pain in their lives. One participant explains:

“There’s not exactly a felt need to you know, actually take up pain as a problem.”  
(Interview 16)

Although this idea that pain is a problem appears to be universally supported by the participants, their descriptions of this concept imply that many other individuals do not hold this view. All of the interview participants talk of the need to improve pain

management across the country, but some of them specifically describe the need to spread the idea of the concept that pain is a problem in itself. This is talked of in reference to various different groups, including most interestingly the patients themselves but also fellow clinicians and other professionals.

Following on from this presupposition that pain is indeed a problem to be treated medically, one of the described barriers to delivery of care is the failure of some members of the profession to wholly sign up to this position. For example, participants explain how their colleagues talk of pain as an expected symptom of a particular disease, a symptom that does not require treatment itself. Their rationale being that by treating the underlying disease that is causing the pain, this symptom will also resolve. In this context a degree of responsibility for patients tolerating poor pain management is placed with the medical profession. For example one participant states:

“Sometimes the patients also are made to believe if there is surgery or if the cancer is growing, I’ll have pain, we have to tolerate.” (Interview 25)

However, there is also an implication of ignorance within the profession, who are only acting as they have been taught to do so. In this context the participants describe a need for more education in order to alter the mind-set of clinicians. The participant below describes:

“We often hear the doctors and nurses telling the patients that, I’m sorry, I wish I could do something, but you probably have to bear the pain because it’s a part of your disease. So that’s how the attitude is, because they really don’t know about it. I’m sure they won’t be callous enough not to try if they knew, but since they’re not taught, they’re not aware, then obviously they don’t know.” (Interview 21)

Moving on to the patients themselves who, in marked contrast to the participants who describe pain as a problem, are, at times, described by as being very accepting of the presence of pain as an expected part of life. A key theme related to this conceptualisation of pain as a medical a problem relates to perceived differences in the Indian population when compared to countries in the global North. One participant says:

“As Indians we, they never express their pain because they think that, you know, ageing is normal and pain with ageing is just normal, which you have to live up and put up with it.” (Interview 3)

This is also related not so much to a fundamental difference between individuals, but to societal pressures. For example a doctor talks of the different support available for patients, albeit for those living a middle class lifestyle:

“Abroad you have to do all the work yourself, here we have maids, even the lower middle class people have maids. So if you are unable to function there is somebody who does the work” (Interview 2)

This described difference between populations has a particular significance when the treatment of pain is discussed. Participants explain that because of the population characteristics or societal differences, directly exported western medical treatments are unlikely to be the most effective. One interviewee explains:

“I think we have culturally grown to accept pain more here. So anything that has to be done, I think we have to find our own solutions here. So, that I strongly believe in, we should not extrapolate what is there from, in the western countries.” (Interview 32)

However, interestingly participants also talk of how this scenario is changing. Specifically within the wealthier and urban communities participants describe a temporal change in attitudes as society modernises, for example:

“Earlier tolerating pain is our culture, they never used to come and complain about the pain. That will be there, that’s all ok, pain means ok, if the trauma is there, pain, we have to tolerate the pain. That is not there nowadays. Now, now they’re explicitly complaining of pain.” (Interview 31)

A final key point of interest here is that although some participants acknowledge that often chronic pain can only be reduced with medical intervention to a certain degree rather than eliminated altogether, I only found one clear example of how this limitation of medicine may be a problem in its own right. One survey respondent described the answer below as a significant barrier to improving their service:

“Unavailability of an ideal modality to control chronic pain.” (Questionnaire 16)

## **3.4 The Healthcare System**

During the interviews I specifically asked participants about hindrances to improving the clinical service they provide, and in the questionnaires I asked them to list the most significant barriers and assets to improving their service. When considering the provision of pain management within the healthcare system of India, either in participants' own places of work or across the country, the key areas that participants highlight relate to a scarcity of resources – both financial and human, and to the presence of multiple types of healthcare delivery. The data described in this section, relating to these issues is derived from the interviews and questionnaires containing both quantitative and qualitative information.

### **3.4.1 Resources**

The lack of resources, described by participants, whether absolute, or relative secondary to unequal distribution, includes a scarcity of financial wealth and a lack of trained personnel. Furthermore, the lack of funding relates both to the organisations providing clinical services and to individual patients. I therefore consider each of these themes in turn.

#### **3.4.1.1 Institutional Funding**

With respect to absolute funding, participants describe problems with the amount or quality of physical space available in which to practice. This is noted to be especially problematic in the large cities where real estate is at a premium. This results in a relative shortage of in-patient beds, in staff having to compete with surgeons to find a time slot in the operating theatres to carry out pain relieving procedures and in having to run out-patient clinics in overcrowded settings. One particularly stark description of these pressures is from a doctor working in a government facility:

“When death happens, we don't have a place to park the dead body, so it is in the middle, and we are doing procedures, on the both side.” (Interview 24)

Participants explain how financial constraints also result in many problems for delivering specific therapies due to a lack of equipment or specialist trained staff. This can result in clinicians modifying their choice of treatments away from the most expensive ‘gold standard’ options. This is sometimes described in utilitarian terms, maximising the number of patients who can be treated. A doctor working in a charitable organisation says:

“If we try to do better for the individual patient then others will be deprived of care, mainly because of limited resources.” (Interview 18)

It is worth noting in my data sample that although many participants talk of a paucity of finances, a number of participants work in institutions they describe as well funded. In these institutions although they do not talk of a dearth of absolute funding they do note that there are still issues with relative finances in that they need to persuade managers of the economic benefits of treating patients’ pain. One participant working in a corporate facility says:

“Well, financially, I don’t think there’s much of limitation from, you know in a hospital like where I’m working, it’s just that sometimes the management doesn’t see the return of investment on such things.” (Interview 10)

Even in the government sector a clinician working in Delhi similarly describes high levels of absolute funding:

“Being in the capital of the country I can tell you, there is no dearth of funding, it is the lack of willingness on the part of the administration authorities.” (Interview 13)

#### 3.4.1.2 Patient Finances

I now move on to consider the finances of the individual patient. When considering the qualitative data, participants describe how the finances of patients affect the treatments they receive. They explain that having to pay for treatment can cause patients to delay seeking medical advice for conditions until they are more advanced and even more resistant to treatment, and that it may deter some people from seeking medical help at all. One interviewee working in palliative care describes this:

“Because there’s no insurance, people pay out of pocket and medicines become the last important thing, because again health becomes the last important thing where you

see people with advanced stages because they don't want to spend on healthcare, they want to spend on everything else before they come into healthcare.” (Interview 19)

One pain specialist notes how patients' ability to pay also affects the actual treatments given by doctors:

“At many times you are forced to you know, change your treatment just because something is not available or the patient can't afford.” (Interview 14)

This is described as compounded within the field of palliative care, where people are often seeking pain relief for a disease such as cancer that they have already spent huge sums of money trying to cure. One physician working in pain management explains:

“When it comes to question of palliation they have already exhausted their funds, they spent thousands of money on chemotherapy, surgery, everything, so they want to keep it simple.” (Interview 12)

Participants explain that those services that are specifically targeting improving access to pain treatments for the poorer members of the community (often government or charitably funded institutions) do not usually offer the more complex or expensive treatments. However, in practice even the private institutions do not actually deliver these high-end treatments because patients choose not to or are unable to spend such significant sums of money. Here a pain doctor talks about using a treatment called spinal cord stimulation:

“For advanced neuromodulation like spinal cord stimulation, which cost around, in Indian rupees it comes to around two-point-five to three lakh [100,000], three-point-five lakh, which is a huge amount, which is almost at par with the amount which is spend on cardiac bypass surgery, when a patient has, so you see how many, you know what percentage of the public can afford that huge amount?” (Interview 13)

Participants talk of the ways in which this situation could be improved – by increasing the funding from government, increasing the number of treatments that are funded by insurers and by reducing the costs of treatments by working with industry. One pain specialist explains how the pharmaceutical industry could be influential:

“Of course the pharma companies and all these drug companies, they should also have subsidised medicines, because in a third world country like ours we have so many financial problems, so many obstacles because in many places you get the idea that pain is only for the affluent, pain relief is only for the affluent, which is not fair.” (Interview 14)

Another interviewee focuses on involving companies who manufacture other devices such as the spinal cord stimulators talked of earlier:

“We cannot do many cases because the cost involved is so high. In my twenty, twenty-five years of practice I have done not more than four to five procedures. On that basis nobody’s going to get convinced to get this treatment. So that’s the reason I have been talking to some of the companies to give us those things, we can, we do the research in thirty, thirty-five, forty patients then we can present our data to the people in India.” (Interview 15)

Another doctor working in palliative care talks of the need to focus attention on finding newer cheaper treatments altogether:

“Research should be focusing on simpler methods, easier methods to control pain, like going into the morphine pump I don’t think the affordability would be zero-point-one per cent, you know. We need to look at techniques which can be used simply without much set up then pain can be controlled much more better.” (Interview 19)

As I demonstrate in more detail below (in Section 3.4.2) participants work in a wide range of healthcare institutions delivering pain management and employ a variety of financing structures. In the questionnaire I asked respondents to indicate the percentage of patients they treat who receive all of their treatment free of charge (Question 7). The results are demonstrated in the bar chart of Figure 3-9.

In Figure 3-10 I separate out the results of Question 7 into two sets of columns each representing the responses from the different conferences attended. The lighter shaded columns depict the responses from those attending ISSPCON and the darker, IAPCON.

Both graphs demonstrate a wide range of answers with at least one respondent selecting each of the options. Of note, however, in Figure 3-9 there are peaks at each end of the spectrum, in the 100% and the 1-10% columns. If the results are separated out, however, into the respondents from each conference (Figure 3-10) there appears to be a different spread, with a peak at 1-10% for those attending ISSPCON and a peak at 100% for those attending IAPCON. Although these are not presented here with comparative statistical analysis, there is a suggestion of a broad difference in the type of practice between the two groups – namely in the degree of charitable work undertaken.

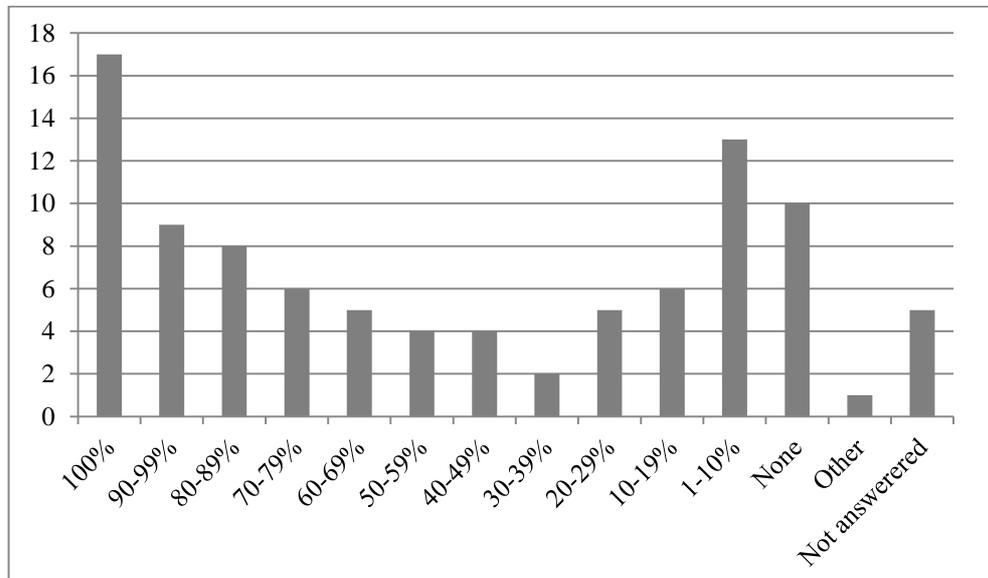


Figure 3-9 Proportion of Questionnaire Participants' Patients Receiving Pain Treatments Free of Charge (N=95)

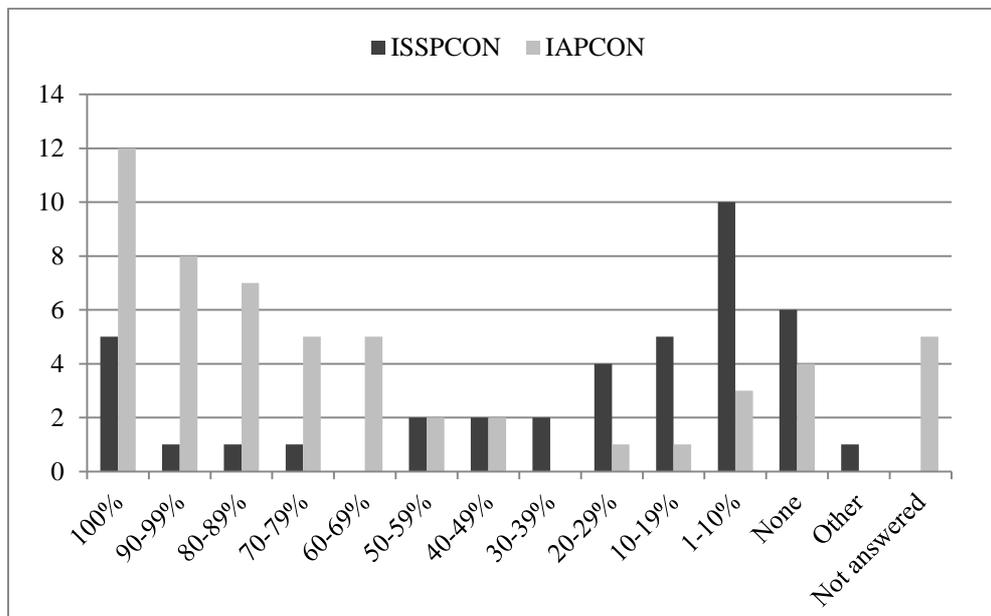


Figure 3-10 Proportion of Questionnaire Participants' Patients Receiving Pain Treatments Free of Charge, by Conference Attended (N=95)

**3.4.1.3 Trained Personnel**

Intimately linked to funding but also worth considering in its own right is the lack of trained personnel. This is talked about both at a local level, within the institutions where the participants work, and across the country as a whole. Some doctors comment on the

dearth of healthcare staff across all areas of healthcare, which means that staffing in pain management is not a priority, for example:

“It is not surprising that pain is suffering, because health, there is no provision for health, so where is the question of pain relief?” (Interview 11)

Specifically within the field of pain management interviewees explain how there are insufficient numbers of professionals who are trained in the field. Although many talk of how the situation has improved a little over recent years there is a striking difference in the availability of services between the urban and rural populations. A doctor working in Mumbai describes this:

“The population of Mumbai itself is about one crore [10 million]. So if, if in a population of one crore in city of Mumbai, we have not more than fifteen pain clinic, you think the situation in the rural areas, in the district places.” (Interview 15)

In the questionnaires, a lack of manpower is listed as a specific reason for clinicians not being able to expand their services.

Patients frequently have to travel great distances to access specialist services as explained by a doctor working in a regional cancer centre:

“Actually our cancer patients, which are visiting my department, they are very much happy with our service, but what happens, you know, the, ours is the only centre for whole of Gujarat, where such services are available, so they have to come, travel a lot, from far off places. So I feel that if they have some follow-up at their own place there, or district level, then they will be much happy, comfortable.” (Interview 4)

This lack of services at a geographical level can lead not only to inconvenience for patients but also to clinicians modifying their choice of treatments. One participant here is explaining why some complex implanted devices requiring on-going medical input are not used:

“What would be the after care? So, due to lack of supportive care, we do not do.” (Interview 11)

The relative lack of doctors means that often there is a severe lack of time available to spend with individual patients for example there may be significant overcrowding in out-patient clinics as described here:

“Many a times, the other practitioners, they don’t have sufficient time, they have got a huge number of OPD patients, so they are not in a position to give sufficient time.” (Interview 6)

Doctors working in pain management often have other clinical commitments, which they consider to impact on the time available to treat each patient. One doctor who also works in the specialty of anaesthesia has to deal with patients’ pain after surgery (in the operating theatre recovery ward) as well as those in out-patient clinics. This tension is explained here:

“The person who is sitting in the chronic pain has to see the pain management in recovery ward also. So, in the afternoon he is tearing between the two.” (Interview 11)

These demanding working conditions are described as adding to the difficulty of recruitment into some posts, which are relatively poorly remunerated further compounding the problems of insufficient funds to pay salaries and the lack of training opportunities. One doctor working in palliative care explains:

“We have actually applied for but the response we have got is very poor because many people are not willing to come to palliative care. See palliative care doesn’t come with incentives. And a country like India, where doctors expect a bit of incentive by seeing a patient, giving rounds, in a charitable institute, where you don’t get additional payment, if there’s no incentive they don’t feel the urgency.” (Interview 26)

However, this particular issue is not specific to those working in palliative care or indeed the charitable or government sector where salaries are traditionally lower. Those working solely in pain management even in the private sector note that there can be financial sacrifices to be made especially when they are setting up an independent practice from scratch with a small number of patient referrals and therefore income base.

The problems of understaffing are not limited to the medical profession. Nurses are also noted to be overstretched leading to delays in attending to patients or even omissions in administering analgesia. There is also a reported shortfall in allied health professionals and administrative staff. One doctor describes how he resolved the problem of not having a dedicated radiography technician to work an x-ray machine (c-arm):

“I have trained even a tea vendor in my hospital in the orienting the c-arm, and this imaging, and now he’s working with us.” (Interview 7)

Other specialised roles are also not filled partly due to a lack of locally trained staff.

One palliative care doctor explains how their service relies on overseas help:

“Whenever the volunteers are available, aromatherapy is available, when the foreign volunteers are not there there’s no aromatherapy.” (Interview 17)

Locally trained volunteers are also often relied upon to deliver pain relief and other clinical care most notably within the field of palliative care where patients frequently require round the clock care at home during the last few days and weeks of their lives.

### **3.4.2 Diversity of Healthcare Provision**

I outlined in Chapter 1, how healthcare in India is provided by a diverse array of practitioners operating outside of the umbrella of western or allopathic medicine, and even within the field of western medicine or allopathy there are many types of clinical institution receiving multiple sources of funding.<sup>131</sup> In the questionnaire I asked about the institutions where participants work, to indicate which sort of institution they work in and how it is funded (Question 6). Many respondents tick more than one box, indicating that they work in multiple organisations and/or with varied sources of funding. One specific limitation of the question format is the difficulty in determining the number of institutions each participant works in. For example, if they tick two boxes in one row, such as a general hospital with private and charity funding, this could either indicate they work in one institution with mixed private and charitable funding, or that they work in two separate general hospitals, each with their own single funding type – one private and the other corporate. Figure 3-11 shows the type of funding indicated for each institution listed, by each respondent, hence the total number of institutions (129) is more than the number of respondents (95).

One respondent does not tick any boxes in the question but writes the free text “I am a private freelance consultant, having my own clinic for Pain Management. This not funded. Affordable patients pay for their own, if they are not affordable, I am doing this free, especially for cancer patients.” This demonstrates another limitation of this type of question, namely that respondents feel the fixed categories presented to them are inadequate descriptors of their answer. Some respondents do not tick any boxes but they do

write the name of an institution in the free text area, these are counted as working in one type of institution, although the data isn't clear enough to be added to the graphical data of Figure 3-11. Figure 3-12 demonstrates the numbers of types of institution each questionnaire participant works in.

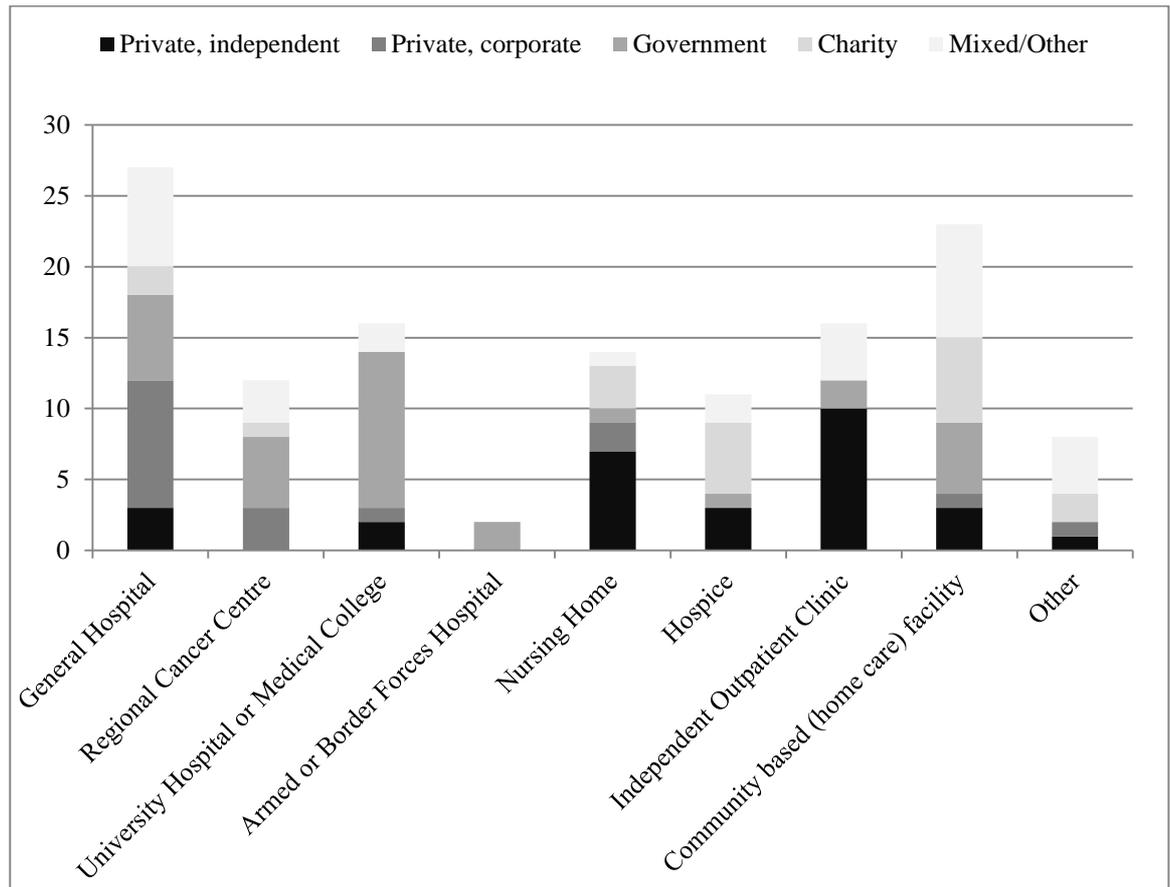


Figure 3-11 Funding of Place(s) of Work of Questionnaire Participants (N=129)

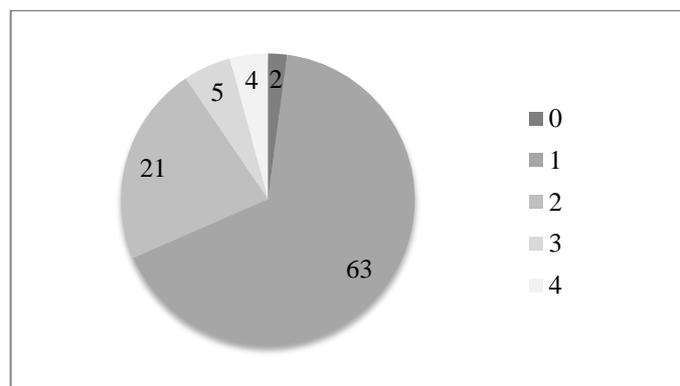
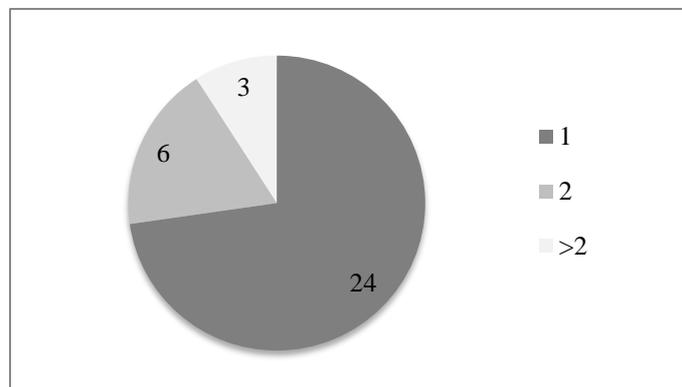
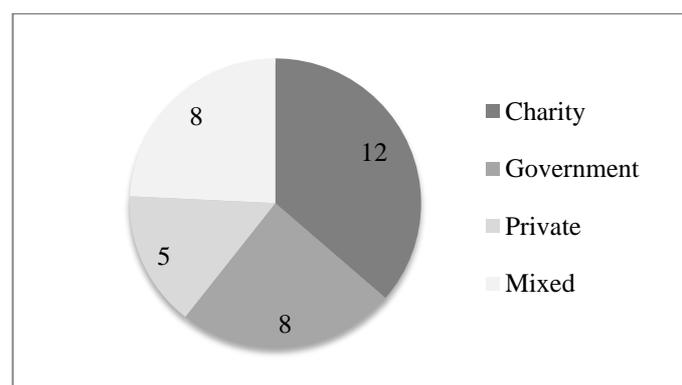


Figure 3-12 Number of Types of Institution Worked in by Questionnaire Participants (N=95)

The interview participants also talk of working in multiple institutions. While the nature of the interview data collection as semi-structured with the use of a guide rather than the fixed questions of the written questionnaire leads to some ambiguity, I have been able to extract some quantitative data relating to place of work from this source. For example, although participants talk about the institutions where they work, I did not consistently ask directly how many hospitals they work in or how their practice varies amongst these institutions. Furthermore, some participants had recently moved their place of work and talk about the institution in which they worked in the past as well as their current post. However, I did ask directly about the funding of their place of work. Figures 3-13 and 3-14 show the number of institutions the interview participants work in and the variation in funding types respectively.



*Figure 3-13 Number of Institutions Worked in by Interview Participants (N=33)*



*Figure 3-14 Funding of Place(s) of Work of Interview Participants (N=33)*

Those noted to have ‘mixed’ funding indicates that they work at an institution with a mixture of funding sources and/or that they work at more than one institution, each of

which has a different type of funding. In keeping with the results of the questionnaire, several participants work in multiple institutions often funded in various ways. Some working primarily in the private sector describe carrying out additional charitable activities, others supplementing their income through private work.

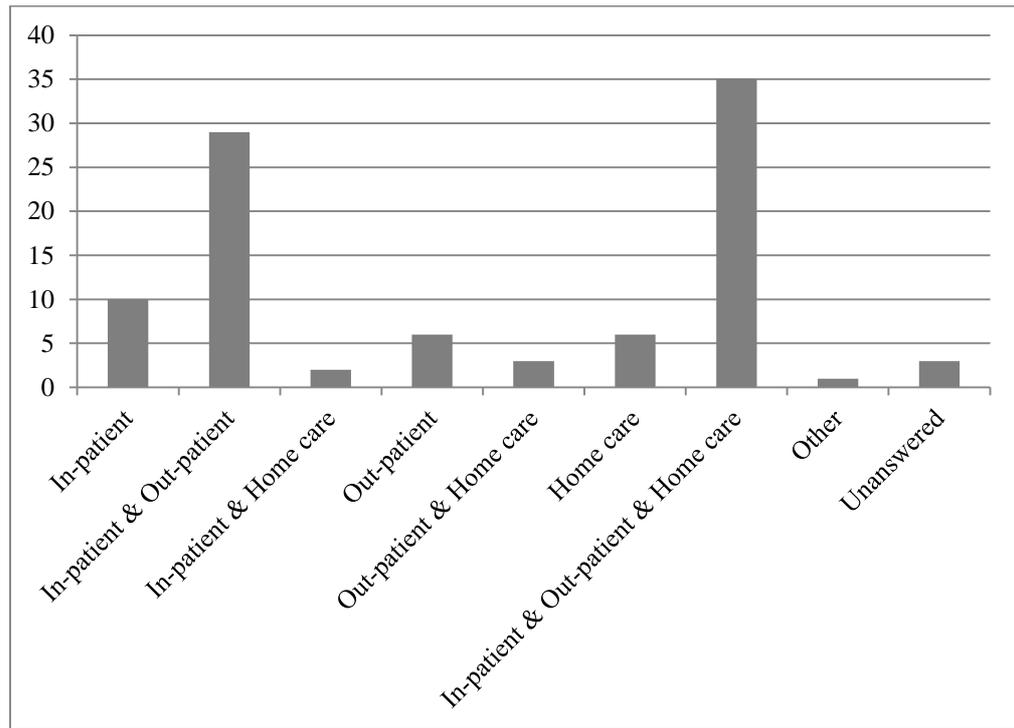


Figure 3-15 Type of Clinical Care Delivered by Questionnaire Participants (N=95)

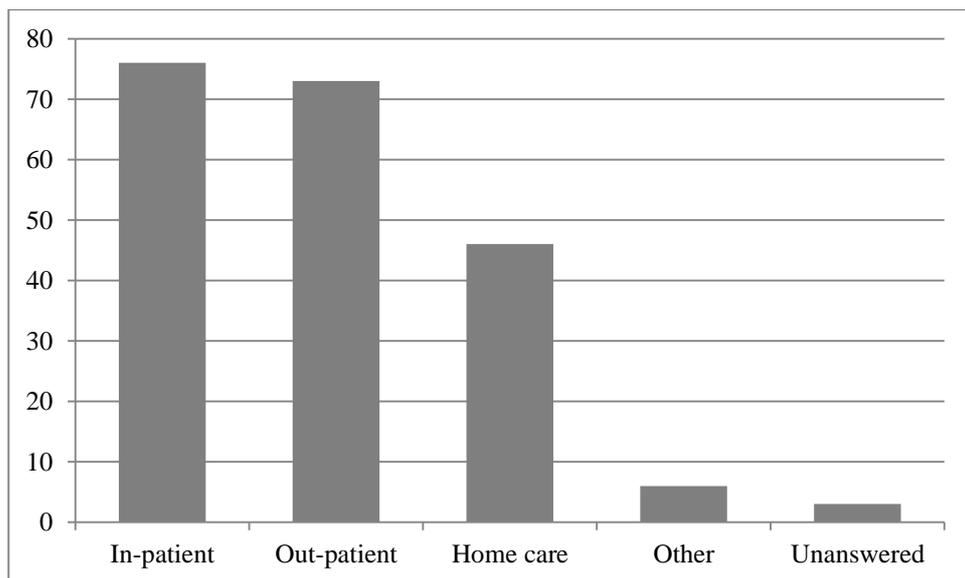


Figure 3-16 Frequency of each Type of Care Given by Questionnaire Participants (N=204)

Leading on from this I asked questionnaire (Question 8) and interview participants about the type of clinical care they give on a daily basis and whether this is in-patient, out-patient or home care. Many questionnaire respondents indicate that they offer more than one type of care so the results of this data are presented here in two ways: firstly, in Figure 3-15, as the number of respondents offering each *combination* of care type and secondly, in Figure 3-16, as the number of respondents offering *each type* of care. In Figure 3-16, therefore, the total number of responses (204) is more than the number of participants (95). In addition to the options provided on the questionnaire, one respondent states that they provide a “teleclinic”.

Similarly, where possible I collated quantitative data from the interviews relating to the type of clinical care given, depicted in Figure 3-17.

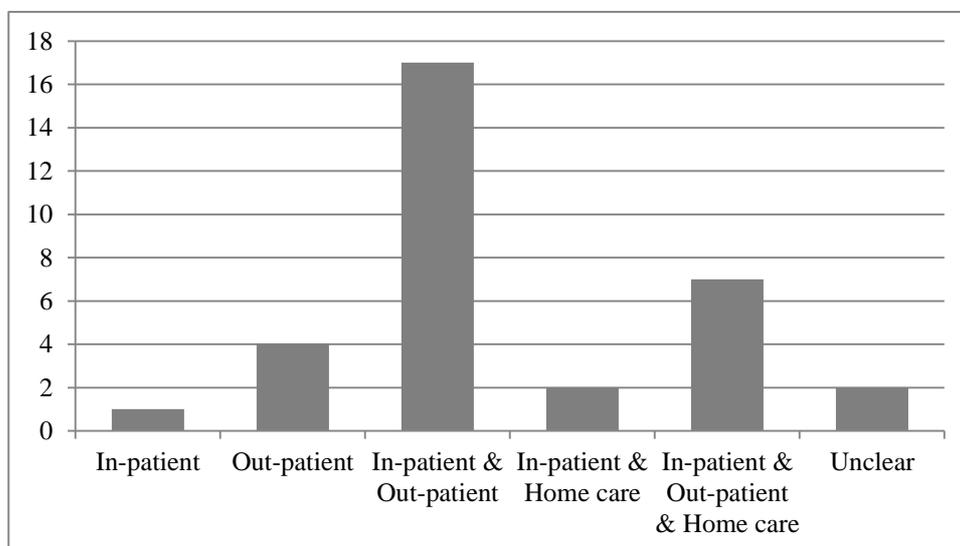


Figure 3-17 Type of Care Delivered by Interview Participants (N=33)

The plurality of provision in the healthcare system of India is a significant theme in the qualitative data. As the results show within the practice of pain management, allopathic doctors work in a range of institutional settings. The participants describe how this makes choosing a doctor difficult for patients, and how this is compounded by the very low level of primary healthcare and presence of family physicians who can help to inform patients' choice. One participant explains how patients will often seek advice from a particular individual because they trust them as a person rather than because they think they have the most appropriate clinical skills for their particular medical condition.

“If I have a problem, I go to a doctor in Mumbai, I know Clare, she’s a good doctor so I go to her, with whatever problem I have, because she has treated my mother or my father, my sister, so I go to Clare.” (Interview 14)

Participants also explain how this plurality leads to a great deal of variation in the actual practice of medicine, which treatments are provided and how training is structured. For example:

“There is no uniform guideline or protocol for pain management, let me say that. People have their own experience and they practise and there is no formal education available.” (Interview 4)

This variation of practice is described as compounded by weak regulation:

“You can inject ozone, you can inject dextrose, you can inject plasma, there’s no regulation. So if Indian Society is strong, they can give guideline. In back pain you do this, this procedure. This procedure is not allowed.” (Interview 30)

One of the noted consequences of the presence of multiple providers is that patients may choose to visit several different practitioners who offer the same modality of treatment rather than progressing through a structured escalated system of referral to try an alternative treatment if one has already failed to provide pain relief. Participants talk of how this system causes both a delay in referral and to patients not seeking the help of a pain specialist at all. One participant describes these problems:

“So typically, they go to an orthopaedic surgeon, get written some anti-inflammatories, they take it for two weeks, it may or may not help, and then they go to another orthopaedic surgeon who again writes the anti-inflammatories in a different name, so they just keep moving around. And three months later, having, and taken anti-inflammatories in different names, and with stomach ulcers all sorts of problems, you know they really are stuck in terms of where to go.” (Interview 3)

This wide array of practitioners is described as leading to issues around competition between these individuals, particularly but not exclusively, within the private sector. One consequence of this is noted to be reluctance on the part of doctors to refer patients on to be treated by their colleagues (competitors). I return to the issue of plurality of healthcare provision and competition later (in Section 3.9.2) due to its relation to the concept of power.

### **3.5 Medical Specialisation**

In the preceding two sections I presented data explaining how pain is conceptualised as a medical problem and of how the medical practice of treating pain occurs in a healthcare system with multiple types of provider and where there is competition for scarce resources. This leads into the discussion of the professional organisation of clinicians themselves. The presence and role of specific subspecialties within healthcare are key themes resulting from my data, with participants describing both the importance of the presence of medical specialities, and of how they should be organised and function.

As well as describing the lack of staff trained to manage pain, participants frequently talk of the creation and function of pain medicine and/or palliative medicine as medical specialties in their own right. As I described in Chapter 1, palliative medicine has only recently been recognised as a specialty in its own right with just one MD (postgraduate training) programme in operation at the time of my data collection.<sup>143</sup> In contrast, pain medicine is not currently officially recognised by the Medical Council of India as a medical specialty or subspecialty in its own right.<sup>149</sup> Many of the interview participants have had preliminary specialty training in anaesthesia and some still spend a proportion of their clinical time working in this field. The idea that pain medicine, could also be recognised as either a specialty in its own right or as a subspecialty of anaesthesia is discussed by the interviewees as one of a number of possible strategies to improve the provision of pain services in India.

The participants talk of several potential consequences of the establishment of a medical specialty to justify their position, such as, an increased awareness within the rest of the medical profession as well for society as a whole, which I return to later in the section related to knowledge exchange (3.8). However, the idea of awareness is very much tied in with prioritisation and how important the treatment of pain is perceived to be. One doctor explains:

“I think in terms of solutions, we need more training programmes and things, and unless it comes from the top, the Medical Council and the professional regulatory bodies say ‘Yes, this is important enough’, so that it becomes a speciality on its own, it’s going to be difficult.” (Interview 3)

Pain specialists talk of having to divide their time between anaesthesia and pain management and some describe how the existence of a medical specialty, with the subsequent creation of a separate hospital department and clinical posts, would help to alleviate this particular tension, at least in the government sector.

“I wish to go, you know, purely into pain management but you know, I also have to do the operating room work so you know, about forty per cent of my time is for operating room, sixty per cent for total for pain management, and I wish to have a hundred per cent devotion for pain management which at the moment is not possible because of the you know, the university, when you’re appointed by the university you know, there is no separate appointment, no separate appointment, because there’s no post of professor of pain management, it is actually the professor of anaesthesiology who’s doing this extra work.” (Interview 13)

They talk of how the creation of a specialty could increase both the numbers of practitioners working in the field and serve as a force to improve education and training. As I showed in the previous section (3.4.2) related to the multiple providers of healthcare, education and training is described as poorly coordinated and regulated. This leads to many participants calling for the creation of national guidelines to inform and, where necessary regulate, day-to-day clinical practice. The participants describe the need to coordinate practice both to improve the clinical care for patients and to maintain or improve the reputation of the specialty.

“The trainings are not from the government agencies, and that is creating a little disparity in the kind of work being done, because few people who were experienced, they start imparting training, there are five, six such pockets, and everybody has different way of working. So, the people who are coming out have different ways of working. So what is required is a protocolised assessment, to treatment, to post-procedure follow-up, and understanding the pain rather than the procedures is what is required, and it is not there.” (Interview 8)

That said there are some, albeit voluntary, healthcare accreditation schemes operating at a national and international level that incorporate some of these ideals. One doctor working in the corporate sector explains:

“It is run by a management which is internationally, you know, accredited by the JCI, so all of our protocols and everything are tested by a central team and, it complies with standards which are international accepted.” (Interview 10)

In general, within my data, the idea that the creation of medical specialities, whose specific aim is to provide treatment for patients in pain, is not contested. Furthermore the idea that

this specialty organisation with its associated top-down guidelines and regulations will lead to improved patient care is also largely undisputed. However, when considering exactly how the medical specialities related to pain management should be organised there is considerable variation.

In the questionnaire I asked participants to state their profession (Question 3) by ticking one appropriate box from the following list of choices: nurse, pharmacist, social worker, psychologist, physiotherapist, volunteer, doctor, other. The results are demonstrated in Figure 3-18.

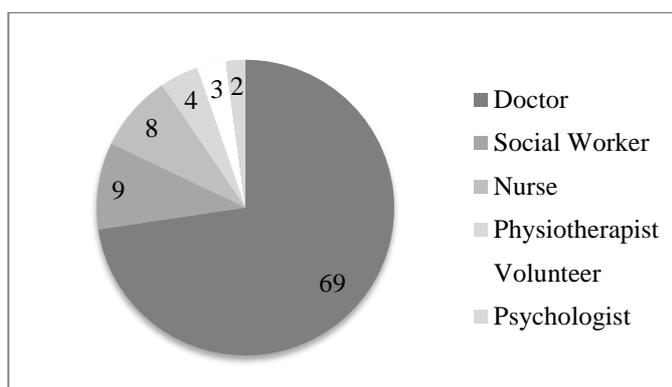
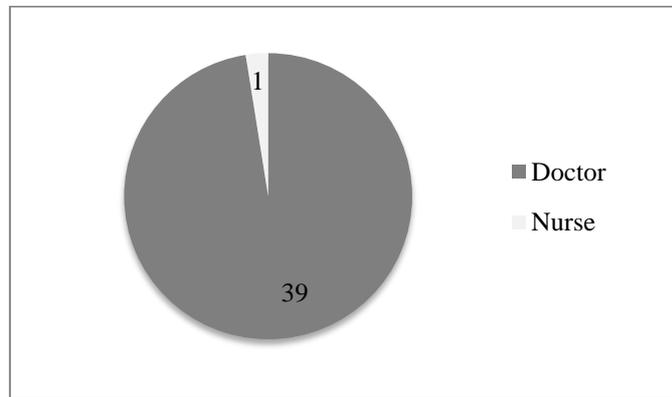
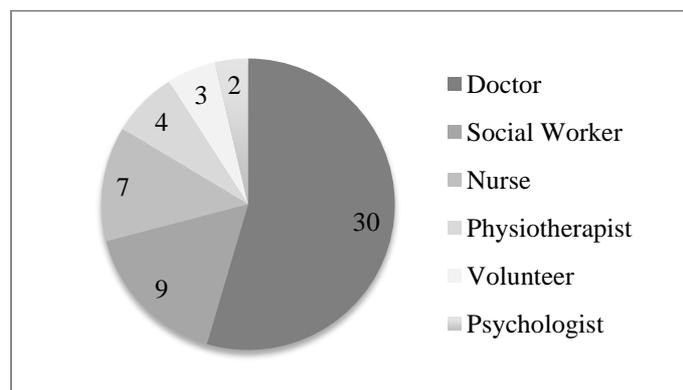


Figure 3-18 Profession of Questionnaire Participants (N=95)

Three respondents tick more than one box. One ticks both ‘psychologist’ and ‘volunteer’. For the purpose of reporting these results I include this respondent as one of two psychologists but note that in the rest of the questionnaire this individual writes “NA” against many answers including those relating to place of work. They state that they spend no time working in pain management and do not give clear answers to the questions related to treatment availability. I refer to these results again later. Two respondents tick ‘doctor’ and ‘other’. In the associated free text box, one of these states that they have an MBA in healthcare management but they also note their medical qualification as “dentist”. The other writes “Clin. Dip (Pall Med) Clin. Fellowship (Pall Med)”, which I interpret as another medical qualification, rather than as indicative of training in a second profession. Both these individuals are counted as doctors. One respondent, a nurse, adds that they are a “pain nurse manager” and another that they are “taking care of palliative care training”. Others add some specific details of their roles.



*Figure 3-19 Profession of Questionnaire Participants at ISSPCON (N=40)*



*Figure 3-20 Profession of Questionnaire Participants at IAPCON (N=55)*

The two pie charts Figures 3-19 and 3-20 demonstrate the profession of questionnaire respondents attending each of the two conferences separately. Most notable in these results is that all bar one respondent at the ISSPCON are doctors; in contrast at the IAPCON almost half of respondents do not identify themselves as doctors. Although those who are not members of the ISSP are able to attend ISSPCON, the conference programme is largely directed towards the education of doctors' practice in pain management. Furthermore, only doctors are eligible to become full members of the ISSP, as opposed to associate members who have no voting rights at the organisation's annual general meeting. This is in contrast to the IAPC whose membership is open to all individuals regardless of their professional training, including volunteers. Of note, all of the interview participants are doctors but this a specific sampling intention.

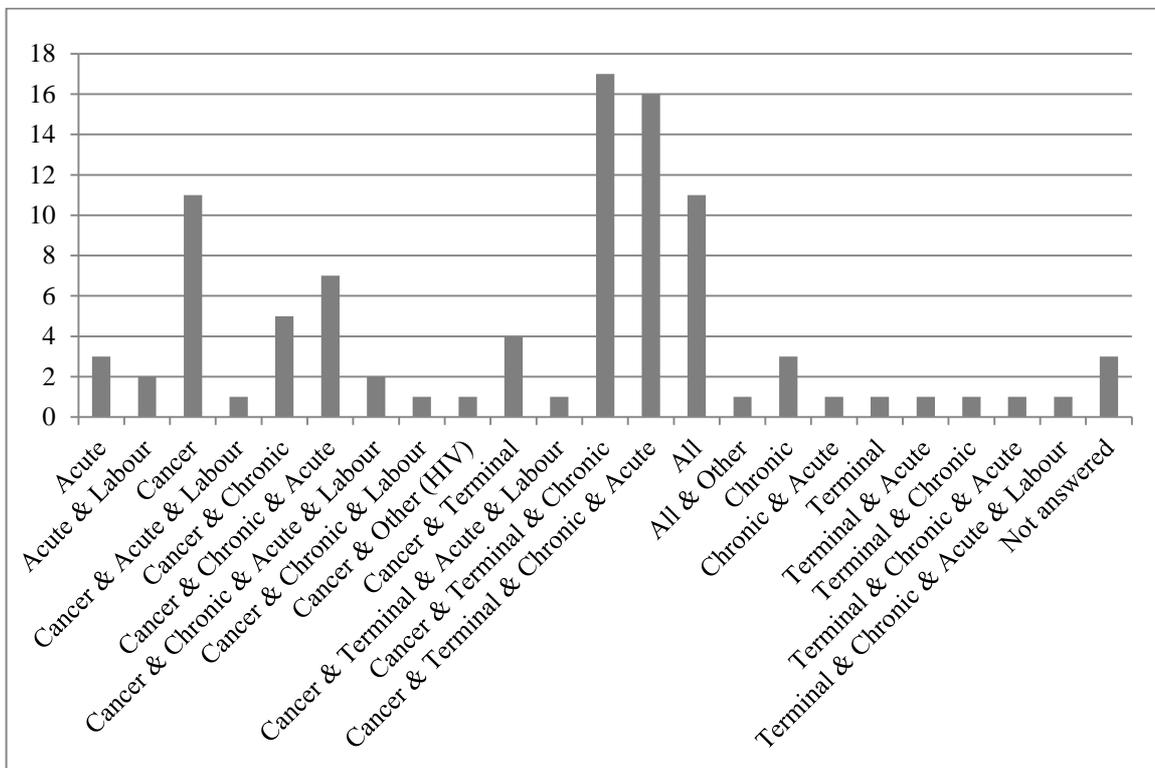


Figure 3-21 Combinations of Conditions Treated by Questionnaire Participants (N=95)

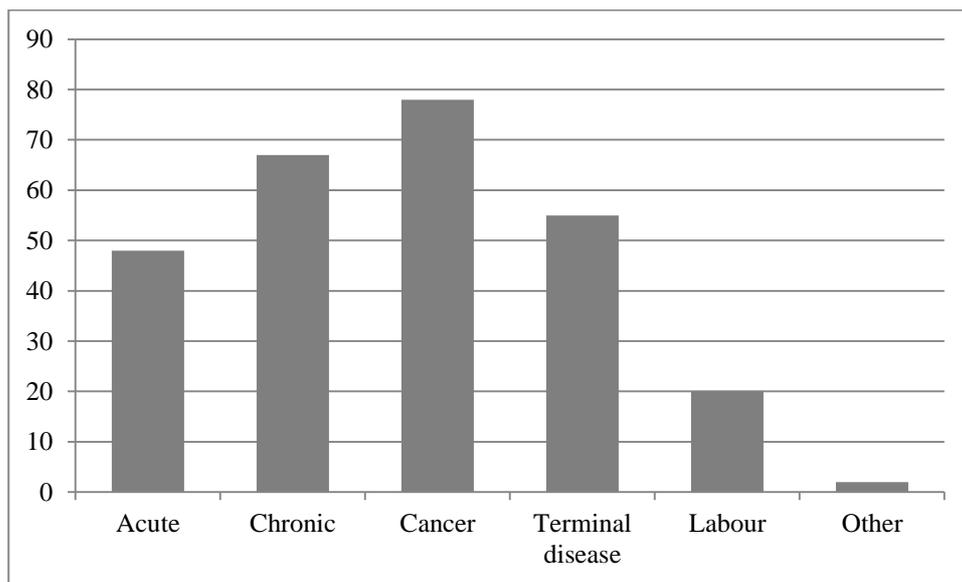
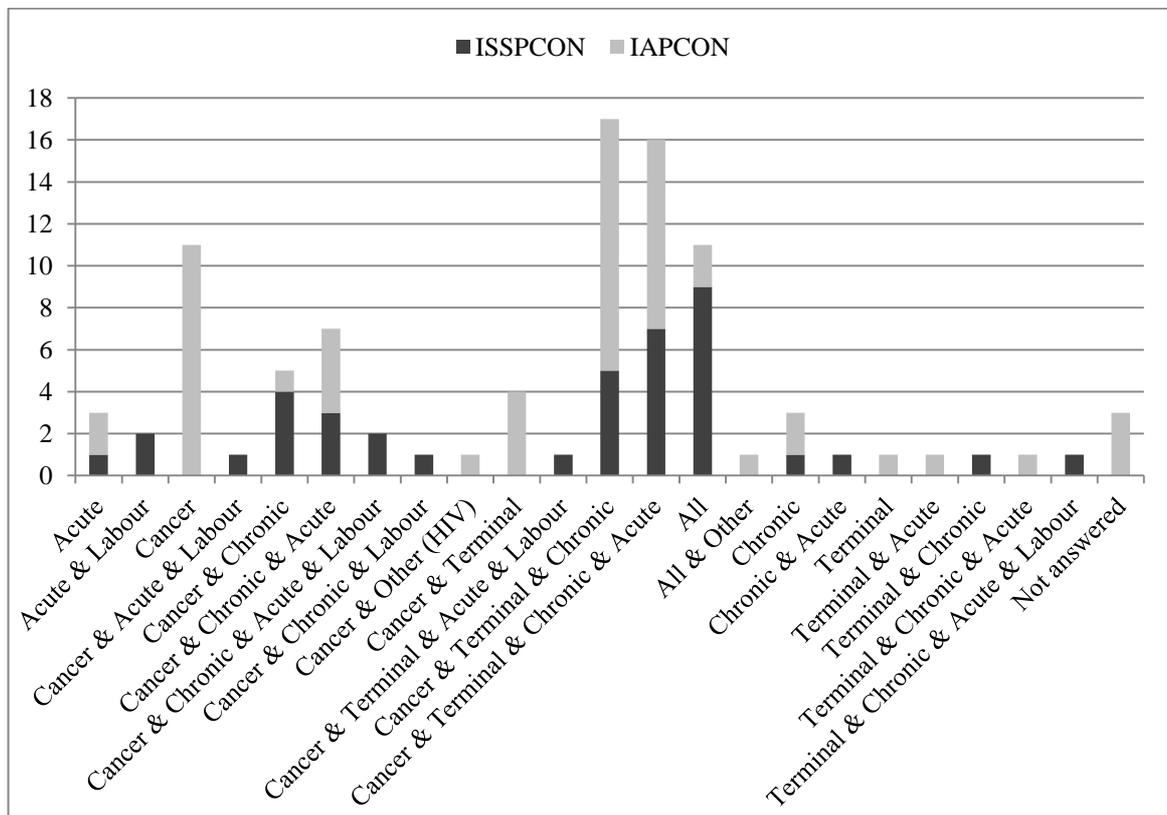


Figure 3-22 Frequency of Type of Conditions Treated by Questionnaire Participants (N=270)

Despite these differences there is considerable overlap in the medical conditions treated by the respondents who attended each conference. I asked in the questionnaire (Question 9)

and in the interviews what sorts of medical conditions patients they treat are suffering from. When considering the questionnaire data, I asked respondents to indicate the range of conditions by ticking boxes from the following list of options: ‘cancer pain’, ‘pain associated with any terminal disease’, ‘any chronic (long standing) pain conditions regardless of the underlying cause’, ‘acute (short term) pain conditions (e.g. trauma, post-operative)’, ‘labour pain’ or ‘other’. The particular categories for each of the types of condition were selected following the interview work I had carried out in 2014 and from my visits to various medical institutions in India. They are categories that were frequently referred to by those working in pain management in India. However, there are limitations with this approach. The categories selected are based on terminology used in western medicine. ‘Acute’ pain refers to pain that is short lived, such as that following trauma or surgery. In contrast, ‘chronic’ pain is defined as a long-term condition. ‘Cancer’ pain is pain due to a specific disease category, which may be short term or long term and/or related to the very final, terminal stages of the patient’s life. Pain of ‘terminal disease’ is specific to the end stage of a patient’s life but may be pain from any disease – not necessarily cancer. There is clearly overlap between several of these categories. For example cancer pain may be terminal, chronic pain may be terminal, patients with terminal disease may suffer short-lived pain following trauma, and so on.

These questionnaire results are presented as graphs in Figures 3-21 and 3-22. Figure 3-21 demonstrates the combination of conditions treated by each respondent. Figure 3-22 represents the number of respondents treating each type of condition. The total number of responses (270) is therefore larger than the number of participants (95), reflecting the multiple options that some respondents tick. Several respondents tick two boxes when one could be considered a subset of the other. For example, four respondents select both ‘cancer pain’ and ‘pain associated with any terminal disease’, and five tick ‘cancer pain’ and ‘any chronic (long standing) pain conditions regardless of the underlying cause’. This will lead to an over-representation in the graph of Figure 3-22, with some respondents’ answers counted in two categories. The highest peaks on the graph of Figure 3-21 are for those respondents treating a wide range of long-term conditions but there is also a notable spike (n=11) for those treating only cancer pain.

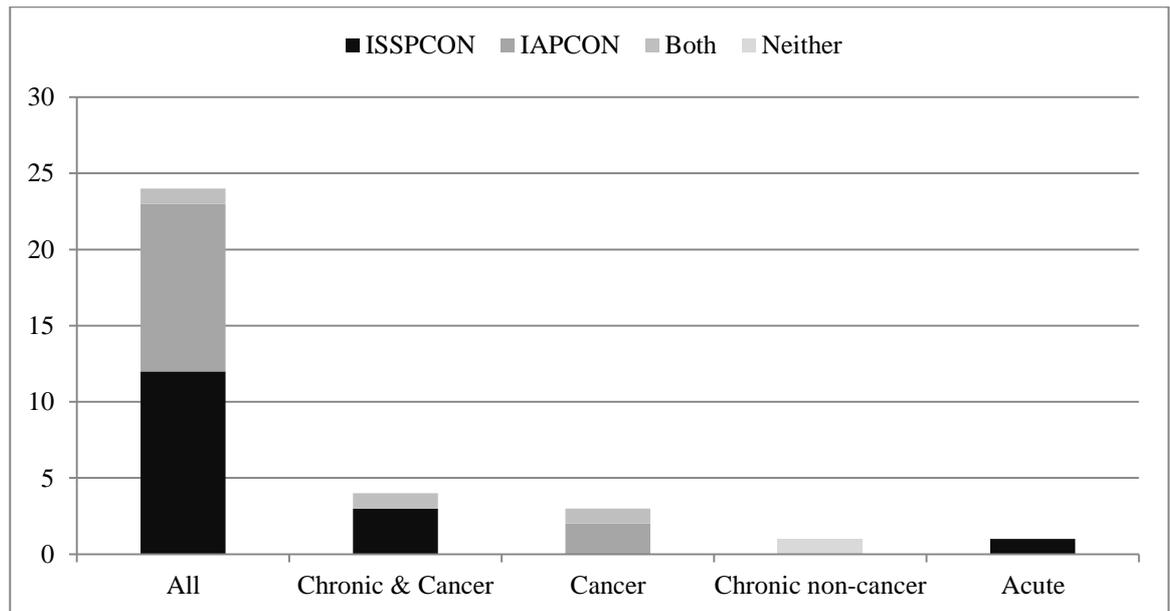


*Figure 3-23 Combinations of Conditions Treated by Questionnaire Participants, by Conference Attended (N=95)*

Figure 3-23 shows the same data as Figure 3-21 but with the added information of the conference attended. This demonstrates that all of those participants who are treating only cancer pain were at the IAPC conference. Two respondents (at IAPCON) one who has ticked 'cancer' and, one who has ticked 'cancer' and 'other', state that they specifically treat pain from HIV/AIDS.

Similarly, when considering the interview data I collated quantitative information regarding the types of condition treated by each participant. Figure 3-24 depicts the number of participants treating each type of condition and the conferences attended. The presentation of the data in Figures 3-23 and 3-24 is particularly pertinent because I have specifically set out to research clinicians working not only in palliative care, due to my perception that the boundaries in India between pain management and palliative care are particularly indistinct. Assuming that those who attend the IAPC conference do indeed consider themselves to be working in this specific field, in practice a significant number are treating patients suffering from all types of pain, not only pain at the very end of life.

Those attending the ISSP conference, assuming these clinicians do not consider themselves to be palliative care specialists but specialists in managing all types of pain, also usually treat pain caused by any medical condition.



*Figure 3-24 Combination of Conditions Treated by Interview Participants, by Conference Attended (N=33)*

In the questionnaires I then asked whether or not respondents ideally wanted to treat a wider range of conditions (Question 10). The results are presented in Figure 3-25. Of note, although the largest portion of respondents (45) wish to treat the same range of conditions, a sizeable minority of respondents (36) wish to widen their clinical remit with only one indicating that they desire it to be narrower. The one respondent who wishes to treat a narrower range of conditions states that they want to treat spinal pain, implying this could or should be a sub-specialty area of work. However, some respondents do not appear to fully understand the question and tick more than one box, so these are counted as ‘miscellaneous/unanswered’. One respondent ticks both ‘same’ and ‘narrower’, and they also list “spine” as the condition they wish to treat. One respondent does not select any box but writes under the section to list the narrower range of conditions “amputation, palliative care”, and three others also write in this free text section despite not ticking the box indicating that they want to treat a narrower range of conditions.

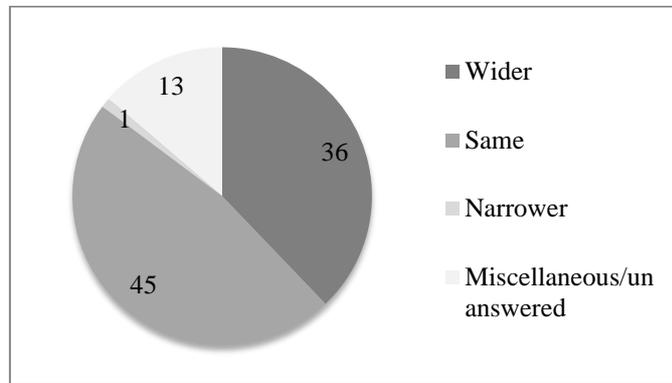


Figure 3-25 Preference for Range of Conditions Treated of Questionnaire Participants (N=95)

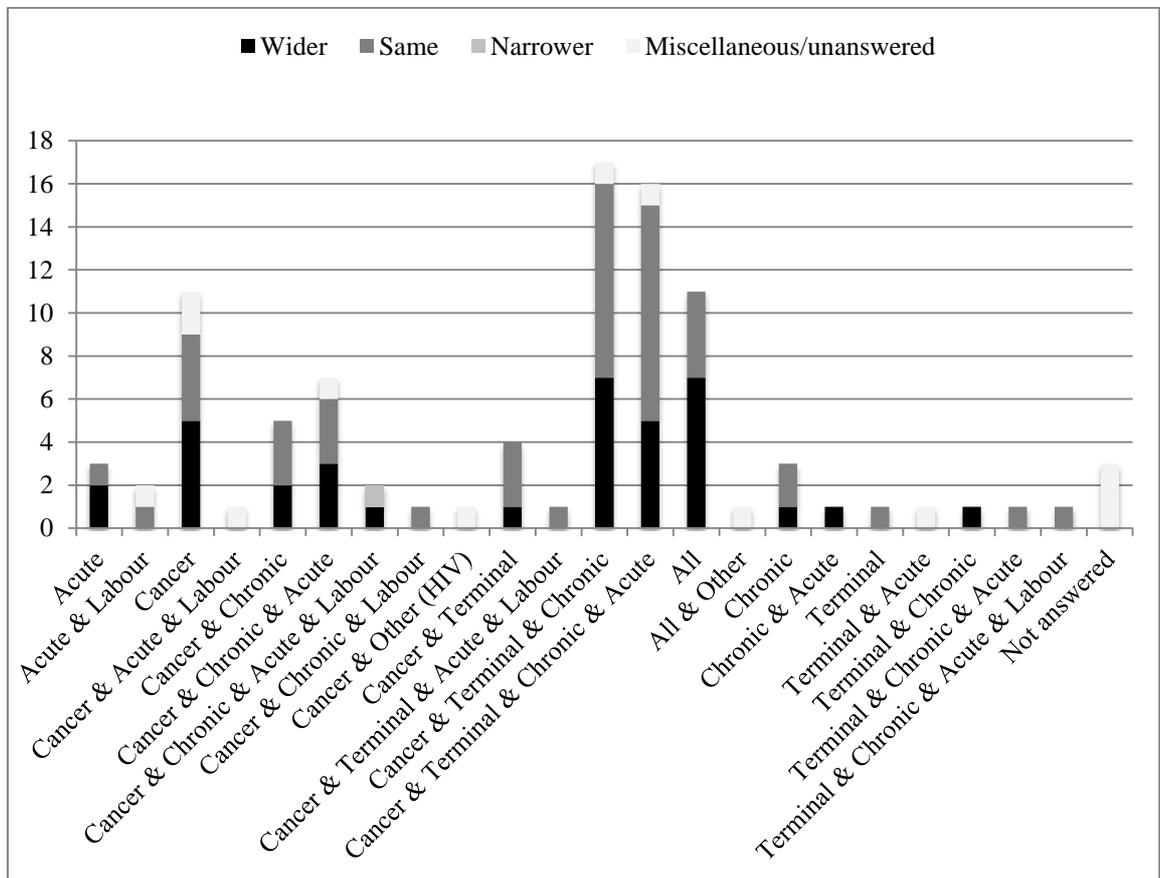


Figure 3-26 Preference for Range of Conditions Treated and Conditions Treated for Questionnaire Participants (N=95)

I also combined the data from Figures 3-21 and 3-25 as Figure 3-26 to demonstrate the range of conditions treated alongside the respondents desire to alter this range. Fourteen respondents tick that they treat ‘Any chronic (long standing) pain conditions regardless of

the underlying cause' but then indicate that they want to be able to widen their remit to treat all types of chronic pain. One says they want to treat the same range of conditions but then write down conditions they would like to treat, and another ticks both 'same' and 'wider'. Seven respondents indicate that they treat all types of pain but also want to widen their remit.

### **3.6 Treatment Availability and Selection**

Leading on from the descriptions of how the specialities of the medical profession should or could be organised is the issue of what actual treatments individual patients receive. As I introduced in Chapter 1, a large amount of research has focused on improving the availability of opioid medications. In contrast, in this research, I incorporate the assessment of the availability of a wider range of treatment modalities. I also include data relating to the different treatment preferences of clinicians.

The quantitative data presented in this section are derived from the responses to Questions 11 and 12 of the questionnaire. I asked all respondents to indicate in detail what pharmacological and non-pharmacological treatments are available to them. When I initially planned this study I aimed only to be questioning doctors, however, due to changes in the methods of data collection of the questionnaire, respondents from any profession were able to complete the forms. Whilst the inclusion of a range of professions is useful to gain information from a breadth of viewpoints, it also presented problems, as the questions, particularly those relating to the availability of specific medication formulations, require a significant level of specialised knowledge.

When analysing the results of this section I considered it highly likely that only those who had clinical training would be familiar with all of the medications I listed. Indeed, when reading the answers from those who were trained as neither doctors nor nurses, respondents left a very large proportion of their answers blank. Two indicate that every treatment is available all of the time, making them outliers in their answers. Even during the data collection itself, respondents verbalised to me that they were unable to answer some of these questions. If I was asked in person, I suggested they leave questions blank if they felt unable to answer. One participant writes "no idea" alongside the pharmacological

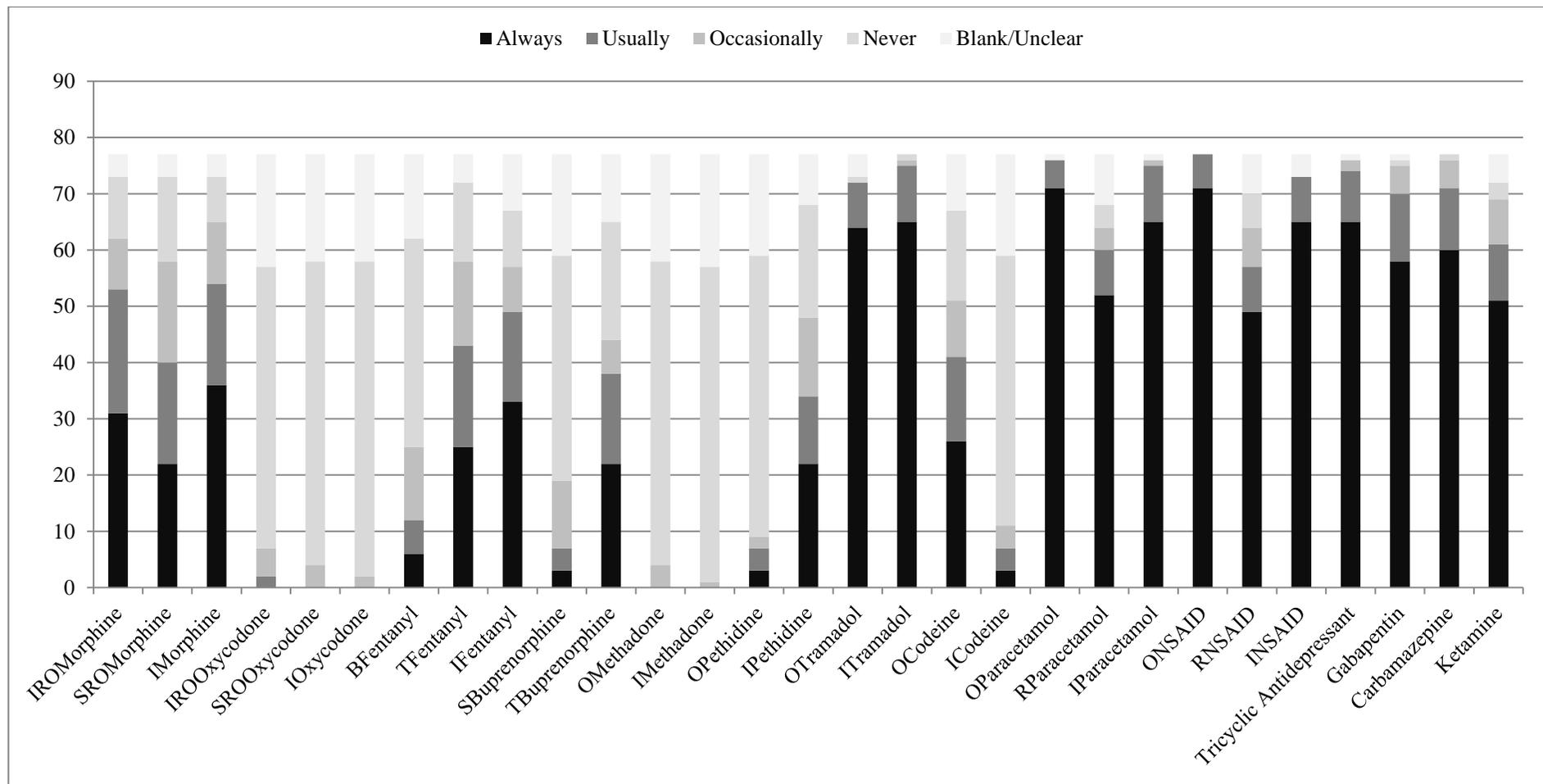


Figure 3-27 Pharmacological Treatment Availability for Doctor and Nurse Questionnaire Participants (N=77) (IR = immediate release, SR = slow release, O = oral, I = injectable, B = buccal, T = transdermal, S = sublingual, R = rectal, NSAID = non-steroidal anti-inflammatory drug)

treatment availability question but does then go on to complete the non-pharmacological section in more detail. For these reasons I only present the responses for treatment availability for those members of the professions that I consider are likely to have a sound understanding of the modalities in question. So, for pharmacological treatments the responses for doctors and nurses (N=77) are presented, and for the non-pharmacological treatments the responses of all participants (N=95) are presented. For each of the graphs in this section each vertical column represents a particular medication or treatment modality divided up into shaded sections representing availability. Each shaded block represents the number of respondents that indicate each frequency of availability, rated as: 'never', 'occasionally', 'usually' or 'always'. On occasions respondents tick more than one box stating two different availabilities for a particular treatment. In these cases I have reported these responses as 'unclear' and included them with the 'blank' answers in the graphs.

### 3.6.1 Pharmacological Treatments

Figure 3-27 shows the availability of all medications for the doctor and nurse questionnaire respondents. For ease of comparison, the data from Figure 3-27 is presented again separated out into opioids in Figure 3-28, and non-opioid medication in Figure 3-29. Of note, there is a stark contrast in the size of the darkly shaded areas indicating 'always available', between these two graphs.

I also selected out those medication preparations included in the *WHO Model List of Essential Medicines*.<sup>36</sup> Some of these, such as ketamine and carbamazepine, are included in the WHO list as treatments for other non-painful conditions, however due to their widespread use in the management of pain I include them here in Figure 3-30. There are still a number of participants indicating low availability of medications particularly in the opioid sections on the left hand end of the graph. Only oral paracetamol and oral non-steroidal anti-inflammatory drugs (NSAIDs) are indicated as available 'usually' or 'always' by each respondent who answered.

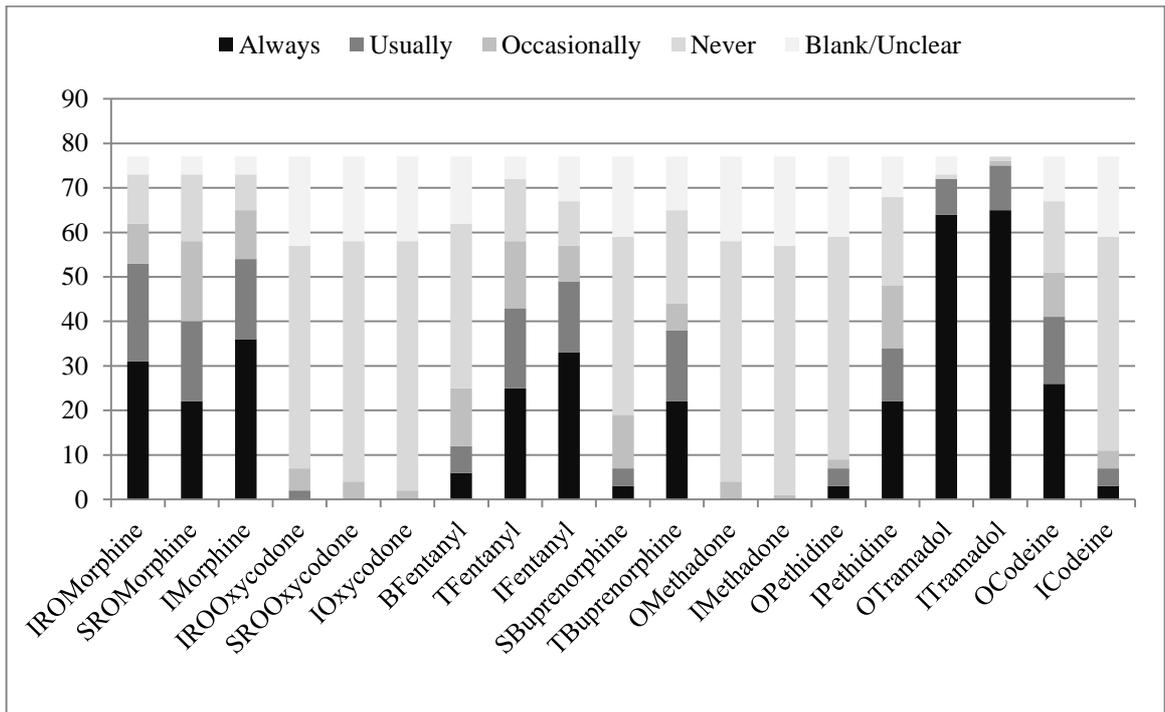


Figure 3-28 Opioid Medication Availability for Doctor and Nurse Questionnaire Participants (N=77) (IR = immediate release, SR = slow release, O = oral, I = injectable, B = buccal, T = transdermal, S = sublingual)

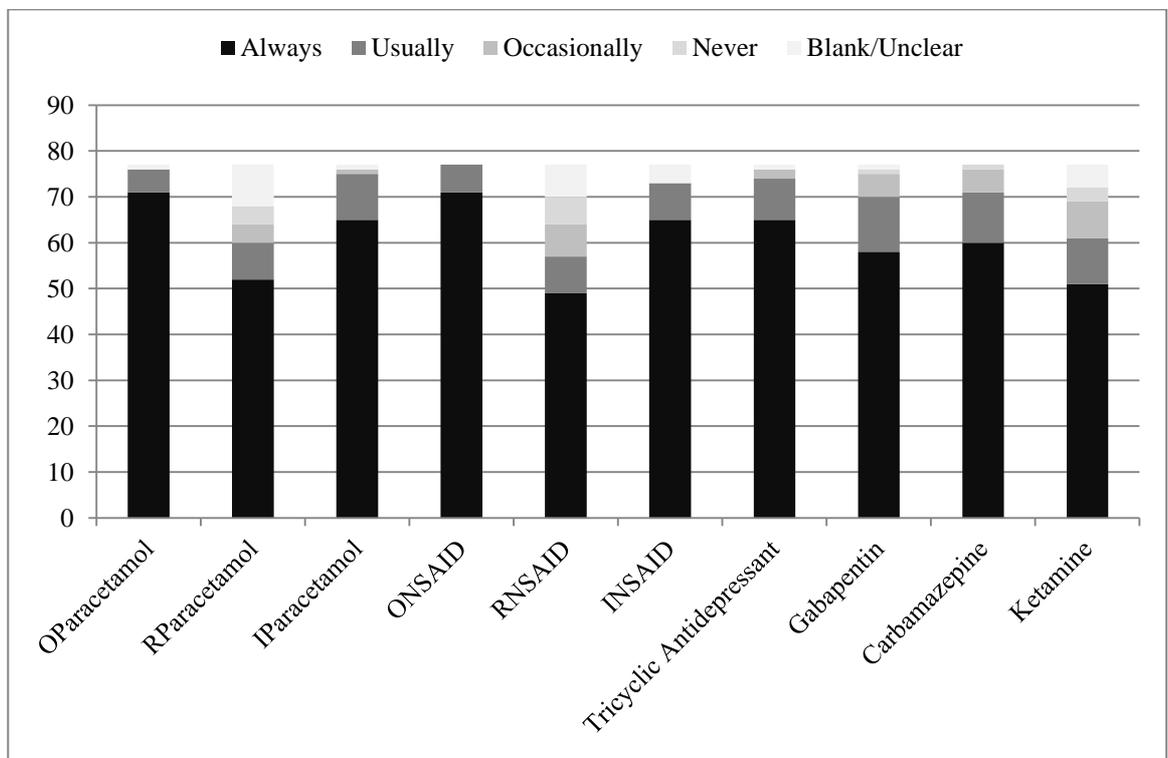


Figure 3-29 Non-opioid Pharmacological Treatment Availability for Doctor and Nurse Questionnaire Participants (N=77) (O = oral, I = injectable, R = rectal, NSAID = non-steroidal anti-inflammatory drug)

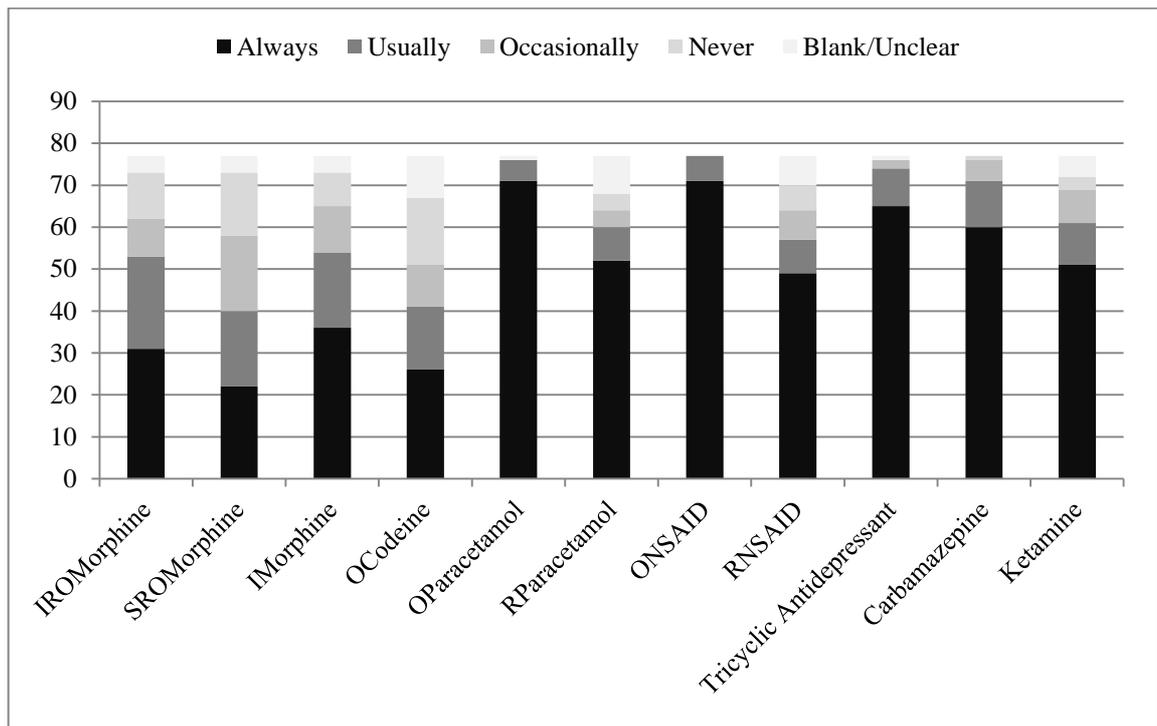


Figure 3-30 WHO Model List of Essential Medicines Availability for Doctor and Nurse Questionnaire Participants (N=77) (IR = immediate release, SR = slow release, O = oral, I = injectable, S = sublingual, R = rectal, NSAID = non-steroidal anti-inflammatory drug)

Opioid medications are often categorised as strong or weak depending on the degree of pain relief they offer. Of the opioid medications included in this survey, codeine and tramadol are usually classified as weak with all the others (morphine, oxycodone, fentanyl, buprenorphine, methadone and pethidine) as strong. Of these strong opioid medications, in my data, injectable morphine has the highest availability. As I noted in Chapter 1, other studies often report the availability of medications by country or state, labelling each drug with a single availability rating. In contrast, I collected data from many individuals, allowing a more nuanced presentation of availability. This is demonstrated in the graph of Figure 3-31, showing the availability of injectable morphine alone, divided up by the state where the participant is practising. There is considerable variation shown both between and within states.

Similarly, the medication codeine is reported elsewhere as having a low availability in India and of never being available in the state of Bihar.<sup>2</sup> However, as shown in Figure 3-32, in this study both respondents from the State of Bihar indicate that codeine is usually or always available. This could be a recent change to the availability or it could reflect a more

complex picture with local variations in availability. Note that only one state with more than one respondent, in each of Figures 3-31 and 3-32 report a uniform availability. In each of these there are only two respondents. Again this implies a complex picture of variable medication availability.

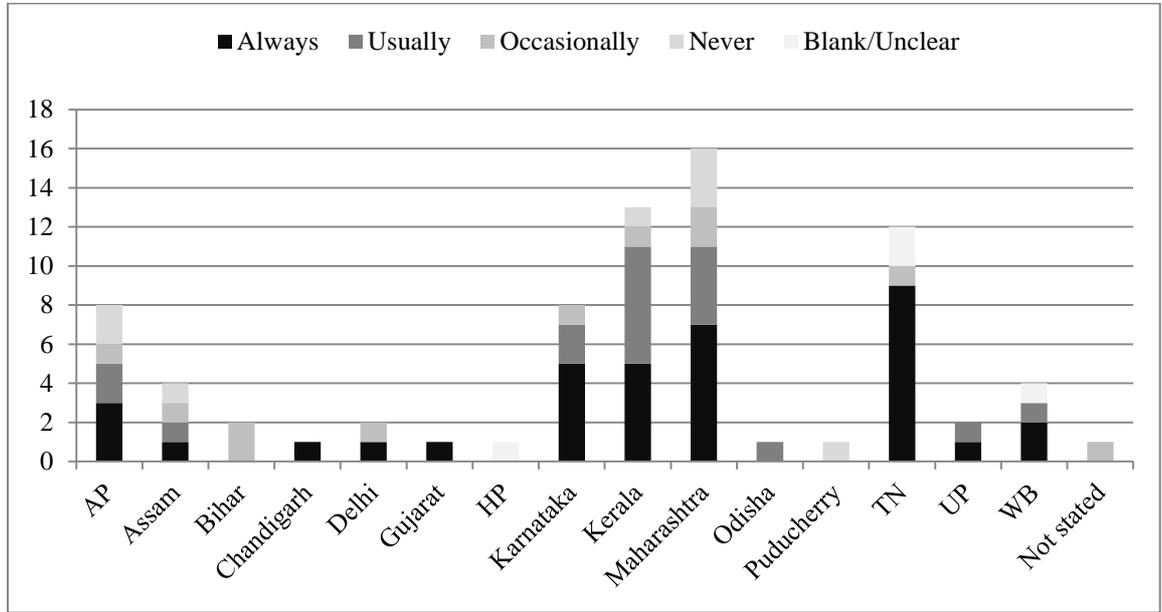


Figure 3-31 *Injectable Morphine Availability for Doctor and Nurse Questionnaire Participants, by State (N=77) (AP = Andhra Pradesh, HP = Himachal Pradesh, TN = Tamil Nadu, UP = Uttar Pradesh, WB = West Bengal)*

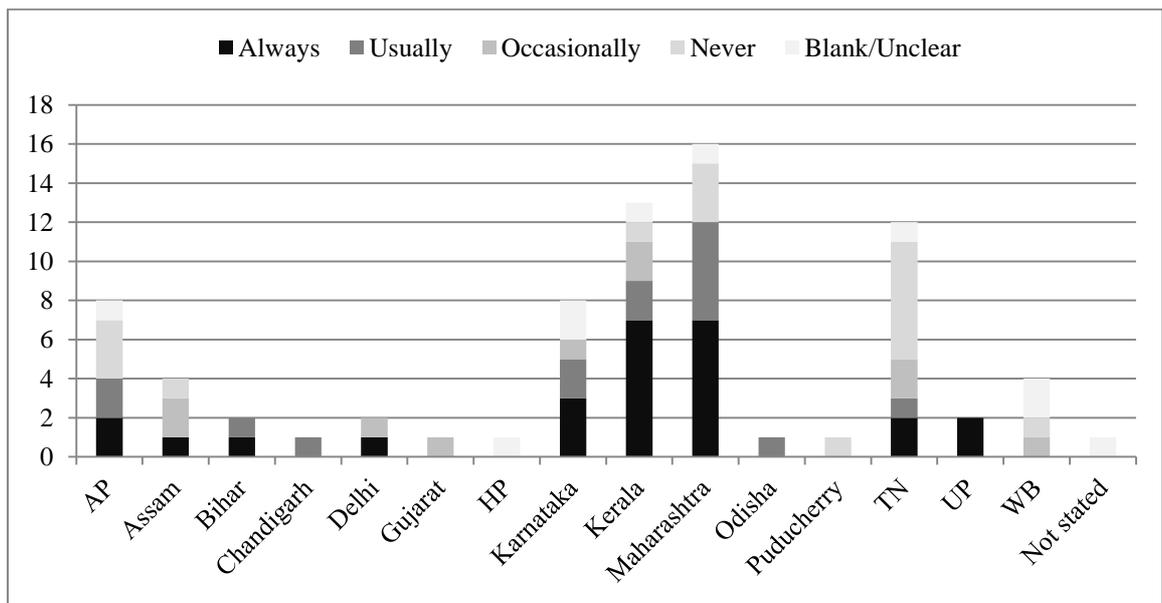


Figure 3-32 *Oral Codeine Availability for Doctor and Nurse Questionnaire Participants, by State (N=77) (AP = Andhra Pradesh, HP = Himachal Pradesh, TN = Tamil Nadu, UP = Uttar Pradesh, WB = West Bengal)*

Many interview participants specifically comment on the problems of poor availability of opioid medications. As I explained, this is already well documented in the literature but given its significance, I briefly describe here some of the key themes arising from my data.

Clinicians, particularly those working in palliative care or treating patients with pain from cancer, explain how there are frequently particular bureaucratic challenges to obtaining, prescribing and administering morphine – the cheapest and most widely available strong opioid. In addition, they talk of the challenges in persuading healthcare workers, administrators and patients, that it is relatively safe to use such medications for the treatment of pain. Participants note that there are regional differences in availability, both between different states, and between urban and rural areas. There are also concerns over the quality of some preparations.

Participants describe problems with obtaining opioids other than morphine. This can be an absolute absence of availability in India where certain medications are not approved at all for use but also a relative lack where certain medications are prohibitively expensive. One such medication is an opioid called fentanyl, which can be administered intravenously or via a patch applied to the skin. Despite its relatively high cost, participants note that these expensive preparations can be available when cheaper ones are not. Another factor noted in my data is that cheaper formulations offer limited profits for pharmaceutical companies who therefore do not put efforts into increasing their availability. Furthermore, it is also important to note that opioid medications are not only used in palliative care but also to treat pain following surgery. One pain specialist succinctly describes several of these issues in relation to post-operative pain:

“We don’t have morphine at all parenteral morphine is not available, we just have fentanyl patches and fentanyl, intravenous fentanyl available. But that is also out of stock at the moment.” (Interview 14)

Not only do participants explain that the medications themselves are difficult to get hold of but for certain techniques, particularly for the treatment of pain following surgery there is a lack of specific equipment such as pumps to infuse the medications. They note this to be due to scarce equipment and a lack of desire to fund such treatments. One doctor working in palliative care describes a particular method used in his organisation to circumvent one such problem:

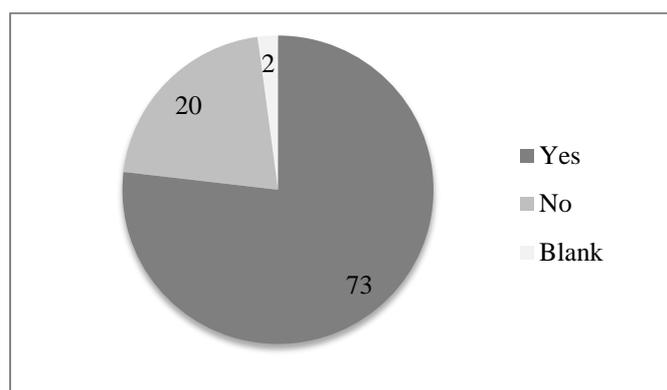
“We taught our families how to put a subcutaneous needle and how to use a combination of drugs. Same drug combinations that we would use in a syringe driver in the UK, we call it the family driver.” (Interview 20)

Although the data presented here show that in general there is better absolute availability of non-opioid medications when compared to opioids, participants note that some are prohibitively expensive in practice. Several participants talk of the need to use medications in a modified manner when working with the Indian population who often seem to require different doses to those described in the western based literature. One clinician who had worked overseas also noted that patients in India were often especially reluctant to take medications at all. He describes both these issues:

“They can be very different when it comes to medications, understanding and accepting medicines. So that’s just the sociocultural factors, but even physiologically, I would see patients getting drowsy with about 100mg of gabapentin, and extremely drowsy, to a point that they’re not able to function.” (Interview 16)

However, there are also discrepancies in the participants’ descriptions of medication availability. One pain specialist working in a large corporate institution says:

“We have, the opioids that are available in India, we have them here. All the medicines that are possibly available in India, in the Indian market, are available here, so there are no restrictions per se, for medications.” (Interview 16)



*Figure 3-33 Preference for Offering a Wider Range of Treatments in all Questionnaire Participants (N=95)*

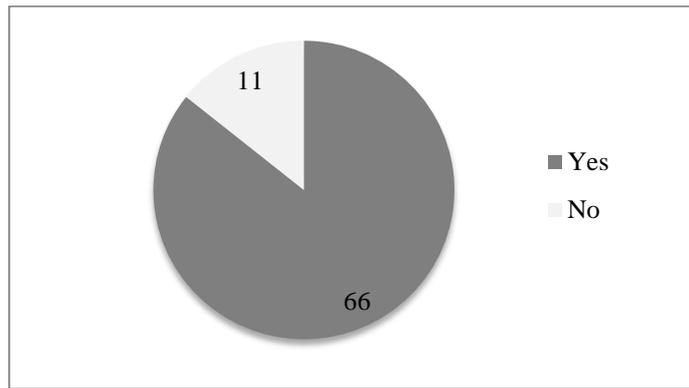


Figure 3-34 Preference for Offering a Wider Range of Treatments in Doctor and Nurse Questionnaire Participants (N=77)

In the questionnaire I asked in Question 13, whether respondents wish to have a wider range of treatments available to them. I present the answer to this question for two separate groups. Firstly, for all respondents in Figure 3-33, and secondly for doctors and nurses only in Figure 3-34. When combining the answers to Question 13 and the availability of pharmacological treatments I include only the responses from doctors and nurses for reasons already explained.

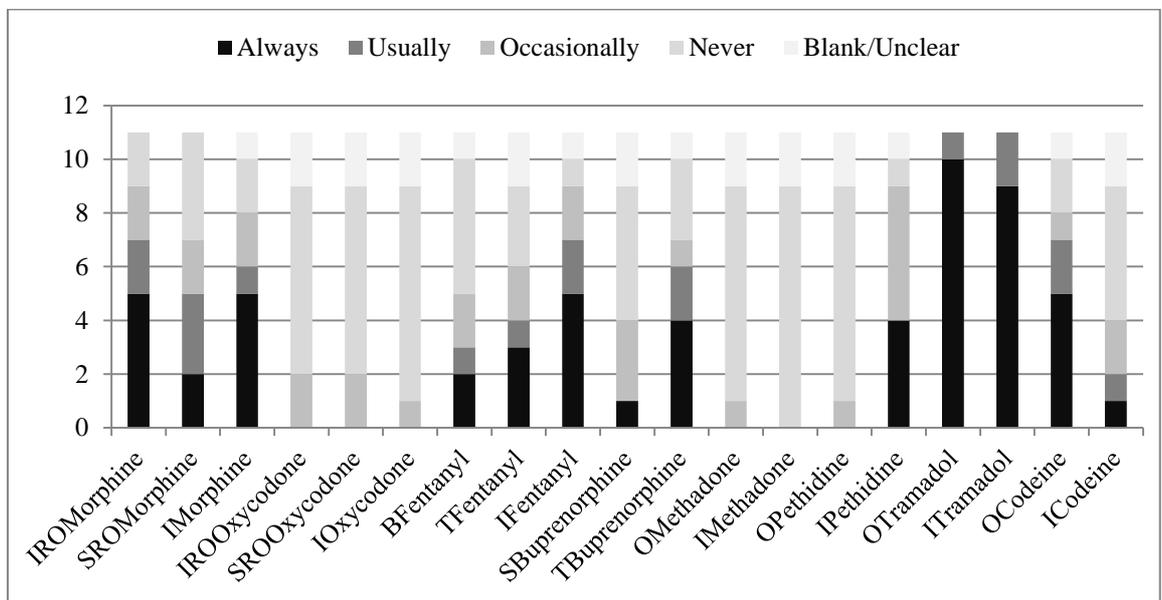
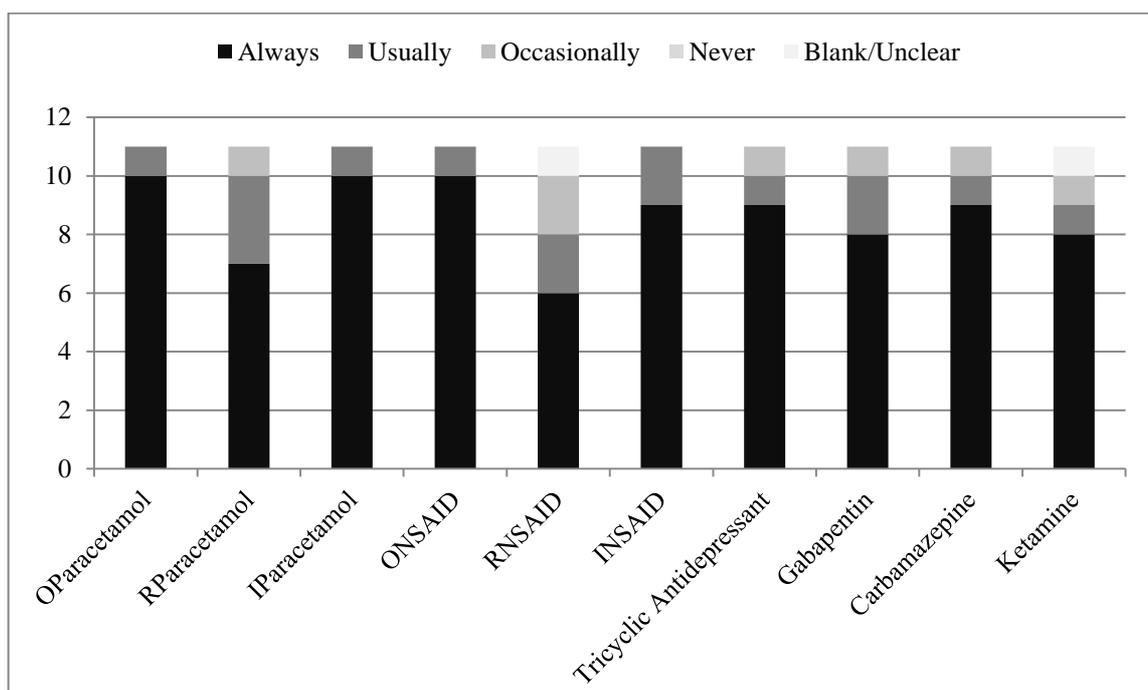


Figure 3-35 Opioid Availability in Questionnaire Participants who Answer 'No' to Question 13 (N=11) (O = oral, I = injectable, R = rectal, NSAID = non-steroidal anti-inflammatory drug)



*Figure 3-36 Non-opioid Pharmacological Treatment Availability in Questionnaire Participants who Answer 'No' to Question 13 (N=11) (O = oral, I = injectable, R = rectal, NSAID = non-steroidal anti-inflammatory drug)*

The majority of respondents do say they would like to see more treatment options available but it is also important to acknowledge the group who do not wish to expand their treatment availabilities. So, when considering only those who answer 'no' to this question, I looked at these respondents' medication availability answers. Figures 3-35 and 3-36 show the availability of opioid and non-opioid medications for the eleven doctors and nurses answering 'no' to Question 13, indicating that they do not wish to offer a wider range of treatments. Even in this group, there is still a relatively low availability of some medications, notably the strong opioids and rectal preparations of the non-opioids.

I also analysed those who answer 'no' to Question 13 in combination with their responses for availability of medications included in the *WHO Model List of Essential Medicines* shown in Figure 3-37 and again there is a low availability of some drugs. These respondents are indicating that they do not want a wider range of treatments to be available even though they do not have consistent availability of the medications considered to be essential by the WHO. This lack of desire to increase the availability of medications, particularly strong opioids, is at odds with widely publicised views at both local and global levels, stating that availability ought to be improved.

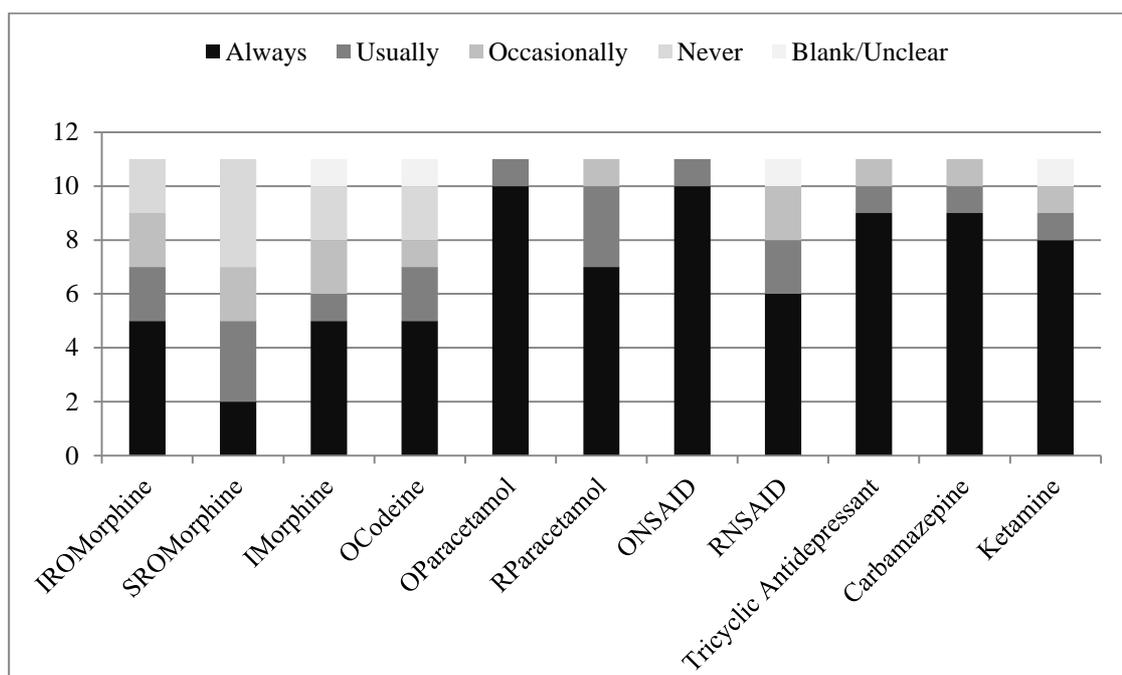


Figure 3-37 WHO Model List of Essential Medicines Availability in Questionnaire Participants who Answer 'No' to Question 13 (N=11) (IR = immediate release, SR = slow release, O = oral, I = injectable, S = sublingual, R = rectal, NSAID = non-steroidal anti-inflammatory drug)

### 3.6.2 Non-pharmacological Treatments

The responses indicating the availability of non-pharmacological treatments for all questionnaire participants are represented in Figure 3-38. While there is no non-pharmacological equivalent of the *WHO Model List of Essential Medicines*, there are of note, low availabilities of several treatments that may well be considered to be core components of the provision of pain management, namely the presence of a social worker, physiotherapist, psychotherapy, counselling, simple interventions and a multidisciplinary team (MDT). One respondent does not tick a particular box in the MDT row but writes across that their team is indeed multidisciplinary – suggesting that this response should have been 'always'.

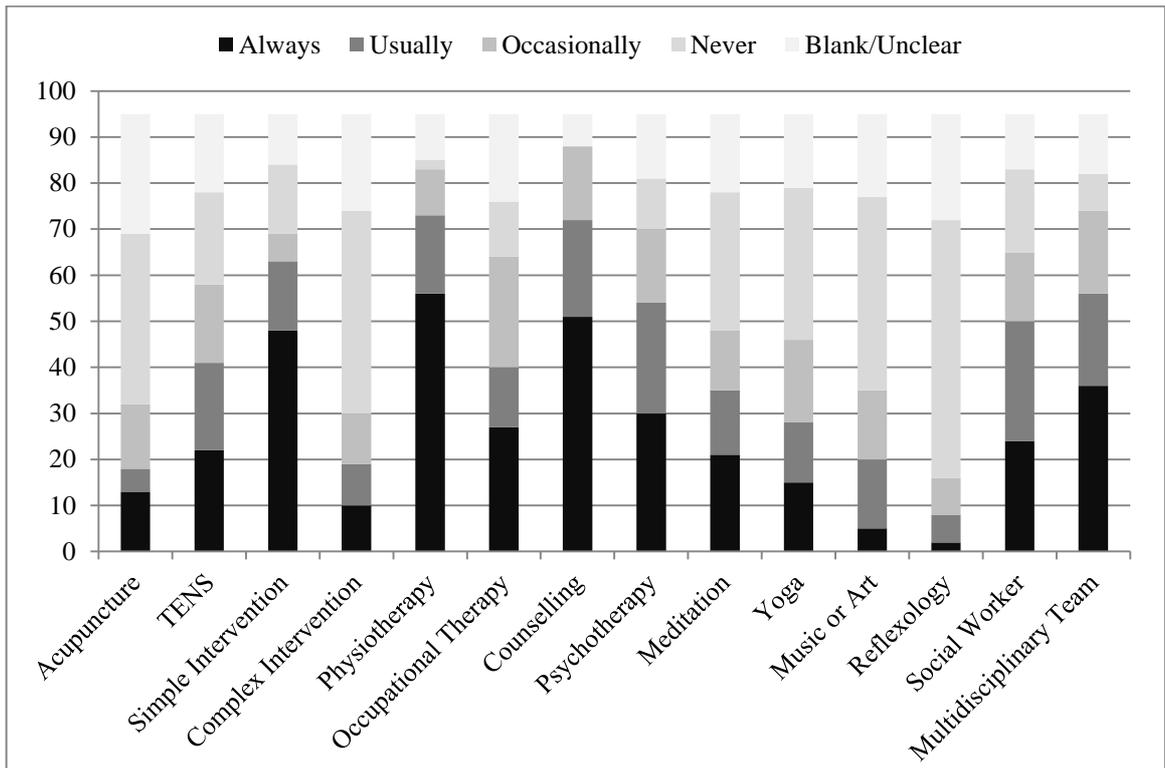


Figure 3-38 Non-pharmacological Treatment Availability in Questionnaire Participants (N=95) (TENS = transcutaneous electrical nerve stimulation)

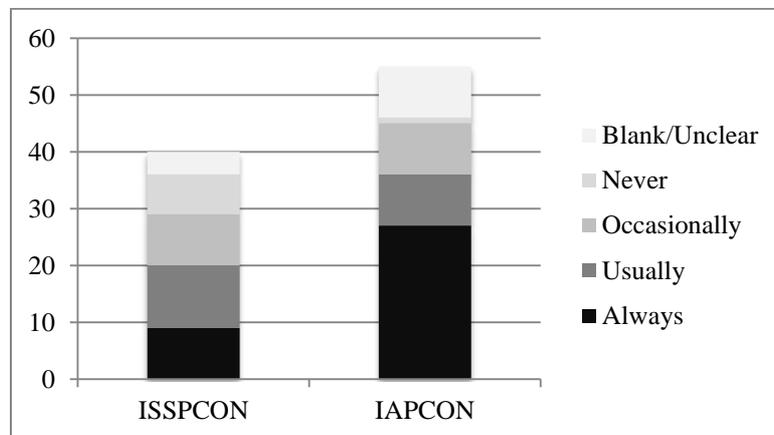
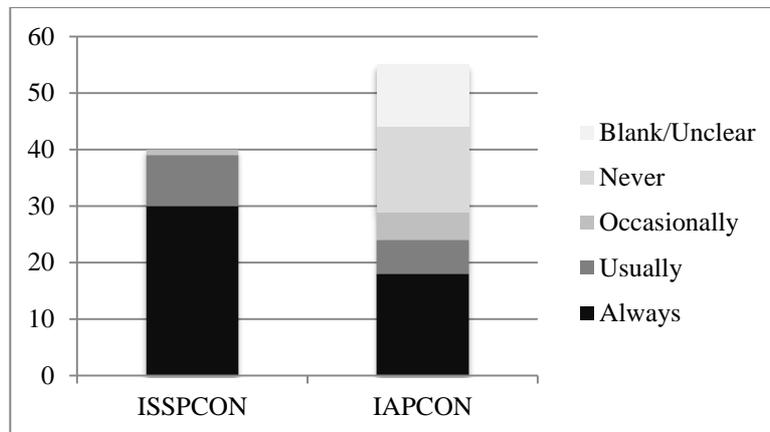


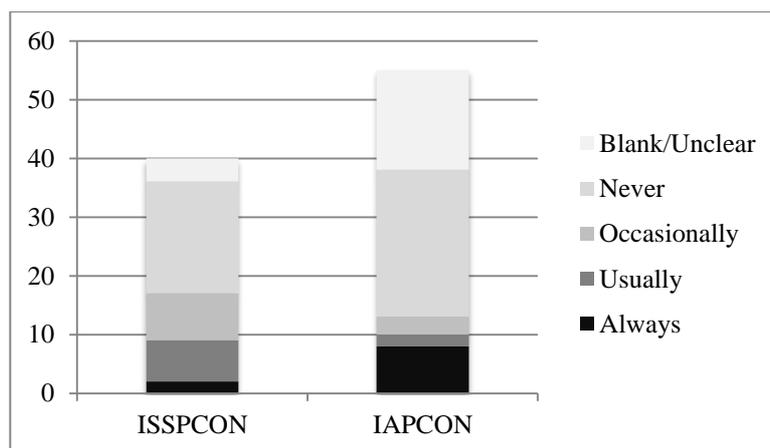
Figure 3-39 Multidisciplinary Team Availability in Questionnaire Participants, by Conference Attended (N=95)

I looked at some of these non-pharmacological treatments in more detail, for example, the availability of an MDT and interventions, both simple and complex. Figure 3-39 shows the availability of an MDT for the attendees at each conference. Of note only 20 out of 40

(50%) ISSPCON respondents and 36 out of 55 (65%) ISSP respondents have an MDT available always or usually.



*Figure 3-40 Simple Intervention Availability in Questionnaire Participants, by Conference Attended (N=95)*

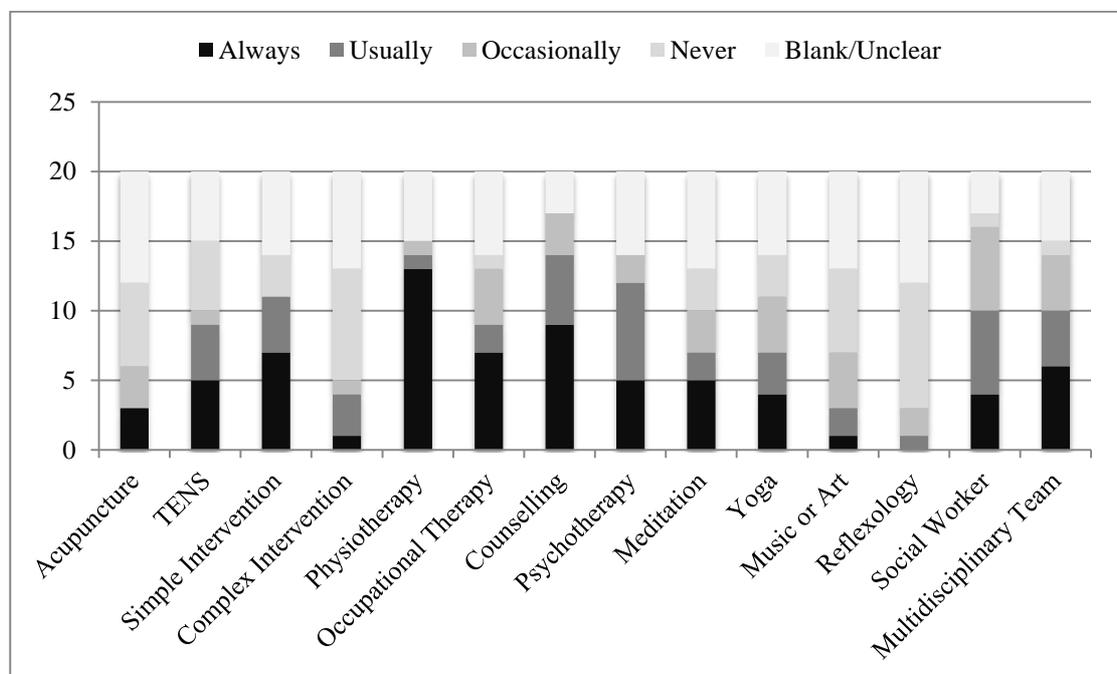


*Figure 3-41 Complex Intervention Availability in Questionnaire Participants, by Conference Attended (N=95)*

The term ‘intervention’ is used here in a specific, western biomedical context with a lot of implied meaning. I use the term to indicate a treatment typically involving a physically invasive process such as an injection to numb a nerve, an epidural injection, or even an operation to insert a pump or electrical device into a patient. These are then considered together as a set of treatments, separate from pharmacological or psychological modalities. Following my interviews (both formal and informal) I decided to subdivide interventions in to ‘simple’ and ‘complex’. The availabilities of these two categories of treatment,

further subdivided by the conference attended, are shown in Figures 3-40 and 3-41. Of note, in contrast to the IAPCON attendees, almost all the respondents at the ISSPCON are able to use simple interventions ‘always’ or ‘usually’.

Furthermore, when returning to the data from questionnaire Question 13, relating to preference for widening the range of available treatments, Figure 3-42 shows the availability of non-pharmacological treatments for the 20 respondents who answer ‘no’ to this question. To be clear, all respondents are included in this analysis, not just doctors and nurses. Again treatments that are often considered to be core components for pain management, such as the presence of a multidisciplinary team or simple interventions are not consistently available.



*Figure 3-42 Non-pharmacological Treatment Availability in Questionnaire Participants who Answer 'No' to Question 13 (N=20) (TENS = transcutaneous electrical nerve stimulation)*

The interview respondents also highlight this variation in treatment preference particularly with respect to interventional procedures such as nerve blocks. One of the reasons for this variation is described as being due to differences in training. Anaesthetists, who provide analgesia after surgery, often carry out the more simple interventional techniques, and indeed that is often the first contact with pain management that many pain specialists

describe in the course of their careers. One palliative care specialist who had originally trained in anaesthesia notes how treatment choices vary between clinicians:

“I think one problem is that either palliative care physicians manage only with pharmacological agents and interventional pain therapists do only interventions, and this I think is a huge problem. Interventional, I mean pain management has to be comprehensive.” (Interview 18)

Some describe how the absence of other treatment options, namely the low availability of opioids, has led them to focus on the use of nerve blocks. Others talk of the need to only use blocks as a last resort when pharmacological routes have failed. In these situations some doctors have the expertise and facilities to perform these treatments, others have to call on the assistance of other colleagues sometimes requiring referral to other institutions. Some doctors explain how with time they have reduced the number of interventions that they feel is necessary. One doctor working in palliative care who originally trained in anaesthesia describes how his practice has changed over the years:

“Used to do a lot of interventions, I mean injections in the past, but when we start getting more confident about the medication we, now only very little, one per cent, less than one per cent of patient. There was a time initially when at least fifteen to twenty per cent of patient had this interventional thing, so this has come down enormously.” (Interview 22)

Some acknowledge that it may be helpful to increase the number of blocks they perform but that the low number of patients that would potentially benefit does not justify the relatively high outlay of costs (for both personnel and equipment) that would be necessary to offer such a service. One pain specialist working in a cancer hospital explains:

“But interventional, still I am not very much unsatisfied with that because the only ten to twenty per cent of the cancer patient needs intervention, it is not must.” (Interview 4)

Another doctor working in palliative care talks about acquiring more equipment (referred to here as an image intensifier, used for taking x-rays):

“The issue about the image intensifier, it is a logistic issue. We do not have that kind of money and if we had more money maybe that would not be the priority because we have to prioritise so many things.” (Interview 18)

As I noted in the earlier section relating to a lack of available space, some doctors describe a constraint to performing blocks as the need to share facilities, namely operating theatres and x-ray equipment with other specialists such as surgeons. X-ray equipment is used to improve the efficacy and safety of these interventional procedures but other imaging techniques including ultrasound can also be used. Interestingly one interviewee talks of the particular hindrances to the use of ultrasound in India where strict legislation is present in an attempt to reduce the amount of gender selection of foetuses.

“You need special permission because the increasing misuse of ultrasound for sex determination, which is, which I don’t blame the government for setting, putting up these stringent rules and sanctions but still I feel that there should be accounting for the people who are not in any way connected with that part of it.” (Interview 14)

As I talked about in the previous sections related to patient finances and the number of trained personnel, participants describe a particular problem with being able to offer more complex interventional treatments such as implantable devices. Whether or not this is actually described as a problem by clinicians does however vary, with some specialists not even entertaining the idea that implanting these devices should be a priority in the Indian scenario. Participants also note that other non-pharmacological treatments such as physiotherapy or psychology may not be funded or as I explained above, there may not be enough adequately trained specialists available. Even pain specialists working in the private sector note that they would like to be able to offer a wider variety of treatments. This lack of availability of trained professionals is compounded by some patients’ reluctance to engage with some of the non-medical treatments. A pain specialist working in a corporate hospital describes this:

“I lack a psychologist, because, not enough trained psychologists around, especially when it comes to pain patients. I don’t have an occupational therapist, so, I would say I lack in those two areas where I don’t have people, and I would also be wanting to run a pain management programme, but because of these things lacking, and also probably patients also not being very willing to kind of come forward for such programmes in India, that’s probably where I’m lacking.” (Interview 10)

One final point, which is rather more controversial with respect to the use of interventions, is that of the income earned by clinicians when carrying out this work. One pain specialist explains that there is a potential conflict of interest if doctors are paid for each procedure they carry out:

“Blocks really are effective in some cases but nowadays anywhere you go that they’ll say, give a block, trigger point, and this, that. And some of the patients are not happy, we are not explaining the real indications and contraindications of selection of patients and that’s giving a bad name to the pain clinicians.” (Interview 25)

Although a holistic approach to treating patients would not be considered by some as a treatment in its own right participants working in all areas of pain management refer to it extensively, and there is considerable overlap between holistic care and the idea that treatment is best offered by a multidisciplinary team. A holistic approach is often talked about within the context of palliative care where pain is described as a ‘total’ phenomenon involving physical, social, psychological and spiritual dimensions.

Although many participants consider a team approach to be an essential component of a pain management clinic they also frequently talk of the particular difficulties in implementing multidisciplinary strategies such as a lack of prioritisation of funding, patients’ unwillingness to engage in such treatments and finding the necessary specialists who are motivated to work in such a team. These issues seem to run across the different treatment sectors although ironically, with the large volunteer base in the charitably funded palliative care organisations, patients can sometimes receive more holistic care than in private clinics. One pain specialist working in the private sector explains:

“The ideal service would be, you know, where you provide support to the patient from, from every angle possible, that’s the ideal thing, which is not, which is not, you know, it’s not even close to, you know, fulfilment in India.” (Interview 3)

In contrast, a pain specialist working in palliative care in a government funded hospital explains how her service functions:

“Once they come is we have time, why is they are very happy is most of the times, most of the people, they speak to them, they are given a lot of importance. So they feel, that, ok, if you go to this department you are, you are taken care of by many people. Not only a doctor, nurse also speaks to them, social worker speaks to them, pharmacist speaks to them, clinic psychologist speaks to them, volunteers, there quite a few volunteers.” (Interview 31)

Furthermore, as I alluded to earlier, seeking the involvement of other medical specialists can bring about issues of competition as one pain specialist describes:

“If a spine surgeon comes and becomes part of the group then we stop getting referrals from the other spine surgeons who think that, you know, their patients would go away, so this is sort of a typical sort of an Indian scenario where they don’t want to lose the patients.” (Interview 3)

The importance of including spiritual and religious elements to therapy is not referred to either frequently or consistently, although a few interview participants do speak on the subject and highlight the fundamental importance of incorporating this dimension to patients’ care, which is often neglected. For example:

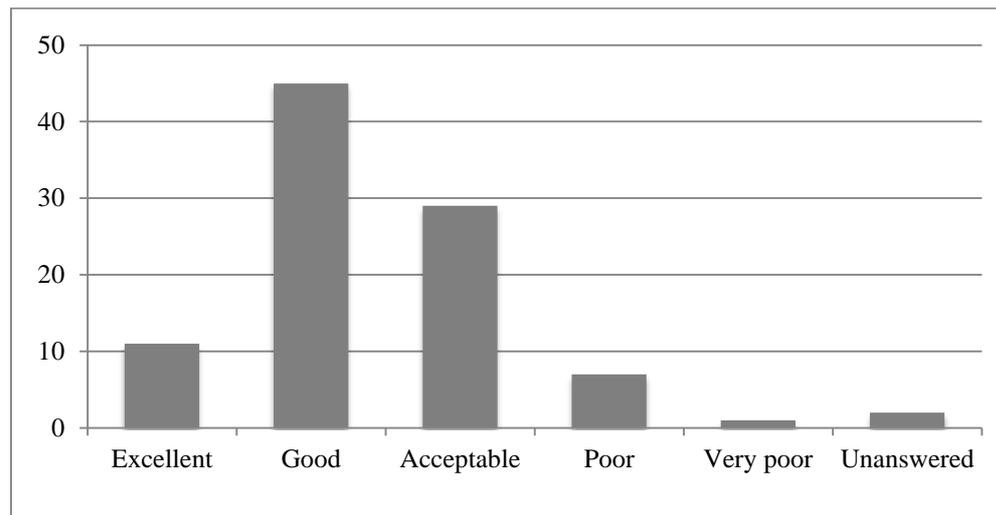
“So this spirituality somewhere I think gives them some strength, which you know in hospitals also we need to have some place where we can offer this to patients.” (Interview 2)

Of note, one interview participant explains that the complexities of offering spiritual guidance in a country of such religious diversity. These issues are addressed for the individual patient by staff who prefer to facilitate access to the requested religious or spiritual professionals rather than providing it as a part of in-house clinical therapy:

“We do not foresee in the future also, a specialised spiritual counsellor, because India is a multi-religious country and the world over, by and large, spiritual counselling is too closely associated with religion and we have to handle it right.” (Interview 18)

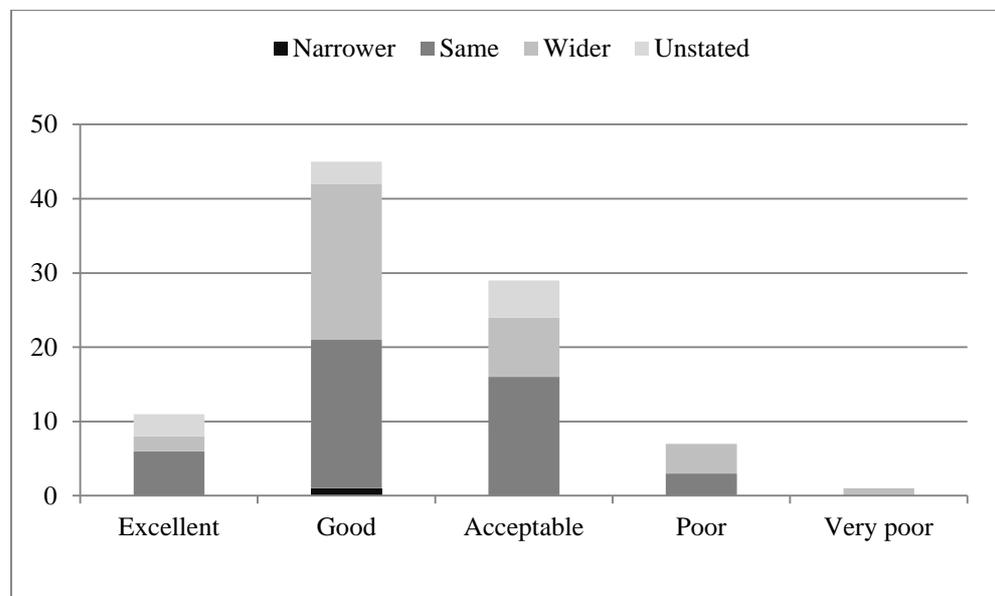
### **3.6.3 Service Quality**

In the final section of the questionnaire I asked respondents about the quality of the service they offer. In Question 14, I asked participants to rate the quality of the care provided in the organisation in which they work as ‘excellent’, ‘good’, ‘acceptable’, ‘poor’ or ‘very poor’. Figure 3-43 shows these responses for each of the 95 participants. It is interesting to note that only eight participants rate their service as ‘poor’ or ‘very poor’ despite the low availability of many treatment options as demonstrated above.

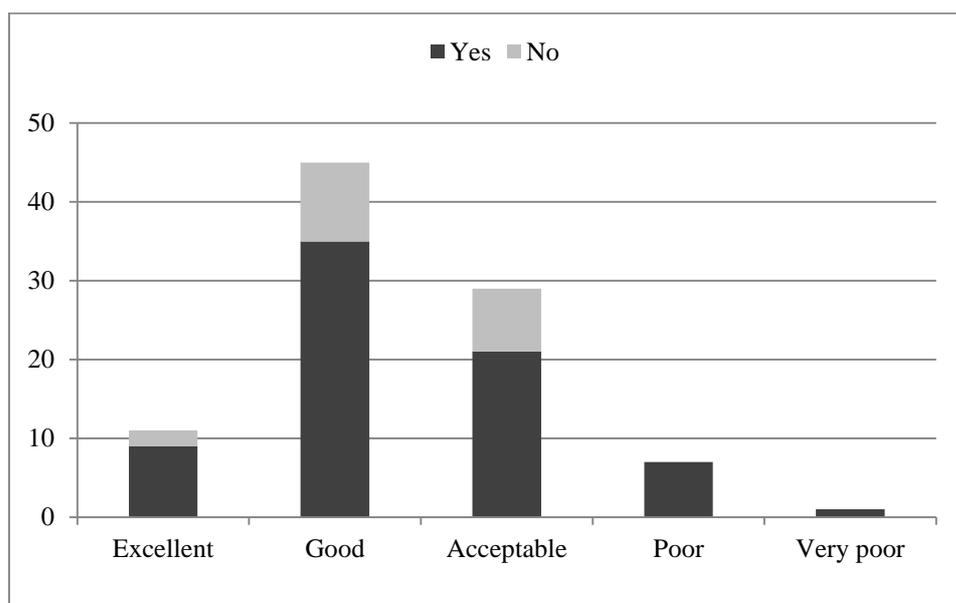


*Figure 3-43 Quality of Service Rated by Interview Participants (N=95)*

I then combined the answers to Question 14, rating quality, with the answers from earlier questions relating to the range of conditions participants would ideally like to be able to treat (Question 10) and the range of treatments they would like to offer (Question 13). The responses are demonstrated below in Figures 3-44 and 3-45. For these two graphs the two respondents who do not rate the quality of their service are omitted giving a total of 93 responses.



*Figure 3-44 Quality of Service Rated by Interview Participants and Desire to Treat a Different Range of Conditions (N=93)*



*Figure 3-45 Quality of Service Rated by Interview Participants and Desire to Offer a Wider Range of Treatments (N=93)*

Only those who rate their service as ‘poor’ or ‘very poor’ consistently say they want to have a wider range of treatments available.

### **3.7 Policy and Governance**

Alongside participants’ descriptions of the problems or barriers related to providing good quality wide reaching pain management, such as: scarce resources, plurality of healthcare provision, variations in clinical practice, the lack of recognition of pain related medical specialties and limitations in treatment availabilities; they also explain some of the possible solutions. Many of these relate to improved governance and altering either the use of or the content of policies. In this context, I interpret the term ‘policy’ as being any initiative relating to the organised creation and implementation of rules or guidance by those with responsibility, whether they be from local managers, professional groups or the Government of India itself. Policies in some contexts, however, are also noted by participants to be barriers.

Tying in with the previous section on treatment availability, I briefly describe the noted problems or barriers of bureaucracy and policy related to opioid medications. The laws in

India governing the procurement and use of opioid medications are complex and stringent, and vary from state to state.<sup>2</sup> Participants refer to these complex laws, which aim to balance the prevention of illicit use of these potentially addictive substances whilst ensuring their availability for legitimate medical use, and note some of the recent amendments to simplification of this legislation. Many participants talk of the difficulty they have in obtaining adequate supplies of opioids for their patients. For example, one doctor working in palliative care explains:

“The strictness for morphine is there all over India, but it is specially so in Punjab. For getting morphine I have to send a form on a prescribed format, each and every patient individually, to Delhi. And somebody has to get that morphine from Delhi. So I don’t have morphine in Punjab. It’s very difficult for me.” (Interview 21)

Bureaucracy is not only a problem for the acquisition of opioid medications. Participants, particularly those working in the government sector, explain how difficult it is to procure new equipment:

“Then there are steps and it will reach to the chief after ten to fifteen steps, it will take three months, then he will find something else, will again write, and it will come down like following those steps again, this is the main problem in India in the government hospitals, are those tables, those steps, and those red tapes, we call them.” (Interview 7)

Continuing on the theme of local management, participants also talk of problems in persuading managers to prioritise the treatment of pain, across all types of institution including those with private, charity and government funding. For example one pain specialist working in a corporate hospital explains:

“Because this is not something which earns money for the corporate hospital. It doesn’t earn money. So, that is a barrier, the management not realising the importance of good pain relief.” (Interview 2)

A pain consultant working in a government institution in Delhi describes his efforts to improve the provision of palliative care services:

“I have subscribed and made a request to the authorities about the hospice and palliative care to be brought in to the, under the government of Delhi, but somehow government is taking time.” (Interview 13)

These previous examples relate to the frequently described perception of top-down control exerted by managers and politicians, a concept I return to at the end of this chapter. There is a notable exception to this, however, in the description of a service operating where the local community provides funding. In this example, the community or end-users largely set the priorities of the service in a bottom-up fashion, as one of the clinicians explains:

“If we are asking the community to support then the agenda also should include what community wants. If we say that we need all your money but then I will decide which patient to give, that’s not right actually.” (Interview 33)

Bureaucracy is often spoken of as a barrier and a hindrance to progress but participants do give positive examples of how rules and regulations may be favourable. For example one of the voluntary accreditation organisations (NABH) has stipulated the presence of a pain clinic as a requirement. One pain specialist explains how this has affected the number of clinics:

“Now because of NABH and it being compulsory for having a pain clinic in the hospital, even those who have passed out earlier are now aware that there is something called a pain clinic.” (Interview 2)

Some also express a desire for more regulation from various groups. They note that if insurance companies agree to fund certain treatments then the delivery of these particular therapies will be significantly facilitated. They also explain how the two national organisations, the ISSP and IAPC can improve the delivery of pain management with advocacy work to improve awareness, coordination of education initiatives, encouraging cooperation, uniform practice and training of clinicians within the specialties, organising research, and lobbying government to change policy. For example one participant describes their evaluation of the IAPC’s recent work:

“I think IAPC is doing a great job, they are involved in almost every part. They are doing work for policy change, they are working for education and awareness, they’re working for better communication skills and they are working for inclusion of palliative medicine in undergraduate and postgraduate syllabus.” (Interview 21)

At a government level the participants also talk of the constructive way in which new policy can be used to improve rather than hinder pain management. They talk of the endorsement from the Medical Council of India (MCI) in establishing formal postgraduate

training programmes, such as the MD in palliative care at Tata Memorial Hospital, Mumbai and its role in lobbying for the compulsory inclusion of pain management in the undergraduate curriculums. Clinicians also talk of the role the government and the MCI can take in ensuring pain management practice and training is more regulated and uniform, by meeting specific nationally defined standards. A pain specialist explains how training could be improved:

“I think we have to standardise, MCI should play a major role, Medical Council of India. They should standardise training, there should be competency-based training introduced. The people will get through when they complete their whole set of things to be done, and then only will they be allowed to give the exam.” (Interview 27)

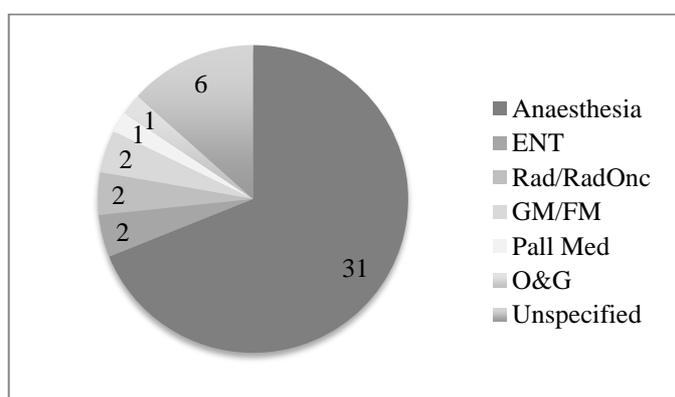
### **3.8 Knowledge Exchange**

The participants’ descriptions of pain management in India – of how pain should be considered a medical problem, the importance of specialisation within the medical profession, the need to increase the allocation of resources and to improve treatment availability, are all linked together by the pivotal theme of ‘knowledge exchange’ frequently referred to in the data as ‘awareness’. Throughout the interview narratives, the questionnaires and my field notes the concept of the need to alter the opinions and actions of others through education and awareness initiatives is striking in its prevalence. So ubiquitous and fundamental is this theme that I have subdivided the reporting of these results into sections relating to the strategies used to influence the different target audiences such as clinicians, patients and managers; and the different aims of and topics used to frame the knowledge exchanged in these initiatives.

#### **3.8.1 Knowledge Exchange Strategies Aimed at Healthcare Professionals**

The descriptions interview participants give of awareness programmes for their fellow professionals include initiatives they call ‘education’ or ‘training’, the aim being to change practice by increasing knowledge. In this section I present both questionnaire and interview results relating to these themes.

In the questionnaires I asked participants to indicate the length and type of training they had received in pain management and I asked the doctors to list their formal medical qualifications (Questions 3 and 4). Of the 69 participants who identify themselves as doctors, 21 list MBBS (the basic allopathic medical degree) as a qualification. Two respondents list degrees in dentistry. Many respondents also have a higher degree, requiring MBBS training, despite not actually writing that they have obtained this qualification. Broadly speaking these Indian higher degrees fit into two categories: MD or MS (doctor of medicine or master of surgery) programmes, and diplomas. Of the 69 doctors, 45 have at least one of these higher degrees from various medical specialities, shown in Figure 3-46. Some respondents write their specialty out in full, for others I assumed it from their degree acronym e.g. DA indicating diploma in anaesthesia. Clearly the most common specialty of training is anaesthesia. Of the 31 that list a higher degree in this specialty – one states their specialty as “anaesthesia and pain medicine”, one as “anaesthesia, pain”, one as “anaesthesiology, pain relief”, and one as “anaesthesia, pain and palliative care”. Of the 6 ‘unspecified’ two list UK qualifications in anaesthesia. Similarly, although, I did not ask directly about the specialty of training, every interview participant either volunteers or implies this in some way. The clear majority (25 out of 33) trained in the specialty of anaesthesia, with the others training in pharmacology, general medicine, surgery and physical rehabilitation.

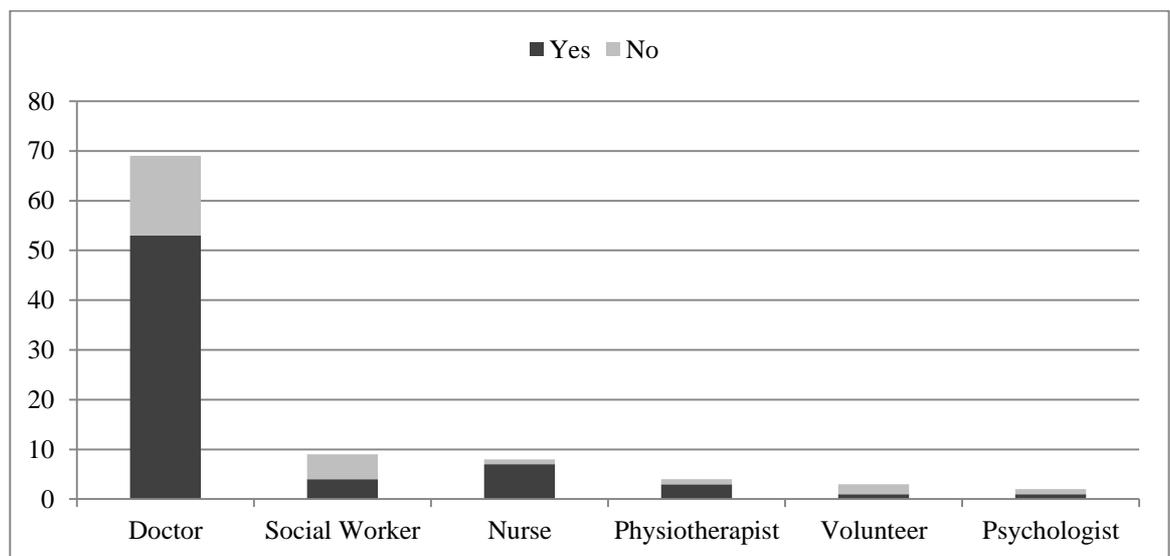


*Figure 3-46 Specialty of Training of Medically Trained Questionnaire Participants with a Higher Degree (N=45) (ENT = ear, nose and throat, Rad/RadOnc = radiotherapy or radiation oncology, GM/FM = general medicine or family medicine, Pall Med = palliative medicine, O&G = obstetrics and gynaecology)*

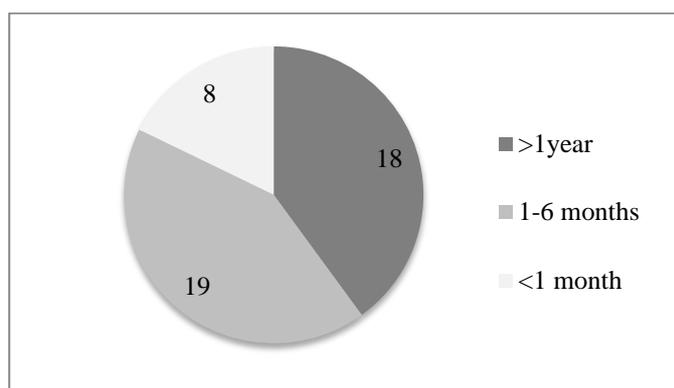
In addition to these Indian qualifications, the following higher degrees from overseas are also listed by questionnaire respondents: three higher degrees in anaesthesia (from the UK

and Ireland) one of whom also has a higher pain qualification from the UK, one lists a diploma in paediatrics from Ireland and two list diplomas in palliative care (from Cardiff and Perth, Australia). Of the 17 with no higher degree noted (either Indian or overseas) the following specialties are indicated: anaesthesia - 9, ear nose and throat (ENT) - 1, palliative medicine - 3, not stated - 4.

Many medical degrees and qualifications are listed often simply as acronyms or abbreviations leading to uncertainty in some cases as to what qualifications the individual has actually been awarded. For example “PGD” or “MMSc” in pain medicine, which without knowing where these were awarded I cannot classify them. Similarly others write simply “anaesthesia graduate” or “trained in Cardiff”. Other listed qualifications are in related fields such as ayurvedic medicine, behavioural medicine and management studies. Where appropriate, other qualifications, not formally accredited by the MCI or the National Board of Examinations are presented with the following data relating to pain training.



*Figure 3-47 Training in Pain Management of Questionnaire Participants, by Profession (N=95)*



*Figure 3-48 Length of Training in Pain Management in Questionnaire Respondents who Received Training (N=45)*

In Question 4 I asked all questionnaire respondents, if they had any formal training in pain management. In total 69 state that they have had formal training. The training of members of each profession is summarised in Figure 3-47, which demonstrates that most of the nurses, doctors and physiotherapists have received formal training. In the second part of the question I asked participants to describe this training and state how long it lasted for. This was a free text section but for the purposes of presentation I summarise the length of training into discrete categories. 45 respondents indicate how long their training has been, shown in Figure 3-48.

As I noted in the previous section, several doctors list a particular pain or palliative care training course in their answers and these are often described as fellowships or certificate courses. Some specific course names are listed relatively frequently. Six doctors say they have done a Basic Certificate Course in Palliative Medicine or BCCPM, three note training on a Post Doctoral Certificate Course (PDCC) and six have the qualification FIPP - Fellow of Interventional Pain Practice from an organisation called the World Institute of Pain. Of note, one respondent says that they have the FIPP qualification but also that they have had no training.

The strategies that interview participants describe to increase awareness amongst healthcare workers cover many areas of practice, multiple professional groups and various stages of training. The professional groups noted to be involved are doctors, nurses and allied healthcare professionals, and each of these groups can receive education throughout

their careers. The participants talk about education frequently as they explain both their own career trajectories and suggestions for how pain management can be improved.

Participants often speak of education as one way to overcome many of the problems described in the previous sections such as improving the quality of treatments given to individual patients, increasing the referral rates to specialised physicians and increasing the popularity of working in pain management. The importance of educating all healthcare workers, not simply doctors, is stressed.

Many of the educational initiatives described occur within each participant's own institution. One pain specialist explains how he has emphasised the importance of ensuring all ward staff in a hospital have a degree of knowledge as to how to assess and treat pain:

“A year or two ago when I came in, pain scores were not absolutely there except for operated patients, so and, so now that thing's changed drastically. So if you, I would, just in about six months time, after being sticking to it, and having the, the, the senior nurses, top down, going about it, we would get calls from the wards, with nurses saying, ‘There's a patient who's in pain, he says it's six out of ten.’ So I don't even need to ask about it, so it's a good thing you know. So that, and I saw that change.” (Interview 16)

Exposure to pain management is often described as inadequate with little or no teaching occurring for undergraduate medical students. Some participants describe teaching initiatives they are involved in for students, as well as emphasising the need to include pain teaching in the undergraduate curriculum and to educate doctors at an early stage in their careers. One participant explains:

“I think education work, the main thing is to educate the junior doctors, because once somebody becomes a specialist, or once somebody reaches a certain phase in career, it's difficult to teach them new things. So, somebody who is just passing out of medical college or you know, a houseman, at that stage it would be good to, kind of, teach them the importance of pain and I think that's where probably the education should come in.” (Interview 10)

Participants talk of the need for this inclusion in the curriculum to be mandatory. One doctor explains:

“We are working with the Medical Council of India to include pain management as a post-doctoral certificate course, so after doing MD of anaesthesia the young graduates

can take that fellowship. And that should be, according to me, at every medical college in India.” (Interview 15)

The need to ensure all doctors have at least a basic training in pain management to prepare them for their careers, particularly when working in the poorly resourced rural areas of the country is described here:

“Basic knowledge has to start with the undergraduates who are going to work in the rural areas, because after undergraduation MBBS, when you finish, you have the, government has put up a commitment that they have to work in the rural areas for one year. So when they go there, these are the doctors who are going to face like people who come with regular pain, like they have back pain, they have other pains, if they can identify what type and everything, and they give the correct medications, I think at least they can solve half of the problem.” (Interview 24)

The need to continue education of all professionals even at a later stage in their career is also noted with some participants running some very successful, widespread introductory courses in general pain management and specifically in palliative care. Others talk of how helpful it can be to speak to medical professionals from other specialties when they hold their own regular educational meetings.

With regards to more specialist training, several participants who have been practising for quite a few years explain that they had negligible access to pain training in India at the start of their careers, and had resorted to seeking out their own training, often overseas. One specialist explains how he taught other colleagues:

“I used to do ten SMS to ten friend who told me that they’re interested and tell me if you are doing anything.” (Interview 30)

As I explained above, specialist training remains relatively uncoordinated with only one formal MD programme (in palliative medicine) running at the time of this data collection. However, many participants describe specialist training courses they run themselves, of varying length and content. Participants also talk of writing textbooks and running specialist, national pain management conferences.

As I described already many participants are running training courses themselves both within their own institutions and across the country. Some are aimed at providing a basic

training in pain management for all clinicians, others at the provision of specialist care. The need for uniformity of training, led by the government is described here:

“The best thing that can happen is the Government of India takes it up as a project to implement pain management as a training in the department of anaesthetics. And through that, the child who comes out, knows what is rational, what is evidence based, how it has to be done, and the protocols are all set, and standardised textbooks are approved by the government.” (Interview 8)

I specifically asked interview participants about research in pain management. Within the context of awareness, research can be thought of as a tool to increase the knowledge base of the participants who go on to exchange this knowledge with others. Although it is widely acknowledged by participants that more audit and research would be beneficial, interviewees explain that often very little is undertaken due to a lack of time, funding and expertise. One participant explains:

“I’m talking from my own practice, and I want to do research and, but I don’t know how to go about it.” (Interview 14)

When considering the specific topics that should be the focus of research projects, several interviewees talk of the need for more research based on the Indian population in order to see which treatments are effective. A pain specialist describes one scenario:

“All the drugs which we’re using has been tried and tested in the western population, we don’t really know whether these drugs suit the Indians, or whether it actually works well or worse than any others, we don’t really understand those things.” (Interview 3)

Another important point participants make is that research can serve to reinforce the current selection of certain treatments but can also cause some treatments to not be offered when studies demonstrate their ineffectiveness.

The professional societies the ISSP and IAPC are often referred to by participants as having a role or potential role in increasing awareness. Whilst acknowledging the initiatives of these groups already underway, participants explain that the societies could increase their work by increasing training and research for clinicians, and providing a unique forum for collaboration and networking, as well as running programmes aimed at other groups. Participants also explain that the societies could advocate for specific goals

such as the inclusion of pain management in the undergraduate curriculum, improving access to opioid medications (mostly this is related to the work of the IAPC) and to improve uniformity of specialist practice by standardising training and establishing national guidelines (mostly referring to the work of the ISSP).

### **3.8.2 Knowledge Exchange Strategies Aimed at Patients and Wider Society**

The need to increase awareness in patients and their relatives and friends is a key theme, and frequently cited. For example, participants explain that better research originating in India will not only improve treatment selection by clinicians but will also serve to persuade those who are funding therapies of their effectiveness, whether they are patients, managers or insurance companies. A participant explains the current situation where local research evidence is lacking:

“Whatever data we have is a foreign data. As you know the medical scenario in the western world and the medical scenario in our country is a totally different. Though there are some patients who can afford these treatments, but they don’t get convinced the moment I discuss with them, they say, ‘Doctor, what is your experience?’”  
(Interview 15)

A number of strategies are described as used to inform patients more directly. For example, at the simplest level, patients’ understanding of pain and its treatment will occur during a doctor patient consultation. The participants talk about taking the time to do this as a specific feature of the management of pain, especially as patients often feel they have received rather dismissive treatment from other healthcare professionals. For example one specialist explains:

“So they’re very happy and they acknowledge that we spend time with them, and they’re very happy that we give them an understanding of what pain is about.”  
(Interview 10)

Some even refer to this increased awareness or knowledge exchange as having therapeutic value in itself:

“If you visit the pain clinic you will realise that much of what happens there is listening to them. The talking part or prescribing or managing part is only a little.”  
(Interview 32)

As I explained above, patients in India frequently choose for themselves which practitioner to seek advice from and therefore often rely on reputation and word of mouth to select their clinician. Some describe this in more explicit terms using the word ‘marketing’. So, although not strictly speaking a strategy from doctors to persuade patients to attend their clinic, reputation is noted to influence patients’ choice of where and indeed whether to seek medical input. One interviewee explains this process:

“I have to show results and I have to build up my own network, it comes to that. So in my community I have to show that I have treated so many patients and I am good and I do this kind of work.” (Interview 14)

Considering society as a whole, not just those who are currently suffering with pain, participants describe the role of public awareness programmes. These are noted to take various formats such as written articles in the press, television and radio interviews, open discussion forums, health camps and work with other community organisations such as the Rotary Club. Several participants say that this particular area of work could be carried out by the national societies, the ISSP and IAPC. A pain specialist talks about how their patients are persuaded to seek treatment:

“I think education in the community is very important, very important, pain awareness programmes, a lot more about how damaging pain can be to you physically as well as emotionally and mentally, is very important. So, we have our pain pamphlets in both the hospitals which educate people on the harmful effects of pain.” (Interview2)

Another participant talks here about running a pain camp together with another local organisation:

“We approach the organisation, they help us in creating awareness about that camp, they gather the people and pain physician and team goes to that particular area, where sixty, seventy, a hundred patients come. We see them at a time and advise them about their treatment, and give them guidance.” (Interview 4)

### **3.8.3 Knowledge Exchange Strategies Aimed at Other Professionals**

I described above how participants explain that one of the roles of the ISSP and the IAPC may take, can be to persuade managers, politicians and industry of the need to prioritise pain management. Similarly, participants explain that clinical research and indeed public

awareness campaigns can be used to persuade funders to ensure particular treatments are made available.

Within an individual organisation, participants note that managers decide which services to prioritise, how many staff to employ and which treatments will be made available. Politicians are described as affecting local service delivery by creating central policy to promote pain management and access to specific treatments (such as opioid medication). At the national level politicians are also noted to play a role in regulating training and clinical practice. The need to persuade managers to fund particular treatments is described as problematic in the private as well as the government sectors. One participant here explains the ironic situation of having to persuade managers to provide a cheaper treatment option, in this case an epidural injection:

“If you are doing some simple epidural the patients might not be needing surgery, but that will be reducing the hospital’s income.” (Interview 28)

Participants also talk of the need to influence private companies operating in healthcare in terms of awareness. For example, pharmaceutical and medical devices companies set the price of their wares and participants talk of negotiating these in order to increase affordability for their patients. Health insurance companies decide on which treatments to fund for particular conditions and participants explain how they need to be persuaded of the benefits.

### **3.8.4 Framing and Aims of Knowledge Exchange**

In Section 3.3 I showed how participants conceptualise pain as a medical problem. This framing of pain as a treatable problem is key to participants’ descriptions of the aims of exchanging knowledge. These aims ultimately relate to improving the quality and coverage of pain management service provision. For example, participants explain how improved knowledge could lead to increased practitioner numbers and ultimately to increased numbers of patients being referred in a timely manner to specialists. For example:

“Patients will not come forward to accept the services, unless they are aware of the benefits. So education has to come at all levels, awareness has to come at all levels, and visibility of the services that are there, that has to be there.” (Interview 21)

Similarly:

“We have reached out in terms of talking about our services and therefore they referred to us. So we, our referral, sort of base, has increased from the hospitals.”  
(Interview 23)

The framing of pain as a medical problem links to participants’ descriptions of the value of the associated medical specialities, the specific treatments that patients receive and the funding of this care. I describe the results relating to each of these issues in turn.

#### 3.8.4.1 Pain as a Problem to be Treated

The need to persuade others of the fact that pain is a medical problem is described by participants as fundamentally important to improving pain management. In order to convince other agents that this is indeed the case, participants sometimes talk of the need to treat pain in humanitarian terms, describing the treatment of pain as a human right.

Participants also describe the scale of the prevalence of pain, despite acknowledging scarce amounts of data. They explain how this prevalence can have significant detrimental effects on society as well as the individual sufferer, not least in financial terms, due to loss of earnings and increased healthcare costs. One interviewee explains,

“We have to impress upon the Medical Council and the professional regulatory bodies, through learned societies like the Indian Society for the Study of Pain, the Indian Society of Anaesthesiologists, and we are in the process of involving as many societies as possible, to tell them, ‘See this is a problem in our country, it’s a big public health burden, though you don’t realise because we do not have the studies to show how many billions of rupees you are losing out.’” (Interview 3)

As I explained, participants talk of the need to increase awareness that pain is a treatable problem within the patient population, in order to persuade them to seek medical advice. Some describe an additional dimension related to this in some patients with terminal cancer who are in a degree of denial regarding their devastating prognosis. This denial may be compounded or indeed initiated by the family choosing to not tell the patient of their diagnosis. For some of these patients, persuading them to come forward to receive pain treatment, particularly under the umbrella of palliative care, would also involve candid and potentially distressing, discussion of their disease. One interviewee explains this,

“Very few cancer patients come to us. Because here again the patients don’t want to hear they are terminal and there’s no treatment available. Many of the terminal patients are not told by the relatives that they are beyond cure.” (Interview 2)

#### 3.8.4.2 The Value of a Medical Specialty

As well as describing the need to increase awareness of the concept that pain is a problem, participants also talk of the need to improve awareness of the medical specialties themselves that deal with the treatment of pain. They also explain that the medical speciality itself will function better if it is regarded as a higher profile area of medical practice, for example through more coordinated education, training and regulation. In doing so they justify their very existence as new and emerging areas of practice. At the simplest level participants explain that the aim of increasing awareness of the existence of the specialties is to increase the number of referrals, either from other clinicians or from patients approaching pain specialists themselves. This can be particularly problematic in poor or rural populations. One participant explains:

“Eight times out of ten, nine times out of ten, they don’t know a pain doctor existed until they came to our hospital.” (Interview 16)

There is also an added importance given to the declaration and widespread awareness of the existence of pain management or palliative care specialties at a more political and strategic level. Participants argue that if a specialty is formally recognised by governmental organisations then more structured training can follow. In the current scenario specialist training is uncoordinated across the country and participants explain that in general, knowledge of pain management strategies amongst all doctors is inadequate. An increased awareness would therefore improve pain management both at a specialist level and amongst all healthcare professionals at a more basic level. One interviewee explains:

“Doctors won’t come forward for education and training unless they are aware, and patients will not come forward to accept the services, unless they are aware of the benefits.” (Interview 21)

Participants also explain that another particularly important consequence of better awareness of the existence of specialties of pain management would be an increase in

popularity of the specialty, resulting in more clinicians choosing to pursue a career in pain management. One participant describes this:

“Then at the same time physicians will also start thinking, yes, this is a new area, so I can be there, that’ll be my identity.” (Interview 7)

#### 3.8.4.3 Treatment Options

Participants talk of how little knowledge both professionals and wider society members have of specific treatment options in pain management. They explain how this can lead to inadequate or poor quality treatment selection by healthcare staff. For example, with respect to opioid medications:

“Because of lack of knowledge on opioids, lot of them think when you talk about morphine and other things, they’re afraid or scared from what the other physicians or their family also knows.” (Interview 19)

At a managerial level, participants explain that a lack of understanding of specific treatment options can lead to a lack of prioritisation of funding and implementation strategies. At a political level, they talk of how there may be policies that restrict access to certain treatments. Within the specialty of palliative care there is a particular concern about how a lack of awareness of opioid medications within all of these groups leads to a lack of patient access to these drugs. One doctor explains:

“If the policy maker’s not educated, morphine will not be available, and if morphine is not available, the doctors can’t work. So I think, this should be simultaneous, the, the awareness of the policy makers and awareness of the doctors.” (Interview 25)

A need to increase the availability of other treatment modalities, however, is also talked about within the context of awareness. One participant explains here how other doctors often do not know of the range of appropriate treatments available for different types of pain:

“What is chronic pain? How to treat? What is, what is the difference between musculoskeletal and neuropathic? Because many a times they treat neuropathic also like a musculoskeletal pain. So this difference is mandatory, they should know.  
“(Interview 5)

Participants talk about how specific non-pharmacological methods of treatment are not known about and of how multi-modal or holistic care could be employed more frequently. For example:

“Many times we advise patient, when patient is affording, he can, he has his insurance, but his surgeons says, oh don’t go for it, because he’s not aware about this procedure, the technique.” (Interview 30)

Another pain specialist talks here about the need to understand the complexity of pain management:

“It took me a while to emphasise that it is not just half an hour thing, pain relief is much more demanding and more intense and comprehensive, modality, it’s not just giving a block, you know.” (Interview 14)

From a patient’s perspective, participants note that the degree of self-funding of healthcare means that patients themselves need to be persuaded of the potential benefits of particular treatments. One pain specialist talks here about the difficulties in referring patients for treatment by a psychologist:

“Some of them refuse, some of them agree, and some of them are undecided so, the, the acceptance is pretty low in India, compared to other countries, being sort of, seen by a psychologist, because there is still that stigma attached there’s a mental health issue when you get referred to the psychologist.” (Interview 3)

When considering what improvements participants think patients themselves would like to see within pain management, participants often explain that a lack of awareness amongst patients meant they are almost unable to evaluate the quality of care they are receiving. One specialist explains.

“It’s difficult what they would like, because they don’t know what we are doing.” (Interview 8)

Furthermore, some participants explain that improving this awareness amongst patients would increase their access to treatments, as they will begin to demand specific treatments from a more informed position. This is explained here by a participant:

“Once they realise the potential to make them better, to make them useful to the society, then they will be in a position to push our cause, so we don’t have to go and make the big noise at the top.” (Interview 3)

Another related point, regarding treatment and educating patients is the concept that a dialogue between the doctor and patient regarding pain, how it occurs and affects individuals, can actually be seen as a therapeutic intervention in itself. One participant says:

“Many times people are happy just, with just the fact that somebody listened to them.”  
(Interview 32)

#### 3.8.4.4 Finances

Many of the areas I talked about above such as increasing practitioner numbers and treatment availability, particularly with respect to influencing managers and politicians, are related to acquiring increased monetary resources. Some participants also talk of the specific need to have increased funding specifically in order to adequately carry out work to improve awareness. This can include lobbying medical device manufacturers to help fund research that will act to persuade patients of the benefits of specific treatments, as described here:

“I have been in constant discussion with the medical companies, especially these expensive equipment companies, that you give us, provide us some equipment so we do research in our India. So we present the Indian data to the people. Whatever data we have is a foreign data. As you know the medical scenario in the Western World and the medical scenario in our country is a totally different. Though there are some patients who can afford these treatments, but they don't get convinced the moment I discuss with them.” (Interview 15)

One participant working in palliative care explains that because they give so much of their care free of cost they have no income spare to spend on awareness work:

“I think that if we have a proper funds we can actually propagate the information of palliative care to all the different parts.” (Interview 26)

Finally, some participants explain that increased awareness will be self-perpetuating with increased knowledge levels leading to more funding to further improve education, research and publicity.

## **3.9 Motivation and Contested Power**

In this final results section I explore how the evaluative judgments presented in the earlier sections, relating to the quality of pain management in India, the descriptions of barriers and solutions to overcoming these problems, are formed. I examine the influences participants describe as informing their career progression and daily practice. I then look at how participants negotiate power, primarily through exchanging knowledge, with members of their own profession and many other groups in society when advocating for change.

### **3.9.1 Motivation**

At the start of the interviews I asked participants to describe how they came to be working in their chosen speciality and location. During their answers presented here respondents describe their underlying motivations for dedicating their professional lives to treating patients in pain. The themes that arise relate to witnessing suffering, feeling personally drawn to the daily clinical work, and specific personal relationships.

#### **3.9.1.1 Witnessing Suffering**

Participants talk of seeing the suffering of patients, relatives, friends or even in themselves and feeling compelled to try to rectify these problems. One anaesthetist explains:

“Seeing the agony of the patients, mainly the cancer patients. And I thought I have to do something, anaesthesia is not going to help them.” (Interview 5)

Others talk of the scale of the problem of untreated pain, estimating the prevalence in the population, often compounded by patients presenting with very advanced disease. One doctor working in a cancer hospital describes how this prompted his career choice:

“I researched and found out that about seventy to eighty per cent of the patients of advanced cancer suffer from unbearable pain. So I understood that apart from chemotherapy, radiation therapy, or surgery, whatever you offer, one has to take care of pain because it is one of the most commonest symptoms of advanced cancer. So, that’s how I decided to explore more about pain, the different pathophysiology of pain and learn more about pain, and hence after that I have taken some training and become a pain physician.” (Interview 26)

Some participants talk in more detail about aspects of the care of patients that they consider to be inadequate, which can be linked to the plural healthcare system described earlier. They explain how patients often seek consultations from many different physicians before finding a pain specialist who has the necessary expertise, and of how they entered the field in order to help to rectify this. One pain specialist explains:

“The chronic pain patients move from pillar to post, and the amount of time and energy and attention given to these patients is quite less. So I felt, why not enter into the field? And do the best possible to give them relief because most of the chronic pain patients they move from pillar to post.” (Interview 8)

Some stipulate specific conditions that they are interested in treating such as cancer pain or in the case below, the pain of childbirth.

“I saw the women suffering so much with labour pain, I thought that it is, it maybe the right of the women to give them the, at least, you know, offer them the analgesia.” (Interview 9)

These examples all refer to the state of pain management in India at a fairly general level, participants also talk on a much more personal level about untreated pain. Some have suffered a painful condition themselves, others talk of how they have witnessed the suffering of loved ones, and view this as a particularly formative episode in their lives. One doctor working in palliative care explains:

“That is how I decided that this is what I have to do. Because I was not getting my peace of mind back after their death, it was just troubling me and I, I would struggle that what is the answer to the end of life? Like, people should not die like this, this is not the end should be. And this is how I came into palliative care.” (Interview 17)

### 3.9.1.2 Specific Treatment Strategies

Some participants explain how the technical aspect of performing interventional techniques such as nerve blocks is a part of their medical practice they are particularly drawn to.

“I passed my anaesthesia MD in 1982, I immediately started my private practice in anaesthesia but when we’re doing our residency, myself and my colleagues were very much interested in giving different blocks for anaesthesia purpose, and in my private

practice I learned that I can give these block for my patients, I started doing some more.” (Interview 6)

In contrast to this, some describe how the ideal of a holistic approach, rather than a focus on one specific treatment modality makes pain management particularly attractive to them. One pain specialist explains:

“The multidisciplinary aspects of pain interest me in terms of looking at the psychology of pain, or even the philosophy of pain as well as the social side.” (Interview 3)

### 3.9.1.3 Personal Drive

Interviewees sometimes talk of a deep driving force inspiring them to work in pain management but also of how this balances some of the difficulties encountered when they chose this particular career path. One such difficulty is sacrificing a higher personal income, particularly if they choose to work in the government or charitable sectors. One participant who has chosen to work in palliative care explains:

“I love my subject, pharmacology, I am a pharmacologist, but this is more, this is more rewarding and more peace giving to me, palliative care.” (Interview 17)

Here a pain specialist working primarily in the government sector explains his move from working as an anaesthetist in the private sector:

“I felt, I am doing nothing. It was a boring job, and the patients are also not, they do not know me, and I also, so this is unethical, this is unethical what I felt, so I stopped going there. Suddenly, people thought I am a fool, but, but I am happy, I am happy with my conscience.” (Interview 7)

Another interesting motivator sometimes described is that of personal autonomy. Those who have originally trained in anaesthesia explain how they often feel very much at the beck and call of surgeons who essentially dictate when they require input from an anaesthetist. Within the private sector the surgeons also control the monetary fee paid to the anaesthetist, resulting in a power differential some find to be personally troublesome. In contrast, working as a pain specialist in their own right ensures they have a higher

degree of ‘ownership’ of their patients, resulting in more autonomy and a feeling of higher status. One pain specialist explains:

“Anaesthesiologists in India, they have their identity crisis. That’s a, that I must say, but it may be everywhere in the world, I do not know, but it is more in India, because they’re dependent on the surgeon, and where, and he is a team member of the surgeon, like an assistant. So, the surgeons also behave like that, and because in the private clinics, the surgeon have a just discussion on the kind of budget of the operation, say for example 60,000 Indian rupees, and so he is thinking, to take 25,000 for himself, and 25,000 or for the hospital, and the medicines, so there’ll be only 5 to 10, 6,000 will be left for the assistants and anaesthetist.” (Interview 7)

Another pain specialist explains how this feeling of low status can be much more fundamental than simply a dissatisfaction with income:

“Even if you save the life of patient, the patient is always thankful to the surgeon and not to the anaesthetist.” (Interview 15)

Of note, this feeling of dissatisfaction with status is not talked about as a reason for choosing to work in the specific area of palliative care.

#### 3.9.1.4 Relationships

Relationships with colleagues are described as both motivators and hurdles, for example, the need to tolerate the negative attitudes of colleagues. This can be simply in their derision of the decision to take up a career in pain management, which is often related to a reduction in income. Pain specialists also describe difficulties in their daily practice with their medical colleagues not appearing to value their clinical work. One pain specialist describes this early on in his career:

“It was not always pleasant, there would be a lot of hostility because I, I have a very respected senior colleague of mine, he said so, ‘What do you mean pain? Everybody does pain. What do you mean? What you, what are you doing? Why don’t you do anaesthetics, you know? We need anaesthetists, why don’t you do anaesthesia?’ That sort of very dismissive.” (Interview 16)

This dismissive attitude is sometimes described as arising from a degree of ignorance of pain management strategies and the work of pain specialists. However, some also describe how, albeit slowly and in relatively few cases, this is changing over time with an improved

understanding of the specialty, as well as an increasing respect when colleagues see how patients can benefit from specialist pain management.

“Initially when we started people were looking at us with, especially oncologists, looking at us with little bit suspicion. But now they realise that this is a good service, and actually they, they even realise that somebody who is registered with us is likely to, likely to complete the therapy, curative therapy, the likelihood is more with somebody who has already been supported emotionally and physically.” (Interview 22)

One pain specialist talks of how this improved appreciation of their work has now led to increased referral from previously sceptical colleagues:

“You’ll be surprised that those doctors who was criticising me are now my patient. I injected them, their back, their you know, one orthopaedic surgeon who was criticising me a lot, his wife is my patient.” (Interview 28)

Linked to this description of overcoming a degree of hostility from within the medical profession is a description of career paths that are in some way pioneering. Participants describe how they needed to persuade many different groups that pain management was a worthwhile enterprise – colleagues, managers and ultimately patients.

“I would remember the, say five years ago I would be knocking at a lot of people’s doors asking for you know, my services to be offered to them, that I can do something in pain, I can do something in pain.” (Interview 16)

Those who have now established careers in pain management, describe how training opportunities within India were almost non-existent for them. This necessitated self-learning and searching out individual teachers, often resulting in periods of training overseas. For example:

“I don’t have any formal training as a pain physician but I learnt by myself, reading, doing the mistakes, and learning from the mistakes. And in the process I attended many international conferences, I visited also Sloan Kettering, for about one month as a pain scholar, on a pain scholarship.” (Interview 15)

Several participants talk of how one specific teacher often based in a country in the global North, was particularly influential in their early career. However, there are also descriptions of how the number of locally trained clinicians fulfilling the roles of teachers and mentors has increased somewhat over recent years, and they are now therefore able to

deliver education more appropriate to the Indian setting. One pain specialist working in palliative care explains:

“Earlier in all our conferences we used to call external faculty, now I think our people also are well equipped and well skilled, or well experienced in palliative care, and we started tailoring for our needs.” (Interview 31)

### **3.9.2 Power Contestation**

Throughout the data, participants talk of contesting power in various forms and with multiple groups, mostly in relation to descriptions of how the delivery of pain management can be improved. Most prominently, power is described as being negotiated in terms of knowledge and money. For example, increasing the knowledge of others in order to persuade them to act in a particular manner is described as a fundamental aim of increasing awareness, which in turn is associated with the aim of increasing financial resources. In the private sector, increasing patient referrals directly increases income, to the hospital and/or to the clinician, depending on the salary structure of the individual institution. Some organisations will pay a fixed salary regardless of the number of patient referrals received by an individual; others will be paid per patient and procedure. In other organisations, participants talk of the need to increase awareness amongst wider society, managers and politicians in order to increase funding to the institution itself as opposed to generating income from patients' individual fees, using this funding to improve facilities or subsidise patient charges. However, even in these situations where the clinician is receiving a fixed salary there is a potential indirect personal gain from increased service funding, with improved working conditions, job security and profile. Power is contested therefore between and within various groups. These relationships take various forms and I describe them below under the following headings: top-down/bottom-up, collaborative-competitive, and global-local.

#### **3.9.2.1 Top-down and Bottom-up**

I described in the preceding section how participants call for more awareness and therefore funding from groups that are perceived to be in more powerful positions than the participants. Classically, these groups are hospital managers and politicians. Participants

describe the role of these powerful individuals both as a hindrance, and as a potential asset. For example, politicians are held responsible for creating policy leading to poor availability of opioid medications but government institutions are hailed as crucial to implementing standardised training and practice. Similarly, managers are viewed as being able to both prevent and facilitate the prioritisation of pain services or research within a hospital. Other examples from my data include accreditation authorities that declare the presence of a pain clinic as ‘essential’ or insurance companies that agree to fund particular treatments.

The national organisations, the ISSP and IAPC, and indeed others such as the Indian Society of Anaesthesiologists can also be considered as top-down groups. Although the members of these societies are of course clinicians themselves, the collective groups can be viewed as more powerful entities than their individual members. These societies lack the authority of government bodies but are described by participants as being potentially powerful advocates for advancing the profile and standards of pain management, almost acting as a stepping-stone to the higher level of government.

Clinicians themselves are often viewed as being in a powerful position, deciding which treatments to offer and to whom. However, as I explained already, participants describe how patients have to choose their own medical professionals, consent to treatment and often pay directly for their healthcare, demonstrating how they and their relatives hold a degree of power. Some participants talk of the need to engage patients and wider society in order to improve pain management from the ‘bottom-up’. However, I argue that participants are actually often talking of top-down control when interacting with patients and wider society. For example, when participants talk of increasing awareness within the patient group, clinicians are talking about aiming to persuade patients that they will indeed benefit from the treatments the clinicians deem to be appropriate.

One notable exception to this top-down exchange is an initiative where local community members who take the lead in directing the aims of the service fund this programme. A participant working for this group explains how the service evolved from treating, almost exclusively, patients with cancer, to seeing those with any medical condition:

“We had a lot of debate within our clinic and then we said this is what we should do. If we are asking the community to support, then the agenda also should include what

community wants. If we say that we need all your money but then I will decide which patient to give, that's not right actually, and for the community the common denominator is suffering. Ok, you may be having cancer, you may be having HIV, or you may be having stroke, and for me as a doctor I can differentiate, but for the villager diagnosis is secondary to that. But all they can see is that those are three people suffering." (Interview 33)

### 3.9.2.2 Competition and Collaboration

Power is also contested within the group of healthcare professionals themselves. Above, I explained how the participants talk of increasing awareness and knowledge through education strategies targeted at their colleagues. There is a degree of competition within the medical profession, described by participants, particularly in the private health sector where clinicians are vying for the custom of patients. For example, a surgeon may be reluctant to refer a patient to a pain specialist, as they may fear that the patient may not return to them again for further input. However, of note in the government or charitable sector, although participants talk of the need to increase awareness partly so that patients seek out treatment, these services are also at times described as being over-subscribed.

Some participants also describe a reluctance to refer to other professionals due to a desire not to admit defeat. One doctor explains.

"There's a kind of ego problem let me tell you, the surgeons, the orthopaedicians, you know, they think once they have failed then only they will refer." (Interview 13)

Participants also note that this competition can play out by clinicians choosing treatments in order to make income despite them not being the most appropriate option. For example, here a participant describes the presence of 'block shops', that is, clinics where nerve blocks are carried out:

"Block shops, that's, again, it is, it is pushed by the corporates. There is good money in it, and you know nerve blocks are not very effective in all cases, you know the limitations of blocks, so that should not be there." (Interview 25)

Furthermore, this can breed mistrust of the medical profession in general, with patients not sure of the motivations of individual doctors. One participant explains:

“They don’t trust the healthcare system, they think the healthcare system, every single person is out there to make money not in their own interest, so they don’t trust it, that becomes a problem.” (Interview 19)

Importantly, there are also many examples of collaborative work. Clinicians frequently talk of the need to refer to their colleagues to provide expertise in a particular area. For example, palliative care specialists who do not have the necessary training or equipment ask colleagues in anaesthesia to perform nerve blocks if pharmacological treatments have not worked. Anaesthetists also refer to specialist palliative care teams and many participants describe holistic patient care delivered by multidisciplinary teams. There is however, a call from many participants for more collaboration both clinically on a day-to-day basis, in other work such as advocacy through membership of the national professional societies, and on education and research projects. Interestingly, one participant specifically notes the need for more collaboration between groups working in palliative care and those working in pain management without expertise in this field:

“I think one problem is that either palliative care physicians manage only with pharmacological agents and interventional pain therapists do only interventions, and this I think is a huge problem. Interventional, I mean pain management has to be comprehensive.

*So, how can that be improved?*

By more dialogue between pain management people and palliative care people, and a joined look at where we are. Which is not easy, but it is necessary.” (Interview 18)

### 3.9.2.3 Global-local Interactions

Many participants talk of how overseas practice influences their daily work. There are numerous examples in both the interviews and the questionnaires of participants receiving training either overseas or from colleagues who are based outside of India, usually but not exclusively, in countries of the global North such as the UK, USA and Australia. Some participants note how this has started to change as more training opportunities become available in India, following the growth of the practice of pain management. Similarly, they explain how the teaching faculty at education meetings is increasingly made up of Indian clinicians. A few participants describe how they in turn are now teaching abroad,

receive overseas students to train in their organisations, and run international educational conferences.

Participants explain that the majority of research and guidelines available to inform their treatment selections originate from countries in the global North. They describe, therefore, how there is a specific need for more Indian based research into understanding how therapies originating in the global North can be effectively implemented in India, or indeed if they are likely to be effective at all. One participant says:

“Whatever data we have is a foreign data. As you know the medical scenario in the western world and the medical scenario in our country is a totally different.”  
(Interview 15)

Participants describe how western medical treatments are inadequately understood in the Indian context and require translation rather than being directly transferred. In some cases participants talk about a change as simple as a dose reduction of a medication but they also talk of how some treatments are likely to require much more modification to work in the different sociocultural environment of India. One participant gives an example here:

“They don’t like western medicines, because they feel that sometimes, they will be more, they will accept complementary and alternative medicine and something that’s indigenous, they relate better to it. Even if it doesn’t work for them, they’d still be more, they’d be happier with it than taking a medicine because there’re a lot of negative connotations about medicines. The commonest thing is pain killers are bad.”  
(Interview 16)

As I described at the beginning of Section 3.3, some participants describe the huge variation between populations in how people perceive and tolerate pain. A pain specialist explains:

“A lot of ideas about pain and how we perceive it, depends on our social background, our environment.” (Interview 14)

Some participants describe receiving support in various forms from international organisations such as the WHO or the International Association for the Study of Pain, and indeed many describe using WHO published guidance in their clinical practice. However, participants also call for more collaboration from these high profile and therefore powerful groups, suggesting they provide more top-down support for local Indian initiatives such as

education programmes and the modification of resources such as guidelines and patient information media for local use. A few participants clearly state they would welcome more direct financial support from wealthier countries and others describe how they have already benefitted from overseas money and volunteers working at their institutions.

### **3.10 Summary**

In this results chapter I presented a combination of quantitative and qualitative data from a range of sources, in order to build up a picture of how pain management is practiced in India and of how clinicians evaluate this work. The data derives from participants working in several regions of the country and in many types of institutions, with various funding arrangements. The results demonstrate features of the Indian healthcare system that are perceived as directly affecting the practice of pain management - such as the paucity of resources, a multiplicity of healthcare providers, weak regulation, and a lack of uniform practice. Within this system the treatment of pain is seen to be given very low priority.

The results demonstrate that the overall need to improve access to pain therapies within the healthcare system is relatively undisputed by the participants who highlight the low levels of availability of opioids as well as many other medications and treatment modalities. They also show that availability patterns vary across the country, as do participants' views on which therapies should be the focus of improvement strategies. There is variation amongst the participants in their desire to increase the availability of specific treatments, as advocated by high profile international organisations including the WHO.

Similarly, the participants describe with a degree of consensus the need to improve the treatment of pain across the country through formalised specialist training in pain management. However, views about the specific form that this specialisation should take, particularly with respect to the organisation of the medical profession and its specialities of palliative and pain medicine are less uniform.

However, the most prominent theme arising from the data is the overwhelming agreement amongst the participants that pain is a problem to be fixed by the medical profession. Participants consistently note a lack of awareness amongst others regarding the need to

consider pain to be a medically fixable problem. They also describe the need to raise the profile of the treatment of pain within healthcare. Low levels of awareness are manifested in multiple ways, from patients not considering pain to be a problem requiring medical intervention, through clinicians not understanding the range of available treatments, to managers and politicians not prioritising pain management within the healthcare system. Participants talk of the need to implement strategies to improve awareness for patients, society, healthcare colleagues, managers and politicians. This process of altering the awareness of a particular issue amongst other individuals can be considered to be a demonstration of the use of knowledge as power. The results reveal how power is negotiated by the medical profession in several forms including as knowledge and money; and in multiple locations at local and global levels.

In the following chapter I discuss these results in detail with particular reference to the conceptualisation of pain as a medical problem, the organisation of the medical profession and treatment selection. I examine the debates that surround these issues and consider the implications these have for the delivery of healthcare.

## **Chapter 4 - DISCUSSION**

### **4.1 Introduction**

In the preceding results chapter I built up a picture, largely from the perspective of practising clinicians, of how pain is treated in India. The data includes descriptions of the Indian healthcare system, details of how individuals practise pain management and their views on how pain ought to be treated.

In this chapter, I discuss these results, beginning in Section 4.2 with an overview of data relating to descriptions of the healthcare system in India. I give particular emphasis to those features that strongly influence the delivery of pain management, namely scarce resources and the diversity of healthcare provision. These features of the healthcare system can be considered to be the backdrop to the discussions presented in subsequent sections (4.3 - 4.5) relating to the professionally constructed phenomena identified in this study. In Section 4.3 I discuss the medicalisation of the treatment of pain, describing how pain is conceptualised as a medical problem to be fixed and the impact this has on the organisation of the medical profession. An important dimension of this medical model is the use of specific treatments by individual clinicians, and in Section 4.4 I discuss these different therapy modalities and their selection. I begin with pharmacological treatments, moving on to non-pharmacological therapies and end by discussing the variations seen in treatment selection. When considering these topics of treatment selection and the organisation of medical specialities dedicated to the treatment of pain, multiple points of view exist within the medical profession and across wider society. In Section 4.5 I discuss how these individual views are negotiated, considering how clinicians enact their professional power both within India and at a global level. I structure this section with reference to theories of the policy process introduced in Chapter 1, discussing in turn agenda setting, policy formation and policy implementation.

Throughout the chapter I highlight the unique contribution this study makes to the current body of knowledge, demonstrating the practical relevance of my findings and the importance of taking a cross-disciplinary approach in order to fully appreciate how pain is treated within a society. Finally, in section (4.6) I discuss the limitations of the data and reflect on how my personal perspective influences the study findings.

## **4.2 Healthcare in India**

India is a huge country with a population of over a billion people spread over 36 administrative states and union territories, making the task of providing health care an immensely complex and indeed highly political process.<sup>124</sup> While it is therefore difficult to generalise, there are some characteristics of the Indian healthcare system highlighted by my study findings that are particularly noteworthy and relevant to the provision of pain management, namely the distribution of scarce resources, and the diversity of healthcare provision.

### **4.2.1 Resources**

As I described in the opening chapter, healthcare generally in India, and specifically the provision of pain management, is widely reported to be grossly under funded and over subscribed. Low levels of trained personnel mirror the lack of financial resource. The results of this study, presented in Section 3.4.1, clearly confirm this lack of resource, with participants describing how they lack the facilities, equipment and staff to provide adequate pain relief to patients. They show that not only are there scarce financial and human resources within individual healthcare facilities but also low numbers of facilities in existence across the country, painting a picture of a system unable to provide high quality care to all of those who require it.

The low levels of palliative care provision in India are already well described in the published literature. They are highlighted again in the recently published report from the Lancet Commission on Palliative Care and Pain Relief,<sup>3</sup> which describes inadequate access to pain relief across the global South. This report continues the trend of so many other global initiatives in focusing on the highly emotive issue of pain relief associated with care at the end of life and the specific problems related to accessing opioid analgesia. The authors describe the gap in access levels between those living in poor and well-resourced environments as an ‘abyss’, replacing the less dramatic term ‘divide’ which is used in earlier descriptions of their work.<sup>41</sup> However, the results of my study take this description of access further by demonstrating this lack of resource for the treatment of pain across multiple clinical areas including those often considered to be beyond the remit of palliative

care, namely in the treatment of chronic pain not associated with terminal disease and acute, short-term pain. My study also demonstrates low levels of access to many other treatment modalities, besides opioids. I argue that the broad approach I have taken is particularly pertinent because the management of acute short-term pain, that is largely amenable to treatment with opioid medications, is frequently overshadowed by highly emotive descriptions of the need to improve access for those suffering with terminal disease. My approach is also relevant due to the expanding remit of palliative care to encompass the treatment of an ever-widening range of diseases. I return to each of these topics later in this chapter.

Not only is access to healthcare in India under resourced, it is also described in the published literature as being inequitable across different strata of society, for example, in relation to caste, gender, wealth and geographical location.<sup>124,133</sup> Unequal access to treatment is confirmed in my study particularly with reference to wealth and geographical location. These two variables often overlap with the poor population living in rural areas being disadvantaged by living a long distance from institutions and being unable to afford to travel, as well as to pay for their treatment. The results of the study also demonstrate, however, the unequal distribution of pain services across different regions of India, with participants reporting large variations in the number of pain management facilities even between different urban areas.

As I have described, private healthcare in India is prolific, with the majority of health services provided by this sector. However, palliative care services in India are frequently provided by the charitable sector meaning that many reports into problems of access to pain treatment fail to encompass detailed analysis of care delivered in the private sector, particularly in large corporate facilities. I explicitly set out to redress this imbalance by including the views of those working in these areas and indeed my results show that clinicians consider there to be a *relative* lack of resource allocated to the treatment of pain *regardless* of the type of institution being discussed. My results confirm the already well described difficulty faced by those working in the government and charity sectors, who are faced with the stark reality of allocating resources in an environment where life saving or disease curing treatments are not available.

It is particularly interesting to note, however, that even in the corporate sector this relative lack of funding is described as problematic. In these hospitals that enjoy high levels of absolute funding and offer similar services to those provided in the global North,<sup>291</sup> participants explain that the treatment of pain is often afforded only very low priority. This is demonstrated by descriptions of fellow clinicians not knowing how to treat pain and even being unaware of the very existence of pain specialists, and also in managers who are unwilling to fund pain services. The treatment of pain is viewed across the healthcare system as a low priority when compared to the provision of disease curing therapies.

The descriptions I included so far relate to the scarcity of resources allocated to the treatment of pain from the perspective of delivery – that is, the supply side of healthcare. This research also highlights factors on the demand side that serve to further reduce access to pain treatments. For example, patients themselves frequently do not prioritise the treatment of pain and are unable or unwilling to fund this aspect of their care. Other studies have shown that despite the costs involved many patients even from the poorest sections of society favour the private sector, partly due to the perceived poor quality of service delivered in other institutions.<sup>292-294</sup> The results of this research show that clinicians view this funding structure as problematic particularly when addressing the medical management of patients in pain, with individual patients described as needing to be persuaded to prioritise, and therefore fund, their treatment. They explain how the treatment of pain is often regarded by both patients, and healthcare professionals as an optional ‘add-on’ luxury. This is in contrast to potentially curative treatments such as cancer chemotherapy which are much more likely to be viewed as essential.

The difficulties in patients funding their own treatment ‘out of pocket’ is highlighted as being particularly problematic when considering those suffering from terminal diseases such as cancer because these patients have frequently exhausted their financial assets through endeavours to cure their underlying condition. Whilst this phenomenon, specifically with respect to cancer treatment, is already well described elsewhere,<sup>295</sup> this study shows how clinicians across each different type of healthcare facility describe patients’ out of pocket funding of pain treatment as problematic, regardless of the underlying cause of the pain or indeed the therapy being offered. For example, clinicians working in charity funded palliative care organisations sometimes describe difficulties in

being able to provide relatively simple nerve block injections or medications, whilst those working in large urban corporate facilities describe how patients are unwilling to pay for high end therapies such as implanted electrical devices. To be clear, this study shows that although there may be variation in the treatments that are offered to patients in different healthcare settings, there is agreement amongst the participants regarding the need to persuade patients, who are generally reluctant to finance these treatments, regardless of the absolute cost. Poor patients are described as needing to be persuaded to pay for relatively cheap treatments, and the wealthy for high-end interventions.

As I described, scarce resources are both financial and human, but the two are inextricably linked. For example, a lack of money directly affects the quantity of human resources available in a given institution through restrictions on the salaries that can be paid. There is, however, an additional constraint in India, as noted in Chapter 1, of an absolute lack of trained medical personnel. This leads to shortages in certain geographical areas because clinicians may favour working in urban and private facilities, and it is compounded by a 'brain-drain' wherein healthcare workers frequently elect to work overseas.<sup>131</sup> This study emphasises the scarcity of trained medical professionals in general and in particular in rural areas and some states. The results show how this leads to the provision of sub-optimal care, especially within the government sector and other over-subscribed services, where the time available to spend with each individual patient is severely limited.

Specifically, the results show that the shortage of manpower is considered to be especially problematic within the medical fields related to the treatment of pain. Participants talk of the difficulty in recruiting into poorly paid posts in the charitable sector, particularly within palliative care, which is often viewed as an unglamorous specialty when compared to others where high salaries or the delivery of life saving treatments are possible. Some describe a reliance on overseas volunteers to provide certain treatments. Even for those working in the private sector and outside of the remit of palliative care, however, there is talk of how specialists had faced ridicule from colleagues and taken significant financial risks when deciding to leave the relative security of a well-paid post in order to pursue a career in the field of pain management. The clinicians in this study add further weight to the argument that the treatment of pain is a low priority within the healthcare system when they describe how they are required by managers to fit their pain management work, around other responsibilities such as the provision of anaesthesia.

### 4.2.2 Diversity

The study results demonstrate the diversity of healthcare provision in India with respect to specialists involved in the treatment of pain (Section 3.4.2). They show that there is a great variety in the way in which institutions are funded (Figure 3-11) and that many respondents work in more than one institution (Figures 3-12 and 3-13). Some respondents working primarily in the charitable sector talk of the need to supplement their income by engaging in private work while simultaneously, those working primarily in the private sector talk of the desire to carry out unpaid charitable activities. Similarly there is considerable variation in the type of care clinicians engage in – whether this be in-patient, out-patient or community based (Figures 3-15, 3-16 and 3-17).

The study also reveals wide variations in clinical practice amongst healthcare workers in that they offer different ranges of treatment modalities. However, it also demonstrates variations in their conceptualisation of what constitutes an ideal range of treatments. Many participants in the study describe a lack of standardised training and inadequate professional regulation, confirming other published reports, and they also talk of the problems that arise from this non-uniform practice. They explain that the quality of pain relief individual patients receive could be improved by implementing clinical guidelines, standardising training at a national level, and improving professional regulation. In the following section I return to the topic of treatment selection, guidelines and standardised training, particularly with respect to the quality of care delivered.

Diversity of healthcare provision is a universal phenomenon well described within the literature, for example, in the field of medical anthropology.<sup>296</sup> Across the world, individuals seek advice regarding their health from numerous disparate groups including western medical professionals, locally trained practitioners and family members.<sup>296,297</sup> As I already outlined, in India there is a vast array of trained practitioners working alongside allopathic doctors in fields of healthcare known as AYUSH (ayurveda, yoga, unani, homeopathy and amchi) and there are also incalculable numbers of untrained practitioners.<sup>298</sup> This diversity can have negative effects on healthcare delivery due to variations in service quality and difficulties in coordinating regulation. Patients can also be faced with an overwhelming choice of practitioner and indeed my results show that this choice can be problematic, particularly when seeking treatment for pain. Factors that affect

patient selection of healthcare provider are numerous and complex, particularly in the more diverse and unregulated systems often present in low and middle-income countries.<sup>299</sup> A vast literature has arisen on this subject but the key factors to be aware of include characteristics of the individual such as age, gender, education level, occupation and financial assets; and factors related to the healthcare system such as accessibility, acceptability of the provider, cost and perceived quality.<sup>300,301</sup>

When considering the provision of pain relief in India the circumstances are particularly complex due to the multiple areas in which diversity exists. For example allopathic and AYUSH practitioners each work in multiple types of institution with funding available from government, charitable and private sectors. Within the allopathic community, as demonstrated in my results, there is little regulation or standardisation of training and huge variation in the clinical treatments offered, and crucially in the normative positions of the practitioners. Issues of trust then become pivotal when patients are choosing a medical practitioner. For example, interview participants explain that the sheer number of providers and the presence of untrustworthy practitioners and practices leads to some patients choosing a doctor based simply on previous experience or a personal recommendation rather than knowledge of their expertise in the relevant medical field. They also talk of the importance of this system of personal recommendation when growing and maintaining referrals to their practices.

In Section 4.2.1 I outlined the problems within the Indian healthcare system of scarce resources – both financial and human, and of how this is particularly problematic within the fields specialising in treating pain. In Section 4.2.2 I described the diverse array of healthcare providers in the country and the generally low levels of professional regulation. The presence of both these factors in combination leads to a very strong market within the field of healthcare wherein practitioners are constantly trying to attract custom – from patients and through referrals from colleagues. Furthermore, with patients paying for their treatment out of pocket and having limited resources do to so, the need to market healthcare directly to patients is a key concern for clinicians. Patients themselves are faced with a healthcare system in which reputable, affordable practitioners are few and far between, and very difficult to identify. In the following sections I discuss how these local healthcare system factors influence, and are influenced by, the professionally constructed nature of the practice of pain management.

## **4.3 The Medicalisation of Pain and Palliative Care**

### **4.3.1 Pain as a Medical Problem**

I noted some of the general factors that affect a patient's decision to access healthcare - such as education level, socioeconomic status, accessibility, reputation and cost of the provider, but a fundamental factor is also the patient's underlying beliefs surrounding the specific condition they are experiencing. These include ideas about the potential diagnosis as well as the perceived benefits of seeking treatment.<sup>300</sup> This is especially pertinent when considering patients seeking treatment for pain, one of the commonest reasons for seeking healthcare.<sup>296</sup> The subjective nature of pain inevitably leads to great variation between individuals' perception of the phenomenon and their interpretation of its meaning.<sup>32</sup> Crucially, the socio-cultural environment also affects whether pain is considered to be abnormal or pathological, as opposed to a normal experience of everyday life. Simple examples include variations in seeking treatment for dysmenorrhoea (period pain) and the pain of childbirth.<sup>302-304</sup> This social-cultural effect is also known to vary over time, particularly in societies that are considered to be undergoing rapid socio-economic development.<sup>296</sup> Furthermore, as I outlined in the introductory chapter, the phenomenon of pain existed before the human species evolved and has been subjected to numerous socio-cultural interpretations, such as those associated with religious and spiritual belief systems.<sup>4,5,8</sup> More recently, following the advent of modern anaesthesia in the 19<sup>th</sup> century, the idea that pain is a medical problem to be fixed has become increasingly prevalent.<sup>5</sup> Variations between individuals' interpretation of painful states (such as period pain and childbirth) as being pathological, and the historical changes that have occurred within society's collective interpretation of pain, leads to the conclusion that the medicalisation of pain is a socially constructed phenomenon. Furthermore, as I introduced in Section 1.4.1, a significant force of influence in this construction process is the medical profession itself.

Within my study, the results (presented in Section 3.3) demonstrate that the idea of pain as a problem to be fixed, is uncontested by the participants. The need to persuade others of this fact is also ubiquitous. Although participants clearly describe how other groups across society, including patients, doctors, managers and politicians possess alternative interpretations of the meaning and management of pain, they describe the need to alter

these views and enlighten others with their superior knowledge rather than entertain the idea that the medical treatment of pain is only one of several possible paradigms. This is very much in line with Freidson's descriptions of the widespread political dominance of the medical profession<sup>176</sup> and the conclusion that the medical treatment of pain is largely a professional construction.

To be clear, with current western medical technology, many types of pain, typically following trauma or surgery and pain of terminal disease, are amenable to treatment and are able to be 'fixed', whereas in contrast, other long-term or chronic pains are generally not cured, although relief may be temporarily or partially achievable. Despite this the study participants make little mention of the limitations of currently available medical treatments and I only found one explicit comment describing the lack of fully effective treatments for all types of pain as a barrier to the improvement of pain management. The participants do not discuss the notion that they themselves as medical professionals are by definition partly responsible for the professional construction of this medical model. Similarly, they do not describe the implications this created phenomenon may ultimately have on the practice of pain management. They do, however, raise some interesting themes that result from the professionally constructed nature of the model. For example, there is recognition that the specific therapies that may be of benefit to those living in India will be different to those in the global North. Several cite examples of using particular drug dosing regimes developed in countries in the global North that are not tolerated by Indian patients, explaining how more medical research is needed in order to solve this problem. Similarly, there is acknowledgement that there are differences in the interpretation of pain between different population groups. For example, they describe how those who are wealthier and living in urban areas are more likely to seek medical advice for chronically painful conditions. There is also a change occurring across the generations with increasing impetus to seek treatment coming from younger members of society.

Interestingly, the recent Lancet Commission report not only reinforces this professionally constructed notion that pain is a medically fixable problem but also expands on this idea, describing a new concept, called 'severe health-related suffering' or SHS.<sup>3</sup> SHS incorporates many other symptoms as well as pain, that are described as requiring medical treatment, particularly highlighting differences in access between those in the global South and North. The creation of this new metric, and the overwhelming scale of its presence

serve to reinforce the call to reduce human suffering through increasing the delivery of western medicine at a global level. This is another clear demonstration of the medical profession's political power or economy as described by Freidson and others.<sup>174</sup> It also relates closely to descriptions of the increasing medicalisation of other conditions, including aging and death, previously considered to be a normal part of the human experience, that are now deemed to require medical treatment.<sup>179,180</sup>

One final point to make here is the description by some participants of the need to consider the treatment of pain as a human right, echoed in the Lancet Commission report whose authors talk of poor opioid access as a “moral failing”.<sup>3(p1)</sup> As I outlined, it has been argued that the very description of humanitarian goals as human rights is problematic.<sup>100</sup> At first glance it may seem like an unarguable act of common sense to describe the relief of human suffering with medical analgesics as a human right, in line with the 1948 *Universal Declaration of Human Rights*<sup>92</sup> and the 1966 *International Covenant on Economic, Cultural and Social Rights*,<sup>38</sup> that describe respectively the right to health and the right to freedom from torture. Some, however, consider these United Nations based declarations to be initiatives dominated by countries in the global North<sup>100</sup> and therefore alienating to other regions of the world. This is in line with postcolonial theorists who argue that power differentials between nations have remained to a large extent the same as those present in the colonial era.<sup>254,255</sup> Furthermore, by describing a particular cause as a human right there is a sense that it becomes sanctified and placed beyond criticism or debate, and this is exactly what the participants seem to be doing when describing access to pain relief in these terms. The terminology is invoked in order to strengthen their position that others need to be made aware of the ‘unarguable fact’ that pain is a phenomenon requiring medical treatment, further adding to the political and economic power of the medical profession.

Despite the widespread support for the use of this medical model, I argue that the medicalisation of pain is in fact an example of the simplistic reductionist models that are criticised for being unrepresentative of the complex social phenomena they aim to represent.<sup>5,260,305</sup> Some authors suggest that the actual use of this model to treat pain can cause harm through inadvertently increasing patients' disability.<sup>306</sup> This, largely professionally constructed, medical model does not readily incorporate the range and complex nature of individual patients' experiences nor does it fully acknowledge the

limitations of western medicine's ability to cure all types of pain. Furthermore, the prevalent and expanding use of the model, exemplified by the Lancet's newly created SHS, implies that with increased scientific research, as called for by several study participants, a more effectively functioning medical profession will ultimately rid the world of pain and suffering. This perspective is akin to Parson's much critiqued functionalist approach in which doctors act only to improve the lives of their patients,<sup>174</sup> but it also demonstrates how power is wielded by the profession as described by Freidson.<sup>176</sup> However, this is not to say that I consider the medical, professionally constructed, model to be entirely redundant, but rather that we need to understand how it is created and modified, its assumptions and limitations, and how it functions in the wider dynamic social context. In particular we need to consider the dominant role played by the medical profession and how its power is wielded in society. I argue that this is best done by adopting an approach, in line with Foucault's social constructionist perspective.<sup>174</sup> Through this, we can then appreciate not only that one model will not be universally applicable to every clinical and social situation but importantly, when the model *will* be useful, and in doing so use it to its fullest potential.

In the following sections (4.3.2 and 4.4) I discuss some of the practical implications of the professional construction of pain as a medical problem namely the creation of medical specialties and the selection of different treatment strategies.

### **4.3.2 Medical Specialisation**

Practitioners of western medicine are bound together in their profession by their specialised knowledge, the growth of which is one of the driving forces behind the creation of professional subsections known as specialties.<sup>307</sup> A result of the conceptualisation of pain as a medically fixable problem, and its associated knowledge base, is the creation of medical specialties dedicated to treating these patients. Medicine and its subsections, in common with other professions, function to control this specialist knowledge base, setting entrance and registration criteria, and practice standards, as well as promoting the common interests of its members and protecting the group from competition.<sup>296,307,308</sup> However, as described by Abbott in his book, *The System of Professions*, the boundaries of professional group's sphere of work or 'jurisdiction' are constantly changing and contested.<sup>309</sup> Each

medical speciality has its own knowledge base, professional standards and internal structure of hierarchy. Of note there is also a hierarchy between different specialties with those focused on particular organs such as the heart and the brain afforded higher status. Similarly, those specialising in caring rather than curing sit lower down the status hierarchy,<sup>296</sup> and these would include those with a focus on pain relief.

As presented in Section 3.5, participants in my study describe the need to create medical specialities dedicated to the treatment of pain, with clinicians explaining how the presence of organised, officially recognised specialties could improve the provision of pain management. They talk of how the creation of specialties would directly promote the interest of the group's membership. They explain how awareness of the need to treat pain would be heightened, leading to increased priority being given to this area of medicine. This would result in more dedicated clinical posts being created, enabling healthcare workers to devote more time to individual patients partly because they would no longer need to juggle their time between other clinical commitments such as the delivery of anaesthesia.

Participants also talk of how knowledge would be better controlled by increasing the impetus to standardise training and clinical practice, ultimately leading to better quality clinical care. This improved quality and reduced corruption would in turn lead to an enhanced reputation of this field of medical practice and to increased levels of trust from the general public, again, promoting the interests of the specialists themselves. It is also important to note, however, the relative lack of effective long-term treatments available within western or allopathic medicine to treat chronic pain. Although as I noted above this may make the specialty sit lower in the medical hierarchy, with many practitioners preferring to work in a field where cure rather than care is possible, it also means that patients who receive short-term benefit from a particular treatment are likely to continue to return to a practitioner for repeated therapy, ensuring an on-going stream of business.

These themes relating to the general function of medical specialties and the justification of their presence are relatively undisputed within my study findings. The emphasis that clinicians in India give to the creation of specialties is likely to be, at least partially, driven by the low priority given to the treatment of pain within healthcare and a desire for medical practitioners to self-promote. This position is echoed by the recent Lancet Commission

report, which specifically describes the need to endorse the practice of palliative care as a medical specialty, calling for it to be officially recognised and licensed in every country.

The professionally constructed nature of medical specialisation means that the creation and presence of each medical speciality is not replicated identically across each country of the world. Many factors are likely to be significant in this process of evolution such as specific qualities of the healthcare system, the professional regulation system and the degree of market forces.<sup>310</sup> When considering the specific case of India, the lack of regulation, the range of service providers and the dominance of the private sector are all likely to be hugely influential in the process of medical specialisation. In India, two medical specialties dedicated to the treatment of pain have begun to emerge over the last 40 years, namely palliative medicine and pain medicine. Although they are frequently referred to using other names such as palliative care or pain management, for the sake of clarity in this discussion I use the terms ‘palliative medicine’ and ‘pain medicine’. These two medical specialties are both very much still in their infancy in India, only just beginning to gain national official recognition, so in practical terms are really more correctly thought of as ‘proto-specialities’. Their constituent members are still negotiating the precise details of how these two groups should function within the healthcare system and this is very much reflected in the results of my study.

My results show that there is a strong call for both palliative and pain medicine to be ‘officially’ recognised, by the Medical Council of India (MCI). The MCI being a statutory body regulating the education and training of doctors in India which publishes a list of institutions, offering recognised postgraduate training courses.<sup>289</sup> In India, the basic medical degree is obtained by doctors trained in allopathic medicine who receive the degree of MBBS. Doctors are then eligible to go on to train in a medical specialty and obtain a higher degree. Broadly speaking these Indian higher degrees fit into two categories: MD or MS (doctor of medicine or master of surgery) programmes, and diplomas. These are listed by medical specialty and subspecialty and include the number of places or ‘seats’ available to study each course per year. Palliative medicine has recently been recognised by the MCI as a specialty, with the first MD students beginning their studies at Tata Memorial Hospital, Mumbai in 2012<sup>164</sup> and an expanding number of postgraduate training posts.<sup>311</sup> In contrast, pain medicine is not listed on the MCI approved courses either in its own right or associated with another specialty. On searching the MCI

list at the time of writing, there was one institution offering an MD in Palliative Medicine (2 seats). In contrast, in anaesthesia, 156 diploma courses were listed (625 seats) and 260 MD courses (1604 seats).<sup>289</sup> This does not include other listed subspecialty courses in anaesthesia such as paediatric anaesthesia, cardiac anaesthesia or critical care. To complicate matters further, another body, the National Board of Examinations also awards postgraduate medical qualifications called Diplomate of National Board (DNB). Again, anaesthesia is listed as a speciality of practice but neither pain nor palliative medicine is. This lack of official recognition from the MCI as well as being described as problematic by the study participants also presents problems when carrying out research in this field due to difficulties in defining the study cohort.

Outwith the official MCI recognition, the medical specialties of pain and palliative medicine have continued to evolve in India. The first pain and palliative care clinics were founded in major cancer hospitals in the 1980s<sup>312</sup> and the Indian Association of Palliative Care (IAPC) was founded in 1994.<sup>139</sup> Palliative care delivery has continued to grow across the country and this expansion is relatively well described in the literature.<sup>53,118</sup> Although less well documented, the impetus to create an officially recognised specialty of pain medicine has also grown since the founding of the national society, the Indian Society for Study of Pain (ISSP) in the 1980s.<sup>148</sup> Despite the lack of MCI recognition, members of the ISSP have recently created a group called the Indian Academy of Pain Medicine, as a step towards creating their own unified practice guidelines and system of accreditation.<sup>313</sup> Various initiatives aiming to move towards a more standardised practice are indeed underway within the fields of both pain and palliative medicine<sup>119,314</sup> and some participants describe how voluntary schemes, such as the National Accreditation Scheme for Hospitals and Healthcare Providers that require particular pain management services to be delivered, have led to improved provision albeit in isolated examples.

When carrying out this research with respect to these two emergent medical specialties, my results show (see Figures 3-2, 3-3 and 3-4) that there is considerable overlap in the membership of the societies. Broadly speaking, however, the ISSP is an organisation representing pain medicine specialists, whilst the IAPC represents those working in palliative medicine, and each has its own national conference. Due to these specialties being in their infancy with very few clinicians currently having received MCI approved training, these societies and their conferences are likely to be the best representation

currently available to study these two groups. Some ambiguity is evident, however, in the distinction between the two groups because several participants attended both conferences and are members of both societies.

In contrast to the call for the creation and registration of medical specialties, the details of what form these specialties should take, which patients should receive treatment and indeed the actual treatments they should be offered, are highly debated. I discuss these issues in the remainder of this section and the following section (4.4).

The key finding from this study relating to the function of the medical specialties is that of the overlap between the clinical remit of the two groups, as demonstrated in Figures 3-23 and 3-24. Although there are a group of attendees at the IAPC conference who only treat patients with terminal disease and a significant minority who treat one specific disease such as cancer, it is more common for participants, regardless of the conference attended to indicate that they treat all types of chronic pain. Of those who indicate that they treat only cancer patients, more than half of those who express a preference, state that they would like to be treating patients with a wider range of conditions (Figure 3-26). In the interviews, those who state that they do not want to treat a wider range of conditions often cite reasons such as a lack of resources hindering expansion, rather than the fact that patients should not be receiving their care.

The fact that this early growth of these two specialties in India is occurring at a time when palliative care on the international stage is widening its clinical remit is particularly pertinent. As I explained, the definition of palliative care is contested both between and within countries and indeed the participants in this study do not have entirely consistent views, however, the IAPC appears to be encouraging an inclusive interpretation. Their website contains a definition of palliative care that includes helping patients with ‘life-limiting illness’<sup>315</sup> – arguably a broader definition than the WHO’s ‘life-threatening’ conditions. At the time of writing, a workshop is also advertised on the IAPC website with the headline ‘Palliative care for all “All diseases, all stages and all settings.”’<sup>315</sup> This is also very clearly demonstrated in the Lancet Commission report in which, despite considerable effort by the authors to give clarity to the specific medical conditions that are being targeted by the Commission, there is a significant degree of ambiguity and indeed contradiction in the writing. For example, they state that they “decided not to focus on

acute or chronic health conditions that are not life-threatening or life-limiting, including chronic, non-malignant pain<sup>3(p11)</sup> but they also list amongst the 20 conditions included in the SHS metric “injury” and “musculoskeletal disorders”.<sup>3(p14)</sup> As a practising clinician I find it very difficult to see the distinction between these groups, and indeed I struggle to think of a condition causing chronic non-malignant pain that is not incorporated in the list of 20 conditions described as contributing to SHS.

It is important to be clear here when considering my study findings, that those who consider themselves to be specialists in pain medicine, as opposed to palliative medicine, are also treating patients with the same inclusive range of medical conditions. Of note, a few participants describe a desire to be less inclusive in the medical conditions they treat, due to an enlarging knowledge base that requires further sub-specialisation, for example when treating conditions of the spine. Furthermore, not only is debate occurring at a global level within palliative medicine, but professionals who consider themselves to be specialists in pain medicine are also questioning the nature of their specialty. For example, recent scientific advances particularly in imaging techniques have led to greater awareness of the physical changes that may be common to some of these conditions and this in turn has led to the call for chronic pain itself to be afforded the status of a disease in its own right.<sup>182,316,317</sup> Despite the argument that this re-classification could raise the profile and increase research funding into effective treatments, the description of chronic pain as a disease is debated.<sup>183</sup> Interestingly, despite the growth of organisations such as the International Association for the Study of Pain, which at the time of writing has, including the ISSP, 95 national chapter societies,<sup>318</sup> pain medicine is not recognised as a specialty in its own right, in many countries, including the UK and the USA, often being a subspecialty of anaesthesia.<sup>13-15</sup>

My results also demonstrate a close relationship in India between the fields of anaesthesia and those that focus on the treatment of pain. Not only do participants from both specialties treat a very overlapping cohort of patients but they have also evolved from the parent specialty of anaesthesia, with the majority of practitioners who gave details of their higher degree having received their early training in this field, shown in Figure 3-46. However there are also some notable differences between the two professional groups. When considering the profession of the attendees at the conferences, there is only one participant at the ISSP conference who is not a doctor, as shown in Figure 3-19. In contrast

nearly half of the IAPC respondents are not doctors, as shown in Figure 3-20, with volunteers, social workers, physiotherapists, psychologists and nurses all represented. This is also reflected in the membership criteria of each society with all professions and volunteers able to join the IAPC whilst only doctors are eligible to take full membership status in the ISSP.

Despite there being significant overlap in the medical conditions that the two specialties treat, and in the original training of many clinicians being in anaesthesia, there are striking differences in the preferences for different treatment strategies between the two groups. I consider this area in more detail in the following section (4.4) but in summary, there is a focus within palliative medicine on improving access to opioid medications, and a relative lack of attention given to the use of interventional techniques such as nerve blocks. In contrast, at the ISSP conference there is a strong predominance of interest in interventional treatments, reflected both in the conference programming and in the treatments offered by the study participants. This difference in practice and a lack of collaboration between the specialities was noted to be a hindrance to improving the provision of pain management. This demonstrates one potential, negative consequence resulting from the treatment of pain being a professionally constructed phenomenon.

As a result of the relatively recent evolution of the two specialties in India, participants often describe themselves as pioneers in their field and of having to overcome significant difficulties when they began their careers (presented in Section 3.9.1). These include tolerating unpleasant treatment from unsupportive colleagues and of putting together their own training programmes, often incorporating time working overseas and learning clinical skills from written materials. They also describe having to make a personal financial sacrifice when entering a job either in the charitable sector with low remuneration or in the private sector with an initially very small client base. When considering those working chiefly in government or charity sectors (although this is not exclusively those working within the field of palliative medicine) participants talk of a specific calling and of how despite taking a financial salary hit this is more than made for up by the personal satisfaction – sometimes even describing this in spiritual or religious terms. Some working in palliative medicine explain how the specialty is unglamorous and unpopular. In contrast, a few working in pain medicine, talk of the desire to have a better identity when compared to playing a supporting role as an anaesthetist to a surgeon.

Furthermore, although the two groups of respondents from each conference were not selected to enable quantitative, statistically significant comparisons, Figure 3-10 shows the differences between the two specialties with respect to the percentage of patients receiving their treatment free of care, with the IAPC group tending to treat a larger proportion of their patients free of charge. Of course this is not an absolute distinction with many who work chiefly in the private sector also undertaking charitable work and those working chiefly in the charitable sector working privately to supplement their income.

These variations in financial structure and clinician motivation add to a wider debate surrounding the funding of healthcare across the country as a whole and particularly with respect to care delivered in the corporate private sector. During one of the IAPC conferences a debate was held called ‘Developing Palliative Medicine is a threat to the corporate world of medicine and specialist physician.’ Tying this in with the idea that palliative medicine is described as being suitable for all patients at all times, there is a suggestion that palliative medicine itself, in the Indian scenario, is actually about providing affordable, holistic care, rather than about treating patients with particular medical conditions at a particular time in their lives. One particularly clear example of this is the highly successful and widely cited model of community based palliative medicine originating from the southern Indian state of Kerala, known as the Neighbourhood Network in Palliative Care or NNPC.<sup>145</sup> In the NNPC patients are identified on the basis of need rather than following a medical diagnosis. In other words, patients are given care, regardless of their underlying disease (as defined by allopathic clinicians) simply if they have symptoms that can be treated. Although the degree to which this model can be successfully transferred to other geographical regions is debated, even within India,<sup>312,319</sup> the local success demonstrates that palliative medicine or palliative care may be conceptualised as a social movement capable of revolutionising healthcare, rather than simply as a subset of western or allopathic medicine. In this scenario the dominance of the medical profession is potentially reduced. The treatment of pain moves away from being solely a professional construction and towards a more Foucauldian model of social construction, with increased influence from patients and the wider community.

## **4.4 Treatment Selection**

I have demonstrated that the medical specialties of pain and palliative medicine are largely professionally constructed phenomena, in part created in response to the increasingly widespread belief that pain is a problem to be fixed with medical treatment. A key element of many of the functions of medical specialties and indeed a key driver in the processes that create them, is the specialist knowledge base that members of the group create and control.<sup>307</sup> I focus in this section (4.4) on the treatments that healthcare workers offer to their patients and crucially on the variation in clinicians' normative positions. Despite a clear consensus amongst my research participants on the adoption of the idea that pain should be medically treated, I demonstrate how the specifics of what form this treatment should take are far more widely contested. Some differences are clearly seen between the specialties of pain and palliative medicine, but there are also debates regarding treatment selection within each of these two groups.

The vast majority of the advocacy work and the resulting literature in the field of pain treatment, at least at a global level, has been dedicated to improving access to opioid medications for patients suffering in the terminal stages of disease, and in particular cancer. This work is primarily targeted towards improving access for populations in the global South.<sup>59,68,69,73,320</sup> Many high profile international organisations such as Human Rights Watch,<sup>121</sup> the World Health Organization<sup>1</sup> and most recently the Lancet<sup>3</sup> have taken up this cause, working alongside internationally focused palliative care groups. However, I argue, as have others,<sup>1,166</sup> that it is also important to consider opioid use in patient groups other than those suffering in the terminal stages of disease. This is particularly pertinent in India where, as I demonstrated, patients treated under the remit of palliative medicine are not always suffering from life-threatening illnesses. Although I touched on the limitation of western medicine's simplistic conceptualisation of pain as a problem to be fixed, the complexity of the phenomenon is acknowledged to a certain degree by clinicians working in both palliative and pain medicine who describe pain as consisting of social, psychological and physical components. Members of both specialties also advocate the use of treatment strategies that involve multiple modalities other than opioids in order to address each patient's pain in its entirety. I argue that it is therefore pragmatic to consider the availability of a wider range of treatment modalities. In the following sections I discuss the

availability of multiple treatment strategies including pharmacological and non-pharmacological therapies.

#### 4.4.1 Pharmacological Treatment Availability

Countries are required to report their annual consumption of strong opioid medications to the International Narcotics Control Board. This data, which is regarded as corresponding to access levels within each country, are collated and published by the Pain and Policy Studies Group (PPSG) at the University of Wisconsin. The latest available data published by the PPSG for 2015 ranks India's per capita morphine usage at 117 out of 144 countries.<sup>321</sup> The PPSG has also played a key role in the high profile study, the Global Opioid Policy Initiative (GOPI) published in 2013, which details the availability of opioids in India, as part of a global project.<sup>59</sup> The GOPI study data for India concentrates on describing availability of several opioid preparations at state level.<sup>2</sup> Small numbers of key informants describe the availability of each medication as categorical data, with a single rating given for each medication in each state. The study includes data for every preparation of morphine and other strong opioids (oxycodone, methadone and fentanyl) as consistently being available either 'never' or 'occasionally' in each state. This ambitious project has created extremely valuable data from many regions of the world, that can be used as a tool for comparison between regions, to monitor change over time within a region, and more widely as an advocacy tool to improve availability. Indeed the data from my study as presented in Figures 3-27 and 3-28 confirm the low availability of opioid medications especially when compared to the availability of non-opioid medications (in Figures 3-27 and 3-29). Even the cheapest, most readily available strong opioid (injectable morphine) is only available 'always' for fewer than 50% the questionnaire respondents.

I argue that whilst the GOPI study data allows for comparison between different groups and times, its simplicity is also a potential weakness, as it inevitably fails to capture more complex patterns of availability within each region or state. This is also true of the recent Lancet Commission report, which depicts opioid access data for each country on a world map, but fails to demonstrate differences that occur within each nation. In contrast, my study focuses on only one country and therefore allows for more detailed analysis of in-country variation. My data drawn from multiple participants working in a variety of

clinical settings, demonstrate these variations in availability within states and even within individual institutions. For example, when injectable morphine, the strong opioid preparation with the highest availability is considered for each state represented in the study, there is considerable variation within the availability patterns, shown in Figure 3-31. No state with more than two respondents reports consistent availability ratings. Similarly when considering the availability of weak opioids such as codeine and tramadol, although availability is broadly higher than for the strong medications there is still variation within states. When considering the availability of codeine, my results in Figure 3-32 show that in the state of Bihar codeine is 'usually' or 'always' available, whereas data from the GOPI study describes the medication as 'never' available. Whilst this could represent a change in availability during the time the two studies were undertaken it is likely that it reflects the complex picture of variation in availability. My results also show variations between urban and rural availability, and between different healthcare sectors. For example there may be much better availability in the well-funded corporate institutions.

My results also show variation that occurs within individual institutions. For example morphine may be available in one department of a hospital, such as in a palliative care or oncology department, but not in other areas of the same institution where it could be of use, such as in operating theatres or in emergency departments. In practice this means that patients suffering from pain that is amenable to treatment with cheap opioid medications are only able to receive the treatment if they have pain caused by a particular disease such as terminal cancer and are unable to receive it to treat pain following surgery or trauma. Whilst some participants in the study do not consider improving the availability of morphine to treat pain following surgery or trauma (acute pain) to be a priority, others are keen to raise it as a concern.

The underlying causes of the low accessibility of opioid medications at an international and local level are also well described in the literature, largely in relation to use in the field of palliative care. These causes, or barriers as they are usually termed, are commonly described as falling into three main areas namely: overly complex or stringent legislation, low levels of education amongst healthcare workers and wider society, and issues surrounding the availability and cost of pharmaceutical preparations.<sup>1,53,73,118,322</sup> Of note, in India the narcotics laws are described as particularly complex with legislation varying between states<sup>2</sup> and there are also widespread reports of poor quality control within the

pharmaceutical industry.<sup>161</sup> The results from this study confirm the presence of each of these barriers with participants talking of problems of medication supply and quality, complex policies and education deficits, largely but not exclusively with respect to the use of opioids within palliative care.

Data related to the availability of non-opioid analgesics is limited<sup>89</sup> and there are no large scale studies published of availabilities in India that parallel the GOPI and PPSG data. There is, however, a body of work relating to improving the availability of all medications that are included in the *WHO Model List of Essential Medicines*<sup>36,90</sup> and a more recent drive to increase the presence of particular non-opioid medications on this list.<sup>63</sup> Data from my study (Figure 3-27) show that although, broadly speaking, non-opioid medications are available more often than opioids, none of the medications included in the study are available to all respondents all of the time. This therefore includes all of the analgesic medications included in the *WHO Model List of Essential Medicines* (Figure 3-30). The Government of India also produces its own country specific list of essential medicines<sup>323</sup> which whilst very similar to the WHO list, does contain some differences. Of note, two pain medications that are included in the WHO list but not the India specific list, namely oral codeine and rectal non-steroidal anti-inflammatories, have relatively low reported availability in this study.

#### 4.4.2 Non-pharmacological Treatments

Several organisations have published recommended standards for the provision of pain management which encompass a wider range of treatments than pharmacological therapy alone, such as the IAHP's *List of Essential Practices in Palliative Care*,<sup>324</sup> the IASP's *Desirable Characteristics of National Pain Strategies*,<sup>325</sup> and local initiatives from the IAPC.<sup>119</sup> However, these lack the detail and specificity of the *WHO Model List of Essential Medicines*. For example, the need to work as a team and to address psychological aspects of pain is widely noted but precisely how this should be delivered is not specified in detail. Similarly, as I outlined above, published data of treatment modality provision beyond the availability of opioids is lacking. In contrast, in this study I included data on the availability non-pharmacological treatments. The results as presented in Figure 3-38 show that there is generally low availability of all modalities of non-pharmacological therapies.

Of those I included, physiotherapy is the most frequently available ‘always’ but even this is only true for fewer than 60% of the respondents. None of the treatments are available all of the time for all respondents.

I discussed in the previous section how there are differences in the range of professions that are represented at the ISSP and IAPC meetings. As shown in Figure 3-39 many respondents from both the ISSP and IAPC groups do not have a multidisciplinary team available all of the time. Specifically, only 50% and 65% of ISSP and IAPC respondents respectively have a multidisciplinary team available ‘always’ or ‘usually’. However, the presence of a wide range of professions at the IAPC meeting does demonstrate a particular emphasis from this group on the need to work collaboratively across disciplines. With the high numbers of volunteers working in palliative care, some of whom are professionals visiting from overseas, it is possible that some patients will receive more holistic care in the charitable sector where resources may, in general, be particularly scarce.

The use of interventional techniques, such as nerve blocks, is particularly notable due to the frequency and manner in which participants describe them. When considering this category there is a particular difference between the responses from those at the IAPC conference and those at the ISSP meeting, as shown in Figure 3-40. All but one ISSP respondent state that these interventions are ‘always’ or ‘usually’ available. This is also reflected in the contents of the agendas of each conference with a particular predominance of discussions on interventional techniques at the ISSP meetings. The difference in availabilities of these treatments between the two conferences is especially noteworthy when considered in conjunction with the data showing that there is significant overlap in the medical conditions of the patients that are being treated by each speciality. A particular barrier to increasing the availability of nerve blocks specific to India was also noted in relation to the regulation of the use of ultrasound machines, which has occurred in an attempt to reduce foetal gender identification. In other countries ultrasound is increasingly being used to enhance the accuracy and safety of nerve block techniques. Of note even those working in the corporate sector describe how scarce resources prevent them from carrying out more sophisticated treatments, as demonstrated by the universally low availability of complex interventions (Figure 3-41).

### 4.4.3 Variations in Treatment Selection

Alongside the differences in the treatment availabilities reported (as discussed in Sections 4.4.1 and 4.4.2), there is also variation in the treatments that the respondents feel *ought* to be available. In other words the normative positions of clinicians vary. This variation is evident in my data when considering both pharmacological and non-pharmacological modalities. I argue that a lack of understanding of these differences in normative position, of how they arise and in turn affect the practice of pain management, is contributing to some of the lack of progress seen in this field at local and global levels. This is directly related to the idea that the medical management of pain is a professional construction.

Although the majority of respondents, as shown in Figures 3-33 and 3-34, wish to be able to offer a wider range of treatments, this is not a universal position. Furthermore, my data demonstrates variation in the desire of practitioners to increase the availability of opioid medications. As shown in Figure 3-35 there is a group, albeit a minority, who despite not having morphine and other opioid treatments available all of the time indicate that they do not want to have a wider range of treatments available. This is also the case with other medications and formulations that are included in the *WHO Model List of Essential Medicines*, as shown in Figure 3-37. I have shown from my data that there are discrepancies between Indian clinicians in the degree of acknowledgment that access to strong opioids is problematic outside of the palliative care setting. Specifically some clinicians do not consider the low levels of opioid available to treat those with injuries in emergency departments or following surgery as an issue that needs to be addressed. This is in contrast to the position of the WHO which explicitly describes the need to improve the treatment of pain in these conditions as a part of its Access to Controlled Medications Programme.<sup>1</sup> Even the Lancet Commission report with its focus on palliative care, notes the importance of treating pain following surgery and trauma, and indeed states that opioids are often indicated in these scenarios.

Similarly, there is no universal view regarding the desire to increase the availability of non-pharmacological treatments and in particular interventions such as nerve blocks. Although the majority of the clinicians in the study have trained in anaesthesia (where interventions are a core part of practice) there is a range of opinions regarding the use of these treatments. Some respondents at the IAPC conference indicate that they would

indeed prefer to perform more interventional procedures and describe the barriers to achieving this, such as a lack of education in knowing when such techniques could be used, a lack of technical expertise, and a general lack of resources in manpower and facilities. Others state that there is little clinical need for such procedures. Some take a more utilitarian stance, explaining that although in a world of unlimited healthcare and funding they would use interventions, the investment needed to help the few people that would benefit would not be a pragmatic use of resources. Some specifically explain how they have modified their practice over time and moved towards using nerve blocks less frequently as they have gained a deeper understanding of the need for a more holistic approach to treatment. Others even talk of the notion that performing interventions is seen as an easy way to earn money, referring to ‘block shops’ – clinicians that are motivated to perform procedures for personal financial gain. This variation in the use of interventional procedures, particularly within palliative care, is also reported in other countries including the UK.<sup>326,327</sup> Furthermore some have stated that in particular settings where access to opioids is restricted, interventions may play a particularly important role in pain management.<sup>86,328</sup>

Interestingly in the survey data, when I asked people to name the treatments which they would like to be available, although some mention wanting more medication, only two people specifically name an opioid – both saying they would like to have fentanyl patches available. Many respondents indicate that they would like to have one or more of the non-pharmacological treatments available. It is possibly that the ordering of the questions with this one following directly on from the non-pharmacological availability question meant that this topic was more likely to be mentioned due to being at the front of respondents minds. Regardless of whether respondents have a stronger preference for increasing the availability of pharmacological or non-pharmacological treatments, it is highly likely that there is general desire to increase the availability of non-pharmacological treatments.

Variation in treatment selection amongst clinicians is a well described phenomenon across the practice of medicine<sup>190,329</sup> and is also specifically noted to occur when treating pain.<sup>193,194,326,327</sup> This decision making process is influenced by a combination of factors including the characteristics of the patient, the clinician and the healthcare setting<sup>192,195-198</sup> and can therefore be considered to be, at least in part, professionally and socially constructed.<sup>330</sup> To examine this process in more detail, the knowledge drawn upon by each

clinician can be considered to be a combination of various different types of knowledge including scientific, experiential, social and political.<sup>199,237</sup> So, in this study when considering the use of interventional techniques, participants draw on experiential knowledge – they describe how their training in anaesthesia drew them into the field of pain management, whereas others explain that they have now moved away from such treatments having come to realise that other modalities can be more effective. They describe how during their training they drew on scientific knowledge gleaned from academic journals, books and conferences. Participants also demonstrate the use social and political knowledge when deciding that the financial outlay needed to provide interventional treatments would benefit too few patients to be considered practical. The more senior clinicians in particular explain how as pioneers in their field they frequently had to seek out knowledge themselves, directing their own training without guidance from local mentors. It is likely that this will further contribute to the variations seen in the current specialist knowledge base and the normative positions of practising clinicians.

Having demonstrated the contested and professionally constructed themes that arise from the results of this study in relation to the conceptualisation of pain as a medical problem, the formation and function of medical specialties dedicated to treating pain and the clinical strategies employed to manage pain, in the following section I discuss in more detail the dynamic social processes that result from these disparate views.

#### **4.5 Power and the Policy Process**

The huge numbers of patients described as requiring palliative care or suffering with chronic pain, and the impact this has on society, has led to the call in recent years for pain management and palliative care to be addressed as public health issues.<sup>111,112,331,332</sup> This conceptualisation leads on to the idea that these complex, multi-faceted problems should be tackled at a population level, requiring inclusion in national healthcare policy. Indeed in 2014, the World Health Assembly unanimously adopted a palliative care resolution describing the need to incorporate palliative care into national healthcare policies<sup>332,333</sup> and the Lancet Commission report continues this trend. However, critical evaluation of the processes involved in this incorporation, particularly with reference to the extensive

academic literature base from the social and political sciences is lacking, and is therefore the focus of this discussion section.

To demonstrate the relevance of this approach to this study, I refer to Jan Stjernsward and colleagues' 2007 paper describing the WHO Public Health Model<sup>104</sup> (Figure 1-1) as a system for guiding the integration of palliative care into a country's healthcare system. The model highlights the need to address four key factors, depicted as education, drug availability and implementation, interlinked in a triangle, underlying the umbrella of policy. Whilst the authors acknowledge the need to take into account other local factors, such as engagement with influential figures and the specifics of each area's healthcare system due to the effects these will have on the policy's creation and implementation, they make little reference to theories from the social and political sciences. Furthermore, they do not acknowledge the assumptions and limitations of the components of the model. However, the results from my study show that each of the four elements of this model are in fact the subject of debate between members of the medical profession practising in India. Specifically, there are differences in professional opinions even amongst specialists, regarding the manner in which pain management should be delivered to individual patients and across the country, with the use of opioid medications being a particularly contentious topic. At a fundamental level there is even a lack of uniformity within the medical profession and across wider society surrounding the notion that pain is a medical problem to be fixed.

The importance of integrating a social constructionist perspective in to the analysis of the policy process is well described,<sup>334,335</sup> and I discuss the professionally constructed themes, highlighted above, that have arisen from my research data with reference to key policy theories. Whilst acknowledging that the term 'policy' itself is open to interpretation and is the subject of numerous, complex definitions,<sup>208</sup> here I use a broad definition of the word as a set of decisions made by those in authority. Hence, I consider local clinical practice guidelines, national specialised training standards and healthcare management strategies in individual institutions, all to be policies. I explore the stages of the policy process<sup>211</sup> (Figure 1-4) in turn, referring to Walt and Gilson's policy triangle<sup>209</sup> (Figure 1-3) as a framework to aid analysis.

To be clear, the aim of my research is to critically evaluate the practice of clinicians and therefore in this discussion I demonstrate the multiple ways in which *one* group of actors affects the dynamic social system that is the policy process, rather than describing a complete picture of every actor involved. Focusing on the treatment of pain as a profession construction, I show that clinicians act as individuals and as members of larger organisations such the Medical Council of India, the WHO, the ISSP, the IAPC, the International Association for the Study of Pain and the International Association for Hospice and Palliative Care.

#### 4.5.1 Agenda Setting

The agenda setting stage of the policy process is concerned with how a particular issue gains attention – from both the public and other relevant actors.<sup>211</sup> Participants in this study describe how pain management is low on the political agenda, being afforded only limited priority within the healthcare system. The results also show that clinicians consistently describe one of the key barriers to the improvement of pain management to be a lack of awareness amongst clinicians, patients, managers and politicians regarding the importance of treating pain within the medical setting. They also universally describe pain as a medical problem to be fixed.

This agenda setting stage of the policy process wherein political priorities are formed is described by Shiffman and Smith<sup>231</sup> as being influenced by four elements: actor power, ideas, political contexts and issue characteristics. Building on Walt and Gilson's policy triangle this framework highlights the importance of considering how an issue is framed by actors, that is, how it is publically depicted,<sup>230</sup> as well as understanding how power is negotiated within the wider socio-political context. With reference to my results, firstly, I discuss power and secondly the framing of pain as a medical problem to be fixed.

In relation to this study and the agenda setting stage, one of the ways in which clinicians or actors, describe asserting their power in order to raise attention of the need to treat pain, is through exchanging knowledge (presented in Sections 3.8 and 3.9). Implicit here is the notion that a superior knowledge base exists within the medical profession that requires dissemination to others. Participants in the study identify many different tools that are used to perform this knowledge exchange depending on the characteristics of their target

audience. For example, they describe exchanging knowledge with other clinicians starting at medical and nursing school, and call for the mandatory inclusion of pain management in the curricula at an early stage of professional training. They also talk of the need to improve specialist education by streamlining national training and delivering CME (continuing medical education) programmes to colleagues. While some of this work is carried out as individuals, participants also describe how they work through larger professional organisations such as the ISSP and IAPC to wield power collectively. They also talk of influencing these processes through lobbying professional colleagues such as the Medical Council of India (MCI) and international organisations specialising in pain or palliative medicine. For example, they explain that if members of the MCI can be persuaded of the importance of treating pain then they can potentially ensure pain training is compulsory for medical students and that specialist MD programmes are widely available across the country.

Other professional groups are also described in this study as potential targets of influence such as politicians who can change national or state level healthcare policy, local managers who can alter the distribution of resources within an institution, pharmaceutical companies who can control the price and availability of medications and clinical devices, and health insurance companies who decide which treatments to fund. Of note, each of these actors has some degree of influence in the allocation of scarce resources that are highlighted as particularly problematic within the diverse healthcare system of India.

Participants also describe knowledge exchange strategies targeted towards patients or potential patients, such as pain camps, media work and direct marketing campaigns. They explain how demand for medical pain treatments and care from specialist physicians will increase if the public are more aware of the possible treatment options available and the existence of trained clinicians.

Each of these strategies of knowledge exchange aims to increase the number of patients who seek specialist medical attention for the treatment of pain. However, this desire to increase demand and the competition that arises between clinicians results in power being contested in terms of money and status, as well as knowledge. This competition within the profession is widely remarked upon by participants in the study, who describe the need to increase the number of referrals they receive from both medical colleagues and directly

from patients. The presence of individual private practice where a clinician is paid per treatment, as opposed to a fixed system of remuneration, which remains constant regardless of the number of patients seen, leads to some individuals attracting patients' custom for their own financial gain, and this study supports the presence of this phenomenon through the description of 'block shops'. A clear demonstration of how power may be wielded by clinicians who directly benefit from their own professionally constructed description of pain as a medical problem.

However, the study also demonstrates that the desire to increase referrals is not only or always financially driven. There are many examples of participants making enormous personal and financial sacrifices in order to provide the very best service they can for patients. They talk of working closely with colleagues to complement each other's skills and of how finances are not their motivator. Nonetheless, competition is also not the sole preserve of the private sector or those seeking financial gain. Those working in the charity and government sectors are also keen to persuade patients to access their services. Without patients' demand, there would be no service and no employment for themselves as healthcare workers. Participants working in the charity sector entirely free of charge talk of the need to encourage patients to attend.

To be clear when it comes to the discussion of competition, the need to attract new referrals is not simply about encouraging patients to seek medical advice for their pain but also about persuading them to choose a doctor trained in a particular medical specialty. So, participants in this study explain how there might be a reluctance to refer on to a colleague despite them having a more appropriate skill set, to the detriment of the patient.

As an aside but related to the descriptions of competition, is the issue of corruption. Within medical practice in India, corruption in the form of taking extra payments is widely reported<sup>133</sup> and although no one explicitly describes examples of this occurring, they do, on occasions, make it clear that they do *not* take extra money. In doing so, they therefore imply that others working in the medical profession do indeed request or at least accept additional financial payments. In one hospital I visited signs were clearly displayed throughout the institution stating that bribes would not be tolerated.

Moving on from descriptions of how the clinicians as actors in the process of agenda setting wield their power, I now consider the various ways that the issue of pain treatment is framed during this process. An issue can be framed, or conceptualised and publically portrayed in many different ways.<sup>336</sup> In their framework, Shiffman and Smith incorporate two categories of frame – ‘internal’ and ‘external’.<sup>231</sup> The internal frame relates to the depiction of an issue within the group of actors that are initiating the policy process, in this case clinicians. In contrast, the external frame relates to the portrayal of the issue to external actors, such as patients or managers. A key consistent finding from my study is the framing by clinicians of pain as a medical problem to be fixed, demonstrating a coherent internal frame within this group. Many of the descriptions of how the profile of pain management should be improved relate directly to this framing of pain as a medical problem. For example, some describe the need to get their fellow clinicians to consider pain a symptom worthy of treatment rather than concentrating on disease modifying or curing therapies, as well as the need to educate colleagues on more specific clinical areas such the appropriate use of particularly complex treatments. In contrast, I have also shown, that the study participants describe other groups in society, even patients and other clinicians, as needing to be persuaded of this fact, thereby demonstrating the contested nature of this external frame.

The widespread descriptions in this study of the need to create the medical specialties of pain and palliative medicine also directly draw on this framing of pain as a medical problem. This relates to encouraging junior doctors to choose pain or palliative medicine as a career, and also to maintaining and raising standards of training and practice in the field. They talk of the role organisations such as the MCI, as well as politicians can play and of how these authority figures can be lobbied from below so that they in turn exert more top-down pressure. Some of this work can be taken up or at least supported by the professional organisations, the ISSP and IAPC, who then act as intermediaries between individual members and larger national or international bodies. Furthermore, they explain that by persuading others including clinicians and the MCI of the importance of describing pain and palliative medicine as medical specialties, the profile of this area of clinical work is raised. In turn, this leads to more authority figures such as managers and politicians being persuaded to allocate more of their resource to the field. Crucially in this context, participants explain how competition to attract patients to visit a particular healthcare

professional is compounded by the relative youth of the specialities and the resultant low levels of awareness of their presence.

When considering descriptions in the study of the need to persuade patients that pain is a problem to be fixed there is an acknowledgement of a difference between populations in India when compared to the global North. There is both an understanding that things are currently different in India - people will tolerate different levels of disability or suffering, but also that times are changing, and with increasing prosperity there is increasing demand from patients. Participants specifically explain that patients themselves should not tolerate pain as they have done in the past. They describe how if patients themselves are persuaded of the benefits of seeking treatment for their pain, both they and their families will start to demand better levels of treatment availability. This increase in demand from patients will in turn influence clinical managers and politicians to increase the provision of services. Clinicians therefore demonstrate how they wield power as knowledge, using their professionally constructed model to influence other members of society.

The framing of pain as a treatable medical problem is also at the heart of the calls, described in this study and many others,<sup>2,3,53,121</sup> to alter specific policies that are already in place, the most notable being the desire to simplify complex legislation surrounding the use of opioid medications. Similarly, although there has been some state level implementation<sup>337</sup> there are calls from within the medical profession and particularly the palliative care community<sup>338</sup> to incorporate the provision of pain and palliative care services into national healthcare policy in India.

#### **4.5.2 Policy Formation**

The descriptions above of how pain is framed by professional practitioners as a medical problem and of how this is, in turn, used within the agenda setting process, through knowledge exchange, to raise the profile of the work of pain management clinicians, are relatively universal within my study findings. For example, the need for nationally coordinated specialist training, the need to persuade managers and politicians to fund pain management services and the need to encourage patients to seek medical advice for their pain. My results also show, however, that the specific detail of the much of the *content* of the knowledge that is exchanged in this process is far more widely contested. This is most

clearly demonstrated by the variations in participants' views regarding treatment selection. In this section, I explore the practical relevance of this debated issue in more detail using the particular example of clinical practice guidelines (CPGs) drawing on theory related to the use of evidenced based medicine (EBM).

The results of this study show that clinicians consider there to be significant variations in the quality of practice in pain management in India, and talk of the need to raise standards and improve clinical care by increasing uniformity of practice. Alongside streamlining education and training at a national level, one of the strategies they highlight is the need to create national CPGs. As I outlined in the opening chapter, however, from a theoretical perspective, CPGs are in part professionally constructed, and their creation, which specifically includes the incorporation of EBM, can be considered to function as a dynamic process involving multiple actors and contests of power.<sup>234,237,238</sup> In order to analyse this process with respect to this study I draw on the framework created by Dobrow and colleagues,<sup>241</sup> introduced in Section 1.4.2, in which they describe three stages of evidence utilisation: introduction of evidence (including evidence selection), interpretation of evidence and application of evidence. At each stage, various context factors, which can be internal, such as the individuals involved and the structure of the process, and external, such as the healthcare and political environments, affect the process.

When considering the creation of pain management guidelines by doctors in India, Dobrow and colleagues' framework can help us understand the various factors affecting this process. Whilst some academics have argued that a deeper understanding of this process is more fundamental to improving healthcare than simply an increase in the content of the evidence base,<sup>206</sup> participants in my study emphasise the limited locally relevant evidence base, with the majority of research being extrapolated from studies carried out in the global North. They also describe the barriers that exist to increasing the amount of relevant research such as a lack of expertise, time and money.

Despite essentially having access to the same evidence base, the individual clinicians in my study differ in their real world selection of treatments and in their views about what ought to be available, that is, their normative positions. For example some argue passionately for increased availability of opioid medications whilst others see the lack of access to opioids as a reason to look to other modes of treatment. This demonstrates

variation in how clinicians select, interpret and apply evidence in their individual practice, which is therefore likely to be reproduced during the CPG formation process.

The study participants also describe some of the factors that are likely to contribute to the variations in treatment preference seen in the research. Within Dobrow and colleagues' framework, these can be considered to be internal, individual factors that contribute to CPG formation. For example, there is a general lack of consistency in training that participants have received in pain management, often creating their own training programmes, working overseas or learning from books rather than through direct clinical care in India; demonstrating the use of various types of knowledge besides the scientific, such as social and experiential. Participants in my study specifically describe a lack of training amongst clinicians, in research methods and evaluation.

Personal subjectivity is specifically described in the literature as affecting the creation of CPGs.<sup>236</sup> In my study, when describing their individual motivation for choosing a career working in pain or palliative medicine, several participants describe being particularly attracted to certain modes of treatment such as the use of interventional techniques or the use of a multidisciplinary, holistic model of care. This personal preference for using a particular modality will be very likely therefore, to affect the decision making of each clinician in selecting, interpreting and applying scientific evidence.

Continuing with Dobrow and colleagues' model, the external healthcare environment of the healthcare system in which clinicians operate, will also influence the CPG process. My results show the differences in opinion between allopathic practitioners, but there are many other professional healthcare providers working in fields such as AYUSH. There are also huge variations in the funding of care seen between different allopathic institutions. These variations will only increase the difficulties in reaching consensus on the content of national CPGs.

It is also important to appreciate the direct role that financial resources can have on the CPG creation process. The role of the pharmaceutical industry in directing the focus of medical research is well described.<sup>203</sup> My study findings show that a lack of funding for research is a specific barrier to carrying out this work, which potentially leaves many researchers reliant on pharmaceutical and device companies. Furthermore, the presence of

financial conflicts of interest is common amongst the authors of CPGs<sup>245</sup> and a recent set of published guidelines for the pharmacological treatment of pain in India includes an employee of a pharmaceutical company in the list of authors.<sup>339</sup>

### 4.5.3 Policy Implementation

To continue the concept that clinical guidelines are a form of policy,<sup>340</sup> the final stage in the policy process that I discuss here is implementation. The aim of clinical guidelines is to improve quality by ensuring all patients receive the most appropriate treatment from appropriately trained individuals in a safe environment. In doing so, variability in practice is reduced and unnecessary procedures are not performed. However, when considering pain treatments in India, my results show variations in implementation of guidelines as well as debate regarding their content. Specifically, my study shows that not only is there variation in opinion within the medical professional as to what constitutes *ideal* practice but there is also variation in the pain management services that *are provided* by different healthcare institutions, reflected for example in the different availabilities of particular treatments.

To consider this process of implementation in more detail I refer to Walt and Gilson's policy triangle (Figure 1-3) in which the importance of appreciating the context, as well as the power relationships between different actors involved, is highlighted. When considering the context of the Indian healthcare system, professional regulation is limited, healthcare policy varies between each state, there is a scarcity of resources, and low levels of health insurance coverage with most patients paying for treatment out of pocket. In addition, my study shows that the training of professionals treating pain in India is variable and that clinicians work in a wide range of institutions. Each of these features of the local context is likely to contribute to local variation in implementation of national CPGs.

In the preceding sections I have shown how clinicians themselves wield power during the process of agenda setting and in the creation of CPGs, demonstrating a degree of top-down influence. Doctors also play a fundamental role and hold significant power during the implementation stage.<sup>341</sup> Therefore, a purely top-down, rational explanatory model of implementation, in which policy is enacted precisely as directed by a central decision maker, is highly unlikely to be representative when considering the use of CPGs in this

particular context, due to its failure to incorporate both the complex power dynamics present and the contested nature of the scientific base.<sup>340</sup> My study shows that through their selection of different therapeutic strategies, doctors enact power when treatments are actually offered to patients. In doing so, regardless of the content of CPGs, clinicians hold significant power when implementing such guidelines, whether or not they are involved in the process of creating them. That is, they are enacting power from the bottom-up, working as Lipsky described as ‘street-level bureaucrats’.<sup>246</sup> In this role, the elite professional status of doctors should also be noted, because their decisions are more likely to be unchallenged.<sup>249</sup>

Acting as street-level bureaucrats, my results demonstrate that clinicians’ treatment choices frequently differ from those of their colleagues. Furthermore, clinicians in my study also talk of influencing the opinions of other actors in the implementation process. They explain how this can be achieved through awareness strategies focused on improving access to particular treatments. These are aimed at several groups such as other healthcare staff, managers, politicians, insurance companies, patients and wider society. In doing so, they are also reinforcing their own actions in the implementation process. Similarly, participants also talk of strengthening the top-down process of implementation by influencing policy makers such as managers and politicians who control the distribution of scarce resources, and by creating their own organisations in the form of professional societies to strengthen their position throughout the policy process.

Finally, but perhaps most pertinently, due to the very low levels of health insurance and the fact that the majority of patients pay out of pocket for their treatment, the power of individual patients and their families is profoundly important. The results of this study confirm this, as participants frequently describe how patients need to be persuaded to pay for pain treatments and of the importance of increasing awareness amongst the general population. As I highlighted in Chapter 1, pain is a subjective experience and is therefore unlike conditions such as high blood pressure or diabetes, which can be measured in an objective manner by the healthcare team and treatment advised accordingly. This enhances the importance of patients’ judgement of the cost effectiveness of individual treatment strategies.

#### 4.5.4 Global Power Dynamics

Throughout Section 4.5 I have shown the multiple ways in which power is negotiated by the medical profession in the practice of pain management in India, with particular reference to the debates surrounding the organisation of the profession and its specialist knowledge base. In this final section I move on to consider the influence of overseas medical practice and the role of overseas practitioners as actors. I demonstrated how the professionally constructed nature of the medical treatment of pain and key associated themes, leads to multiple viewpoints and debated ideas. Therefore when considering the wider picture of global healthcare I argue that there is also the need to take a postcolonial perspective and appreciate the dominance in the debates of those from the global North.

Throughout the study, participants talk of how they have been influenced by those working in the global North. Many talk of gaining specialist pain training, sometimes even to the equivalent of an MD, in countries such as the UK, USA and Australia, and of how this has shaped their early careers. Similarly, others explain how they have learned from overseas practitioners usually palliative care providers and pioneers in their field at home, who have visited India. Many refer to research, publications and guidelines from the global North, and celebrate international guest speakers at their conferences. Others talk of how volunteers attend their organisations and provide services that would otherwise be unavailable to patients. Many participants describe, however, the need to have locally created guidelines and modifications to treatment regimes created in the global North, in order for them to be appropriate in the Indian context. Others explicitly call for those from India to come up with the solutions and changes that are needed, rather than relying on external resources. Participants describe the gap being so vast between recommendations for ideal practice in the North and the reality that is healthcare in India as to make comparison almost futile.

I described how those in the global North lead the vast majority of initiatives aimed at improving pain management on an international scale, and the author list of the Lancet Commission's report confirms this dominance. International groups including the WHO explicitly talk of the need to increase the provision of western medical treatments, and the Lancet Commission specifically describes the importance of introducing standardised teaching curricula and of increased medical specialisation. This serves to enhance the

position of Indian allopathic practitioners who are working to raise the profile of pain management locally and increase the number of patients receiving treatment through influencing medical professionals, managers, politicians and wider society. Indian clinicians are in turn reinforcing the dominance of those in the global North and encouraging others including patients to do so too. This, I would argue, is a demonstration of power being enacted within society in each of the three dimensions I described in the opening chapter. First, and most explicitly, western medicine is described as being necessary to treat pain, and great effort is being devoted to persuading those living in the global South to adopt this view. Secondly, authors and organisations from the global North dominate both the descriptions of how these treatments should be delivered and the debates that follow, with those in the South given little voice. Finally, power is exerted at its most covert level when actors in the global South are persuaded that it is in their best interests to support and reinforce this dominant ideology of the North.

In practice, however, as I have shown with respect to the creation of medical specialties, there are in fact a number of difficulties encountered when transferring a model to the global South that was conceived in the North. For example, the types of conditions that patients are suffering from that are treated under the remit of palliative care remains a topic of debate, and is reflected in the range of different models of care delivery present in India, from Kerala's community based Neighbourhood Network in Palliative Care to others run along lines that are much more similar to those in the UK.

Similarly, when considering the specific treatments used to treat pain, the literature is dominated by descriptions, largely from those in the global North, of the need to increase access to opioid medications for those living in the global South being treated in a palliative care setting. Again this is demonstrated in the Lancet Commission report, which contains a map of the world with each country re-sized according to the estimated amount of morphine available to patients. It shows the US, Canada and Australia as grossly swollen landmasses, monopolising the entire picture. Although the aim of the map is to demonstrate the low levels of opioids available to those in the global South, it also serves as a graphic reflection of the dominance of the North.

My study, however, demonstrates that the narrow focus of these strategies, while commanding an immensely powerful and emotive message, can inadvertently become a

weakness, hindering their success. The simplistic descriptions of this field, fail to take into account the specific organisational details of local practice, clinicians' normative positions, the treatment of pain outside of palliative care, therapeutic modalities besides opioids and perhaps most pertinently of all, global power dynamics. To be clear, while I support the aim of the Lancet Commission and other similar initiatives to improve appropriate access to opioids across the world, I argue that there are assumptions and inconsistencies contained in their work as currently presented that will unfortunately reduce its impact.

## **4.6 Study Limitations and Reflexivity**

In Chapter 2 I presented the generic limitations of the data collections tools I used in this project. Here, in Section 4.6.1, I focus on the more specific issues resulting from this study and consider the limitations of my data and the generalisability of my findings. In the reflexivity section (4.6.2) I discuss how my own personal socio-cultural position affected the research process.

### **4.6.1 Study Limitations**

The nature of my data collection means that I recorded a snapshot of clinicians' practice and evaluations, at one particular period. Both these entities, as with any socially situated research, are highly likely to be dynamic and to change with time. Furthermore, the dynamic nature of such processes also makes it impossible to completely replicate research findings.<sup>263</sup> In this study, however, in order to seek reliability or replicability, I kept a clear log of my strategies and decisions regarding planning, data collection and analysis, and made these explicit throughout the thesis. Furthermore, as the sole researcher I was able to ensure consistency in my methods.

Throughout the questions in both the interviews and questionnaires I specifically asked about the details of how clinicians deliver care on a daily basis. It is impossible to know how the participants' descriptions of their work differ from their actual practice. I argue,

however, that is it important to understand how clinicians evaluate their work as well as to ascertain accurate data detailing the care that patients receive.

When collecting the interview and survey data particularly during the conferences, time was inevitably a restriction for both participants and me, with many participants having multiple commitments during the relatively short time period of the meetings. From a more technical perspective, when conducting the interviews, privacy was challenging at times with some participants choosing to be interviewed in open public spaces where interruptions and background noise were common.

Moving on to generalisability, that is, the degree to which this study can be applied to other settings. Interview data collection was purposively sampled with the aim of including key informants working in a variety of clinical and geographical settings. While this method ensures inclusivity of specific, targeted groups, the data cannot be used to make statistically significant, quantitative comparisons. Similarly, the questionnaire data was a convenience sample, which while adding breadth to the interview data, and being the only pragmatic way of collecting much of the data presented, it is not, statistically speaking, representative of the target population and its constituent groups. As a study of a single case, however, the findings here can be generalised in the sense that they add to our understanding of theory, a concept known as 'theoretical generalisation'.<sup>277</sup> For example, this study demonstrates the value of critically evaluating the practice of clinicians from the perspective of a cross-disciplinary academic framework, and the practical application of theories from the field of policy studies.

Moving on from issues of sampling methods, there is also no data to confirm what the overall denominator or the target population is, from which my sample is drawn. The majority of my primary data was collected at the ISSP and IAPC national conferences but it is difficult to know how representative this group is of those working in these fields across the country. The number of doctors working in pain management is both unrecorded and difficult to define. Arguably all doctors working in a clinical environment with face to face patient contact are likely to treat pain at some time or another, although it is also highly unlikely that they would describe themselves as having a particular interest or expertise in this area. More pertinently, there are other fields of medicine where doctors treat a large number of patients with painful conditions, such as neurologists, rehabilitation

specialists and rheumatologists. Those attending the ISSP and IAPC conferences are clearly likely to have a strong interest in the field of pain management but they are also a subset of this group with a strong interest, who are able to spare the time and the money to attend, and indeed who feel that this will be of benefit to them. The specific nature of these events with a series of didactic lectures and workshops, linked with the ability to network with peers is a very standard, widely practiced format within the field of western medicine but it may not be everyone's preferred way of receiving professional education. Given that my aim, however, was to engage with those who are practising and leading the field both clinically and politically, these national conferences are an efficient and practical way of meeting many of these figures where they reliably converge each year.

Furthermore, with regards to geographical representation, while I recruited participants from multiple states and regions, there was variation in the numbers of participants from each location, and as I already described it is not possible to identify a detailed regional denominator for the sample. The reasons for the high numbers of participants from particular states is likely to be multifactorial and include the high number of clinical services operating, large urban conurbations and the location of the conferences. Similarly, data relating to the proportion of practitioners working in pain management in different clinical settings is not available.

In order to ensure I included data relating to the treatment of pain outside of the remit of palliative care, I specifically asked clinicians about how they treated patients suffering from chronic (long term pain), acute pain (short term pain following surgery and trauma) and even more specifically the pain of labour (childbirth). However, the study yielded limited data related to the treatment of acute and labour pain, which is likely to be due to the following reasons. Within the Indian context, the management of acute pain and labour pain are largely the preserve of anaesthesia and surgical clinicians, rather than those who consider themselves to be pain or palliative care specialists. Furthermore, the presence of specialist acute pain teams in India is not widespread,<sup>156</sup> and in contrast to practice in the global North, as some participants noted, the provision of analgesia for labour in India is far from routine.

### 4.6.2 Reflexivity

The researcher's personal attributes impact each stage of the research process which is particularly apparent in qualitative research. A clear account of reflexivity is therefore an essential part of the process of seeking methodological rigour.<sup>275</sup>

During my field trips I was introduced to many high profile individuals through clinicians whom I knew personally through my professional work as a doctor. This access means I recruited several high profile individuals as interview participants. Furthermore, because the participants knew that I was a clinician working in pain management their interview responses reflect a degree of assumed knowledge on my part – a tacit understanding between fellow professionals. Both of these issues, however, whilst imperative to allowing me to engage in this work in a way few others would be able to, do inevitably lead to a degree of bias both in sampling – the individuals introduced to me were partially selected or filtered by others, and in the interview responses which were tailored to what the participants thought I would be interested in hearing. Clearly, some potential participants will have declined the invitation to participate in the research and I cannot know what their reasoning was for making this choice. There is the potential, however, for my role as an outsider (a non-Indian) to have prevented some from participating.

While my professional status gave me unique access and enabled me to carry out the research, it also informs my academic, cultural and political perspective. I am a physician working almost solely in the field of western medicine in the UK, which necessitates me having a knowledge base heavily weighted in this field. The study participants and I were openly aware of this fact but nevertheless it will have had an effect on the study data and indeed on my analysis. As a partial balancing influence to this, I have also taught pain management overseas, in Africa, Asia and Europe, and have visited a variety of clinical institutions during these trips, which have added to the range of healthcare environments that I have experienced.

While I would not describe this research project as a postcolonial piece of research in itself, in the sense that I am not aiming to actively redress a power differential during the process of carrying out the project, I am, and therefore the project is, influenced by the postcolonial literature. My aim is to deepen our understanding of pain management in

India by asking those who are actually involved in delivering this work. This is in contrast to describing practice only in relation to an ideal defined by those in the global North. A key concept here is that there is a power imbalance with the North dominating the process of defining ideals and remedial strategies. An argument follows that because I am also from the global North this work inherently perpetuates the power imbalance as I filter the data I have collected. Indeed the project is my research, my sample, my questions, my data and my analysis. My aim here, however, is to at least start to redress the balance by describing the fact that an imbalance actually exists – albeit through description from my own privileged perspective. I hope that this work will at least encourage those in the global North to acknowledge and evaluate this power imbalance, and open the door to encourage more related work from those even better placed to further our understanding of this complex field. That said, I would argue that I am uniquely placed to begin this process, through my professional status as a clinician working in the UK NHS that has afforded me incredibly easy access to the world of pain management in India, in part due to relationships with colleagues but also through a common language and tacit understanding.

Of note, when I presented my early findings at a conference in India, while there was widespread encouragement regarding the utility and relevance of the results, one clinician said it was a shame that this work had not been carried out by Indian doctors themselves. This particular idea is something I have grappled with throughout the project. The idea that the voice of the Indian clinicians is unheard and drowned out by the louder, more privileged words of practitioners from the global North. That is, practitioners such as me. The fact that I then have initiated the research could be argued to further empower the dominant North and indeed my own voice. While I acknowledge this viewpoint, I would draw attention to the fact that many participants stated that they lack the time, experience and resources to carry out such a research project, and are therefore highly unlikely to be able to carry out such work in the current climate. Furthermore, I reiterate my hope that this project is just a starting point. If further research is subsequently initiated in India and if the Northern based international organisations shift even a little to incorporate more locally based research then I will consider this project a success.

Throughout my field notes I commented on the mix of the familiar and the strange, and of how these evolved and switched over time. I specifically noted how the conferences I attended were a complex mixture of home (the familiar) and abroad (the strange). Despite

being many thousands of miles from home, I was able to walk in to the ISSP and IAPC conferences, intuitively know where to go, essentially how to behave, and crucially to understand almost all of the lecture material due to its familiar format and presentation in English. I knew how the meeting would function: as a mixture of small group lectures and plenaries, of opening and closing ceremonies, a registration procedure, a conference bag and of course the social event. Woven into familiarity, however, was a totally alien world: a complex healthcare system to comprehend, an unfamiliar social hierarchy to negotiate, a different approach to learning and teaching, not to mention the differences in cuisine and hospitality. My dual training as a clinician and social science researcher has positioned me optimally to present the complexities of this field of research.

#### **4.7 Summary**

Despite widespread internationally led efforts to improve the delivery of medical pain management, progress has been limited. In this chapter I demonstrated some of the specific issues related to the healthcare system in India resulting from my data, that contribute to the difficulties in improving service delivery. These include a wide variety of service provision, weak regulation and scarce resources. I also demonstrated, however, that much of the work directed at improving pain management is based on professionally constructed concepts. This includes the fundamental notion that pain is a medical problem to be fixed – a foundational concept, which I argue underpins the entire practice of pain and palliative medicine. This medical model of pain management and many ideas that follow on from it, such as the organisation of medical specialties and their specialised knowledge base, are rarely acknowledged within the published literature relating to global pain management as being professionally constructed. Furthermore, there are multiple often-disputed ideas relating to these issues, for example, the precise nature of how pain should be treated and of how the associated medical specialties should function. Even, the appropriateness of using a medical model is itself contested, with many individuals not regarding pain as a medical problem. This leads to those working in this field universally describing the need to raise awareness of the medical treatment of pain.

In contrast to the medical scientific literature, there is ample discussion within the field of policy theory aiming to increase our understanding of the dynamic, social processes that

occur when multiple groups negotiate a contested knowledge base. In the setting of this study the literature related to agenda setting, policy creation and implementation are particularly useful. In this chapter I demonstrated how the medical profession holds and negotiates power in the form of knowledge, money and status, with multiple other actors; and of how this power fuels these dynamic social processes. Crucially, I demonstrated how power is wielded at an international level, and how the dominance of those in the global North can potentially adversely affect the effectiveness of initiatives designed to improve patients' access to care.

I argue that only by acknowledging the professionally constructed nature of the medical model upon which much clinical practice is based, and understanding how this model functions in society, can we make significant progress in improving the healthcare that patients receive. This requires accepting that knowledge will always be contested and that its application will take the form of a complex dynamic process of negotiated power between multiple actors, each with their own social, cultural and political persuasions.

## **Chapter 5 - CONCLUSIONS**

### **5.1 Introduction**

Pain is a universal experience that has existed in the animal kingdom since before the existence of the human species. It confers a survival advantage, demonstrated in the disability and shortened life expectancy of those afflicted with the rare condition of congenital insensitivity to pain. Sufferers are unable to sense pain and as a result do not remove themselves from injurious situations, and seek medical attention only when conditions have progressed in severity.<sup>342</sup> The diversity of meanings and uses of the word 'pain', listed in the *Oxford English Dictionary* as both a noun and verb, are extensive and includes the description of bodily suffering following physical injury, the experience of mental anguish, the description of an irritating situation, the effort taken in carrying out a task, and in conjunction with punishment.<sup>343</sup> Similarly throughout history pain has been the subject of multiple cultural and social interpretations.<sup>4,5</sup> Only recently, within the field of western medicine, has pain been conceptualised as a problem to be fixed<sup>5</sup> with an increasing array of ever more technical weaponry. The pharmaceutical and devices companies have invested huge sums of money in developing treatments. Medical specialties are dedicated to the treatment of pain and their member practitioners utilise numerous medical, surgical and psychological therapies. Nevertheless, by using current western medical science, doctors remain unable to cure many painful conditions. There is still a remarkable dependence on the use of opioid medications - derivatives of opium, a naturally occurring substance that has been used to relieve pain for thousands of years.<sup>344</sup> Meanwhile the WHO reports that the vast majority of the world's population are not able to access these substances for medical use. I argue therefore that we have to question the appropriateness of our current use of a western medical model to treat pain at a global level.

### **5.2 The Professional Construction of Pain Management**

Throughout this thesis I described the treatment of pain within a medical paradigm as a professionally constructed phenomenon and I explained the implications of this

conceptualisation. I demonstrated the professionally constructed facets of pain management by examining in detail the normative positions and evaluative judgements of clinicians practicing in India. I showed, that not only do clinicians describe pain as a problem requiring medical attention but also that they describe the limitations that become apparent when using this model, such as: ineffective treatments, poor access to effective therapies and low levels of knowledge amongst physicians, should be addressed by more research, better created and implemented policies, and improved education. That is, they describe solutions only in terms of increasing or improving medicalisation and the implementation of a medical model, rather than questioning the inherent assumptions of the model itself. They do this despite universally describing how others, including colleagues and patients, frequently do not prioritise treating pain within a medical paradigm. This failure to question the assumptions behind the use of a professionally constructed medical model reflects the tendency amongst the members of the medical profession to search for technical solutions rather than to consider the wider sociocultural context of their work, and indeed the resulting paucity of cross-disciplinary work with experts in the fields of social science.<sup>168</sup>

The participants in this study talk of the need to create and implement policies in order to ensure the most appropriate treatments are available to patients and to improve resource allocation. These policies are implemented in many areas of clinicians' work such as in the creation of medical specialties, the direct authorship of national clinical practice guidelines, advocating for government policy to be modified to improve access to opioids and in wider strategic areas addressing financial and workforce resource allocation within healthcare. As is described elsewhere in the literature however, the preponderance of these clinicians' descriptions are focused on the content of these policies rather than on the complex negotiated processes that exist between the multiple actors involved in the creation and implementation of such work.<sup>209</sup> Furthermore, this study also reveals the contentious nature of the specific content of many of the topics which clinicians deem appropriate to be included in policies. Despite demonstrating this complexity and the presence of a range of views, there remains an assumption that the best way to deal with these differing standpoints is to aim for a resolution by finding a definitive answer, through increasing research and improving education. That is, the participants tend very much towards a positivist perspective. I argue, however, that the professionally constructed nature of many of the topics of contention, leads to the existence of different viewpoints

from practitioner groups. Rather than trying to eliminate these multiple views, therefore, we should be aiming to take a social constructionist approach - understanding and embracing each practitioner group, and indeed incorporating views of non-professionals. I argue that we should be considering the nature of pain management, particularly at a global level, to be of such complexity and (at least partially) professionally and socially constructed, that when viewed through the lenses of different individuals, multiple different perspectives exist. While these perspectives may initially appear incompatible, in fact, each may be equally valid and indeed all may be mutually compatible. As I outlined, however, the adoption of this approach by the medical profession would require a fundamental philosophical shift in ideology for many of its members, a group not known for its willingness to embrace uncertainty.<sup>345</sup>

### **5.2.1 Two Tales of Opioid Use**

A clear example of the idea that there is more than one mutually compatible point of view is the medical use of opioids to treat pain. My study shows that the desire to increase opioid availability is not universal amongst clinicians who specialise in treating pain. Furthermore, there is variation in opinion as to how opioids should be used within clinical institutions and to which patients should have access. I described throughout this work, how the majority of discussion related to improving the treatment of pain in India is related to improving access to opioids and focuses on patients being treated within the field of palliative care. I also demonstrated, however, the broadening remit of palliative care globally and within India, to include the treatment of patients suffering from an increasing number of medical conditions at ever-earlier stages in their disease. There arises, therefore, an inevitable overlap between the clinical remit of the two medical specialties of palliative and pain medicine. This overlap, however, and the ambiguous nature of resulting terminology further muddy the waters around discussions of increasing opioid availability for the treatment of pain. I argue that there is too little acknowledgement within the global palliative care literature of the potential problems that may arise from the misuse and diversion of opioids as the remit of palliative care widens. This is despite documented evidence of opioid diversion and misuse in India.<sup>346</sup> I also argue that the lack of inclusion of these issues in advocacy work will only hinder progress, an example being the Worldwide Palliative Care Alliance's 2016 World Hospice and Palliative Care Day theme

‘Living and dying in pain: it doesn’t have to happen’.<sup>101</sup> It would appear, that with our current abilities and when using a medical model to treat pain, this statement is only true in particular situations and when viewed through one particular lens.

I described in detail in the introductory chapter the variation of global levels of access to opioid medications to treat pain, particularly noting the devastating consequences of low availabilities in countries of the global South. In other parts of the world, however, particularly in North America, an alternative story is being told, a story of opioid overuse, which at first glance may seem incompatible with that being told of the South. In 1971, President Nixon declared a war on drugs, describing substance abuse as “America's public enemy number one”.<sup>347</sup> Despite the colossal efforts invested in this conflict in the decades that followed Nixon’s statement, reports of the death, destruction and crime arising from drug misuse show no signs of abating, and the war on drugs has often been described by the media to have failed.<sup>348,349</sup>

Most recently and particularly pertinent to this thesis is the focus on the rise in misuse of prescription drugs and in particular of opioids prescribed for pain relief. The government of the USA has described the problem of addiction and misuse of prescription opioids as “the Nation’s fastest growing drug problem”.<sup>350(p1)</sup> The country’s Centers for Disease Control and Prevention estimate that deaths from overdoses of prescription opioids are higher than those from heroin and cocaine combined,<sup>351</sup> and emotive tales of this escalating disaster are numerous.<sup>352</sup> Many, frequently high profile voices, attribute this problem of misuse at least in part, to an increase in the prescribing of opioids by the medical profession.<sup>81,353</sup> This viewpoint has been partly fuelled by the case of one particular opioid drug called OxyContin, which was ruled in the USA courts to have been inappropriately marketed by the pharmaceutical company Purdue Pharma, resulting in a \$600 million fine, one of the largest ever issued in such a case.<sup>354</sup> Similarly, in Canada, a recent ruling has ordered Purdue Pharma to settle a class-action lawsuit for \$20 million.<sup>355</sup> Furthermore, there is a suggestion that the increasing tendency to describe pain relief in terms of human rights and to focus heavily on assessing and recording patients’ pain has further contributed to the problem.<sup>81</sup> This has led to a call from the American Medical Association to stop clinicians from routinely asking patients about their pain.<sup>84</sup> Although this scenario is largely being played out in North America, it is crucial to appreciate the dominance of the voice of this part of the world in the arena of global healthcare,

particularly when enforced by the USA's government and its largest medical society. Many fear there is the potential for these stories from North America to perpetuate and exacerbate some of the causal factors leading to the low availabilities of opioids that are present in so much of the global South, which only serves to fuel the global debate.

I argue, however, that these two seemingly opposite views are in fact mutually compatible, but only when a more nuanced scenario is presented, as emerges from this thesis. There are some specific controversies in the case of overuse described in the USA. The causal link between the rise in overdoses of prescription opioids and the rise in prescriptions of these drugs is debated. For example, many of the deaths reported are related to the use of multiple medications, not solely to opioids.<sup>79</sup> When compared to the UK, the USA has a particular healthcare model that makes acquiring opioids from multiple prescribers relatively easy. This is compounded by the low illicit market cost of prescription opioids in comparison to, for example, heroin.<sup>79</sup> Furthermore, the litigious framework and complexities surrounding insurance company funding of healthcare in the USA are also described as contributing to the problematic use of opioids.<sup>81</sup>

Perhaps most importantly of all, the overzealous prescription of opioids described in North America, is largely attributed to the treatment of chronic pain that is not associated with terminal disease. Although there are some individuals suffering with this type of pain who do benefit from the long-term use of opioids, there is little evidence of long term effectiveness for the majority.<sup>80</sup> Medical professionals in the global North are still overwhelming in support of the use of opioids to treat pain associated with terminal disease and acute pain, with revised guidance on prescribing only called for in relation to the treatment of chronic pain that is not associated with terminal disease.<sup>82,83</sup> I argue therefore that it is entirely reasonable for there to be a call for both an increase in the use of opioids in some circumstances and a reduction in others. The two positions are not incompatible.

### **5.2.2 The Funding of Healthcare in India**

Another demonstration of the need to consider the medical treatment of pain as professionally constructed is more specific to the Indian scenario. One of the most dominant and consistent findings in my study is the description by clinicians of the need to

persuade others, including patients, that pain is a medical problem requiring fixing. The implication being that others, including many medical professionals do not currently consider this to be the case. These individuals are described as needing education and access to awareness campaigns. So, while there is generally consensus among the research participants they also acknowledge the differing views of other members of their profession and wider society. The study participants work in a variety of healthcare settings including corporate hospitals, private clinics, government institutions and charity organisations. Many, particularly those in palliative care, work for very low levels of remuneration, sometimes none. The idea, however, that patients need to be persuaded by clinicians of the need to have their pain treated by medical professionals, can be considered to be a self-serving notion, and a demonstration of the power the medical profession wields. Power is enacted here in potentially its most covert form, wherein the less powerful individual is persuaded to be complicit in maintaining their position of subordination by believing it to be in their best interests.<sup>221</sup>

I also explained how much of the scientific knowledge base related to treating pain is contested at a global level, resulting in variations in practice preferences of different clinicians in this study, for example relating to the use of nerve blocks. This has the potential, however, to be particularly problematic in India. As I explained, plurality is an integral component of the Indian healthcare system, and it has indeed been described as a key facet of the country of India as a whole by Amartya Sen in his book *The Argumentative Indian*.<sup>356</sup> Within this study, even amongst those working in the private sector and outside of palliative care, there is an acknowledgment of the need to address the wide variation in practice standards that exist within the field of pain management in India. This appears to be compounded by low levels of regulation and a reliance on private healthcare providers. The general lack of healthcare coverage across the country leads to a huge gap in the market, open to a multitude of practitioners, and the description of pain as a medical problem serves to increase the size of this market.

Interestingly, despite widely reported endemic corruption within the medical profession<sup>124,138</sup> there is little direct acknowledgement of this in my interview and survey data. However, I did see reference to it during informal conversations and during visits to healthcare institutions. Furthermore there was a very clear demonstration of tensions that currently exist between healthcare professionals related to the funding of care by the

presence of the debate at an IAPC conference entitled ‘Developing Palliative Medicine is a threat to the corporate world of medicine and specialist physician.’ Contained within this debate was a wide reaching claim that palliative care could present a revolutionary healthcare model, rather than a specific set of specialist treatments provided to patients with a limited range of medical conditions.

To be clear, I consider that it *can* be in the patients’ best interest to seek medical treatment for their pain. There are numerous distressing examples of patients suffering in such severe agony from pains that are potentially easily and cheaply treatable, such as the pain of terminal cancer, who consider suicide to be their only option.<sup>121</sup> Attempts to address this situation by improving the availability of medications are clearly laudable as is any attempt to help relieve another individual’s suffering, but they cannot be easily separated out from the interests of the individual doctor. This is likely, however, to be especially relevant when considering private practice and in particular the treatment of chronic pain not associated with terminal disease, where patients are potentially the clients of practitioners, attending for repeated consultations and treatments for many years. There is of course therefore the potential for unethical practice. As George Bernard Shaw explains in his *The Doctor’s Dilemma: preface on doctors*, the profession is in danger of acting as the judge, the jury and the executioner.<sup>357</sup>

### 5.2.3 The Dominance of the Global North

The final key area I wish to highlight from this research is the dominance in debates of concepts originating in the global North. I explained in the opening chapter how organisations based in countries of the global North command power and therefore skew the debates in the field of global health, these include the WHO, the Lancet, the Institute for Health Metrics and Evaluation, the International Association for Hospice and Palliative Care, the Worldwide Palliative Care Alliance, the International Association for the Study of Pain, the World Institute of Pain, the Pain and Policy Studies Group, and Human Rights Watch.

The idea that pain is a problem to be fixed by western medicine originates, by definition, from the global North. In this study I demonstrated how allopathic doctors working in India describe the gradual assimilation of this concept into the Indian healthcare system,

adopting practices from those working in the global North. This is reinforced by visits from overseas practitioners to India, through formal and informal training of Indian clinicians overseas, and through academic publications and research, that are again dominated by countries in the North. This has occurred despite the failure of western medicine to cure many painful conditions particularly those associated with chronic pain not associated with terminal disease, and a reliance on opioid medications that have been in use since before recorded history. I also demonstrated, in this concluding chapter, how reactions to the disastrous problems associated with opioid abuse in the North, blamed at least in part on the use of this western medical model, are in danger of overshadowing efforts to improve poor access to opioids in the global South, where further devastation and loss of life are occurring. This is not to imply that the use of a western medical model to treat pain is always unhelpful, but rather that it is only a useful and appropriate model to use in particular circumstances for certain patients. Similarly, within the field of global palliative care there is a reliance on a western model of care delivery with the widely cited WHO models, maps and rankings tied into ideals originating in the global North.

My research also demonstrates that although there is a distinct influence from the global North in the areas of training, education and research, there is also a clear acknowledgement from Indian clinicians of the need to modify models of healthcare, that have originated in other countries, for use in India. This notion is precisely in step with the postcolonial theories of Chakrabarty<sup>257</sup> who talks of the need to translate rather than transfer knowledge from one country to another. I argue, however that in the current state of play, dominated and therefore skewed by a Northern perspective that incorporates a western medical model of pain and its treatment, ideas are indeed more often transferred than translated. This is compounded by a lack of willingness on the part of healthcare professionals and wider society to accept the limitations of western medicine, and a reluctance to embrace the idea that global pain management could evolve to reveal multiple different futures, each held in equally highly regard in their own unique context, rather than as a single uniform ideal.

### **5.3 Implications for Further Research**

In this study I focused on critically appraising clinicians' descriptions of practice and their evaluative judgements. I demonstrated the importance of understanding how clinicians influence numerous areas of healthcare delivery – both clinical and political, and the value of carrying out cross-disciplinary research. The study is intentionally broad by design and therefore paves the way for numerous future in-depth projects.

The research identifies many actors besides doctors who are involved at each stage of the clinical and policy processes, and of how the wider social environment impacts these systems. Although I demonstrated the complexity of these processes and the role clinicians play, future research could focus on gaining a more nuanced understanding of each process and the role of other actors. For example, if we wanted to understand in more detail how pain management clinical practice guidelines are created in India, a study could include an examination of the various actors involved in this process, including doctors, but also institutional managers and representatives of pharmaceutical companies, each of whom would be operating within a particular socio-cultural context. There are numerous other possible areas of research relating to policy processes and pain management, such as understanding how government level policies are created and implemented, and how clinical guidelines are put into practice. In each case, I argue that future research should be aimed at understanding these processes and incorporating a cross-disciplinary perspective, rather than concentrating on their content as so much in the published literature has done to date.

On a more specific level, in this thesis, I demonstrated the breadth of treatments that are considered to be useful in pain management, beyond opioid medications. Future research could target increasing our understanding of the reasons for the observed variations in the availability of such treatments. Furthermore, when considering opioid drugs I showed that there are a variety of opinions from clinicians regarding the prioritisation of their use, particularly with respect to areas of pain management traditionally not included within the remit of palliative care. Further research could be dedicated to looking in more depth at the treatment of acute pain and chronic pain not associated with terminal disease, and of how therapeutic strategies are implemented in these groups of patients.

One group of actors that is most notable in their absence from this study are the patients themselves. As I explained, the aim of this project is to critically evaluate the practice of clinicians, but doctors are ultimately acting to change the lives of patients. Clearly, understanding the perspective of patients is of fundamental importance. Further research would be useful to examine patients' conceptualisations of pain – do they fit with the western medical model of a problem to fixed or are there alternative paradigms? When and how do Indian citizens suffering from pain decide to access medical input, what other strategies do they employ, which treatments do they favour and why?

I used the country of India as a single case of study to deepen our understanding of global issues of pain management. Drawing again on the postcolonial theorist, Chakrabarty's concept of multiple futures, I argue that it is important to use future research projects to examine in more detail regional differences that occur within India and between other countries. In other words, how does the practice of pain management in other countries compare and contrast to that observed in India?

One of the key drivers to this entire research process is the notion that some of the lack of progress in improving pain management at a global level has been as a result of limited acknowledgment of the assumptions, complexities and contested nature of the issues being addressed; issues such as using a western medical model to conceptualise pain, increasing opioid availability within the field of palliative care and advocating for alterations to healthcare policy. However, demonstrating the presence of these assumptions, complexities and controversies is only the first step on the ladder to actually improving the rate of progress that is being hindered. As well as advocating for more specific avenues of research, there is a fundamental need to engage with other practitioners, particularly those key players based in the global North who are working for internationally influential organisations. I argue that their assumptions regarding pain and its treatment, and their globally dominant position in research and advocacy work, although well intentioned, need to be acknowledged and challenged.

## **5.4 Autobiographical Reflection**

In the reflexivity section of the previous chapter I outlined how my own personal experiences, cultural and political persuasions have influenced this research project. In this section I add a personal reflection on the work in its entirety, having completed the project.

Ever since spending my elective period as a medical student in the 1990s in southern Africa I have been fascinated by the tensions I witnessed that arise when western medicine is transferred to countries of the global South. Throughout my career that has followed in the NHS I have continued to be involved with overseas projects relating to the treatment of pain across resource poor settings, primarily within Africa and Asia. I continue to work in the NHS where I have been a full-time consultant in anaesthesia and pain management for over ten years treating patients suffering from a range of painful conditions including acute, chronic and cancer pain. This combination of work in the UK and overseas, treating patients in a clinical setting and working academically in the social sciences, has given me a uniquely broad view of the interconnecting issues across many disciplines relating to the treatment of pain at a global level. It has also enabled me to be well positioned to gain access to my field of study with relative ease. I felt very much at home at medical conferences discussing topical issues with fellow members of the medical profession but simultaneously able to identify pertinent differences in practice. Inevitably however, there is an insider-outsider tension between gaining access to privileged information and yet maintaining the ability to notice the uniquely local quotidian. So whilst I was welcomed to conferences, invited to visit many clinical institutions and granted numerous interviews, I was only able to communicate in English and noted differences between the topics discussed on and off the record.

The literatures of the social sciences and postcolonialism speak to me in particular as they address many of my own questions relating to the use of western medicine on a global scale, enabling a more critical understanding of these issues. As a medical student I was troubled by an awkward feeling of forcing a square peg into a round hole, borne out through my own and others' frustrations with local systems, staff and patients not acting as we had been taught that they should. The field of postcolonial studies serves to explain the power differentials that remain in the world as a result of the colonial era and as a transformative paradigm, to redress this balance of power. This study is not intended to be

a transformative postcolonial work in the sense of actively altering power through the research process itself, and indeed I acknowledge a degree of conflict here due to my privileged voice as a citizen of the global North and sole researcher. Nevertheless, I see this work as heavily influenced by postcolonialism, and through this, seek to open the door to future transformative research. I aim to increase our understanding of the need to look more critically at and beyond current frameworks that are so profoundly dominated by the voice of the global North.

Drawing on theories from anthropology, sociology and policy studies enables us to gain a deeper understanding of the wider context of healthcare and crucially its limitations, and I argue that it is essential to do so in order to fully realise medicine's potential. Throughout this project, I have been struck by the paucity of cross-disciplinary engagement. Similarly, during my own medical training and education, I have been aware of a lack of appreciation of the importance of understanding the social context of clinical medicine. This is, however, juxtaposed against a daily recognition, by colleagues working in clinical environments, of the need to engage with social and political agendas, frequently accompanied by frustration, perhaps fuelled in part by a lack of understanding. As doctors we are taught relentlessly how to apply a medical model and to fix each problem we encounter. Appreciating our limitations and acknowledging that fixes are not always possible is counterintuitive to our training and frequently to society's expectations. I argue, however, that there is a moral imperative to engage across society and with candour, regarding these limitations.

Carrying out this research has been a fascinating and profoundly rewarding experience and I feel privileged to have witnessed the hard work of a multitude of professionals and volunteers who are dedicating their lives to improving pain management in India. I have, however, also been struck by how many, including those at the very top of their field, fail to engage across academic disciplines and therefore lack insight into their own assumptions. Throughout this project I have taken part in many events in the UK and overseas aimed at exchanging knowledge and facilitating cross-disciplinary engagement. These events have been invaluable not least in demonstrating to me the need to present with simplicity and clarity, novel concepts and complex theories to experts in other fields.

The scope of this thesis may seem impossibly ambitious, engaging as I have with challenging and provocative issues of such overwhelming size as to be considered beyond influence, including the world's opioid crises, the role of corporate healthcare and the power relations operating in the field of global health. While I acknowledge that I cannot resolve these issues, I have demonstrated that by understanding the impact they have on the practice of medicine, we can potentially improve the quality of healthcare provision across the world.

## Appendices

### Appendix 1: Oral History Collection Data

No. of interviews	No. of participants
Single: 59 (38)	Interviewed once: 64 (38)
Paired: 6 (5)	Interviewed twice: 5 (5)
Triplet: 2 (1)	Interviewed thrice: 1 (1)
<b>Total: 67 (44)</b>	<b>Total: 70 (44)</b>

*Table A-1 Oral History Collection India Interview Data  
(44 interviews selected for further analysis in brackets)*

Profession	No. of participants
Management	1
Medicine	38
Nursing	3
Non-Health Care	2
<b>Total</b>	<b>44</b>

*Table A-2 Profession of 44 Oral History Collection India Participants*

Location (Indian state or country)	No. of Participants
Assam	2
Chandigarh	3
Gujarat	1
Karnataka	4
Kerala	12
Madhya Pradesh	2
Maharashtra	3
New Delhi	3
Rajasthan	4
Tamil Nadu	4
Uttar Pradesh	2
UK	3
Undetermined	1
<b>Total</b>	<b>44</b>

*Table A-3 Location of Work of 44 Oral History Collection India Participants*

## Appendix 2: Interview Guide version 3a

### **A Study of Pain Management in India**

#### **Interview Guide (v3a)**

Proposed question wording in italics.

#### **Preamble/introduction**

*Thank you for agreeing to take part in this interview. As I have already explained the purpose of this study is to try to understand in more detail some of the issues that influence the practice of pain management in India.*

*Can I start by asking you how you first became interested in pain management?*

*Can you tell me how you came to work at [current place of work]?*

*Can you describe the pain management work that you do here?*

Possible probe:

*What exactly does this work involve on a day to day basis?*

#### **Service quality / innovation**

*In a perfect world, what do you think would constitute an 'ideal' pain management service?*

*How do you think the service in which you work compares to this ideal?*

Possible probes:

*What do you consider to be the strengths and weaknesses of your service?*

*Is there anything you would like to change in your service?*

*Could you explain what has prevented you from making any changes?*

Possible probe:

*What would help you to bring about any improvements?*

*Can you say what you think the community would like to see change?*

Possible probe:

*How do you think the community views the quality of the pain management service?*

*What do you think the community would prioritise within the service?*

*Can you say what you think the patients would like to see change?*

Possible probe:

*How do you think patients view the quality of the pain management service?*

*What do you think the patients would prioritise within the service?*

#### **Patients**

*What sorts of conditions do the patients you treat suffer from?*

Possible probes:

*Does this include all pain conditions?*

*Are some patients excluded?*

*Can you explain why some patients are not treated here?*

*Would you like to alter this case mix?*

Possible probes:

*Why or why not?*

*Is anything preventing you from altering the types of conditions you treat?*

*What would you require to bring about these changes?*

**Treatments**

*Can you tell me about the treatments and therapies you offer to patients?*

Possible probes:

*Which specific physical treatments do you offer?*

*Which pharmacological / surgical / psychological / spiritual / social etc?*

*Would you ideally like to be able to offer any others?*

Possible probes:

*Can you explain specifically which treatments you would like to provide?*

*Is anything preventing you from offering these treatments?*

*What would help you to provide these treatments?*

**Wider strategic considerations**

*So far we have been discussing the delivery of pain management where you work. If I may, I'd now like to ask you some broader questions relating to India as a whole.*

*How good do you consider pain management provision to be across the whole of India?*

*What do you think could/should be done/is needed to change things?*

*What are the main issues preventing these changes?*

*How do you think clinicians working in other areas view these issues?*

Possible probe:

*What do you think are the priorities of other clinicians?*

*What do you think should be the main focus of the [ISSP/IAPC] professional organisations?*

*What areas do you think research should focus on?*

*What areas do you think educational work should focus on?*

**Conclusion**

*Thank you very much for your time and help with this work. Is there anything else you wish to mention that we have not managed to discuss so far?*

*And finally, Is there anyone else you think I should contact or interview for the purpose of this study?*

**Overview:**

A key element of the interview is to discuss what the participant considers would constitute an ideal pain management service, and how their service compares to this ideal concept. By the end of the interview I would like to have developed a picture of the service in which the participant works, detailing the specific types of pain conditions patients suffer from and the treatments provided. I would also like to have discussed conditions and treatments that are not provided for and what the barriers to this wider provision may be. I would also like to discuss some of the wider implications relating to pain management across the country of India as a whole.

## **Appendix 3: Interview Guide version 3b**

*Additional notes added during data collection underlined and italicised*

### **A Study of Pain Management in India**

#### **Interview Guide (v3b)**

Proposed question wording in italics (changes from v3a in italic and underlined).

*NB: 'Is there a particular patient that springs to mind when you think of that issue?'*

#### **Preamble/introduction**

*Thank you for agreeing to take part in this interview. As I have already explained the purpose of this study is to try to understand in more detail some of the issues that influence the practice of pain management in India.*

*Can I start by asking you how you first became interested in pain management?*

*Can you tell me how you came to work at [current place of work]?*

*Can you describe the pain management work that you do here?*

Possible probe:

*What exactly does this work involve on a day to day basis?*

*Type of hospital?*

#### **Service quality / innovation**

*In a perfect world, what do you think would constitute an 'ideal' pain management service? Dream?*

*How do you think the service in which you work compares to this ideal?*

Possible probes:

*What do you consider to be the strengths and weaknesses of your service?*

*Is there anything you would like to change in your service?*

*Could you explain what has prevented you from making any changes?*

Possible probe:

*What would help you to bring about any improvements?*

*Can you say what you think the community would like to see change?*

Possible probe:

*How do you think the community views the quality of the pain management service?*

*What do you think the community would prioritise within the service?*

*Can you say what you think the patients would like to see change?*

Possible probe:

*How do you think patients view the quality of the pain management service?*

*What do you think the patients would prioritise within the service?*

#### **Patients**

*What sorts of conditions do the patients you treat suffer from? Work with acute pain/pall care/pain management/anaesthesia*

Possible probes:

*Does this include all pain conditions?*

*Are some patients excluded?*

*Can you explain why some patients are not treated here?*

*Would you like to alter this case mix?*

Possible probes:

*Why or why not?*

*Is anything preventing you from altering the types of conditions you treat?*

*What would you require to bring about these changes?*

**Treatments**

*Can you tell me about the treatments and therapies you offer to patients?*

Possible probes:

*Which specific physical treatments do you offer?*

*Which pharmacological / surgical / psychological / spiritual / social etc?*

*Would you ideally like to be able to offer any others?*

Possible probes:

*Can you explain specifically which treatments you would like to provide?*

*Is anything preventing you from offering these treatments?*

*What would help you to provide these treatments?*

**Wider strategic considerations**

*So far we have been discussing the delivery of pain management where you work. If I may, I'd now like to ask you some broader questions relating to India as a whole.*

*How good do you consider pain management provision to be across the whole of India?*

*What do you think could/should be done/is needed to change things?*

*What are the main issues preventing these changes?*

*How do you think clinicians working in other areas view these issues?*

Possible probe:

*What do you think are the priorities of other clinicians?*

*What do you think should be the main focus of the [ISSP/IAPC] professional organisations?*

*What areas do you think research should focus on?*

*What areas do you think educational work should focus on?*

**Conclusion**

*Thank you very much for your time and help with this work. Is there anything else you wish to mention that we have not managed to discuss so far?*

*And finally, Is there anyone else you think I should contact or interview for the purpose of this study?*

**Overview:**

A key element of the interview is to discuss what the participant considers would constitute an ideal pain management service, and how their service compares to this ideal concept. By the end of the interview I would like to have developed a picture of the service in which the participant works, detailing the specific types of pain conditions patients suffer from and the treatments provided. I would also like to have discussed conditions and treatments that are not provided for and what the barriers to this wider provision may be. I would also like to discuss some of the wider implications relating to pain management across the country of India as a whole.

## **Appendix 4: Interview Plan Language Statement**



### Plain Language Statement

#### **Study Title and Researcher Details:**

A Study of Pain Management in India.

A research project conducted by Dr Clare Roques, consultant anaesthetist and pain specialist working in the UK, and PhD student at the University of Glasgow.

#### **Study Details:**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

The purpose of this study is to understand in more detail some of the issues that influence the practice of pain management in India.

I am undertaking interviews with key informants working in various areas of pain management in India. My aim is to discover professionals' experiences of their work and their views on whether and how the management of pain could be improved.

At a later date I will also be collecting anonymous survey data.

#### **Participation:**

Your participation in this project is entirely voluntary and you are free to withdraw at any time, without giving a reason.

If you agree to take part, I will conduct an interviewing that should last approximately 30-60 minutes. The interview will be audio recorded. At a later date the interview will be transcribed and analysed.

If you agree, the initial recording will be 'on the record' with your name, occupation and place of work identified. I expect to use direct quotations from this recording in the works that result from this study. However, if you would prefer to have identifiable details removed from the transcript and any resulting publications please indicate this on the consent form. Please note, given the nature of the interviews, with many participants expected to be high profile individuals, it may be difficult to completely conceal every participant's identity.

#### **Results:**

This research study forms a part of my PhD at the University of Glasgow, UK, and as such will be written up as a thesis. I also plan to publish the results in academic journals and to present the findings at academic conferences.

The data will be kept for five years after the completion of the project and then deleted electronically or confidentially destroyed.

#### **Ethics Approval:**

This study has been reviewed by the College of Social Sciences Research Ethics Committee of the University of Glasgow.

For further information regarding this study please contact me at [c.roques.1@research.gla.ac.uk](mailto:c.roques.1@research.gla.ac.uk)

If you have any concerns regarding the conduct of this research project please contact the College of Social Sciences Ethics Officer, Dr Valentina Bold ([Valentina.Bold@glasgow.ac.uk](mailto:Valentina.Bold@glasgow.ac.uk)).

## Appendix 5: Interview Consent Form

College of Social Sciences Research Ethics Committee



### Consent Form

**Title of Project: A Study of Pain Management in India**

**Name of Researcher: Dr Clare Roques**

1. I confirm that I have read and understand the Plain Language Statement for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand that the interview will be audio-recorded.
4. I confirm that I agree / do not agree (delete as applicable) to be identified by name and occupation, including place of work, in any publications arising from the research.
5. If I have agreed to the use of identifiable information (as indicated in point 4 above), I understand that copies of specific quotations used in these publications containing such identifiable information will be sent to me via email for verification.
6. I agree / do not agree (delete as applicable) to take part in the above study.

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Researcher                      Date                      Signature

1 copy for subject; 1 copy for researcher

## Appendix 6: Questionnaire

### A STUDY OF PAIN MANAGEMENT IN INDIA – QUESTIONNAIRE

**\*\*\*Please only complete this survey if you currently work in India\*\*\***

#### Questions about you (Q 1-5)

1. a) Are you a member of the Indian Society for the Study of Pain (ISSP)?

No  Yes

b) Are you a member of the Indian Association of Palliative Care (IAPC)?

No  Yes

2. In which State of India do you work? \_\_\_\_\_

3. What is your profession? (Tick one box only)

<input type="checkbox"/> Nurse	<input type="checkbox"/> Pharmacist
<input type="checkbox"/> Social worker	<input type="checkbox"/> Psychologist
<input type="checkbox"/> Physiotherapist	<input type="checkbox"/> Volunteer
<input type="checkbox"/> Doctor - please specify your medical qualifications and speciality of training	

Other - please specify \_\_\_\_\_

4. Have you had any formal training in pain management?

No  Yes

If 'yes' please describe what form this training took and for how long it lasted

\_\_\_\_\_  
\_\_\_\_\_

5. Approximately what proportion of your clinical time do you spend working in pain management? (Tick one box only)

<input type="checkbox"/> 100%	<input type="checkbox"/> 25-49%
<input type="checkbox"/> 75-99%	<input type="checkbox"/> Less than 25%
<input type="checkbox"/> 50-74%	<input type="checkbox"/> None
<input type="checkbox"/> Other, please specify _____	

**Questions about your place of work (Q 6-7)**

6. Please indicate what type of organisation you work in and how it is funded. If you work in more than one type of organisation, please tick as many boxes as needed.

	Government funded	Privately funded via a company (corporate)	Independently privately funded	Charity funded	Other (please specify below)
General Hospital					
Regional Cancer Centre					
University Hospital or Medical College					
Armed or Border Forces Hospital					
Employees' State Insurance Hospital					
Nursing Home					
Hospice					
Independent outpatient clinic					
Community based (home care) facility					
Other (please specify below)					

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

7. Approximately what proportion of the patients you treat receive all of their pain treatments (including doctors fees and medicines) free of charge? (Tick one box only)

- |  |                                 |
|--|---------------------------------|
| <input type="checkbox"/> 100%                        | <input type="checkbox"/> 40-49% |
| <input type="checkbox"/> 90-99%                      | <input type="checkbox"/> 30-39% |
| <input type="checkbox"/> 80-89%                      | <input type="checkbox"/> 20-29% |
| <input type="checkbox"/> 70-79%                      | <input type="checkbox"/> 10-19% |
| <input type="checkbox"/> 60-69%                      | <input type="checkbox"/> 1-10%  |
| <input type="checkbox"/> 50-59%                      | <input type="checkbox"/> None   |
| <input type="checkbox"/> Other, please specify _____ |                                 |

**Questions about the clinical care you provide on a daily basis (Q 8-10)**

8. What type of clinical care do you provide? (Tick all that apply)

- In-patient care  
 Out-patient care  
 Home care  
 Other, please specify \_\_\_\_\_

9. What types of painful conditions are the patients you treat suffering from? (Tick all that apply)

- Cancer pain  
 Pain associated with any terminal disease  
 Any chronic (long standing) pain conditions regardless of the underlying cause  
 Acute (short term) pain conditions (e.g. trauma, post-operative)  
 Labour pain  
 Other, please specify \_\_\_\_\_

10. Ideally, would you like to be able to offer treatment to patients with: (Tick one box only)

- The same conditions that you currently treat  
 A wider range of conditions  
Please specify which conditions here \_\_\_\_\_

\_\_\_\_\_

What do you think is needed to bring about this change?

(List all the reasons you can) \_\_\_\_\_

\_\_\_\_\_

- A narrower range of conditions  
Please specify which conditions here \_\_\_\_\_

\_\_\_\_\_

What do you think is needed to bring about this change?

(List all the reasons you can) \_\_\_\_\_

\_\_\_\_\_

**Questions about treatment availability where you work (Q 11-13)**

11. Please indicate what analgesic medicines are available where you work by ticking one box for each of the medications listed below.

	Never available	Occasionally available	Usually available	Always available
Immediate release oral morphine (liquid or tablets)				
Slow release oral morphine (granules or tablets)				
Injectable morphine				
Immediate release oral oxycodone				
Slow release oral oxycodone				
Injectable oxycodone				
Buccal or sublingual fentanyl				
Transdermal fentanyl patches				
Injectable fentanyl				
Sublingual buprenorphine				
Transdermal buprenorphine patches				
Oral methadone				
Injectable methadone				
Oral pethidine				
Injectable pethidine				

Oral tramadol				
Injectable tramadol				
Oral codeine				
Injectable codeine				
Oral paracetamol				
Rectal paracetamol				
Injectable paracetamol				
Oral NSAIDs				
Rectal NSAIDs				
Injectable NSAIDs				
Tricyclic antidepressants				
Gabapentin or pregabalin				
Carbamazepine				
Ketamine				

Please list any other analgesic medications available \_\_\_\_\_  
 \_\_\_\_\_

12. Please indicate what other types of treatments are available where you work by ticking one box for each of the therapies listed below.

	Never available	Occasionally available	Usually available	Always available
Acupuncture or 'dry-needling'				
TENS				
Simple interventional techniques (e.g. epidural injections, nerve blocks or radio frequency ablations)				
Complex interventional techniques (e.g. spinal cord stimulators or intrathecal pumps)				
Physiotherapy				
Occupational therapy				
Counselling				
Psychotherapy				
Meditation				
Yoga				
Music or art therapy				
Reflexology				
Input from a social worker				
Treatment from a multidisciplinary team - including allied health professions such as specialist nurses, physiotherapists or social workers				

Please list any other treatments available \_\_\_\_\_  
 \_\_\_\_\_

13. Ideally, would you like to be able to offer a wider range of treatments than you currently offer?

No

Yes

If yes, please list which treatments you would like to offer \_\_\_\_\_

\_\_\_\_\_

Why do you think these treatments are not available?

(List as many reasons as you can) \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

#### Questions about service quality (Q 14-17)

14. In the organisation in which you work, do you think that pain management is:  
(Tick one box only)

Excellent

Good

Acceptable

Poor

Very poor

15. What do you consider to be the three most important assets in your service?  
In order of importance 1-3

I. (the most important) \_\_\_\_\_

\_\_\_\_\_

II. (second most important) \_\_\_\_\_

\_\_\_\_\_

III. (third most important) \_\_\_\_\_

\_\_\_\_\_

16. What do you consider to be the three most significant barriers to improving your service?  
In order of importance 1-3

I. (the most significant) \_\_\_\_\_  
\_\_\_\_\_

II. (second most significant) \_\_\_\_\_  
\_\_\_\_\_

III. (third most significant) \_\_\_\_\_  
\_\_\_\_\_

17. From your experience, what do you think patients would like to be done to improve pain  
treatment where you work? \_\_\_\_\_  
\_\_\_\_\_

**Thank you for taking the time to answer this questionnaire**

**Please return it to me (Clare Roques) at any time during the conference**

Please add any other comments related to the questions in this survey in the space below:

Clare Roques – PhD

## **Appendix 7: Questionnaire Plain Language Statement**



### Plain Language Statement – Questionnaire

#### **Study Title and Researcher Details:**

A Study of Pain Management in India.

A research project conducted by Dr Clare Roques, consultant anaesthetist and pain specialist working in the UK, and PhD student at the University of Glasgow.

#### **Study Details:**

You are being invited to take part in this research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

My aim is to discover more about professionals' experiences of their work and their views on whether and how the management of pain could be improved. I am collecting information from a survey and am distributing this questionnaire to all attendees at the ISSP and IAPC national conferences. I have also collected interview data from professionals working in pain management in India.

#### **Participation**

Your participation is entirely voluntary, but if you would like to take part, I would be very grateful if you could take the time to answer this short survey. It should take about 10-15 minutes to complete. The data will be collected anonymously.

#### **Results**

This research study forms a part of my PhD and as such will be written up as a thesis. I also plan to publish the results in academic journals and to present the findings at academic conferences. The data collected here will be deleted after completion of the project.

#### **Ethics Approval**

This study has been reviewed by the College of Social Sciences Research Ethics Committee of the University of Glasgow.

Thank you for taking the time to read this.

For further information regarding this study please contact me at [c.roques.1@research.gla.ac.uk](mailto:c.roques.1@research.gla.ac.uk)

If you have any concerns regarding the conduct of this research project please contact the College of Social Sciences Ethics Officer, Dr Valetina Bold ([Valentina.Bold@glasgow.ac.uk](mailto:Valentina.Bold@glasgow.ac.uk)).

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