L-Università ta' Malta
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Physiotherapy for Patients with Chronic Pain: Ethical Aspects

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ABSTRACT

20% of adults worldwide have chronic pain; and another 10% of adults are newly diagnosed yearly with chronic pain. The intensity of such distress and associated impairment are significant factors in the assessment of its burden since chronic pain affects the quality of life profoundly. A large and widening gap exists between sophisticated pain knowledge and competent utilisation of this knowledge in practice. On September 3, 2010, the Declaration of Montreal was adopted by delegate countries of the International Pain Summit affiliated to the International Association of the Study of Pain. The Declaration of Montreal was adopted to draw attention to insufficient knowledge of pain management by health professionals and the absence of national policies addressing pain as a global health problem. It is now recognised that what disables patients are usually not their actual conditions but those barriers they face, such as financial dependency, stigma, etc. Due to the biomedical culture devaluing psychosocial contexts of pain, particular difficulties arise in addressing the pain experience. The chronic pain patient, at some point during his/her illness, is forced to face transcendent dilemmas, where his role/meaning in the world, has to be redefined. When suffering is observed as a singular phenomenon for every patient, with a strict focus on the body or the mind, it neglects the soul and ignores the most central part of being human. Understanding the patient in pain, therefore, has implications for adoption of the biopsychosocial-existential approach. Reviving dormant capacities and enabling those skills needed for meaningful action, the Capability Approach is a form of thinking about how individuals are coping, and how their quality of living can be assessed. Persistent pain necessitates phenomenological inquiry, where the possible roots of symptoms may be derived from the patients' subjective responses, through their *narratives.* Narratives can serve to enact justice to patients and respect their autonomy since they give them a sense of relevance by recognising them as partners in their care. In morally challenging circumstances, such as chronic pain, there is conflict between ethical principles and specific judgement results, and no ethical principle is *a priori* privileged. By utilising ethical principles and virtues, the physiotherapists will be able to resolve ethical dilemmas specific to the unique pain experience of their patients in a robust physiotherapeutic relationship.

Keywords: chronic pain, physiotherapy, ethics, suffering, care

I humbly dedicate this piece of work to the memory of my father Mario DeBattista.

My loving parents have always instilled in me the virtues of perseverance and commitment and relentlessly encouraged me to strive for excellence. Throughout my life, they have always set a good example and were a constant source of inspiration to face those eventualities in life with zeal, enthusiasm, and fear of God.

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"In order to truly help someone else, I must understand more than he – but certainly first and foremost understand what he understands. If I do not do that, then my greater understanding does not help him at all."

Soren Kierkegaard on the 'art' of helping

Introduction

Chronic pain is a persisting relentless type of pain which by its own nature is very debilitating since no cure is available. Chronic pain can be associated but is not limited to various medical conditions such as arthritis, sciatica, multiple sclerosis, fibromyalgia and previous injury or trauma. However, chronic pain can also develop in the lack of discernible disease.

In this thesis, chronic pain refers only to adult pain which is not associated with malignant disease. The latter would entail a full exposition of literature in its own right.

The global burden of chronic pain in terms of pain and suffering, economic considerations, and human resource allocation are enormous. Despite the policies, recommendations, and guidelines, there is a gap between what is required in this field, and what actually happens in practice. The Declaration of Montreal (Appendix A), stipulated by the International Association of the Study of Pain, in 2010, addressed unrelieved pain by stating that the access to the management of pain is a fundamental human right. Health authorities and healthcare professionals are thus obliged by this clause to take appropriate measures, ensuring that pain management is catered for, in all its varied manifestations.

Explicating how the intellectual effort of understanding pain and how it manifests in the chronic pain patient and the pain experience, thus, constitute a moral responsibility of the physiotherapist, and is fundamental to the ethical process of respecting autonomy, supporting agency and ultimately respecting the right to health. However, one must first start by analysing the nature and extent of the existing informational gaps and improve those assessment methods that help bridge the gaps. What are the unintended effects of the dominant biomedical philosophy in healthcare? There is a trickle-down effect of dominant ideologies on patients and without changes taking place at macro level, physiotherapists may become restricted in improving care.

The phenomenon of chronic pain poses to all healthcare professionals, and the healthcare system as a whole, diverse and profound challenges. Although there is medical knowledge and treatment to manage persistent pain, and with current pain studies there is a better understanding of pain pathophysiology, the actual patient satisfaction with his/her pain management has not improved proportionately, and many are still suffering.

It is estimated that 40% - 60% of chronic pain sufferers are inadequately managed.[1] Also, further in its statement, what the Declaration of Montreal means in practice by access to non-discriminatory treatment, de-stigmatisation of pain, better training for health professionals and effective pain management policies, is that these are critical to addressing pain worldwide.[2] However, the meaning of this access to pain management is not clear. What tools in the effort at pain management are included? What are the goals of this effort? Is it reducing pain, improving functionality, or improving the quality of life? Who chooses these objectives? Do they capture what is vital for chronic pain sufferers seeking care? What we understand about chronic pain will influence how we respond to it.

As a physiotherapist working with such patients for over 20 years, I have first-hand experience in treating chronic pain patients. I have worked directly with specialist consultant physicians in pain clinics. Like other physiotherapists, being confronted with such patients I have witnessed the suffering of these patients and their dependence on physiotherapy and pain clinics. Living in chronic pain can mean days spent in bed, missing appointments with alternate days where the patient in chronic pain seems fine. In chronic pain, there is so much that does not meet the eye. Symptoms, most of which are invisible to others, have life-impacting implications that are not always obvious. Physiotherapists, can therefore, feel overwhelmed when managing such complex phenomena. The chronic pain patient is a person who needs time, and the prolonged interaction and the time-constraints and technicalities involved tend to be particularly stressful on the therapist, where the necessary skills are intuitively learnt by experience. Patients teach us an entirely different perspective on pain and life, since the pain experience is not mere cause and effect. Patients talk about pain in an entirely different manner than textbooks.

I went into physiotherapy because I wanted to make a difference in the lives of other people. However, I never saw myself working with people in chronic pain, where eliminating pain is futile. In the course of studying Bioethics, I tended to have a special focus on topics related to suffering. I felt I owed it to my patients. I came to the realisation

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[1] Dale J. Langford et al., "Treat the Patient, Not the Pain: Using a Multidimensional Assessment Tool to Facilitate Patient-Centered Chronic Pain Care," *Journal of General Internal Medicine* 33, no. 8 (2018), 1235-1238.

[2] Louise Frenkel and Leslie Swartz, "Chronic Pain as a Human Rights Issue: Setting an Agenda for Preventative Action," *Global Health Action* 10, no. 1 (2017), 1348691.

that Bioethics held a strong relevance to the management of chronic pain. This fact introjected the question of whether better advancement in the topic of ethics would lead to betterment of understanding and management of chronic pain. The constant suffering and helplessness these patients experience, and my perceived helplessness of dealing with the latter, were the driving force to furnish the impetus to write this thesis. My ingrained biomedical model of dealing with pain in general appeared to fail these patients' requirements.

The biopsychosocial approach has gained a lot of awareness in physiotherapy and although in theory this is the standard model of care, what do we really intend when using this approach? Are there difficulties with implementing the biological, psychological, and social dimensions as an integrated whole in the clinical scenario? What are the unintended harms that can result from these difficulties? What are the necessary competencies required by the physiotherapist in the field of chronic pain? Do they suffice to meet the unique patient's needs?

As a physiotherapist working with these patients, I felt the need to study what ethics had to offer in this field to acquire the best treatment outcomes and improve both at a personal and professional level. While searching for other ways that could aid the target of achieving better control of the affective and physical suffering associated with chronic pain, I came across the topic of Narratives and I found its application by listening more to what the patient had to say and focusing attention to their specificities and idiosyncrasies. The greatest harm we can do to our patients is rob them of their dignity and ability to believe in themselves. There is no greater gift the physiotherapist can give the patient than listening to his/her pain and acknowledging it.

Chronic pain patients are often ostracized and stigmatised and blamed for their infirmities, due to their pain being misunderstood. Chronic pain needs to change the way it is perceived, judged, and treated. There are numerous social entities beyond physiotherapy that have the ability, to help/harm those in chronic pain. Physiotherapists have the potential to find their way to the community through social advocacy. Although the healthcare system gives patients in chronic pain the least amount of power, physiotherapists can have a great role in how these patients are viewed and treated.

The case of an ethical construct of properly delivered physiotherapy for patients with chronic pain, is one that requires research on various topics. The research applied to this project was primarily accrued from a cumalative knowledge gathered by a detailed and extensive background reading on this topic. I read about the subject from many angles so as to garner as much information as possible. The topical issues and core principles of the relevant bioethical issues were vastly researched on various databases and specific professional websites, so as to assume a comprehensive review of the literature. Henceforth, I could present a better way of dealing with the relative complexities involved. Ideas that propped up while doing further reading were also included. The fullness of the material relevant to this field and pertaining to the title of this thesis, were dealt with in enough detail that would be instructive for anyone with an interest on the subject at hand.

Concluding arguments about the many facets which were elucidated during the literature search was then carried out. The conclusion of this thesis, will hopefully see its use for more generalized discussions about physiotherapy for patients in chronic pain, and provide further insight into its management to address the gap that exists in the physiotherapeutic relationship with these patients. As a result, this thesis will hold great potential for extending and developing physiotherapy into the future of chronic pain management, and can also serve to lay the groundwork for further improvement of pain clinic physiotherapy interventions in the such clinics in Malta.

Physiotherapists, like any other healthcare professional, have a moral obligation to do their best in trying to ameliorate the pain and quality of life of their patients. The prevailing biomedical model is failing these patients in most cases. Looking into those biopsychosocial and existential concerns in a healing therapeutic relationship through the narrative process, will result in more effective practice. This new *modus operandi* will presumably go to a great length in improving treatment outcomes and assure the patient's right to health as stated in the Declaration.

The pain experience generally necessitates expression in the search for meaning. Through narratives and open reflection on the unique features of the patient's life, the patient not only discloses the *self*, but this process also creates the *self*. As a result, pain narratives serve as a diagnostic tool and create a healing therapeutic relationship by patient participation and the sharing of goals, needs and values. By actively listening to the patient's narrative, a robust therapeutic relationship is construed, and through shared decision-making, the maximum potential for those capabilities to achieve a meaningful life, and thus, the life with dignity, is enhanced.

In our current discussion this appears to be an easy task. However, translating it to the actual therapeutic encounter is not easy. It is mistaken to think that the physiotherapist is simply in for a story with a clear-cut lesson. Attending to the narrative of the patient in chronic pain could be straightforward, but things get murkier when attempting to use those narratives to achieve ethical ends. The correlation between the understanding of the pain experience and ethical decision-making about adequate care is not obvious nor uncomplicated.

However, this is difficult to achieve if the dominant ideologies in physiotherapy practice, and what is understood by autonomy in chronic pain are not revisited. The gap will remain between knowledge and practice. The first step in the right direction that upholds the dignity of the patient in chronic pain and his/her right to health is revisiting our working philosophy in this domain.

The first chapter of this work will argue that understanding chronic pain and the ideologies of its management is morally significant since although The Declaration of Montreal recognises access to the management of pain as a fundamental human right, chronic pain remains a global burden. Since physiotherapists have an essential role in the management of these patients, this chapter continues to discuss that addressing the philosophy of physiotherapy practice and the ethical implications in this domain is crucial.

Chapter Two will discuss why an understanding of the patient's *lived* experience and concern of the psychosocial and existential domains are fundamental in achieving health in chronic pain. Unlike physiotherapy in acute pain, diminishing symptoms and pain intensity are not the ultimate goals in physiotherapy for chronic pain, since situations of chronic pain are generally transformed into conditions of human suffering; where patients continuously struggle with the meaning of life. Physiotherapy should, therefore, enhance self-management skills and self-efficacy within shared decision-making for patients to live a life as independent as possible and achieve the maximum possible threshold of those capabilities that are central to living a dignified life.

The third chapter will argue that Narratives in physiotherapy, allow for a better understanding of the patient's unique pain experience and gives the patient in pain the voice to be heard and acknowledged. Through the narrative process, professional virtues in physiotherapy are enhanced, so that with the necessary skills, individualised care is given in a robust physiotherapeutic relationship.

Finally, concluding arguments and recommendations will be made for the physiotherapist to better serve the patient in chronic pain.

Chapter 1: Managing Chronic Pain

The Declaration of Montreal (Appendix A) states that access to the management of pain is a fundamental human right. Yet chronic pain remains a global burden, both in terms of the suffering it entails and the financial costs it involves for society. Understanding chronic pain and the ideologies of its management is, therefore, morally significant. Physiotherapists have an essential role in the management of these patients. It is, therefore, time to revise the philosophy of physiotherapy practice and the ethical implications in this domain.

This chapter is, therefore, divided into three sections. The first section explains the global burden of chronic pain and the Declaration of its management as a human right. The second section discusses the moral significance of understanding chronic pain and the ideologies that surround it. The third and final section explains the philosophy of physiotherapy practice and the ethical implications of this philosophy in the field of chronic pain. It also addresses the moral obligation the physiotherapist has, to understand chronic pain and to recognise the intrinsic dignity of the patient, as stated in the Declaration.

1.1 Managing Chronic Pain as a Public Health Priority

1.1.1 Chronic Pain as a Global Burden

The 2016 Study of the Global Burden of Disease reconfirmed that pain-related diseases and the high prominence of pain is the primary cause of disability worldwide.[1] When calculating years lived with impairment, neck pain, and especially low back pain have consistently been the primary causes of disability globally.[2] Also, the burden caused by chronic pain is increasing, and conditions presenting with persistent pain feature in the top ten list of the causes of disability.[3] 20% of adults worldwide have chronic pain; and

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[1] Sarah EE Mills, Karen P. Nicolson and Blair H. Smith, "Chronic Pain: A Review of its Epidemiology and Associated Factors in Population-Based Studies," *British Journal of Anaesthesia* 123, no. 2 (2019), e273-e283.

[2] *Ibid*.

[3] *Ibid.*

another 10% of adults are newly diagnosed yearly with chronic pain.[4] Thus, more than 1.5 billion people globally have various degrees of chronic pain, and considerable costs accrue with the numerous healthcare visits related to the pain intensity, consequent interference and disability.[5] The severity of such distress and associated impairment are also significant factors in the assessment of its burden since chronic pain affects the quality of life profoundly and can have physiological, psychological and social repercussions with multiple and severe sequelae.[6]

Health economists from the John Hopkins University reported the United States' annual cost of chronic pain to be $635 billion yearly, with this cost surpassing those for diabetes, heart disease and cancer.[7] Amongst the factors influencing this market is the increasing demand for more effective medication and pain-related medical devices. Also, the socioeconomic impact of chronic pain is stronger than other identified priorities in healthcare.[8] The burden associated with persistent pain is not only due to healthcare costs, but also the result of considerable productivity losses from work absences and compensatory payments.[9] Since the economic costs are partially driven by the effects of lost productivity, absenteeism, and early retirement, the management of chronic pain must strive to rehabilitate patients and not merely to alleviate pain.[10]

Akin to the global burden of disease, chronic pain and its treatment are highly unequally distributed.[11] The vulnerable, such as those living in detrimental socioeconomic conditions, and ethnic and racial minorities, endure higher burdens of chronic pain with a lower probability of having an effective evaluation, treatment and

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[4] Daniel S. Goldberg and Summer J. McGee, "Pain as a Global Public Health Priority," *BMC Public Health* 11, no. 1 (2011), 770.

[5] Elizabeth G. Mann, Ana Johnson and Elizabeth G. VanDenKerkhof, "Frequency and Characteristics of Healthcare Visits Associated with Chronic Pain: Results from a Population-Based Canadian Study," *Canadian Journal of Anesthesia/Journal Canadien D'Anesthésie* 63, no. 4 (2016), 411-441.

[6] Nicholas B. King and Veronique Fraser, "Untreated Pain, Narcotics Regulation, and Global Health Ideologies," *PLoS Medicine* 10, no. 4 (2013), e1001411.

[7] Darrell J. Gaskin and Patrick Richard, "The Economic Costs of Pain in the United States," *The Journal of Pain* 13, no. 8 (2012), 715-724.

[8] Harald Breivik, Elon Eisenberg and Tony O'Brien, "The Individual and Societal Burden of Chronic Pain in Europe: The Case for Strategic Prioritisation and Action to Improve Knowledge and Availability of Appropriate Care," *BMC Public Health* 13, no. 1 (2013), 1229.

[9] María Dueñas et al., "A Review of Chronic Pain Impact on Patients, their Social Environment and the Health Care System," *Journal of Pain Research* 9 (2016), 457.

[10] Breivik, Eisenberg and O'Brien, "The Individual and Societal Burden of Chronic Pain in Europe: The Case for Strategic Prioritisation and Action to Improve Knowledge and Availability of Appropriate Care," 1229

[11] Goldberg and McGee, "Pain as a Global Public Health Priority," 770.

care.[12] Moreover, demographic research is also suggesting that since the prevalence of chronic pain increases with age, chronic pain will become an even greater global burden and stress on healthcare resources due to an ageing population.[13]

1.1.2 Access to Pain Management as a Human Right

Recognising access to pain management as a fundamental human right makes its control a public health priority. A large and widening gap exists between sophisticated pain knowledge and the competent utilisation of that knowledge in practice.[14] Pain management is failing for a wide variety of attitudinal, cultural, logistical, political and educational reasons.[15] Frustrated with this sluggish pace for change, on October 11, 2004, the International Association for The Study of Pain (IASP), the European Pain Federation of IASP Chapters and The World Health Organisation, met for the '*Global Day Against Pain'* and declared the management of pain as a human right.[16] On September 3, 2010, the Declaration of Montreal (Appendix A) was adopted by delegate countries of the International Pain Summit affiliated to IASP. This served as an essential step in managing and controlling all types of pain including chronic non-malignant pain worldwide due to its foundations for political action; with the overarching aim that the Access to the Management of Pain is a Fundamental Human Right.[17]

> …recognising the intrinsic dignity of all persons and that withholding of pain treatment is profoundly wrong, leading to unnecessary suffering which is harmful, we declare that the following human rights must be recognised throughout the world:
>
> *Article 1.* The right of all people to have access to pain management without discrimination.
>
> *Article 2.* The right of people in pain to acknowledgement of their pain and to be informed about how it can be assessed and managed.
>
> *Article 3.* The right of all people to have access to appropriate assessment and treatment of pain by adequately trained health professionals.[18]

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[12] Diana Zidarov et al., "Performance and Quality Indicators for the Management of Non-Cancer Chronic Pain: A Scoping Review Protocol," *BMJ Open* 6, no. 2 (2016), e010487.

[13] Barry J. Sessle, "The Pain Crisis: What it is and what can be Done," *Pain Research and Treatment* 2012 (2012).

[14] Breivik, Eisenberg and O'Brien, "The Individual and Societal Burden of Chronic Pain in Europe: The Case for Strategic Prioritisation and Action to Improve Knowledge and Availability of Appropriate Care," 1229

[15] *Ibid.*

[16] International Pain Summit of the International Association for the Study of Pain, "Declaration of Montreal: Declaration that Access to Pain Management is a Fundamental Human Right," *Journal of Pain & Palliative Care Pharmacotherapy* 25, no. 1 (2011), 29-31.

[17] Lívia Vieira Lisboa, José Augusto Ataíde Lisboa and Katia Nunes Sá, "Pain Relief as a Way to Legitimate Human Rights," *Revista Dor* 17, no. 1 (2016), 57-60.

[18] International Pain Summit of the International Association for the Study of Pain, "Declaration of Montreal: Declaration that Access to Pain Management is a Fundamental Human Right," 29-31.

However, articulating this right where its nature is not precise poses some difficulty. Is a right to pain relief a statement of law, a clinical recommendation or an exercise in moral persuasion? The Declaration of Montreal was adopted to draw attention to insufficient knowledge of pain management by many health professionals, and the absence of national policies in the developing and developed world; addressing the severity of pain as a global health problem. Under the right to health and according to international human rights law, countries now have the responsibility to provide adequate pain management, since health is a fundamental human right established in various international human rights instruments.[19] The International Covenant on Economic Social and Cultural Rights stipulates that everyone has the right "…to the enjoyment of the highest attainable standard of physical and mental health."[20] Since countries have different levels of resources, the progressive realisation of rights concept as in healthcare obliges signatories to take measures to aid in basic needs as the minimal level necessary of each right. Therefore, in accordance with international agreements, a government should recognise the right to health and use its available resources to the full in applying it in practice. High-income nations would typically need to provide healthcare services at a higher standard than those with scarce resources, but concrete steps towards improved services are expected to be taken by all countries.[21]

By pain management, the Declaration was not referring solely to the judicious use of opioids; it was also referring to the moral obligation of the public health sector and healthcare professionals to provide adequate services for pain management. Failure to take appropriate steps to ensure that pain sufferers have access to proper pain treatment results in a breach of the duty to protect against inhumane treatment which is a fundamental human right.[22]

The inaccurate interpretation of the right to pain relief may potentially disrupt the fundamental tenets of the clinical assessment. Balancing the pain management message as a right is important since different types of pain demand different attention.[23] When healthcare providers regard pain management as a human right, this implies a sensible

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[19] Diederik Lohman, Rebecca Schleifer and Joseph J. Amon, "Access to Pain Treatment as a Human Right," *BMC Medicine* 8, no. 1 (2010), 8.

[20] Article 12, UN General Assembly, *International Covenant on Economic, Social and Cultural Rights*, https://www.ohchr.org/Documents/ProfessionalInterest/cescr.pdf (accessed Oct 15, 2019).

[21] *Ibid.*

[22] *Ibid.*

[23] Marko Jukić and Livia Puljak, "Legal and Ethical Aspects of Pain Management." *Acta Medica Academica* 47, no. 1 (2018).

and proportionate response to the kind of pain and its intensity experienced by the individual.[24] Patients or their advocates must appreciate that the right to pain relief does not mean a right to total analgesia, and such misinterpretation can cause patient dissatisfaction or even litigation. Therefore, healthcare professionals have a responsibility to continually improve their pain management skills, including pain-related medical, legal and ethical aspects.

Pain management is now generally considered to be one of the criteria for assessing the quality of healthcare systems. Chronic pain management is complex, requiring an integrated network approach between all the levels in the healthcare system, and involving health professionals from various disciplines.[25] Improving the quality of care necessitates the measurement of the performance providing care to people in pain. Consequently, the use of relevant quality and performance indicators are required.[26] These can be used by policymakers and organisations, to collect data and to determine the relative standard of care offered by hospitals or countries and the impact that chronic pain has on individuals and their social lives, their relatives and society.[27] In this way, the gap between the targeted and actual performance of the management of chronic pain can be assessed. Besides, one can determine better how improvement in healthcare relates to the cost of healthcare per capita.[28]

The 10th anniversary Societal Impact of Pain Symposium '*Bringing Pain Policy to the Next Decade'* on November 7, 2019, in Brussels, held discussions on the recommended policy actions on four key areas; education, employment, research and health indicators. Attention was given on pain as a health quality indicator.[29] The Societal Impact of Pain called on the European Commission and the Member States to analyse the possibility of building on presently available instruments that determine, enact and adopt pain as an evaluation of healthcare systems' quality. Regardless of the substantial political consensus, the urgency remains to translate intention into conclusive and productive

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[24] Frank Brennan and Michael J. Cousins, "Pain Relief as a Human Right," *Pain Clinical Updates* 12, no. 5 (2004), 1-4.

[25] Zidarov et al., "Performance and Quality Indicators for the Management of Non-Cancer Chronic Pain: A Scoping Review Protocol," e010487.

[26] *Ibid.*

[27] *Ibid.*

[28] *Ibid.*

[29] Bart Morlion, "26th Edition of the Societal Impact of Pain", *SIP Newsletter*, October 25, 2019, https://www.sip-platform.eu/resources/details/id-26th-edition-of-the-societal-impact-of-pain-sip-newsletter (accessed Oct 29, 2019).

action, to advance pain management in the everyday practice, thus, preventing harm and ensure justice to patients and the general public.[30]

The management of chronic pain as a healthcare priority is a difficult task because of the problem it entails. The new study '*Prioritising Pain: An analysis of the policy environment affecting patients suffering from chronic pain across Europe,'* presented at the 2019 European Pain Federation of IASP Chapters Congress in Valencia, confirmed a disparity in the reforms and pain-related policies across Europe.[31] The study revealed that while specific policies and programs exist, chronic pain is not made a priority through national strategic plans. It also showed that while patient advocacy organisations are the driving forces for awareness-related change in policy and adoption, they only obtain limited support from the government. Besides, the study showed that although clinical recommendations on the diagnosis, management and treatment have been developed, their implementation is often restrictive, contributing to suboptimal management of chronic pain.[32]

1.2 The Moral Significance of Understanding Chronic Pain and the Ideologies that surround it

1.2.1 Ethical Reflection in Chronic Pain Management

Understanding health as a human right poses responsibility on states to guarantee quality healthcare that is affordable, acceptable, equitable and timely, with consideration to the determinants of health. This right, however, cannot be achieved in isolation but must be closely linked with other principles such as individual autonomy, respect for evolving capacities, social inclusion and participation. Limited functions are worsened when the condition is stigmatised and, thus, leads to less social and financial support.[33]

The literature has described various problems in the management of chronic pain, suggesting that its undertreatment, societal burden and prevalence are underestimated;

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[30] Morlion, "26th Edition of the Societal Impact of Pain," Oct 25, 2019.

[31] Thomas R. Tolle, Serge Perrot, "Europe's Chronic Pain Problem", *Politico (Europe)*, October 18, 2019, https://www.politico.eu/sponsored-content/europes-chronic-pain-problem/(accessed Oct 28, 2019).

[32] Tolle, "Europe's Chronic Pain," Oct 18, 2019.

[33] Norman Sartorius, "Stigmatized Illnesses and Health Care," *Croatian Medical Journal* 48, no. 3 (2007), 396.

with treatment not adequately managed or instituted.[34] Techniques and pharmacologic agents are over utilised *without* chronic pain being addressed in a holistic approach. Also, conflicts and tensions exist between those stakeholders involved at the different levels in the management of chronic pain.[35]

In a study carried out by McGee and colleagues, six significant issues regarding the diagnosis and management of chronic pain emerged; all of which had ethical components to them. These included the importance of reducing disparities in the access to pain management such as those in lower socioeconomic groups; a proper definition of *quality of care* in pain management; proper pain education and research; adequate policies that regard opioid use; awareness of multimodal therapies for chronic pain to prevent opioid abuse; and the public awareness regarding chronic pain and its impact.[36] Understanding these as moral issues requiring the attention of policymakers, health professionals and patients, provides the justification and impetus for addressing them in a patient-centred and timely manner. An ethical foundation is therefore necessary; one that focuses upon the *experiences* of chronic pain sufferers who are invalidated in a culture of distrust and stigma which undermines their dignity.[37]

Thus, to have an ethically sound approach, it is also imperative to raise public awareness of chronic pain and shift the consensus view that pain is simply a symptom and that individuals with intricate pain syndromes are troubled individuals who abuse drugs, feign disability or worse.[38] It is therefore fundamental to legitimise chronic pain as a condition in its own right…. an illness that disrupts the *narrative* of life, creating dissonance in the life, work, and *self* of the person in pain. These people suffer from feelings of helplessness, isolation and disappointment with our care system, and feel that their needs are overridden by other practical, professional and political concerns.

Adequate chronic pain management is, therefore, a moral imperative that respects the dignity of people in pain. Also, the practical implications in the practice and study of pain merit bioethical analysis. An ethical framework for chronic pain management,

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[34] Hans-Georg Kress et al., "A Holistic Approach to Chronic Pain Management that Involves all Stakeholders: Change is Needed," *Current Medical Research and Opinion* 31, no. 9 (2015), 1743-1754.
[35] Michael E. Schatman and Allen H. Lebovits, "On the Transformation of the "profession" of Pain Medicine to the "business" of Pain Medicine: An Introduction to a Special Series," *Pain Medicine* 12, no. 3 (2011), 403-405.
[36] Summer J. McGee et al., "Defining Chronic Pain Ethics," *Pain Medicine* 12, no. 9 (2011), 1376-1384.
[37] *Ibid.*
[38] Roger Collier, ""Complainers, Malingerers and Drug-Seekers"—the Stigma of Living with Chronic Pain," *CMAJ: Canadian Medical Association Journal* 190, no. 7 (2018), E204.

should, therefore, aspire to link epistemic realms of the management of pain to their anthropological foundations for an improved quality of life. Any attempts to ameliorate the management of chronic pain, therefore, necessitates efforts not only at policy, regulatory and institutional levels but at a conceptual level too.[39]

1.2.2 Understanding Chronic Pain

At the moment, the most accepted definition of pain is approved by the International Association of the Study of Pain. It defines pain as “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.”[40] Persisting pain past reasonable healing time, exceeding 3 months, is recognised as chronic pain.[41] Unlike acute pain, which is induced by a sudden response to injury, chronic pain lacks the warning purpose of physiological nociception, and the pain system becomes progressively sensitive, uninformative and imprecise.[42]

The aetiology of chronic pain is multifactorial and complex and could have been originally provoked by inflammatory, ischaemic, infectious, autoimmune, iatrogenic or idiopathic conditions.[43] Chronic pain can be associated but is not limited to various medical conditions such as arthritis, sciatica, multiple sclerosis, fibromyalgia and previous injury or trauma. However, chronic pain can also develop in the lack of discernible disease; thus, diverting pain from being a symptom to the harbinger of a daunting future.[44] Most often, in chronic low back pain, for example, there is a lack of an identifiable pathoanatomic cause to justify the pain.[45] This poses a problem for those clinicians who attempt to explain the cause of pain, and for the patients who are struggling to make sense of it. Also, frustrated by the intractable nature of non-specific chronic pain,

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[39] Ana Sofia Carvalho et al., "Ethical Decision Making in Pain Management: A Conceptual Framework," *Journal of Pain Research* 11 (2018), 967.

[40] International Association for the Study of Pain, IASP Terminology, updated December 14, 2017 https://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698#Pain (accessed Nov 3, 2019).

[41] Rolf-Detlef Treede et al., "Chronic Pain as a Symptom Or a Disease: The IASP Classification of Chronic Pain for the: International Classification of Diseases: ICD-11," *Pain* 160, no. 1 (2019), 19-27.

[42] G. Lorimer Moseley and David S. Butler, "Fifteen Years of Explaining Pain: The Past, Present, and Future," *The Journal of Pain* 16, no. 9 (2015), 807-813.

[43] Marie Crowe et al., "“Pain Takes Over Everything”: The Experience of Pain and Strategies for Management," in *Meanings of Pain*, (Springer, 2019), 59-76.

[44] *Ibid.*

[45] Chris Maher, Martin Underwood and Rachelle Buchbinder, "Non-Specific Low Back Pain," *The Lancet* 389, no. 10070 (2017), 736-747.

which is also resistant to various medical treatments, clinicians often doubt the veracity of pain reports and add to their marginalisation.[46]

The distress, fear, hopelessness, catastrophisation, anxiety and depression associated with chronic pain, all contribute to the triggering of pain. These combined effects are described in terms of a biopsychosocial situation, in which the complex interaction between pain and nociception endures changes that entwine suffering and pathological transformations of the pain system architecture.[47] The impact of psychosocial and environmental factors, thus, contribute to persistent pain, and their assessment is, therefore, a potential therapeutic benefit. As conceptualised by Manzotti, there is no definitive proof that neural underpinnings alone are sufficient to elicit pain. He argues that in all known chronic pain cases, not only neural structures are involved, but bodies, the environment, tissue damage, stimuli, social interactions and future and past behaviour are involved too.[48] Therefore, what will determine a particular stimulus as being painful will *also* depend on the *context* within which it is experienced along with associated memories, beliefs and emotions.

1.2.3 Ideologies in the Management of Chronic Pain

The belief that pain intensity, measures best the need for treatment, has spread from cancer pain and palliative care to treating chronic non-malignant pain.[49] In 1996, the notion of pain as the fifth vital sign was introduced by James Campbell before the American Pain Society. Here, he argued that if pain were to be given the same consideration as the other vital signs, it would not be undertreated. The American Pain Society advocated pain assessment along with the other traditional vital signs which eventually gave rise to the 0 to 10 Numeric Rating Scales.[50] However, since chronic pain is complex, can measuring pain intensity assess the burdens that chronic pain poses on the patient?

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[46] Gillian Bendelow, "Chronic Pain Patients and the Biomedical Model of Pain," *AMA Journal of Ethics* 15, no. 5 (2013), 455-459.

[47] Crowe et al., "“Pain Takes Over Everything”: The Experience of Pain and Strategies for Management," 59-76.

[48] Riccardo Manzotti, "No Evidence that Pain is Painful Neural Process," *Animal Sentience: An Interdisciplinary Journal on Animal Feeling* 1, no. 3 (2016), 11.

[49] Mark D. Sullivan and Jane C. Ballantyne, "Must we Reduce Pain Intensity to Treat Chronic Pain?" *Pain* 157, no. 1 (2016), 65-69.

[50] *Ibid*.

The biopsychosocial model is presently the most widely recognised model used to understand and treat chronic pain disorders.[51] However, is this model actually being applied in the clinics? Application of this model to chronic pain is said to acknowledge the complexity of the pain experience and its interdependency on biomedical, emotional and cognitive, behavioural and social factors, whose relationships can change over time.[52] It, therefore, promised insights into enigmatic circumstances such as pain in the absence of tissue damage, individual responsiveness and unpredictability to identical treatments, and lack of a foreseeable relationship between pain and disability/impairment. With the biopsychosocial model in mind, interdisciplinary pain treatment programs were attempted to address the complexity of persistent pain. Indeed, for this model to be *effectively* implemented, integrated pain programs should be present to emphasise regular coordination of the several healthcare providers involved. Also, constant communication is essential among these members, and should, therefore, be located in the same facility. There should also be a common treatment philosophy which would be then ingrained in the chronic pain patient, to ensure effective treatment.[53]

However, such organised pain clinic services are lacking. Although the cost-effectiveness of the interdisciplinary pain treatment programs is well documented, third-party payers are still reluctant to compensate for care.[54] Such comprehensive programs are viewed as too costly without appreciating the costs saved in the long run. Furthermore, managed care organisations have been carving out important portions of these programs in an attempt to reduce costs; thus, diluting successful outcomes and allowing them to fail.[55]

Purchasers of healthcare, such as the health ministries, governmental bodies, and insurance companies, contribute to the financial impetus for the healthcare system. Faced with the constant increase in the cost of medications, non-pharmacological interventions and equipment such as pumps and stimulators, they are apprehensive about rising the

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[51] Shaquir Salduker et al., "Practical Approach to a Patient with Chronic Pain of Uncertain Etiology in Primary Care," *Journal of Pain Research* 12 (2019), 2651.
[52] Peter Stilwell and Katherine Harman, "An Enactive Approach to Pain: Beyond the Biopsychosocial Model," *Phenomenology and the Cognitive Sciences* (2019), 1-29.
[53] Robert J. Gatchel et al., "Interdisciplinary Chronic Pain Management: Past, Present, and Future." *American Psychologist* 69, no. 2 (2014), 119.
[54] W. I. Niagara and Laxmaiah Manchikanti, "Interventional Pain Management at Crossroads: The Perfect Storm Brewing for a New Decade of Challenges," *Pain Physician* 13 (2010), E111-E140.
[55] Gatchel et al., "Interdisciplinary Chronic Pain Management: Past, Present, and Future." 119.

expenditure to proper management.[56] This is considered a drain on the resources that should be better spent on prevention and cure, and the indirect costs to health care and society are not accounted for.[57] Therefore, although the biopsychosocial model is considered today's clinical standard of care, in practice, this is NOT the case. The clinical application has been stated as being dualistic from both the patient's and clinician's point of view, and reductionist views of body and mind relations still influence the medical opinion of this phenomenon.[58] Therefore, substantial 'doctor shopping' and significant costs result, and patients blindly seek appropriate treatment for their pain which is often not understood by the primary care physicians. Primary care doctors who were surveyed in a study reported managing chronic pain of their patients mainly with opioid medication.[59] Also, the evidence suggests that patients who wait for longer than six months to be treated are more likely to experience depression and a decrease in the quality of life.[60] On average chronic pain patients in Europe, wait for an average of 2.2 years from seeking help to achieving a diagnosis, with another 1.9 years of waiting time before actual treatment occurs.[61] Therefore, with the still very dominant biomedical ideology, the management of chronic pain competes for those resources that are considered a priority in healthcare. These comprise diseases with well organised and high-profile organisations, which consonant with the biomedical paradigm prioritise the search for a *cure*. This ideology views chronic pain as a failure, and therefore, it's funding a waste of resources.[62]

Striving to eliminate chronic pain by adopting the biomedical approach has also led to iatrogenic injury.[63] Iatrogenic injury is the harm caused to the patient in pain, due to the adverse effects that result from the search for a physical cause of the pain and subsequent unnecessary treatment; such as side effects from medications, and anxieties

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[56] Kress et al., "A Holistic Approach to Chronic Pain Management that Involves all Stakeholders: Change is Needed," 1743-1754.
[57] *Ibid.*
[58] Elisa Arnaudo, "Pain and Dualism: Which Dualism?" *Journal of Evaluation in Clinical Practice* 23, no. 5 (2017), 1081-1086.
[59] Maya Vijayaraghavan et al., "Primary Care Providers' Views on Chronic Pain Management among High-Risk Patients in Safety Net Settings," *Pain Medicine* 13, no. 9 (2012), 1141-1148.
[60] Kress et al., "A Holistic Approach to Chronic Pain Management that Involves all Stakeholders: Change is Needed," 1743-1754.
[61] *Ibid.*
[62] King and Fraser, "Untreated Pain, Narcotics Regulation, and Global Health Ideologies," e1001411.
[63] Mark D. Sullivan and Jane Ballantyne, "Is there a Duty to Relieve Pain?" in *Developments in Neuroethics and Bioethics*, Vol.1, Elsevier, (2018), 11-23.

from unnecessary investigations and treatment.[64] Typical biomedical interventions for persistent pain such as opioids and surgery can lack long-term benefit.[65] After analysing the electronic records of over 26,000 pain patients, in a study carried out in 2011 by Deyo and colleagues, it was concluded that long term use of opioids was linked with psychological disturbance and healthcare utilisation.[66] Opioids present a serious risk for misuse, and although they can be beneficial with short-term use, their benefit declines with persistent use, leading to opioid-induced hyperalgesia.[67] The idea that these medications can safely alleviate chronic pain while improving the quality of life exposes the sufferers to unrealistic expectations. Of equal concern are the surgical interventions; where studies have revealed their significant increase. Between 1998 and 2008, an increase of 137% in spinal fusion surgery was reported for lower back pain and an 11.8% increase in laminectomies.[68] Disability rates related to lumbar spinal fusion are also of great concern.[69] Many patients are being *deactivated*; leading them into a vicious cycle, where high doses of opioids might not suffice. The lives of these patients, thus, become consumed with an unreal search for an unachievable goal. An upper pain score could be the cry for the understanding of the *whole* experience of their pain and not necessarily the need for opioids or interventions!

Thus, chronic pain cannot be understood by adopting a biomedical paradigm, and although this is relevant for several disease-based illnesses, a biomedical view embraces reductionism. With this ideology, the following assumptions about chronic pain are made: Signs and symptoms arise due to abnormal pathology (e.g. back pain due to herniated discs as explained by an MRI, and lifting can, therefore, aggravate the condition); all diseases give rise to symptoms; health is only present in the absence of pain; mental phenomena, such as depression are unrelated to physical problems; the patient is a victim of the situation with minimal responsibility for the cause/presence of pain and disability;

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[64] Ivan Illich, "Medical Nemesis," *Journal of Epidemiology & Community Health* 57, no. 12 (2003), 919-922.

[65] Gatchel et al., "Interdisciplinary Chronic Pain Management: Past, Present, and Future." 119.

[66] Richard A. Deyo et al., "Opioids for Back Pain Patients: Primary Care Prescribing Patterns and use of Services," *The Journal of the American Board of Family Medicine* 24, no. 6 (2011), 717-727.

[67] Gatchel et al., "Interdisciplinary Chronic Pain Management: Past, Present, and Future." 119.

[68] Sean S. Rajaee et al., "Spinal Fusion in the United States: Analysis of Trends from 1998 to 2008," *Spine* 37, no. 1 (2012), 67-76.

[69] Sami Tarnanen et al., "Randomized Controlled Trial of Postoperative Exercise Rehabilitation Program After Lumbar Spine Fusion: Study Protocol," *BMC Musculoskeletal Disorders* 13, no. 1 (2012), 123.

although the patient is expected to cooperate during treatment, he/she remains a *passive* recipient.[70]

To highlight the burden of chronic pain on society and the healthcare systems, on May 25, 2019, in light of the Societal Impact of Pain's promotion, the World Health Assembly, embraced the 11th revision of the World Health Organisation International Classification of Disease (ICD–11). This is the first classification system to incorporate a systematic representation of chronic pain that will include chronic pain conditions in the ICD – 11 code.[71] Chronic pain will no longer be viewed as a symptom but as a disease in its own right, and attention will be mainly given to chronic primary pain, where persistent pain is present in the absence of known aetiology.[72] This inclusion has the aim of recognising that at the core of suffering there is the patient's experience which is characterised by persistent pain; irrelevant of its origin.[73]

1.3 Physiotherapy in Chronic Pain Management

1.3.1 The Philosophy of Physiotherapy Practice in Chronic Pain

Physiotherapy is a dynamic healthcare profession having established theoretical and extensive clinical applications consistent with the international guidelines set by the World Confederation for Physical Therapy (WCPT), in the maintenance, improvement and restoration of movement and optimal physical function at any stage in the individual's life.[74] Limited movement and function can result from various conditions, disorders or diseases, ageing, injury or pain, with physiotherapists understanding that *functional movement is significant to what it means to be healthy*.[75] Physiotherapists have expertise in the body and its movement and the implementation of objectivity, reason and logic, in

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[70] Derick T. Wade and Peter W. Halligan, "Do Biomedical Models of Illness make for Good Healthcare Systems?" *Bmj* 329, no. 7479 (2004), 1398-1401.

[71] The ICD code is the standard diagnostic tool for epidemiology, resource utilisation, strategic and operational planning, reimbursement and performance management. Till today, medical conditions without an ICD code, are not considered relevant and therefore not included in most of the reimbursement systems. Consequently, they receive no political attention, appropriate treatment resources or professional training. The ICD-11 will come into effect on January 1, 2022.

[72] Blair H. Smith et al., "The IASP Classification of Chronic Pain for ICD-11: Applicability in Primary Care," *Pain* 160, no. 1 (2019), 83-87.

[73] Arnaudo, "Pain and Dualism: Which Dualism?" 1081-1086.

[74] World Confederation for Physical Therapy. Policy statement: Regulation of the physical therapy profession. London, UK: WCPT; 2017 https://www.wcpt.org/policy/ps-descriptionPT (accessed Dec 2, 2019).

[75] *Ibid.*

order to determine the normal or dysfunctional.[76] Physiotherapists are trained to be first contact autonomous practitioners, skilled to assess, diagnose, determine outcomes, treat and discharge patients without necessitating referrals from other sources.[77] Generally, however, patients still rely on their doctors for recommending physiotherapy.[78]

In chronic pain, physiotherapy guidelines recommend the assessment of the biopsychosocial factors.[79] However, physiotherapists adhere poorly to this.[80] Physiotherapy assessments are predominantly biomedical and concentrate on the symptoms and intellectualising the problem.[81] Also, studies in back pain reveal that while physiotherapists theoretically adhere to the biopsychosocial model, there are difficulties in managing the work-related psychosocial issues related to back pain.[82] The physiotherapeutic relationship is, therefore, mostly limited to a conversation about the physical symptoms. Thus, within the limited timeframes available for treatment sessions, these patients find it challenging to express their feelings, and treatments mostly include a physical modality such as exercise, electrotherapy, manual therapy, etc. to compensate for the associated *physical* symptoms.

Consequently, physiotherapists predominantly follow the biomedical model, where assessments are assumed to be mainly objective, and the potential physiotherapists have in their subjective judgements can go unnoticed.[83] The biomedical philosophy in physiotherapy is, thus, a powerful constraint which could be limiting emancipation in physiotherapy practice.[84] What will physiotherapy gain if the profession overturns its

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[76] David A. Nicholls et al., "Connectivity: An Emerging Concept for Physiotherapy Practice," *Physiotherapy Theory and Practice* 32, no. 3 (2016), 159-170.

[77]World Confederation for Physical Therapy. Policy statement: Direct access and patient/client self-referral to physical therapy. London, UK: WCPT; 2017 https://www.wcpt.org/policy/ps-direct-access (accessed Dec 2, 2019).

[78] D. I. Odebiyi et al., "Evaluation of the Mode of Referral of Patients for Physiotherapy by Physicians," *African Journal of Physiotherapy and Rehabilitation Sciences* 2, no. 1 (2010), 14-20.

[79] World Confederation for Physical Therapy. Physical Therapy Pain Network. Updated: Thurs 21 May 2020 https://www.wcpt.org/ptp (accessed May 24, 2020).

[80] Tania Gardner et al., "Physiotherapists' Beliefs and Attitudes Influence Clinical Practice in Chronic Low Back Pain: A Systematic Review of Quantitative and Qualitative Studies," *Journal of Physiotherapy* 63, no. 3 (2017), 132-143.

[81] K. Kulikowski, "The Importance of Interpersonal Communication in the Process of Rehabilitation," *Review Article.Medical Rehabilitation* 17, no. 1 (2013), 15-20.

[82] Heather Gray and Tracey Howe, "Physiotherapists' Assessment and Management of Psychosocial Factors (Yellow and Blue Flags) in Individuals with Back Pain," *Physical Therapy Reviews* 18, no. 5 (2013), 379-394.

[83] Jenny Setchell, "What has Stigma Got to do with Physiotherapy?" in *utp journals.press* (2017), 1-3.

[84] Nicholls et al., "Connectivity: An Emerging Concept for Physiotherapy Practice," 159-170.

history of validating independence? What will be achieved if dependencies were enabled and diversity embraced?

Another study carried out in chronic low back pain, shows that physiotherapists still express a preference for dealing with biological aspects when treating their patients in pain.[85] The same research also revealed that physiotherapists might stigmatise those behaviours suggestive of psychosocial contributions to this type of pain. This study continued to state that academic training at university and the training in professional development, do not instil the required skills to address the complexity of pain.[86] Chronic low back pain, for example, therefore, continues to remain an enigma for physiotherapists and other professions.[87]

In an attempt to find a reason for the unexplained pain, patients are overdiagnosed and subjected to a panoply of tests.[88] As a result, patients can present with pain that is not attributable to any underlying condition. However, a medical diagnosis is given to imply an underlying structural cause; suggesting that patients have no pathology to explain their pain, can understandably upset them.[89] Such a scenario also creates problems for health bureaucracy and funding, where the specific diagnosis of the patient is essential. This biomedical model fails to consider that the majority of healthcare costs are related to disability. Therefore, limited attention is given to other measures despite evidence of their effectiveness.

Consequently, health care systems operating predominantly from the biomedical model cause a barrier to individualised care in physiotherapy. The long waiting lists for patients to get an appointment and the consequent short treatment sessions are examples.[90] Chronic pain patients are not identified in the present outpatient settings (designed for acute conditions and quick turnarounds) as requiring a different model of

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[85] Aoife Synnott et al., "Physiotherapists may Stigmatise Or Feel Unprepared to Treat People with Low Back Pain and Psychosocial Factors that Influence Recovery: A Systematic Review," *Journal of Physiotherapy* 61, no. 2 (2015), 68-76.

[86] *Ibid.*

[87] James E. Eubanks et al., "Changing Pain: Making Sense of Rehabilitation in Persistent Spine Pain," in *Meanings of Pain,* (Springer, 2019), 77-102.

[88] Michael Von Korff, "Healthcare for Chronic Pain: Overuse, Underuse, and Treatment Needs: Commentary on: Chronic Pain and Health Services Utilization–Is there Overuse of Diagnostic Tests and Inequalities in Non-Pharmacologic Methods Utilization?" *Medical Care* 51, no. 10 (2013), 857.

[89] *Ibid.*

[90] Dawn Connelly, " Some Patients with Chronic Pain Facing Waiting Years to See a Specialist," *The Pharmaceutical Journal,* 6 February 2020 https://www.pharmaceutical-journal.com/news-and-analysis/news/some-patients-with-chronic-pain-face-waiting-years-to-see-a-specialist/20207637.article?firstPass (accessed Mar 7, 2020).

care than patients with acute pain. Chronic patients attend physiotherapy outpatient clinics with more serious complexities than those of acute pain. Physiotherapists, therefore, struggle to incorporate the personalised care necessary to manage chronic pain, due to functioning predominantly from the biomedical paradigm.

When managing chronic pain physiotherapists operate predominantly from the biomedical model also because the biopsychosocial model is said to be a *fragmented* model and, therefore, incomplete.[91] When considering advancement in pain research, coupled with phenomenology and cognitive scientists' advanced methods of understanding perception, the biopsychosocial model is rendered incompetent.[92] When the biopsychosocial approach is applied, there is the tendency to divide the patient's pain into two or three *distinct* parts; either biological and psychosocial or biological, psychological or social domains. In clinical and educational settings, after the separation of these domains, the tendency is to focus mostly on the biological.[93]

Physiotherapists acknowledge that psychosocial factors influence pain neuroscience. However, lack of clear guidelines and teaching on how best to administer their assessment, leaves physiotherapists wondering on how to implement them in practice.[94] Also, the biopsychosocial model lacks philosophical coherence, with no safeguards against either the under-representation or dominance of any one of the three components.[95] Consequently, within this model, there is limited room for improvement to acknowledge the phenomenology of the pain experience, by *integrating* these three domains. Without a strong theoretical foundation for this model of care, the clinical application, research and teaching of chronic pain will lack clear direction also in physiotherapy. As described earlier, chronic pain is ecologically and socially grounded. Therefore, fragmenting pain into compartments incorrectly regards the person as dissociable and undermines his/her dignity.

Another example of how physiotherapists operate predominantly from the biomedical model is when one looks at research. Physiotherapy is closely aligned with

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[91] Stilwell and Harman, "An Enactive Approach to Pain: Beyond the Biopsychosocial Model," 1-29.
[92] *Ibid.*
[93] *Ibid.*
[94] Amarins J. Wijma et al., "Clinical Biopsychosocial Physiotherapy Assessment of Patients with Chronic Pain: The First Step in Pain Neuroscience Education," *Physiotherapy Theory and Practice* 32, no. 5 (2016), 368-384.
[95] Tony B. Benning, "Limitations of the Biopsychosocial Model in Psychiatry," *Advances in Medical Education and Practice* 6 (2015), 347.

medicine and its commitment to the positivist perspective.[96] Therefore, this can explain why during the past decades, research within the physiotherapy profession was predominantly based on biomedical perspectives such as best practice guidelines and assessment of outcome measures for patients.[97] Quantitative research alone does not suffice to understand the patient's disability experience and the reliance on questionnaires to achieve psychosocial information is challenged due to the research design limitations.[98] Also, due to the format of these questionnaires, the depth of data obtained is obviously limited.[99] The complexities comprising one's quality of life and personal perspectives, cannot be reduced to tick box responses and reduced to numerical scores since the uniqueness of the patient's *narrative* and sensitivity to treatment is lost. Also, the therapeutic process cannot be limited to the clinical session, but it transcends the day-to-day life between physiotherapy sessions. Such research takes for granted the ultimate value of the broader perspective, such as the impact of the health issue on the lives of patients, which is fundamental in chronic pain. Here, growth in this research raises numerous questions as much as it gives answers. Within the context of physiotherapy care in constant pain, what does evidence-based practice mean? What outcomes are physiotherapists measuring? Outcomes as perceived by their patients or outcomes as measurable by external variables? What is the implication for those epistemologies underlying the profession in the field of chronic pain? Therefore, in chronic pain, a tension exists between *standardised*, evidence-based ideals (population homogeneity), and *individualised* approaches to care.

The biopsychosocial model is more holistic than the biomedical model, in view of the obvious fact that people live out their lives in a socio-cultural context. However, the former model is *vaguely* defined, and educators, clinicians and researchers struggle when applying and teaching this model holistically.[100] Recent studies suggest that although physiotherapists recognise the importance of addressing the broader needs of patients, they lack the skills to address psychosocial issues that accompany chronic

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[96] Chris Carpenter, "The Contribution of Qualitative Research to Evidence-Based Practice," *Qualitative Research in Evidence-Based Rehabilitation* (2004), 1-13.

[97] David A. Nicholls and Barbara E. Gibson, "The Body and Physiotherapy," *Physiotherapy Theory and Practice* 26, no. 8 (2010), 497-509.

[98] Mark Jones et al., "Challenges in Applying Best Evidence to Physiotherapy," *Internet Journal of Allied Health Sciences and Practice* 4, no. 3 (2006), 11.

[99] *Ibid.*

[100] Stilwell and Harman, "An Enactive Approach to Pain: Beyond the Biopsychosocial Model," 1-29.

pain.[101] Managing patients with chronic pain and emotional distress can be frustrating for physiotherapists when their training has focused mostly on biomedical processes and relief of symptoms.

1.3.2 The Ethical Implications of the Biomedical Culture in Physiotherapy

The dominance of the biomedical model has led to a thin conception of justice, especially in resource-poor countries, since the root cause of illness within this ideology is not addressed. A sociological explanation of illness causation is also needed to broaden ethical principles.[102] Deepening our understanding of this ideology has implications for research priorities, policy, and education as part of the continuous struggle to improve the current situation, not just in quality but also in the equity of chronic pain management.[103]A renewed understanding of the patient-physiotherapist relationship and the risks and benefits of treatment should also be provided.

The typical failure of chronic pain to fit within the biomedical's view of cure over care, and disease over illness, causes tension between the physiotherapist and patient. Many studies reveal dissonance between excellent technical skills of the physiotherapists and the low level of patient satisfaction with treatment as a result of inadequate communication competencies.[104]Due to pain lacking objective measures and being also psychosocially complex, successful outcomes rely, particularly on excellent communication. However, precisely for these reasons, physiotherapists can find talking about pain, difficult and annoyingly time-consuming. Therefore, within this philosophy of care that prioritises diseases responsive to treatments, chronic pain patients are at a disadvantage. Patients can be easily seduced by the physiotherapists who point to degenerated and bulging discs on images as causes for the pain. However, it is well known

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[101] Susan Carolyn Slade, Elizabeth Molloy and Jennifer Lyn Keating, "The Dilemma of Diagnostic Uncertainty when Treating People with Chronic Low Back Pain: A Qualitative Study," *Clinical Rehabilitation* 26, no. 6 (2012), 558-569.

[102] Jacquineau Azétsop and Stuart Rennie, "Principlism, Medical Individualism, and Health Promotion in Resource-Poor Countries: Can Autonomy-Based Bioethics Promote Social Justice and Population Health?" *Philosophy, Ethics, and Humanities in Medicine* 5, no. 1 (2010), 1.

[103] Megan Crowley-Matoka et al., "Problems of Quality and Equity in Pain Management: Exploring the Role of Biomedical Culture," *Pain Medicine* 10, no. 7 (2009), 1312-1324.

[104] Anna Wloszczak-Szubzda and Mirosław J. Jarosz, "Professional Communication Competences of Physiotherapists–practice and Educational Perspectives," *Annals of Agricultural and Environmental Medicine* 20, no. 1 (2013).

that many patients with no symptoms have similar findings.[105] Discord between the patient's biomedical understanding of pain and the physiotherapy guidelines that promote the biopsychosocial approach, could also encourage the physiotherapist to give advice to patients, that is more closely aligned to his/her reductionistic understanding of the symptoms, thus, limiting tension to the therapeutic relationship.[106] The dominant biomedical culture can also influence the physiotherapist's approach to chronic pain and challenge its legitimacy, occasionally causing negative perceptions about these patients with possible hidden agendas.[107]

Due to the biomedical culture devaluing psychosocial contexts of pain, particular difficulties arise in addressing the pain experience. Here, disadvantaged groups are hurt the most due to a preferred focus on biological causes. Social stressors are closely linked with increased mental and physical issues in the underprivileged populations.[108] The biomedical ideology fails to address this adequately since it is strictly focused on efficiency and efficacy and fails to address broader social injustices responsible for health-related risks and vulnerability.[109] Moreover, when the patient's chronic pain is viewed as distinct from the social context, patients are once again more likely to be stigmatised and problems resulting from their economic/social factors as negative features of the patient themselves.[110]

Unsurprisingly then it follows that the combination of minimal open communication, incomplete assessment of those complexities, and high levels of frustration, can hinder adequate treatment planning, especially those in the vulnerable groups. Physiotherapy, such as in chronic pain, raises ethical issues such as about setting the goal and the limits to treatment when there is the uncertainty of what are the aims to be achieved.[111] Disability and suffering and their impact on the quality of life should be

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[105] Eugene Carragee et al., "Are First-Time Episodes of Serious LBP Associated with New MRI Findings?" *The Spine Journal* 6, no. 6 (2006), 624-635.

[106] Gardner et al., "Physiotherapists' Beliefs and Attitudes Influence Clinical Practice in Chronic Low Back Pain: A Systematic Review of Quantitative and Qualitative Studies," 132-143.

[107] Tom Sanders et al., "Biopsychosocial Care and the Physiotherapy Encounter: Physiotherapists' Accounts of Back Pain Consultations," *BMC Musculoskeletal Disorders* 14, no. 1 (2013), 65.

[108] Paula S. Nurius, Edwina Uehara and Douglas F. Zatzick, "Intersection of Stress, Social Disadvantage, and Life Course Processes: Reframing Trauma and Mental Health," *American Journal of Psychiatric Rehabilitation* 16, no. 2 (2013), 91-114.

[109] Azétsop and Rennie, "Principlism, Medical Individualism, and Health Promotion in Resource-Poor Countries: Can Autonomy-Based Bioethics Promote Social Justice and Population Health?" 1.

[110] Peter A. Clark, "Ethical Implications of Pain Management," *Health Progress* 83, no. 4 (2002), 19-28.

[111] Kati Kulju, Riitta Suhonen and Helena Leino-Kilpi, "Ethical Problems and Moral Sensitivity in Physiotherapy: A Descriptive Study," *Nursing Ethics* 20, no. 5 (2013), 568-577.

more concerned with the *meaning* of pain. Pain intensity is only a *part* of the whole experience and may not be responsible for the crucial part of the patient's suffering. Chronic pain is often not the cause of suffering but is caused by it, in a vicious cycle of misery and infirmity.[112] A broader model would, therefore, acknowledge both biological embeddedness as well as social embeddedness; especially in those situations where people are dependent on each other and customs and traditional behaviour is strong.

This philosophy in healthcare systems assume that treatments after diagnosis act quickly and brief. Budgetary systems, health commissioners and healthcare professionals unintentionally disregard the impact of the person's emotional state resulting from chronic pain. A meaningful approach to rehabilitation also necessitates action from agencies such as employment, housing, and social services.[113] Therefore allocation of resources needs to be prioritised from modalities that aim to diagnose and treat, to educative and rehabilitative programs. People in chronic pain attend physiotherapy clinics in hopes that their symptoms are explained and relieved. Aggregate costs of treatment are substantial, and this does not necessarily mean that the patients' best interests are served.[114]

1.3.3 The Moral Obligation of the Physiotherapist to Manage Chronic Pain

Currently, there is no medical cure for chronic pain, and patients on long waiting lists can hold *unrealistic* expectations of biomedical interventions with a significant deterioration in their condition.[115] Also, physiotherapy referrals for chronic pain in primary care are still underused.[116]

Due to the extended times the physiotherapists spend with their patients, they have the potential to play a significant role in the translation, interpretation and contextualisation of the broader public health messages; thus making them relevant to the

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[112] Sullivan and Ballantyne, "Must we Reduce Pain Intensity to Treat Chronic Pain?" 65-69.

[113] Wade and Halligan, "Do Biomedical Models of Illness make for Good Healthcare Systems?" 1398-1401.

[114] Von Korff, "Healthcare for Chronic Pain: Overuse, Underuse, and Treatment Needs: Commentary on: Chronic Pain and Health Services Utilization–Is there Overuse of Diagnostic Tests and Inequalities in Non-Pharmacologic Methods Utilization?" 857.

[115] Mary E. Lynch et al., "A Systematic Review of the Effect of Waiting for Treatment for Chronic Pain," *Pain* 136, no. 1-2 (2008), 97-116.

[116] Elizabeth Cottrell, Edward Roddy and Nadine E. Foster, "The Attitudes, Beliefs and Behaviours of GPs regarding Exercise for Chronic Knee Pain: A Systematic Review," *BMC Family Practice* 11, no. 1 (2010), 4.

individual patient.[117] Given the relevance physiotherapy has in the management of chronic pain to educate and offer reassuring advice, as well as addressing the related impairments in patients, physiotherapists have the ethical duty to re-visit the existing ideologies of their practice, to serve better their patients in pain and alleviate their suffering. Also, guidelines focusing on cost-effective measures that aim at the purported underlying origin of persistent pain, prove to be ultimately costly, while strategies enhancing *self-management* are associated with lower levels of disability.[118]

Physiotherapists are morally bound by the World Confederation for Physical Therapy (WCPT) ethical principles to respect the rights and dignity of their patients by assuring the highest quality of service.[119] However, is there the moral imperative for physiotherapists to treat all their patients with chronic pain irrespective of the potential benefits from their therapeutic interventions? The ethical duty of the physiotherapist to provide effective, safe and compassionate care is not similar to the moral imperative to treat, where benefits and cost-effectiveness of physiotherapy have not yet been adequately established. The patient's subjective understanding of his/her functional limitations and the ability to achieve personal goals need to be the main targets for physiotherapy outcome measures and interventions. Given that no two chronic pain patients are entirely the same, more *meaningful* therapeutic strategies should be adopted. However, specific skills are necessary for the physiotherapists to meet these moral challenges and to understand the patient's perspective in those *particular* circumstances.[120] Evidence suggests that a determinant of pain disability is not only the pain in itself but rather how the patient *interprets* that pain.[121] Chronic pain, regarded as a human experience, with human interactions having a pivotal role, cannot only be considered a neural

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[117] Clare Delany, Caroline Fryer and Gisela Kessel, "An Ethical Approach to Health Promotion in Physiotherapy Practice," *Health Promotion Journal of Australia* 26, no. 3 (2015), 255-262. doi:10.1071/HE15052.

[118] Michael K. Nicholas and Fiona M. Blyth, "Are Self-Management Strategies Effective in Chronic Pain Treatment?" *Pain Management* 6, no. 1 (2016), 75-88.

[119] World Confederation for Physical Therapy. Policy Statements: Ethical responsibilities of physical therapists and WCPT members. London, UK: WCPT; 2017 https://www.wcpt.org/sites/wcpt.org/files/files/resources/policies/2017/PS_Ethical_responsibilities_of_physical_therapists_and_WCPT_members_FINAL.pdf (accessed Dec 5. 2019).

[120] Bruce H. Greenfield and Gail M. Jensen, "Understanding the Lived Experiences of Patients: Application of a Phenomenological Approach to Ethics," *Physical Therapy* 90, no. 8 (2010), 1185-1197.

[121] Mark P. Jensen et al., "Psychosocial Factors and Adjustment to Chronic Pain in Persons with Physical Disabilities: A Systematic Review," *Archives of Physical Medicine and Rehabilitation* 92, no. 1 (2011), 146-160.

phenomenon, but a moral one too, and despite experiencing meaningfulness for patient's functioning is significant, this seems to be often neglected in the clinics.[122]

People in chronic pain still suffer, although a Declaration bullet point emphasised the human right to its access, and that health professionals acknowledge and adequately manage the pain experience. The Declaration, thus, states two obligations (refer to Appendix A): the first concerned healthcare access and changes in policies, and the second, which is more relevant for this thesis, concerned revision of the way health care professionals (including physiotherapists) are taught about pain, to be competent and ethical in their practice "in a treatment relationship with a patient."[123]

Physiotherapists are, therefore, morally obliged and have the potential to act against the disparities associated with chronic pain management by engaging in research to identify strategies that: prevent, assess and manage chronic pain; minimise disparities in accessing physiotherapy; promote societal awareness about chronic pain and the positive impact of physiotherapy; identify productive educational methods for the public and healthcare professionals; explore the cultural meanings of pain; identify the consequences of its undertreatment. Thus, the patient's dignity and autonomy are supported irrespective of his/her beliefs, values and characteristics.

The September, 8 of every year, is '*World Physiotherapy Day*', and this gives the opportunity to all physiotherapists to raise awareness about the vital contribution the profession makes. The theme of the year 2019 was '*The Physiotherapist's role in the field of Chronic Pain*,' which gave the chance to showcase to the world that physiotherapists are fundamental in the management of chronic pain.

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[122] Jessie Dezutter, Laura Dewitte and Siebrecht Vanhooren, "Chronic Pain and Meaning in Life: Challenge and Change," in *Meanings of Pain* Springer, (2016), 211-226.

[123] International Pain Summit of the International Association of the Study of Pain, "Declaration of Montreal: Declaration that Access to Pain Management is a Fundamental Human Right," 29-31.

Chapter 2: Living Meaningfully with Chronic Pain

Physiotherapy for patients in chronic pain needs to be tailored for the individual patient. An understanding of the patient's *lived* experience is fundamental, and importance given to the psychosocial and existential domains is crucial. Achieving health in chronic pain is not merely diminishing symptoms and pain intensity since situations of chronic pain are generally transformed into conditions of human suffering, where patients continuously struggle with the meaning of life. Physiotherapy should, therefore, enhance self-management skills and self-efficacy within shared decision-making for patients to live a life as independent as possible. Health achieved in chronic pain, thus, refers to achieving the maximum possible threshold of those capabilities that are central to living a meaningful life which is, therefore, also dignified.

Chapter Two is, therefore, divided into three sections. The first section explains what it means to live with chronic pain and the significance of a holistic assessment in physiotherapy. In the second section of this chapter, the Capability Approach is addressed. Its relevance to this chapter is the recognition this approach gives to human diversity. It acknowledges the ways individuals differ in their resources, skills, and capacities to translate their opportunities into meaningful actions. This approach also extends further to mention basic functionings that are vital for the patient to achieve, at least at satisfactory levels, if he/she is to live a flourishing life (refer to Appendix B). The physiotherapist must, therefore, strive to maximise the potential of the patient in achieving a meaningful life, thus, upholding his/her dignity. The third section of this chapter explains how the physiotherapist can help the patient to advance these capacities.

2.1 Understanding the Patient in Chronic Pain is Central to Achieve Health

2.1.1 Living with Chronic Pain

Since the meaning of chronic pain, is associated with complex affective and cognitive states, it influences the degree of suffering patients experience, affecting secondary concerns such as social displacement, functional disability, sleep disturbance, fatigue, and work disruption. The pain intensity in chronic pain cannot serve as the adequate measure to quantify the problem, and no quantitative measures can capture the burden of chronic pain to that *particular* patient in his *unique* circumstances.[1] The major impact of living with chronic pain is a poor quality of life. When pain is intense, function is impaired and is refractory to therapy, constant pain can become associated with increased depressive symptoms.[2] Also, studies reveal increased comorbidity levels between depression and chronic pain, with an increased possibility of suicide.[3] Although the International Association for the Study of Pain (IASP) clearly defines chronic pain (refer to Chapter One section 2.2), this definition, however, does not capture the *human impact* and what it is like to live with chronic pain.

Patients reporting persistent pain, generally complain of limitations in their activities of daily living (such as dressing/undressing, lifting, housework, driving); when compared to people who lack constant pain.[4] Insomnia and other sleep disturbances are also prevalent in patients with continuous pain.[5] Women, in particular, indicate a high impact of diminished activities and an increased tendency of being less physically active; such as going out for a walk.[6] This activity decline causes further disability, with increased limitations in social life; such as that of fulfilling the role of grandparent or engaging in recreational activities. Avoidance behaviour could be one way of diminishing symptoms; therefore, people limit their activities or renounce their personal life goals in an attempt to minimise their symptoms.[7] Employment becomes also challenging due to psychological obstacles (e.g. fear of worsening pain, anxious about what others might think) and attitudinal barriers (e.g. stigma and lack of managers understanding chronic

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[1] Jane C. Ballantyne and Mark D. Sullivan, "Intensity of Chronic Pain—the Wrong Metric?" *New England Journal of Medicine* 373, no. 22 (2015), 2098-2099.

[2] Giovanni Gambassi, "Pain and Depression: The Egg and the Chicken Story Revisited," *Archives of Gerontology and Geriatrics* 49 (2009), 103-112.

[3] Mélanie Racine, "Chronic Pain and Suicide Risk: A Comprehensive Review," *Progress in Neuro-Psychopharmacology and Biological Psychiatry* 87 (2018), 269-280.

[4] S. V. Björnsdóttir, S. H. Jónsson and U. A. Valdimarsdóttir, "Functional Limitations and Physical Symptoms of Individuals with Chronic Pain," *Scandinavian Journal of Rheumatology* 42, no. 1 (2013), 59-70.

[5] Jo Nijs et al., "Sleep Disturbances in Chronic Pain: Neurobiology, Assessment, and Treatment in Physical Therapist Practice," *Physical Therapy* 98, no. 5 (2018), 325-335.

[6] Björnsdóttir, Jónsson and Valdimarsdóttir, "Functional Limitations and Physical Symptoms of Individuals with Chronic Pain," 59-70.

[7] Amanda E. Young et al., "Workers' Perspectives on Low Back Pain Recurrence: "it Comes and Goes and Comes and Goes, but It's always there"," *Pain®* 152, no. 1 (2011), 204-211.

pain).[8] Loss of work results in financial burdens with further feelings of helplessness, anger and frustration; causing further limited social interaction. Therefore, one can also appreciate the tension that can occur within families, such as marital conflict, role tension, sexual dysfunction, resentment in other family members, etc. Unemployed men with fibromyalgia, report feeling irritated due to their inability to provide for the family; with this anger being directed mostly at their families.[9]

Various similarities exist in the experience of chronic pain irrespective of its cause, which ruptures the very core of the patient's existence, causing depersonalisation.[10] The relation between the self and the body is disrupted in chronic pain, and sufferers experience a false sense of betrayal.[11] Chronic pain destabilises this relation, marked by the body's submission to the self.[12] As patients in the clinics often point out, their body becomes alien to them and also an enemy, preventing their ability to function. Due to this disruption, the person's self-relation is also transformed, as the patient's capacity to accomplish basic activities of daily living are diminished.[13] Patients are crippled when their self-reliance and self-confidence are robbed, as simple tasks like walking down a few steps or getting out of bed cannot be done. The loss of family roles and those of work, undermine self-worth, and as a result, guilt sets in from not meeting the expectation of others and being a burden.[14]

Chronic pain disrupts one's conceptual, affective and perceptual relation with the surrounding world; transforming the body into a living wall that divides the self from the rest of the world.[15] Patients in pain feel increasingly isolated, and frustrated by being chronically impaired by an experience invisible to others, thus comprising both a sense

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[8] Mary Grant et al., "Obstacles to Returning to Work with Chronic Pain: In-Depth Interviews with People Who are Off Work due to Chronic Pain and Employers," *BMC Musculoskeletal Disorders* 20, no. 1 (2019), 486.

[9] Margareta Paulson, Ella Danielson and Siv Söderberg, "Struggling for a Tolerable Existence: The Meaning of Men's Lived Experiences of Living with Pain of Fibromyalgia Type," *Qualitative Health Research* 12, no. 2 (2002), 238-249.

[10] Crowe et al., "“Pain Takes Over Everything”: The Experience of Pain and Strategies for Management," 59-76.

[11] Saulius Geniusas, "Phenomenology of Chronic Pain: De-Personalization and Re-Personalization," in *Meanings of Pain,* (Springer, 2016), 147-164.

[12] *Ibid.*

[13] *Ibid.*

[14] Francine Toye et al., "Patients' Experiences of Chronic Non-Malignant Musculoskeletal Pain: A Qualitative Systematic Review," *Br J Gen Pract* 63, no. 617 (2013b), e829-e841.

[15] Geniusas, "Phenomenology of Chronic Pain: De-Personalization and Re-Personalization," 147-164.

of not being credulous and an attitude of stoicism.[16] Patients find it difficult to disclose their pain experience, and this isolation increases if their authenticity is questioned.

Another experience which is generally similar to that of chronic pain patients is that the unpredictability of pain also makes them hyper-aware of their body.[17] Since actions that could exacerbate their pain are not easily identified, patients become hesitant to engage in certain activities and act very cautiously. Patients, therefore, continually struggle with pain by balancing competing forces such as hope and despair with limited plans and expectations for their future.[18]

Unfortunately, the patient experiences depersonalisation also within the healthcare system.[19] The contested, subjective and invisible nature of constant pain, causes patients to experience difficulties to the legitimisation of their pain. In the face of such scepticism, patients do not always feel valued and heard, and struggle to prove themselves with health care professionals.[20] Underestimating their pain causes the risk of inadequate care, with potentially devastating consequences to their health. Moreover, since patients in constant pain anticipate stigmatisation and risk misunderstanding, talking about their pain becomes uncomfortable.[21] Also, patients often struggle to negotiate the healthcare organisation and are commonly referred back and forth to different health professionals.[22] These explain an ambivalent stance since although reticent to participate in a system where their expectations are not met, at the same time, they continue to hope for a better future.[23] Not only is there a lack of privacy and dignity associated by being a chronic pain patient, but a loss of *personhood* can also be experienced. Such patients are often identified by their ailments, and in a hospital setting, one can become ‘the neck’ or ‘the back’ while discussions about the patient’s condition

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[16] Crowe et al., "“Pain Takes Over Everything”: The Experience of Pain and Strategies for Management," 59-76.

[17] *Ibid.*

[18] Toye et al., "Patients' Experiences of Chronic Non-Malignant Musculoskeletal Pain: A Qualitative Systematic Review," e829-e841.

[19] F. Toye et al., "A Meta-Ethnography of Patients' Experience of Chronic Non-Malignant Musculoskeletal Pain," *Osteoarthritis and Cartilage* 21 (2013a), S259-S260.

[20] Francine Toye, Kate Seers and Karen L. Barker, "Meta-Ethnography to Understand Healthcare Professionals’ Experience of Treating Adults with Chronic Non-Malignant Pain," *BMJ Open* 7, no. 12 (2017), e018411.

[21] Elaine Wainwright et al., "The Social Negotiation of Fitness for Work: Tensions in Doctor–patient Relationships Over Medical Certification of Chronic Pain," *Health:* 19, no. 1 (2015), 17-33.

[22] Toye et al., "Patients' Experiences of Chronic Non-Malignant Musculoskeletal Pain: A Qualitative Systematic Review," e829-e841.

[23] *Ibid*.

can be easily overheard.[24] Also, patients experience a desire to be trusted and listened to, and continually struggle to feel understood and able to influence their situation.[25]

To summarise, it can, therefore, be appreciated that persistent pain impacts broadly and significantly the person's quality of life. Those in pain are restricted to perform their activities of daily living or go to work; thus, losing their independence. Subsequent tension on personal relationships and roles, on emotions and sleep, set in. Patients with chronic pain lose all enjoyment in life and attempt to preserve a positive identity, seek effective treatment and legitimise their pain. Basically, these are a patient group that suffer and heavily depend on the support of their family and friends, health professionals and social services.

The *psychosocial* and *existential* concerns these patients experience, thus, explains the struggle to describe the pain experienced within the biomedical paradigm. A more holistic approach that addresses these domains is, therefore, vital, if patients in chronic pain are to be treated with the dignity they deserve!

2.1.2 Understanding the Patient in Chronic Pain has Implications for Physiotherapy

Traditionally, chronic pain has been considered a *medical* issue impacting individuals, meaning that a great deal of study focused solely on diagnosis, symptoms, individual distress and the milieu of that *immediate* relationship.[26] Also, this biomedical model sees the patient in pain as having either a disturbed mind or a disordered body, and in the absence of objective evidence, will default to the disturbed mind.[27] The status of patients, therefore, becomes ambiguous, since this can also result in stigmatisation, medical scepticism and inappropriate treatment. Consequently, due to the lack of visible evidence of chronic pain, the moral character of the sufferer becomes a fundamental issue.

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[24] Michael E. Schatman, *Ethical Issues in Chronic Pain Management* CRC Press, (2016).

[25] Renée Allvin, Erika Fjordkvist and Karin Blomberg, "Struggling to be seen and Understood as a person–Chronic Back Pain Patients' Experiences of Encounters in Health Care: An Interview Study," *Nursing Open* 6, no. 3 (2019), 1047-1054.

[26] Tapio Ojala et al., "Although Unseen, Chronic Pain is real–A Phenomenological Study," *Scandinavian Journal of Pain* 6, no. 1 (2015a), 33-40.

[27] Milton Cohen et al., "Stigmatization of Patients with Chronic Pain: The Extinction of Empathy," *Pain Medicine* 12, no. 11 (2011), 1637-1643.

In chronic pain, meaningfulness, relatedness, freedom, and mortality become themes of great concern.[28] Patients in chronic pain cut off from those sources that give them meaning, causing them to wonder how their life can be meaningful once again; e.g. active caregiver for grandchildren, career.[29] In a sample of patients with osteoarthritis, the experience of meaningfulness was associated with higher wellbeing and diminished distress.[30] Meaningfulness also enhances better psychosocial functioning.[31]

The chronic pain patient, at some point during his/her illness, is forced to face transcendent dilemmas, where his role/meaning in the world has to be redefined.[32] Questions such as '*why me?'* also haunt the sufferer and how this question is answered is prognostically significant. The physiotherapist must, therefore, enable the patient to reflect critically to make good choices. Also, living with declining productivity, and increasing dependency requires the continuous re-definition of the self as every new level of impaired function is realised.[33] One of the initial steps in the search for renewed meaning is a shift from asking '*why me?'* to '*what now?'*

When suffering is observed as a singular phenomenon for every patient, with a strict focus on the body or the mind, it neglects the soul and ignores the most central part of being human. Understanding the patient in pain, therefore, has implications for physiotherapy. Attention should also be given to the *psychosocial* and *existential* domains of the patient in pain.[34] An in-depth analysis of the meaning of one's life allows insights about the past and future essential choices.[35]A study carried out by Dezutter et al., revealed that patients in chronic pain report dissatisfaction due to the lack of attention

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[28] Jessie Dezutter et al., "Chronic Pain Care: The Importance of a Biopsychosocial-Existential Approach," *The International Journal of Psychiatry in Medicine* 51, no. 6 (2016), 563-575.

[29] Jennifer Bullington et al., "Meaning Out of Chaos: A Way to Understand Chronic Pain," *Scandinavian Journal of Caring Sciences* 17, no. 4 (2003), 325-331.

[30] Bruce W. Smith and Alex J. Zautra, "The Role of Purpose in Life in Recovery from Knee Surgery," *International Journal of Behavioral Medicine* 11, no. 4 (2004), 197.

[31] Jessie Dezutter, Koen Luyckx and Amy Wachholtz, "Meaning in Life in Chronic Pain Patients Over Time: Associations with Pain Experience and Psychological Well-Being," *Journal of Behavioral Medicine* 38, no. 2 (2015), 384-396.

[32] Schatman, *Ethical Issues in Chronic Pain Management*.

[33] *Ibid.*

[34] Dezutter et al., "Chronic Pain Care: The Importance of a Biopsychosocial-Existential Approach," 563-575.

[35] de Siqueira, Silvia Regina Dowgan Tesseroli, "Existential Meaning of Patients with Chronic Facial Pain," *Journal of Religion and Health* 57, no. 3 (2018), 1125-1132.

given to their existential and social domains.[36] Additionally, it was concluded that addressing the patients' existential concerns was significant for their functioning.[37]

In the clinics, pain is turned into a technical matter, thus depriving suffering of its intrinsic personal meaning. Questions such as '*Why am I in Pain?'* are not addressed, but the focus is mostly made in answering questions about how the pain is brought about and how it can be treated. Personal questions about the experience and meaning of pain are answered in impersonal terms so that pain becomes a technical and not a personal problem. Talks about suffering are thus turned into talks of pain. As a result, patients in chronic pain are transitioned from managers of their pain to consumers of health care. Their ability to express their values and face reality while accepting their impairment and attempt to maximise their potential is, therefore, undermined. Inadequate pain management, with a lack of coping skills and motivation, will eventually lead to further physical impairment due to disuse.[38] A study carried out recently in the Chinese population revealed that neck and back pain is associated with physical and mental health comorbidity and disability levels.[39] Patients, thus, progressively adopt the *sick role*, during which they are excused from social obligations and other responsibilities. Unfortunately, these may also become potential drivers for not being healthy.

The pain experience necessitates the revision of the patient's life goals, and a more in-depth process that requires the physiotherapist to search for the patient's meaning and enable those skills necessary for a meaningful and flourishing life. Experiencing meaningfulness is related to greater wellbeing and decreased distress, with greater psychosocial functioning.[40] Also, high levels of patient satisfaction, increase treatment success and improved health-related behaviour, with consequent lower risks of disability and depressive symptoms.[41] Discussions about existential topics are not the standard physiotherapy roles, and it can feel inadequate to handle such talk. However, *presence to*

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[36] Dezutter et al., "Chronic Pain Care: The Importance of a Biopsychosocial-Existential Approach," 563-575.

[37] Dezutter, Dewitte and Vanhooren, "Chronic Pain and Meaning in Life: Challenge and Change," 211-226.

[38] Robert J. Gatchel, "Comorbidity of Chronic Pain and Mental Health Disorders: The Biopsychosocial Perspective." *American Psychologist* 59, no. 8 (2004), 795.

[39] Yifeng Xu et al., "The Comorbidity of Mental and Physical Disorders with Self-Reported Chronic Back Or Neck Pain: Results from the China Mental Health Survey," *Journal of Affective Disorders* 260 (2020), 334-341.

[40] Dezutter, Luyckx and Wachholtz, "Meaning in Life in Chronic Pain Patients Over Time: Associations with Pain Experience and Psychological Well-Being," 384-396.

[41] Dezutter et al., "Chronic Pain Care: The Importance of a Biopsychosocial-Existential Approach," 563-575.

listen to these concerns is vital if we are to treat the patient as a *person* and provide competent care. Every patient is unique, and specific approaches are therefore needed; thus, turning the distinct *narrative* of the pain experience into the main tool. This will, therefore, be the focus of Chapter Three.

2.1.3 Health in Chronic Pain as Capacity for Wellbeing

Health should not be considered a phenomenon that is only related to the body; it must, however, reflect the physical and social influences of the environment on the person in pain.[42] If an individual lacks the capacity to act for a positive change in behaviour, because something or someone restricts this capacity, the individual is disabled and therefore *not* in health.[43] Reviving those capacities and enabling those skills needed for meaningful action, changes the suffering individual from a patient to an empowered *person*.[44] The patient in chronic pain is *healthier* when those personal goals are able to be pursued.[45]

In chronic pain, physiotherapists are usually placed in a situation of dual advocacy, where their patient desires help, but giving that help such as *passive* treatment, can include what the physiotherapists feel is unnecessary/unhelpful treatment. Personal costs of such sessions can include one of the primary barriers to positive changes in behaviour for those seeking help.[46] The physiotherapist should consider whether the role of a dual advocate is being balanced effectively. These conflicts are hardly spoken of in undergraduate physiotherapy training, especially since objectivity and technical expertise are prized. In a study of individuals living well with chronic pain, it was found that these, only started considering living with their pain when they were told that their pain required *management* instead of a cure.[47]

Physiotherapists should, therefore, reconceptualise their contribution to health in chronic pain. Here, the role is not to treat the pain, but to *advance* the patient's *capacity*

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[42] Sridhar Venkatapuram, "Health, Vital Goals, and Central Human Capabilities," *Bioethics* 27, no. 5 (2013), 271-279.
[43] *Ibid.*
[44] Mark Sullivan, *The Patient as Agent of Health and Health Care: Autonomy in Patient-Centered Care for Chronic Conditions* Oxford University Press, (2016).
[45] *Ibid.*
[46] Toye, Seers and Barker, "Meta-Ethnography to Understand Healthcare Professionals' Experience of Treating Adults with Chronic Non-Malignant Pain," e018411.
[47] Bronwyn Lennox Thompson, Jeffrey Gage and Ray Kirk, "Living Well with Chronic Pain: A Classical Grounded Theory," *Disability and Rehabilitation* (2018), 1-12.

for individually meaningful action. Chronic pain affects persons in unique ways, relying on the meaning the patient associates with the experience. Thus, the priorities that are unique to the person should be considered the relevant outcome of physiotherapy. Understanding these priorities need therapeutic stance that shifts away from the assumption that an improved life is only equivalent to reduced pain.

As stated by the World Health Organisation: "Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity."[48] This definition of health contributes unthinkingly to the medicalisation of chronic pain.[49] The prominence given to *complete physical wellbeing* encourages medical dependency with a consequent increase in healthcare costs. Since 1948, at the time when the definition of health was formulated, acute diseases represented the main burden.[50] This definition underestimates the human capacity of the patient to function with chronic pain and his/her potential to act autonomously within biopsychosocial and existential challenges.[51] Various proposals for a different definition of health have been made, and the Ottawa Charter was considered the best. Here, the personal resources including physical capacity and the social circumstances were emphasised, and more relevance was given to coping capacity and societal participation; a vision of health that upholds one's ability to adapt and self-manage.[52]

What will follow in the next section is a brief explanation of an approach known as the Capability Approach. The specificity of this approach is that it asks not only whether people are being healthy, but also considers whether they have the necessary resources and skills to convert them into wellbeing.[53] It, therefore, acknowledges human diversity and that individuals differ in their potential to translate their opportunities and resources into function. This approach appreciates that individuals foster various relationships throughout their lives and are socially embedded. Much attention is given

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[48] World Health Organization, "WHO Definition of Health. Preamble to the Constitution of the World Health Organization as Adopted by the International Health Conference, New York, 19-22 June, 1946; Signed on 22 July 1946 by the Representatives of 61 States (Official Records of the World Health Organization, no. 2, P. 100) and Entered into Force on 7 April 1948," *Geneva: World Health Organization* (2003).

[49] Machteld Huber et al., "How should we Define Health?" *Bmj* 343 (2011), d4163.

[50] *Ibid.*

[51] *Ibid.*

[52] Monica Eriksson and Bengt Lindström, "A Salutogenic Interpretation of the Ottawa Charter," *Health Promotion International* 23, no. 2 (2008), 190-199.

[53] Rodrigo López Barreda, Joelle Robertson-Preidler and Paula Bedregal García, "Health Assessment and the Capability Approach," *Global Bioethics* 30, no. 1 (2019), 19-27.

to the connections between the material, social and mental wellbeing, and even to the political, economic, social, and cultural dimension of one's life.[54]

2.2 Achieving Health in Chronic Pain

2.2.1 The Capability Approach

The Capability Approach initially developed as a form of thinking about how advantaged or disadvantaged individuals are or how the quality of living can be assessed. In recent times, the Capability Approach has been developed for work on social justice and human development by Martha Nussbaum, Amartya Sen, and others.[55]

Sen's Capability Approach broadens the interests of human development policies that are beyond economic wellbeing such as income, and includes the analysis of political and social processes too.[56] For example, famine is not solely the result of a lack of food, but political and social factors have a decisive role. To fully broaden development policies beyond economics, Sen developed the concept of *functionings* and *capabilities*.[57] For a just society, health equity does not solely necessitate the access to health care, but that its citizens have *capabilities* and valuable *functionings* to achieve health.[58] The concept of *functioning* reflects the different things the individual may value doing or being. These vary from something basic, such as being nourished, to personal states such as having self-respect or even being able to participate in an activity such as riding the bike to work or walking. This *functioning* concept is paired with the concept of *capabilities*. *Capabilities* are those opportunities individuals have to accomplish the actual *functionings*.[59] For example, the physiotherapist cannot expect her patients to walk if there are no paths for people to go walking, parks do not feel safe, the lack of family support makes the activity difficult, or the patient is depressed and lacks the motivation

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[54] Ingrid Robeyns, "The Capability Approach: A Theoretical Survey," *Journal of Human Development* 6, no. 1 (2005), 93-117.
[55] Vikki A. Entwistle and Ian S. Watt, "Treating Patients as Persons: A Capabilities Approach to Support Delivery of Person-Centered Care," *The American Journal of Bioethics* 13, no. 8 (2013), 29-39.
[56] Thomas L. Jacobson, "Amartya Sen's Capabilities Approach and Communication for Development and Social Change," *Journal of Communication* 66, no. 5 (2016), 789-810.
[57] *Ibid.*
[58] Afschin Gandjour, "Mutual Dependency between Capabilities and Functionings in Amartya Sen's Capability Approach," *Social Choice and Welfare* 31, no. 2 (2008), 345-350.
[59] Jacobson, "Amartya Sen's Capabilities Approach and Communication for Development and Social Change," 789-810.

to change his behaviour. Also, riding the bike to work is not possible if the person lacks the skill to ride (personal factor) or the roads are of poor quality (environmental factor).

Thus, in chronic pain, where the patient is encouraged to live his/her life as fully as possible, despite the persistence of symptoms, these *capabilities* are fundamental to determine as to whether the patient will achieve what he/she values most in life. The Capability Approach, therefore, contributes to a useful perspective on how health in chronic pain can be achieved, and the possible causes of disability, by differentiating two stages of the problem: the *capability* stage and the *functioning* stage. The interaction of the patient's characteristics (self-efficacy, self-management, decision-making skills, motivation), environment (political, economic, social, physical) and the available resources must, therefore, be analysed to determine how they result in diminished health. The Capability Approach, therefore, acknowledges that individuals differ in their potential to translate their resources into *functionings*.[60]

With the Capability Approach, a relational, rather than the individualistic ontology of individuals and their capabilities, are incorporated.[61] Therefore, this is widely consistent with relational views of autonomy. It acknowledges that who we can be, and how we can provide for ourselves, rely on our social circumstances and relationships, and also on our skills and resources.[62]

2.2.2 Physiotherapy as the Means to a Dignified Life in Chronic Pain

Nussbaum expanded Sen's Capability Approach to develop ten Central Human Functional Capabilities (Appendix B), that are capabilities central to living the life in conformity with human dignity.[63] This list and their explanations which are quoted from Martha Nussbaum's book '*Women and Human Development: The Capabilities Approach,'* in Appendix B of this thesis, offer the essentialist basis about what a dignified

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[60] Caroline Harnacke, "Disability and Capability: Exploring the Usefulness of Martha Nussbaum's Capabilities Approach for the UN Disability Rights Convention," *The Journal of Law, Medicine & Ethics* 41, no. 4 (2013), 768-780.

[61] Matthew Longshore Smith and Carolina Seward, "The Relational Ontology of Amartya Sen's Capability Approach: Incorporating Social and Individual Causes," *Journal of Human Development and Capabilities* 10, no. 2 (2009), 213-235.

[62] Vikki A. Entwistle et al., "Supporting Patient Autonomy: The Importance of Clinician-Patient Relationships," *Journal of General Internal Medicine* 25, no. 7 (2010), 741-745.

[63] Martha C. Nussbaum, *Women and Human Development: The Capabilities Approach*, Vol.3 Cambridge University Press, (2001),78-80.

human life constitutes, and what makes life lack human character. Nussbaum built her version of the Capability Approach on virtue ethics and holds that human beings have human dignity and are fundamentally free.[64] Like Kant, she initiates from the primary premise that equal respect should be given to the dignity of each individual. In practical terms, this implies that each individual should acquire threshold levels of each of these capabilities to have dignity. It thus follows that institutions should aid individuals to enhance their dignity by providing the opportunity to people to cultivate their capabilities freely.[65] Nussbaum conceptualises the human being as a *dignified, free being who shapes his/her own life, rather than being passively shaped* and views the person as having activity, projects and goals.[66] Nussbaum claims that when the individual has different capabilities, he/she can choose to fulfil those *functionings* parallel with one's view of the good life. Nussbaum notes that justice requires that every human being achieves at least the threshold level for each capability on the list.[67] These capabilities are human species-wide and valid across all societies. Therefore ethical standing results from their significance of equal human dignity, and therefore no human life is privileged over another.[68] Thus, emanating from the individual's human dignity, these central human capabilities are considered moral entitlements.[69] Consequently, it is the moral duty of the physiotherapist to empower their patients in chronic pain to develop the necessary skills to maximise their potential to acquire those capabilities for a dignified life.

Nussbaum states that the idea about capabilities is central to how human rights are understood.[70] She continues to say that this list of capabilities, carries equal weight, and one should not be prioritised over the other. However, according to her, the Capabilities of *Practical Reason* and *Affiliation* "stand out as of special importance, since they both organise and suffuse all the others making their pursuit truly human." [71] Their importance is appreciated when she continues to explain that the basis of the intuition of human functioning is that of the free, dignified person who plans his/her way of life in

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[64] Alexander Bertland, "Virtue Ethics in Business and the Capabilities Approach," *Journal of Business Ethics* 84, no. 1 (2009), 25-32.
[65] *Ibid.*
[66] Martha Nussbaum, "Women's Capabilities and Social Justice," *Journal of Human Development* 1, no. 2 (2000), 219-247.
[67] Nussbaum, *Women and Human Development: The Capabilities Approach*.
[68] Venkatapuram, "Health, Vital Goals, and Central Human Capabilities," 271-279.
[69] Nussbaum, *Women and Human Development: The Capabilities Approach*.
[70] *Ibid.*
[71] Nussbaum, *Women and Human Development: The Capabilities Approach*, p.82.

reciprocity with other individuals, and not just following and being constructed by others.[72]

The *Practical Reason Capability* (refer to Appendix B no.6) is relevant to physiotherapy practice in chronic pain for guiding patients to identify their personal goals/meaningful activities and enable them to plan their lives. Barriers, (such as diminished motivation and lack of self-management skills and self-efficacy), affecting the patient to reflect critically in planning his/her life, should, therefore, be targeted. Patients in chronic pain require continuous support and motivation in decision-making. Coping with the pain and subsequent losses such as diminished mobility, unemployment, and diminished social networks is not easy.

The *Affiliation Capability* (refer to Appendix B no.7) concerns the ability of the person to live with others and towards the others, thus, sharing a mutual sense of belonging. It deals with engaging in various forms of social interaction and being treated with dignity, respect and non-discrimination. The physiotherapist can play a significant role in enhancing Affiliation capabilities of patients in chronic pain, by advocating for their patients, assisting patients in accessing the necessary resources, and provide patients with the required tools and skills to maximise their potential in achieving their goals. Thus, patients can also participate in their care.

Personal and structural support assuring maximum functioning capabilities for people with disabilities, lack across all societies.[73] Therefore, physiotherapy in chronic pain can have value in ensuring that the potential to achieve the Central Human Functional Capabilities is maximised, by assessing whether patients are enabled to achieve their personal goals and live a flourishing life despite pain. Nussbaum, however, also indicated that her list could be made more specific for different population groups.[74] This list of these central capabilities also engages with the strength of narratives (this will be the focus of Chapter Three) to grasp the individual's motivations, hopes, aspirations and decisions.

A list of capabilities relevant to patients in chronic pain was identified in a study carried out in a pain clinic in London. These included: "Love and Social Inclusion";

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[72] Nussbaum, *Women and Human Development: The Capabilities Approach.*
[73] Tahmineh Mousavi et al., "Occupational Therapists' Views of Nussbaum's Life Capability: An Exploratory Study," *OTJR: Occupation, Participation and Health* 35, no. 4 (2015), 239-249.
[74] Nussbaum, *Women and Human Development: The Capabilities Approach*.

“Enjoyment”; “Respect and Identity” (such as not being stigmatised and coming to terms with the condition); “Remaining Physically and Mentally Active”; “Independence and Autonomy”; “Societal and Family Roles”; “Physical and Mental Wellbeing”; “Feeling Secure about the Future”.[75] It can be noted that there are similarities between this list and that proposed by Nussbaum. These are those capabilities related to control, and the planning of one’s own life, independence, the ability to perform basic daily/recreational activities, love, friendships, and attachments. These capabilities echo in those situations, and experiences explained earlier in section 2.1.1 *Living with Chronic Pain*.

Enabling and maximising these capabilities in patients with chronic pain should, therefore, be the role of the physiotherapist, if justice with patients is to be served and their dignity upheld. Thus, wellbeing in chronic pain extends beyond physical symptoms. It is, therefore, the moral duty of the physiotherapist to provide the vehicle to achieve and extend those capabilities consistent with Nussbaum’s Capabilities.

2.2.3 Not a Right to Health but a Right to Health Capability

Health policy should, therefore, be broadened to encompass the causes and constraints in achieving central human capabilities, and not confined solely to the management and prevention of disease.[76] This ethical concept of health moves towards a holistic view that is not focused exclusively on biology. If the ability to achieve vital personal goals is indeed the most significant in one’s life, then these goals should be the most important societal goals. Health understood as moral entitlements to capabilities to achieve vital goals, catapults citizen’s health to the forefront of societal agendas to become recognised as fundamental political principles grounded in equal human dignity and social justice.[77]

Jennifer Ruger’s notion of *‘Health Capability’* applies Sen’s ideas to health policy so that health policies focus on the capabilities of people.[78] The Health Capability Approach, thus, comprises both health functionings and *health agency*. Health agency is one’s ability to accomplish valued health goals. The achievement of health agency is the

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[75] Philip Kinghorn, Angela Robinson and Richard D. Smith, "Developing a Capability-Based Questionnaire for Assessing Well-being in Patients with Chronic Pain," *Social Indicators Research* 120, no. 3 (2015), 897-916.

[76] Venkatapuram, "Health, Vital Goals, and Central Human Capabilities," 271-279.

[77] *Ibid.*

[78] Jennifer Prah Ruger, "Health Capability: Conceptualization and Operationalization," *American Journal of Public Health* 100, no. 1 (2010), 41-49.

realised action of the individual as opposed to *potential* action. Thus, justice should not only be analysed on the level of health resources, but the focus should be given to the *capacity* to translate those resources to achieve health.[79] The Health Capability Approach informs health policies in targeting health outcomes and health agency. In other words, *how* health goals, namely improved functioning, are attained, is as crucial as the attainment in itself. Conceptually, Ruger's health capability addresses, for example, why patients in chronic pain have difficulty translating health resources to health outcomes and their difficulties or constraints in adhering to given treatment regimes.[80] It also addresses why the pursuit of health depends on personal capabilities such as health literacy, self-management, and even external capabilities, such as wealth, education, emotional support, enabling healthcare systems etc.[81]

Health capability is not just being free from constraint. It is also being free to do and be what one values, by encompassing the acquisition and development of skills with the necessary resources to attain this mentioned doing and being.[82] Therefore, a significant step to measure health in chronic pain would be to measure health capability. The focus is not on pathology, but on health in terms of basic capabilities that are intrinsically valuable.[83]

Nussbaum emphasises the positive duty governments have to provide resources to encourage capabilities, which are significantly related to human rights and, thus, basic human entitlements.[84] Concentrating only on *disease* as the main goal for health rather than *living* in general, carves out only finite and mortality-relevant health concerns, instead of concerns about life goals and priorities. Human flourishing should be the ends of all political activity.[85] Therefore, health should be placed in the broader policy context for a greater understanding of social justice, and the effect of social policies on the broader determinants of health should also be evaluated.[86]

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[79] Jennifer Prah Ruger, "Rethinking Equal Access: Agency, Quality, and Norms," *Global Public Health* 2, no. 1 (2007), 78-96.

[80] Prah Ruger, "Health Capability: Conceptualization and Operationalization," 41-49.

[81] *Ibid.*

[82] *Ibid.*

[83] Hareth Al-Janabi, Terry N. Flynn and Joanna Coast, "Development of a Self-Report Measure of Capability Wellbeing for Adults: The ICECAP-A," *Quality of Life Research* 21, no. 1 (2012), 167-176.

[84] Martha C. Nussbaum, "Capabilities, Entitlements, Rights: Supplementation and Critique," *Journal of Human Development and Capabilities* 12, no. 1 (2011), 23-37.

[85] Jennifer Prah Ruger, "Toward a Theory of a Right to Health: Capability and Incompletely Theorized Agreements," *Yale Journal of Law & the Humanities* 18, no. 2 (2006), 3.

[86] Jennifer Prah Ruger, "Health and Social Justice," *The Lancet* 364, no. 9439 (2004), 1075-1080.

2.3 The Chronic Pain Patient Living a Healthy Life

2.3.1 Being Autonomous with Chronic Pain

For the management of chronic pain to be effective, patients need to feel empowered to manage their health and partake *actively* in this mission; thus not merely be a means to the mission. Therefore, the primary role of the physiotherapist in managing chronic pain is not to focus on the pain and attempt to treat it directly but to encourage the patient to focus on his or her intrinsic motivation to accomplish these vital goals. Only here will health in chronic pain be achieved. Direction and energy for this empowerment must be drawn from the patient's passion for living; thus, achieving personal autonomy of doing and being what the patient desires.

In clinical health care, respecting patient autonomy is a fundamental ethical principle.[87] This concept originated in the context of acute care, centering on the patient's ability to make voluntary decisions after understanding all the necessary information. In the acute setting, it is the patient's task to authorise the treatment after a deliberative process. The benchmark for judging the autonomy of the patient in this paradigm targets the patient's ability to partake in the informed consent process, where authorisation can be either given or withheld. In acute care, the patient is then expected to comply, after consenting to treatment.[88] Here, the patient's knowledge and comprehension of the choice in question is mainly dependent on the advice and recommendations received. Indeed, evidence-based knowledge and professionalism take priority over the patient's perspective.[89]

However, in chronic care, this concept of autonomy is no longer relevant, and decisions about informed consent are usually less applicable.[90] Chronic pain is an integral part of the patient's daily life. Consequently, autonomy should be concerned more about achieving the maximum potential of those capabilities to cope with the pain, rather than making decisions regarding treatment. Therefore, in chronic pain, one should ask: How can the physiotherapist help the patient become an autonomous person? As explained

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[87] Øystein Ringstad, "Being an Autonomous Person with Chronic Disease," *Croatian Medical Journal* 57, no. 6 (2016), 608.

[88] Aanand D. Naik et al., "Patient Autonomy for the Management of Chronic Conditions: A Two-Component Re-Conceptualization," *The American Journal of Bioethics* 9, no. 2 (2009), 23-30.

[89] Ringstad, "Being an Autonomous Person with Chronic Disease," 608.

[90] *Ibid.*

earlier, patients with persistent pain cannot always maintain their employment or pursue activities with their families and friends. Therefore, with chronic pain, autonomy must be understood as the ability to retain control over one's life, notwithstanding the physical impairments and dependence on others. When past roles and activities that were significant constituents of the patient's self-concept, cannot be continued as before, the physiotherapist's role becomes that of helping the patient search for new answers to questions that contribute to his suffering, such as Who am I? What relevance do I now have? What kind of person do I want to be? Where do I belong? Here, the physiotherapist enables those capabilities of *Practical Reason* (Appendix B no.6) and *Affiliation* (Appendix B no.7).

In these circumstances, the patient's perceptions and experiences that concern living with pain, become more significant sources for the physiotherapist in planning treatment. The concept of the patient in chronic pain with autonomy, therefore, presupposes the biography and identity of a person who is unique. This process of identification will reveal what patients value most, with whom they identify, and who they want to be. Therefore, in chronic pain, autonomy is not only a value in the clinical care, but the goal of physiotherapy. If the physiotherapist has to work *through* the patient in chronic pain to achieve therapeutic goals, then the patient has to be the focus of physiotherapy. A successful physiotherapist working with such patients must understand the importance of the limited capabilities the patient might have to achieve health, and therefore identify and cultivate these capabilities to make the patient autonomous.

2.3.2 Self-Management and Self-Efficacy to be Autonomous in Chronic Pain

Once chronic pain patients are discharged from care, they are expected to be active and self-responsible members in the community again. However, in chronic pain, cessation of symptoms cannot serve as the main goal in the long-term. The patient can reasonably avoid a pain-related activity for a week, but extending pain-avoidance behaviour for longer, makes life impoverished for the individual. Physiotherapy should, therefore, encourage the patient to move from being passive to active, and from being a patient to becoming a person who is active, and in pursuit of his/her vital goals to achieve health agency. Since chronic pain cannot be conquered but only managed, health, here becomes the capacity for action and achieving maximum threshold levels of capabilities.

The physiotherapist, therefore, has the duty to remove those barriers to resumption of self-directed activity and create the capabilities to have a meaningful life despite the pain. The foundation for achieving the capability to be healthy requires the patient to have self-management skills and self-efficacy, and the physiotherapist must, however, not assume that the patient has sufficient control over his circumstances to respond.

Professional ethics, therefore, requires that the physiotherapist weighs the benefits of the treatment session that aims to 'fix' the physical problem only temporarily, against the benefit that arises from that treatment that will eventually empower the patient to develop self-management skills and self-efficacy to optimise his/her health.[91] The approach of making the treatment decisions for chronic pain patients, and eliminating their perspective from the process, has proved to be unsuccessful.[92] Therefore instead of the physiotherapist searching for a solution, the physiotherapist should ask the patient to be part of that solution. A collaborative and trusting relationship (discussed in Chapter Three), is necessary to create care in chronic pain, which is also equitable with power asymmetry, so the patient can have an equal say in his/her care.[93] The physiotherapist should also be mindful that when promoting health, the strategies designed to modify the patient's behaviour do not add burdens, such as extra responsibilities, where the resources (economic, cultural, social), to implement behavioural changes are lacking.[94]

Barlow *et al.,* describe self-management as that ability to manage all those life changing situations inherent in living with chronic illness, such as those physical and psychosocial consequences.[95] However, a change in the patients' expectations is necessary so that a cure for their persistent pain, implying a passive treatment approach, is no longer expected.[96] Self-management encourages the *active* participation of the patient and the learning of skills to manage and take responsibility for their chronic

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[91] Kadija Perreault, "Linking Health Promotion with Physiotherapy for Low Back Pain: A Review," *Journal of Rehabilitation Medicine* 40, no. 6 (2008), 401-409.

[92] *Ibid.*

[93] Daniel Z. Buchman, Anita Ho and Daniel S. Goldberg, "Investigating Trust, Expertise, and Epistemic Injustice in Chronic Pain," *Journal of Bioethical Inquiry* 14, no. 1 (2017), 31-42.

[94] Daniel S. Goldberg, "Social Justice, Health Inequalities and Methodological Individualism in US Health Promotion," *Public Health Ethics* 5, no. 2 (2012), 104-115.

[95] Julie Barlow et al., "Self-Management Approaches for People with Chronic Conditions: A Review," *Patient Education and Counseling* 48, no. 2 (2002), 177-187.

[96] Jeremy Lewis and Peter O'Sullivan, "BMJ Publishing Group Ltd and British Association of Sports and Exercise Medicine," *Is it Time to Reframe how we Care for People with Non-Traumatic Musculoskeletal Pain?* (2018).

condition.[97] The necessary self-management skills include self-monitoring, self-tailoring, action planning, resource utilisation, decision-making, problem-solving and creating a patient-physiotherapist partnership.[98] With self-management, the physiotherapist can include, motivational interviewing, shared decision-making, cognitive behavioural therapy, acceptance and commitment therapy and education. Every patient is different with regard to health locus of control and self-management competency, despite patients presenting with similar symptoms. Therefore, based on the patient's individual characteristics and goals, the physiotherapist can focus on the patient's skills, knowledge, social influence, and self-efficacy regarding his chronic pain.[99]

Motivation, and therefore adherence to self-management, is influenced by self-efficacy.[100] Self-efficacy is the strength of the patient's belief in his/her ability to accomplish goals, i.e. the more it is believed that the patient can achieve the goal, the more likely it will be achieved.[101] Having confidence in the ability to perform a particular behaviour is also believed to be a more significant predictor of impairment than catastrophization and fear of movement.[102] Self-efficacy and fear due to pain, both contribute to pain levels and disability in chronic pain patients. However, since self-efficacy beliefs have a greater predictor of impairment than pain-related fear, self-efficacy beliefs mediate the relation between disability and/or pain intensity and pain-related fear.[103] Accomplishing a particular task successfully is, therefore, an effective way of encouraging self-efficacy, due to it being determined by the patient's mastery experiences.[104] Therefore, directly exposing patients gradually to activities, and empowering them throughout, is fundamental in physiotherapy.

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[97] Nini H. Jonkman et al., "Self-Management Interventions: Proposal and Validation of a New Operational Definition," *Journal of Clinical Epidemiology* 80 (2016), 34-42.

[98] Shizheng Du et al., "Self-Management Programs for Chronic Musculoskeletal Pain Conditions: A Systematic Review and Meta-Analysis," *Patient Education and Counseling* 85, no. 3 (2011), e299-e310.

[99] Nathan Hutting et al., "Promoting the use of Self-Management Strategies for People with Persistent Musculoskeletal Disorders: The Role of Physical Therapists," *Journal of Orthopaedic & Sports Physical Therapy* 49, no. 4 (2019), 212-215.

[100] María José Martos-Méndez, "Self-Efficacy and Adherence to Treatment: The Mediating Effects of Social Support," *Journal of Behavior, Health & Social Issues* 7, no. 2 (2015), 19-29.

[101] Steve R. Woby, Martin Urmston and Paul J. Watson, "Self-Efficacy Mediates the Relation between Pain-related Fear and Outcome in Chronic Low Back Pain Patients," *European Journal of Pain* 11, no. 7 (2007), 711-718.

[102] Eva Denison et al., "Musculoskeletal Pain in Primary Health Care: Subgroups Based on Pain Intensity, Disability, Self-Efficacy, and Fear-Avoidance Variables," *The Journal of Pain* 8, no. 1 (2007), 67-74.

[103] Woby, Urmston and Watson, "Self-Efficacy Mediates the Relation between Pain-related Fear and Outcome in Chronic Low Back Pain Patients," 711-718.

[104] *Ibid.*

However, self-management is also influenced by the perceived importance of the change in behaviour.[105] Even if the patient in persistent pain acknowledges his ability to change, he/she will unlikely change what is considered irrelevant. For example, if a patient is not convinced that losing weight is important to control his/her back pain, the likelihood of giving up the pleasure of eating is minimal, even if it is believed manageable to lose weight.

2.3.3 Participation in Physiotherapy by Shared Decision-Making

Since goal-negotiation is a crucial element of self-management and necessitates an agreement between the patient and the physiotherapist, shared decision-making is fundamental. This is because evaluating the patient's personal needs, capabilities and values, and the deliberation on reasonable goals, are all considered a precondition for goal-setting in self-management.[106] Also, if the physiotherapist struggles to talk about the pain as being long-term, and does not perceive living well with chronic pain as a favourable option, the therapeutic approach will focus on pain reduction.[107]

Shared decision-making skills of the physiotherapist, first require an appreciation of the guiding ethical principles.[108] In chronic pain, autonomy is the desired goal, and this is fully supported by building a good therapeutic relationship, respecting both the patient's competence and his/her interdependence on the others.[109] In chronic pain, the patient's lifestyle, personal values, and preferences are indicative of the most suitable choice of treatment. Studies reveal that informed preferences are the optimal goal because when decisions are made on personal preferences, patients will have a better knowledge about the possible positive and negative consequences.[110]

Shared decision-making also has the critical tenets of both relational autonomy and self-determination. This is because shared decision-making acknowledges the

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[105] Mark P. Jensen, Warren R. Nielson and Robert D. Kerns, "Toward the Development of a Motivational Model of Pain Self-Management," *The Journal of Pain* 4, no. 9 (2003), 477-492.

[106] Stephanie A. Lenzen et al., "Setting Goals in Chronic Care: Shared Decision Making as Self-Management Support by the Family Physician," *European Journal of General Practice* 21, no. 2 (2015), 1-7.

[107] Bronwyn Lennox Thompson, "After the Tango in the Doorway: An Autoethnography of Living with Persistent Pain," in *Meanings of Pain,* (Springer, 2019), 17-35.

[108] Glyn Elwyn et al., "Shared Decision Making: A Model for Clinical Practice," *Journal of General Internal Medicine* 27, no. 10 (2012), 1361-1367.

[109] *Ibid.*

[110] *Ibid.*

necessity to uphold autonomy by building healthy relationships, respecting one's competence, and interdependence on the community.[111] This person-centred approach not only builds the patient's resilience to endure suffering but also gives hope that maintaining activities is possible.[112] Thus shared decision-making *confers agency* since patients are making their own free choices and acting independently to have a meaningful life while being *partners* in their care. Choosing how to stand in front of suffering can result in real freedom, and aiding patients with self-transcendence by permitting the reconstruction of the past and designing the future, allows the patient in pain to find meaning in the inevitable suffering.[113] For example, through patient participation, the patient can also be involved in re-designing services and driving change that shapes an increased person-centred approach that improves the patient's experience in healthcare. In this way, the capabilities of *Affiliation* (Appendix B no.7) and *Control over the Environment* (Appendix B no.10) are also enabled.

Therefore, patient behaviour has a considerable effect on the outcome of physiotherapy in chronic pain. Thus, it is no secret that the key to a healthy outcome and cost-effective care for chronic pain is patient engagement in healthy behaviour. However, physiotherapists require to think deeper about this engagement, since attempts to improve this have had some success in the short-term, and many failures in the long-term since many patients till today still suffer as discussed in Chapter One. Patients in chronic pain need to be empowered, and the physiotherapist requires to switch from feeling responsible *for* the patient to feel responsible *to* the patient. To accomplish this, the physiotherapist needs to provide not just skills and information to the patients, but continuous support in formulating and accomplishing personal goals. In chronic pain, this means that treatment and physiotherapy should be administered *through* the patient. Here, strategies that are obedience-focused are de-emphasised and more attention is given to capacity for niche construction and intrinsic motivation to his/her vital goals. Thus, physiotherapy should be grounded in trust. Narratives of patients in pain can provide

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[111] Glyn Elwyn et al., "Shared Decision Making: A Model for Clinical Practice," *Journal of General Internal Medicine* 27, no. 10 (2012), 1361-1367.

[112] Helena Lööf, "“Let Me be a Meaningful Part in the Outside World”: A Caring Perspective on Long-Term Rheumatic Pain and Fear-Avoidance Beliefs in Relation to Body Awareness and Physical Activities," in *Meanings of Pain*, (Springer, 2019), 103-116.

[113] Thomas R. Egnew, “A Narrative approach to Healing Chronic Illness.” *The Annals of Family Medicine* 16, no.2 (2018), 160-165.

useful insights into the pain experience at the juncture of expert knowledge and trust in a robust physiotherapeutic relationship.[114] This will be the focus of the next chapter.

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[114] Buchman, Ho and Goldberg, "Investigating Trust, Expertise, and Epistemic Injustice in Chronic Pain," 31-42.

Chapter 3: Narratives in Physiotherapy for Chronic Pain

Narratives in physiotherapy, allow for a better understanding of the patient's unique pain experience and gives the patient in pain the voice to be heard and acknowledged. Through the narrative process, professional virtues in physiotherapy are enhanced, so that with the necessary skills, individualised care is given. In this way, the physiotherapeutic relationship is strengthened to better serve the patient in pain.

This chapter is, therefore, divided into two sections. The initial section explains how narratives serve to address the unique pain experience by acknowledging those particular biopsychosocial and existential concerns. The second section discusses the physiotherapeutic relationship and those professional virtues necessary in the narrative process for ethical decision-making in chronic pain.

3.1 Narratives in Chronic Pain

3.1.1 The Patient in Chronic Pain requires a More Holistic Approach

Patients in chronic pain can be disempowered during their care, due to their lack of self-awareness, knowledge, attitudes and skills that are relevant to advance their quality of life.[1] Consequently, these must be looked into, during the physiotherapy assessment, so that adequate shared decisions can be made, to enhance the patient's capacity, to make those necessary changes to live a meaningful life.

Since chronic pain is long-term, complex, and multidimensional, holistic support to patients, to self-manage their unique pain experience, is, therefore, necessary, and consideration must also be given to their constant needs in the biological, psychological, social, and existential domains. Thus, this contrasts the on-off support, which is often

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[1] Janette Barrie, "Patient Empowerment and Choice in Chronic Pain Management," *Nursing Standard (through 2013)* 25, no. 31 (2011), 38.

short-term, that is usually received.[2] These self-management programs, often imply that the patient in pain needs to comply with a given, standard exercise program, accompanied by some basic education about pain. Here, the focus on patients' *unique* experience, that includes their *particular* psychosocial influences, capabilities and skills is absent.[3] Therefore, since chronic pain is not only a physiological process, an understanding of the *lived* body, *in relation* to the mentioned factors, is fundamental, for effective self-management. An increasing body of literature is pointing to reciprocal effects, that indicates that the social and psychological experiences themselves, can directly impact chronic pain.[4] A study also confirmed how chronic pain affects the person holistically when it revealed that the most compelling complaints were not physical pain, but its psychosocial repercussions, such as the diminished quality of life, loss of identity, distress and isolation.[5]

However, social and existential discussions are still underdeveloped in pain care, although these are topics preferred by patients to discuss in the treatment encounter, with the existential domain being highly significant for depressive symptoms; with depression being closely linked to chronic pain.[6] Consequently, these findings have implications for physiotherapy practice. This is because patient functioning, depends on patient satisfaction.[7] Also, since meaningfulness is a vital role in the adaptation of chronic pain, the existential domain cannot be ignored.[8] Persistent pain, being an experience, and not necessarily or solely an aversion symptom, necessitates *phenomenological* inquiry, where the possible roots of symptoms may be derived from the patients' subjective responses, through their *narratives*.[9] Of course, the physiotherapist cannot solve all the problems in the patient's mentioned life domains that are impacted by chronic pain. However, the openness of *listening* to the patient's concerns that might emerge during treatment is

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[2] Crowe et al., ""Pain Takes Over Everything": The Experience of Pain and Strategies for Management," 59-76.

[3] Marie Crowe et al., "Self-management and Chronic Low Back Pain: A Qualitative Study," *Journal of Advanced Nursing* 66, no. 7 (2010), 1478-1486.

[4] Dezutter et al., "Chronic Pain Care: The Importance of a Biopsychosocial-Existential Approach," 563-575.

[5] Tapio Ojala et al., "Chronic Pain Affects the Whole Person–a Phenomenological Study," *Disability and Rehabilitation* 37, no. 4 (2015b), 363-371.

[6] Dezutter et al., "Chronic Pain Care: The Importance of a Biopsychosocial-Existential Approach," 563-575.

[7] *Ibid.*

[8] Dezutter, Luyckx and Wachholtz, "Meaning in Life in Chronic Pain Patients Over Time: Associations with Pain Experience and Psychological Well-Being," 384-396.

[9] Bruce Greenfield and Gail M. Jensen, "Beyond a Code of Ethics: Phenomenological Ethics for Everyday Practice," *Physiotherapy Research International* 15, no. 2 (2010), 88-95.

fundamental.[10] This presence for meaning-related worries can, therefore, serve as the necessary tool to detect those patients who require referral to other disciplines, such as social workers, psychologists, etc. Accordingly, within this vein, addressing the needs of patients adequately by openness through narratives can optimise patient function, by increasing their satisfaction.

Considering narratives as a tool in the clinic challenges the conventional way of assessing the patient in chronic pain. However, due to the complexity of chronic pain, the physiotherapist cannot learn about the patient's experience by systematic assessments and by asking every patient the same set of questions. Also, the physiotherapist requires the skills, to interpret and act upon these unique narratives. With this connection that these stories enhance, the physiotherapist can envision and learn about patients and their desires, to act upon them when making shared decisions.

3.1.2 What are Narratives and Why do They Matter?

Pain is related to the compelling need to *tell* others about its existence, and oversimplifying the pain experience, will not encourage positive changes in behaviour.[11] Nurturing this change includes recognising and promoting those aspects unique to that individual that boost his/her incentive to act.[12] The initial step to reduce pain and suffering is for the physiotherapist to acknowledge its existence, even if the patient's suffering is difficult to understand.[13] Illness narratives offer the best way to assess pain since these offer the patient's interpretations about events and their relationships, accomplishments and daily challenges, that all are significant in the patient's life and values.[14] Narrative medicine developed as a clinical and academic discipline, to strengthen the healthcare professional's empathic connection with their patients and prevent ethical erosion.[15] It, therefore, challenges the reductionist, Cartesian legacy, that gives little consideration of the patient's life story; with this role of language having significant implications for

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[10] Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* Oxford University Press, (2008).
[11] Eubanks et al., "Changing Pain: Making Sense of Rehabilitation in Persistent Spine Pain," 77-102.
[12] *Ibid.*
[13] Donald L. Gabard and Mike W. Martin, *Physical Therapy Ethics* FA Davis, (2010).
[14] *Ibid.*
[15] Hung-Chang Liao and Ya-huei Wang, "Storytelling in Medical Education: Narrative Medicine as a Resource for Interdisciplinary Collaboration," *International Journal of Environmental Research and Public Health* 17, no. 4 (2020), 1135.

strengthening relationships and not simply collecting medical information.[16] Narrative medicine, thus improves the care of the patients in pain, by giving them recognition, and by also affirming their personhood, with the ultimate aim to serve them, not for profit or personal interest, but to assure justice, and enhance health to all, irrelevant of patients' different socioeconomic groups.

By giving attention to the patient's story, with narrative medicine as a clinical discipline, the patient's perspective is incorporated in the clinic, and a more effective and humane approach is adopted.[17] Also, narrative approaches in the clinics enhance the practice of empathy, trust, reflection and professionalism.[18] Having *narrative competence*, therefore, entails the skills of the physiotherapist to identify, absorb, decipher, and be activated by the patients' stories.[19] Such stories, help make sense of illness and bear its onslaught while identifying patients' limitations, their required needs and skills to achieve health. Since these stories are often related to the patients' pain and symptoms, contextualised knowledge of patients and their support networks are made.[20] These subjective experiences, and how they connect in shaping the whole pain experience, is of utmost significance in chronic pain.[21] Narratives allow patients to integrate past events, culturally applicable information and particular social situations such as loss of social roles, etc.. into the assessment.[22] Moreover, such stories inform the physiotherapist about essential people in the patient's life, reveal whether they are supportive or even abusive, and how they assist in the patient's care. Therefore relevant questions would be for example, "Tell me about that time when your husband helped you with the housework?" or "Do you recall a time when someone made the situation more difficult?" or "What happened in those circumstances?" instead of direct questions such as, "How are you?" or "Do you have help?" Acknowledging and incorporating the patient's unique circumstances into sustainable self-management strategies allows for a

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[16] Berkeley Franz and John W. Murphy, "Reconsidering the Role of Language in Medicine," *Philosophy, Ethics, and Humanities in Medicine* 13, no. 1 (2018), 5.
[17] Rita Charon, "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust," *Jama* 286, no. 15 (2001), 1897-1902.
[18] *Ibid.*
[19] Charon, *Narrative Medicine: Honoring the Stories of Illness*.
[20] Joanne M. Hall and Jill Powell, "Understanding the Person through Narrative," *Nursing Research and Practice* 2011 (2011).
[21] Joletta Belton, "Exploring the Meanings of Pain: My Pain Story," in *Meanings of Pain*, (Springer, 2019), 1-15.
[22] *Hall and Powell, "Understanding the Person through Narrative."*

deeper engagement with patients and their particular situation.[23] This ensures that self-management strategies closely match the patient's individual needs, and for the physiotherapist to act accordingly.[24]

Narratives, help attach meaning to the pain experience by exposing what is salient and relevant for patients narrating the stories and how they perceive their future with pain.[25] Therefore, narratives contrast sharply with the standard therapeutic communication techniques, since with narratives, eliciting stories about meanings and feelings is implied, which also provide ways to learn about, for example, the patients' cultural beliefs.[26] Rita Charon, a firm advocate of narrative medicine, argues that for the patient to find meaning in his/her suffering, and grapple with his/her health, healthcare professionals cannot only be scientifically competent but *listening* to patients' narratives and *accompanying* them in their suffering, is fundamental to honour their meaning.[27] Consequently, the narrative competence of the physiotherapist should be considered *complementary* to scientific expertise, and on equal footing. When an objective diagnosis is made, independent from the patient's narrative, the understanding of the patient's illness will be limited. This behaviour on the part of the physiotherapist excludes one of the most significant forms of patient agency (where here agency refers to the patient's narrative capacity), and consequently, from the understanding of the illness. For example, persistent low back pain can be diagnosed as muscle strain, degenerative joint disease or a ruptured disc when viewing the MRI report. However, a more effective assessment can be made, when the compensation status by stronger muscle groups involved, coupled with the patient's inability to exercise, due to lack of resources, is, for example, considered. Also, for example, the chronicity of back pain and the resulting sickness absence from work indicates a relation between poor job satisfaction and limited social support.[28] Therefore, although patients have no diagnostic expertise, and should not have the same diagnostic authority as the health professional, narratives must be integrated into chronic care. In the above example, chronicity of the back pain will remain if the patient's limited

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[23] Ian Edwards and Barbara Richardson, "Clinical Reasoning and Population Health: Decision Making for an Emerging Paradigm of Health Care," *Physiotherapy Theory and Practice* 24, no. 3 (2008), 183-193.
[24] *Ibid.*
[25] Andrew Soundy et al., "Do You Hear what Your Patient is Telling You? Understanding the Meaning Behind the Narrative," *Way Ahead* 18 (2014), 10-13.
[26] Hall and Powell, "Understanding the Person through Narrative."
[27] Charon, *Narrative Medicine: Honoring the Stories of Illness*.
[28] W. E. Hoogendoorn et al., "High Physical Work Load and Low Job Satisfaction Increase the Risk of Sickness Absence due to Low Back Pain: Results of a Prospective Cohort Study," *Occupational and Environmental Medicine* 59, no. 5 (2002), 323-328.

resources to exercise are not addressed. Also, the patient's hopes and fears, have vital implications for physiotherapy, that will also determine how much he/she will participate in his/her health.

The narrative approach, therefore, also views listening to patients' stories as playing a part in the professional and moral growth of the physiotherapist. However, these narratives also provide a significant *epistemic function* in the world of that particular patient in pain.[29] Chronically ill patients, such as those in chronic pain, are prone to epistemic injustice, due to the compelling negative stereotypes, such as being psychologically fragile, being drama queens, malingerers or having diminished agency.[30] This notion of epistemic injustice was presented by Miranda Fricker to allude to types of injustice, where it is referred to as, "a wrong done to someone specifically in their capacity as a knower."[31] Since chronic pain patients are often insecure and anxious, the physiotherapist can stigmatise patients, and unconsciously include negative epistemic prejudices, such as deficits in credibility, which consequently makes patients lose their testimonial authority and reliability in the clinics.[32] Due to accumulative negative experiences in health care steadily eroding their credibility, patients in chronic pain, progressively stop believing in their epistemic competence; which is their ability to relate their story to understand their pain, with the result that they will find it challenging to make sense of their illness.[33] A constant complaint ill patients make is that of healthcare professionals being dismissive, impersonal and cold.[34] Patients are, therefore, not *enabled* to discern and recount their pain experience, which is frequently complicated and painful to communicate.

The narrative approach, on the other hand, has the potential to empower patients' epistemic practice and tackle epistemic injustice by giving them the *voice* to be heard and be witnessed.[35] Therefore, narratives can serve to enact justice to patients and respect

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[29] Buchman, Ho and Goldberg, "Investigating Trust, Expertise, and Epistemic Injustice in Chronic Pain," 31-42.

[30] Ian James Kidd and Havi Carel, "Epistemic Injustice and Illness," *Journal of Applied Philosophy* 34, no. 2 (2017), 172-190.

[31] Miranda Fricker, *Epistemic Injustice: Power and the Ethics of Knowing*, (2007) quoted in Ian James Kidd, and Carel Have, *Epistemic Injustice and Illness*, Journal of Applied Philosophy 34, no.2 (2017): p.175.

[32] Ian James Kidd and Havi Carel, "Epistemic Injustice and Illness," *Journal of Applied Philosophy* 34, no.2 (2017), 172-190.

[33] *Ibid.*

[34] *Ibid.*

[35] Charon, *Narrative Medicine: Honoring the Stories of Illness*.

their autonomy, since it gives them a sense of relevance by recognising them as partners in their care, as it opens their epistemic space for meaning, discernment and health.

3.1.3 Narrative Ethics in Chronic Pain

Comprehending how the chronic pain patient edits and re-tells his/her narrative during the different physiotherapy sessions, therefore, helps the physiotherapist understand those unfair situations and social determinants, which can either enhance or limit the patient's sense of agency.[36] As a result, narratives, expand what is meant to respect the principle of autonomy by allowing the unique story of the individual to take prominence during treatment.[37] Therefore, through narrative reasoning, the physiotherapist focuses on what the patient can *actually* do (by considering his/her present circumstances and resources), as opposed to what the patient *ought to do*.

Since with illness as in chronic pain, patients experience severe health losses, such as diminished mobility, with consequent changes in their lifestyles and priorities, a transition in their values may also take place over time.[38] Attention to narratives in the clinic, therefore, also shows us how the patient changes as treatments progress; depicting moral growth with character development, as the health professional is empathically engaged in his/her care.[39] Also, this telling of stories does not solely describe significant features of the clinical scenario, but a *moral end* is in itself achieved through these narratives. This is because patients are given the opportunity to make sense of their experience by giving them the voice to be heard. Consequently, this characteristic of narratives corresponds directly to ethics, since ethics is concerned with practical questions such as how to be or whether to be or what to do.[40]

Now, consider, for example, a well-educated man with chronic bilateral knee pain who attends for physiotherapy. This man who is also overweight with high cholesterol levels and diabetes, enters the clinic and is reluctant to take up a home exercise program and get fit as advised by his physiotherapist, but prefers to stay passive. The physiotherapist, in this case, cannot presume that the man has a well-informed narrative

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[36] Clare Delany, Caroline Fryer and Gisela van Kessel, "An Ethical Approach to Health Promotion in Physiotherapy Practice," *Health Promotion Journal of Australia* 26, no. 3 (2016), 255-262.
[37] *Ibid.*
[38] Greenfield and Jensen, "Beyond a Code of Ethics: Phenomenological Ethics for Everyday Practice," 88-95.
[39] Jodi Halpern, "Narratives Hold Open the Future," *Hastings Center Report* 44, no. s1 (2014), S25-S27.
[40] *Ibid.*

and respects his decision not to exercise. This *static* account of respecting this man's autonomy, who is ambivalent regarding treatment, does not encourage any change in behaviour. The man's autonomy, on the other hand, can be recognised, by acknowledging his difficulty to anticipate what his future self might value, while also examining his capacity and opportunity to reflect on his choice.[41] In this way, the physiotherapist is enabling his capability of *Practical Reason* (Appendix B no.6) and guiding him to make the right decisions. The physiotherapist acknowledges the man's medical complexities and morbidities; which are also common in the lower socioeconomic groups.[42] While the physiotherapist *listens attentively to his story, in an empathic therapeutic relationship,* this father of two young children, had also disclosed that his wife had lost her job and consequently he was also facing economic problems. This economic burden and the struggle to meet all the family needs was also having a toll on his marriage and giving him anxieties. The physiotherapist knows well that addressing his knee pain necessitates also facing his weight issue and not just merely handing out a standard exercise program, giving him some essential advice or other forms of passive treatment. However, due to the man's financial constraints and limited resources, his capability to act for change is hampered. Also, his anxieties resulting from problems in his marriage could be contributing to more pain. The physiotherapist, listening to this man's story, is faced with a dilemma how best to assist him within the constraints of the time and caseload and within the limitations of the man's priorities and social conditions. Through narrative reasoning, the physiotherapist has to play the *formative* role in this man's narration and offer the scaffold for value development by supporting his capacity for deliberation about the necessary changes in his health.[43] The purpose of the physiotherapist in this case scenario is not only to offer advice but to guide him in connecting with the required employment agencies and family therapists to eventually have the empowerment and capabilities to adopt the necessary positive changes. Therefore, with this narrative approach, the patient's *unique* story in his *particular* circumstances was recognised and the appropriate action taken.

With narrative reasoning, ethical principles do not remain static, and insensitive to the details of particular cases and specific life events, but expand moral imagination,

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[41] Delany, Fryer and Kessel, "An Ethical Approach to Health Promotion in Physiotherapy Practice," 255-262.

[42] Nikoline Lund Jensen et al., "The Impact of Socioeconomic Status and Multimorbidity on Mortality: A Population-Based Cohort Study," *Clinical Epidemiology* 9 (2017), 279.

[43] Halpern, "Narratives Hold Open the Future," S25-S27.

by respecting the autonomy of this man in pain and *in transition* but within his particular circumstances. In morally challenging circumstances, such as chronic pain, the conflict between ethical principles and specific judgements results, and no ethical principle is *a priori* privileged.[44] Wiggins and Schwartz contend that clinical ethics is real in *actual* human relationships that exist among patients, friends, families and healthcare professionals; principles serve only as of the starting point of those moral considerations particular to the individual's lifeworld.[45] The lifeworld is those daily experiences of patients, and their social circle, as their meaning of illness is encountered through the subtle interactions taking place each day.[46] This meaning in human life emerges from the lived experiences of patients, and what determines what is right or wrong does not depend on a set of given rules but from the *lived* experience *within* that particular context, time, culture and perspectives.[47]

The physiotherapist, therefore, cannot assume that a patient will not make well-informed decisions and be paternalistic. Respecting the autonomy of the patient in pain, thus, involves listening to the patient's story, and providing the space to engage in those existential concerns. This allows the patient to discover new possibilities and increases the potential to express new values, thus, maximising the potential for meaningful function. This narrative approach and its other way of legitimising ethical decisions target the relational dimensions of a moral situation, where it is the whole journey of the patient's life as conceived by that same patient *in relation* with his/her environment, that is honoured.[48] Therefore, ideally, narrative ethics acknowledges the supremacy of a person's story, while also endorsing the critical voices and stories necessary to be heard in this deliberative process. These can include the patient's family members and carers, friends, social-workers and other healthcare professionals.[49]

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[44] Joan McCarthy, "Principlism Or Narrative Ethics: Must we Choose between them?" *Medical Humanities* 29, no. 2 (2003), 65-71.

[45] Osborne P. Wiggins and Michael A. Schwartz, "Richard Zaner's Phenomenology of the Clinical Encounter," *Theoretical Medicine and Bioethics* 26, no. 1 (2005), 73-87.

[46] *Ibid.*

[47] Charon, *Narrative Medicine: Honoring the Stories of Illness*.

[48] McCarthy, "Principlism Or Narrative Ethics: Must we Choose between them?" 65-71.

[49] Arthur W. Frank, "Narrative Ethics as Dialogical Story-Telling," *Hastings Center Report* 44, no. s1 (2014), S16-S20.

3.2 Narratives Enhance Healing Relationships and Professional Virtues

3.2.1 The Physiotherapeutic Relationship in Chronic Pain

Poulis highlights an ethical dimension in physiotherapy that concerns how the *required active participation* of the patient affects the physiotherapeutic relationship.[50] In physiotherapy practice and chronic pain, the patient's trust extends beyond believing and accepting treatment, to the *willingness* to participate actively in his/her care. When patients feel that decision-making is shared, patients are more satisfied and beneficial outcomes result.[51] However, in chronic pain, there is often a mismatch in the patients' treatment goals and that of the physiotherapist, since patients usually expect long-term pain reduction.[52] Therefore, it can be appreciated that if these discrepancies are not addressed, patients and their physiotherapists will work to achieve different goals.

Physiotherapy, thus, encompasses those concepts identified with leadership and those skills that are necessary to motivate patients to encourage changes in behaviour. With modernisation of health care that focuses on maximising efficiency that saves money and accomplishes greater health outcomes, clinical *effectiveness* of physiotherapy in chronic pain is crucial. Therefore, physiotherapists need to demonstrate leadership and develop the profession's role, self-concept, and identity in this field. Strategies, such as developing leadership/coaching opportunities in physiotherapy could enable the advancement of such leaders in physiotherapy.[53]

Physiotherapy practice in chronic pain raises questions such as How is it ethically appropriate to persuade a patient to participate? How can shared decision-making be best incorporated in the clinical setting? How are the ethical principles of autonomy, beneficence and justice incorporated when planning treatment? As it can, therefore, be appreciated, the physiotherapist needs to capture the significance of those interactions

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[50] Ioannis Poulis, "The End of Physiotherapy," *Australian Journal of Physiotherapy* 53, no. 2 (2007), 71-73.

[51] Lisa Maria E. Frantsve and Robert D. Kerns, "Patient–provider Interactions in the Management of Chronic Pain: Current Findings within the Context of Shared Medical Decision Making," *Pain Medicine* 8, no. 1 (2007), 25-35.

[52] Kevin E. Vowles and Miles Thompson, "The Patient-Provider Relationship in Chronic Pain," *Current Pain and Headache Reports* 16, no. 2 (2012), 133-138.

[53] Emer McGowan and Emma Stokes, "Leadership in Physiotherapy: Experiences of Leaders of Physiotherapy Professional Organisations," *BMJ Leader* (2019).

between the patients in pain and their values, with the social, environmental, economic and political factors. When the treatment encounter is taken a step further, and the broader ethical and social issues are addressed, the physiotherapy profession matures, and *moral agency* is achieved.[54] In partnership with the patient, the physiotherapist nurtures moral agency when the patient is made aware through the narrative process about those factors that constrain his/her capacity to act for change (*Practical Reason* enabled Appendix B no.6). The capacity for change involves maximising those capabilities such as that of *Affiliation* (Appendix B no.7), for the patient to experience that sense of belonging once again. This approach, therefore, serves to enact justice to patients with chronic pain by upholding their dignity. However, a qualitative study carried out in rheumatoid arthritis patients revealed discrepancies in what patients experience in the clinical encounter and those policies that advocate for shared decision-making and patient-centred care.[55]

The narrative process, thus necessitates that the physiotherapist listens actively, thinks reflexively and reasons critically.[56] Actively listening constitutes more than just an exchange of information, since the patient's perspective is upheld and the physiotherapist is actively engaged by making connections between the patient's situation, values, beliefs, life goals and available resources through narratives. To recognise the ethical dimensions that physiotherapy in that situation entails, physiotherapists also need to be self-aware and appreciate their unique role and identity in the care of their patients and think reflexively about their care.[57] Through professional reflexivity, the physiotherapist is self-aware about those emotions, values and competencies brought to the clinical encounter, and how these have the potential in influencing patient outcomes.[58] Questions that can enhance professional reflexivity can be, e.g. "How might the patient perceive me?" "What is shaping the patient's view?" "What competencies must be applied in this clinical scenario?" "What are the patient's beliefs?" "What values am I bringing to the

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[54] Ian Edwards et al., "Moral Agency as Enacted Justice: A Clinical and Ethical Decision-Making Framework for Responding to Health Inequities and Social Injustice," *Physical Therapy* 91, no. 11 (2011), 1653-1663.

[55] A. Townsend et al., "Everyday Ethics and Help-Seeking in Early Rheumatoid Arthritis," *Chronic Illness* 6, no. 3 (2010), 171-182.

[56] Clare M. Delany et al., "Closing the Gap between Ethics Knowledge and Practice through Active Engagement: An Applied Model of Physical Therapy Ethics," *Physical Therapy* 90, no. 7 (2010), 1068-1078.

[57] *Ibid.*

[58] Rachel Landy et al., "Educational Strategies to Enhance Reflexivity among Clinicians and Health Professional Students: A Scoping Study" Forum Qualitative Sozialforschung, (2016).

clinic?”[59] Without this understanding of professional stance, connectivity with patients and professional responsibility are only conveyed in a vacuum.

Unfortunately, if physiotherapists were to be asked which patients are considered the most challenging to manage, the odds will be that those with persistent pain will top the list. Patients in chronic pain, also feel this relational strain, mostly due to their struggles to establish credibility.[60] Also, patients suffer psychological repercussions when they perceive a lack of information about their condition and its management.[61] When pain complaints are validated, and patients are allowed to participate in their health through shared-decision making, patients experience greater satisfaction, and positive relationships are therefore encouraged.[62] The compelling need for successful physiotherapeutic relationships for effective pain management in an atmosphere of empathy and trust is, therefore, significant. Since pain is a subjective experience, the patients’ self-reports are fundamental for the assessment. The physiotherapeutic relationship is the leading source of information, and no matter how far treatments in chronic pain advance, chronic pain will remain a burden if there is no effective communication that is built on trust.[63]

However, due to the complexity of chronic pain, physiotherapists can engage in critical and confrontational behaviours that limit effective outcomes with their patients.[64] Indeed, the research shows that healthcare professionals working in the field of chronic pain necessitate more effective communication skills that incorporate reflection and empathy with their patients.[65] In chronic pain, the relationship can also be weakened due to discrepancies in the identification of the physiotherapy goals.[66] For example, a large-scale survey revealed that people in chronic pain desire mostly improvements in areas

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[59] Delany et al., "Closing the Gap between Ethics Knowledge and Practice through Active Engagement: An Applied Model of Physical Therapy Ethics," 1068-1078.

[60] Anne Werner and Kirsti Malterud, "It is Hard Work Behaving as a Credible Patient: Encounters between Women with Chronic Pain and their Doctors," *Social Science & Medicine* 57, no. 8 (2003), 1409-1419.

[61] Dianna T. Kenny, "Constructions of Chronic Pain in Doctor–patient Relationships: Bridging the Communication Chasm," *Patient Education and Counseling* 52, no. 3 (2004), 297-305.

[62] Carole C. Upshur, Gonzalo Bacigalupe and Roger Luckmann, "“They Don'T Want Anything to do with You”: Patient Views of Primary Care Management of Chronic Pain," *Pain Medicine* 11, no. 12 (2010), 1791-1798.

[63] John C. Norcross and Bruce E. Wampold, "Evidence-Based Therapy Relationships: Research Conclusions and Clinical Practices." *Psychotherapy* 48, no. 1 (2011), 98.

[64] *Ibid.*

[65] Scott A. Baldwin, Bruce E. Wampold and Zac E. Imel, "Untangling the Alliance-Outcome Correlation: Exploring the Relative Importance of Therapist and Patient Variability in the Alliance." *Journal of Consulting and Clinical Psychology* 75, no. 6 (2007), 842.

[66] Vowles and Thompson, "The Patient-Provider Relationship in Chronic Pain," 133-138.

such as overall energy, social relationships, employment, recreational activities, sleep etc.[67] This aspect was also explained earlier in Chapter Two when those capabilities valued particularly by chronic pain patients were identified. As a result, the patient-desired outcomes elicited from the patient narratives should be the treatment goals in physiotherapy. Therefore, collaborative efforts to achieve meaningful functioning in the context of chronic pain are vital.

Since physiotherapy is firmly anchored to discourses of positivism (the hallmark of biomedicine), the physiotherapist's search for the patient's pain experience in the clinic is challenging.[68] Physiotherapy practices depend on established principles of independence were quality of life is associated with the level of the assistance one needs; thus prompting unnecessary treatments.[69] On the other hand, connectivity in narratives dismisses the notion that dependency limits the quality of life and acknowledges the personal connections between the patient and his community and how they can connect in diverse ways to enable health.[70] Therefore enhancing strong partnerships through robust physiotherapeutic relationships is vital for meaningful outcomes.

This physiotherapeutic relationship is also characterised by power asymmetry due to the patient's vulnerability as a result of the pain and disproportionate knowledge.[71] Here, the physiotherapist has the moral obligation to prevent harm of the patient and protect him/her from exploitation. As a steward of medical expertise, the physiotherapist is also obliged to acknowledge the limits of understanding of the unique pain experience. Such honesty enables the patient in pain to engage in participation and shared decision-making by acting as the informed agent. This empowerment strengthens the physiotherapeutic relationship, reduces the patient's vulnerability, and upholds his/her dignity.[72] This moral accountability, therefore, implies another moral imperative which is the *fiduciary* nature of the relationship where empathy and trust are ineradicable. In chronic pain, the kind of decisions necessary are a combination of scientific and moral components where *science* and *morality* are both connected to enhance the patient's

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[67] Dennis C. Turk et al., "Identifying Important Outcome Domains for Chronic Pain Clinical Trials: An IMMPACT Survey of People with Pain," *Pain®* 137, no. 2 (2008), 276-285.

[68] Nicholls et al., "Connectivity: An Emerging Concept for Physiotherapy Practice," 159-170.

[69] *Ibid.*

[70] Barbara E. Gibson, "Parallels and Problems of Normalization in Rehabilitation and Universal Design: Enabling Connectivities," *Disability and Rehabilitation* 36, no. 16 (2014), 1328-1333.

[71] James Giordano, "Moral Agency in Pain Medicine: Philosophy, Practice and Virtue," *Pain Physician* 9, no. 1 (2006), 41.

[72] *Ibid.*

health. This covenant of care established in this healing relationship ensures that the primary obligation of the physiotherapist is the care of the person in pain. Physiotherapy is, therefore, a moral enterprise, where the physiotherapeutic relationship is the most critical factor for ensuring patient satisfaction.[73] An essential component of this interaction is the information given to patients regarding their health circumstances, such as the aims of treatment and their significance as they participate in their care.[74] Patients who have low levels of health literacy have decreased autonomy in shared decision-making due to feeling disempowered.[75] Physiotherapists should, therefore, tailor the population-based information to fit the patient's circumstances. Going back to the case about the overweight man with bilateral knee pain, the physiotherapist, therefore, needs to query also the man's understanding about exercise and weight loss, his knowledge about modifying his diet and his motivation to engage in positive behavioural changes. This approach reduces patient uncertainty which is also fundamental for beneficial health outcomes.[76]

Therefore, within physiotherapy, patient-centredness is adopted by acknowledging patient uniqueness through robust therapeutic relationships that involve empowerment, communication and education.[77] However, while the importance of shared-decision making is recognised, physiotherapists find it challenging to apply it in practice.[78] A qualitative study underscored this when physiotherapists working in chronic pain perceived their patients' views as barriers to their paternalistic wishes to get their patients 'on board' with their opinions.[79] The physiotherapists in this same study, also expressed uncertainty and anxiety when their patients' expectations conflicted with their own.[80] Moreover, although the significance of the biopsychosocial approach was

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[73] Kulikowski, "The Importance of Interpersonal Communication in the Process of Rehabilitation," 15-20.
[74] Paul Beattie et al., "The MedRisk Instrument for Measuring Patient Satisfaction with Physical Therapy Care: A Psychometric Analysis," *Journal of Orthopaedic & Sports Physical Therapy* 35, no. 1 (2005), 24-32.
[75] Michelle Edwards et al., "The Development of Health Literacy in Patients with a Long-Term Health Condition: The Health Literacy Pathway Model," *BMC Public Health* 12, no. 1 (2012), 130.
[76] Kulikowski, "The Importance of Interpersonal Communication in the Process of Rehabilitation," 15-20.
[77] Amarins J. Wijma et al., "Patient-Centeredness in Physiotherapy: What does it Entail? A Systematic Review of Qualitative Studies," *Physiotherapy Theory and Practice* 33, no. 11 (2017), 825-840.
[78] Katreine Dierckx et al., "Implementation of Shared Decision Making in Physical Therapy: Observed Level of Involvement and Patient Preference," *Physical Therapy* 93, no. 10 (2013), 1321-1330.
[79] Nick Sullivan, Clair Hebron and Pirjo Vuoskoski, "“Selling” Chronic Pain: Physiotherapists' Lived Experiences of Communicating the Diagnosis of Chronic Nonspecific Lower Back Pain to their Patients," *Physiotherapy Theory and Practice* (2019), 1-20.
[80] *Ibid.*

acknowledged, physiotherapists found it posed challenges to apply in the clinic; with this resonating with broader literature.[81]

3.2.2 The Virtues of the Physiotherapist

Due to the profound nature of chronic pain and its need for healing relationships, the moral agency of the physiotherapist is fundamental. By utilising ethical principles and virtues, the physiotherapist will be able to resolve those ethical dilemmas specific to the unique pain experience.[82] With the physiotherapist's benevolent intentions and fidelity to this covenant of care, both moral and therapeutic responsibility are upheld, and non-abandonment ensured.[83] Such compassion in physiotherapy allows a basis of care, where the patient’s concerns and the effects of pain on the patient’s lifeworld are better understood.[84] Indeed, Pellegrino argues that ethical understanding is only enhanced through a meaning-based relationship between practitioner and patient. To achieve ethical ends in the care of patients, no single set of rules can be applied, but emphasis is given to that *disposition of character* that best conforms with the *telos* of medicine.[85] The physiotherapist’s most effective therapeutic instrument is, therefore, oneself, where the physiotherapist becomes attuned to the person in pain through compassion and at his/her disposal through reflection.

However, healthcare professionals, including physiotherapists, are not trained to listen to their patients with an interpretive ear, and immediate questions such as “How sharp was the pain?” or “ Could you identify a number on this pain intensity scale?” interrupt the patient and limit the understanding of pain.[86] In chronic pain, *active* listening to stories is what physiotherapists must learn to do. This kind of listening must not only record facts but must also identify what the patient is disclosing about the self. Physiotherapists might think that this will divert attention from what the patient may have actually been referred for. However, as we explained earlier in this thesis, chronic pain is complex. Although time may be limited for such stories, incorporating this type of

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[81] Nick Sullivan, Clair Hebron and Pirjo Vuoskoski, "“Selling” Chronic Pain: Physiotherapists’ Lived Experiences of Communicating the Diagnosis of Chronic Nonspecific Lower Back Pain to their Patients," *Physiotherapy Theory and Practice* (2019), 1-20.

[82] Giordano, "Moral Agency in Pain Medicine: Philosophy, Practice and Virtue," 41.

[83] *Ibid.*

[84] *Ibid.*

[85] Edmund D. Pellegrino, "What the Philosophy of Medicine Is," *Theoretical Medicine and Bioethics* 19, no. 4 (1998), 315-336.

[86] Charon, *Narrative Medicine: Honoring the Stories of Illness.*

listening into physiotherapy is *invested* time, that will be recouped by having developed a robust therapeutic relationship in the initial sessions.[87]

Therefore, how to talk and listen to the patient in pain is fundamental, so that patients are not redirected to furnish information that is only medically relevant. Thus, physiotherapists working with chronic pain patients should not listen passively to their patients and must acquire those skills necessary to be partners, that build meaningful relationships with those who suffer. This prevents the physiotherapist from focusing solely on what is medically relevant and allows the physiotherapist to look beyond those narratives. This does not mean abandoning clinical judgement, but quite the opposite. This is because here, the physiotherapist also applies the medical competence *individually* at the patient's disposal while acknowledging the personhood of those who suffer through empathy and capacity of bearing witness to the patient's unique story.[88]

Narrative empathy is consequently crucial, and the physiotherapist must actively listen and give weight to what patients say, even if what is told can seem to be nonsense.[89] This involves the physiotherapist acting humbly to offer oneself to listen and care with deep empathy and compassion.[90] It considers what Levinas terms the *face of the other* to recognise the construction of meaning NOT in the physiotherapist's view but in light of the patient's narrative.[91] Thus, the physiotherapist becomes the instrument that receives the meaning of the patient in pain to give him/her voice. Addressing the patient's lifeworld and vicissitudes enables patients to step forward as *storied-beings* and not simply as *consumers* who compete for care.[92]

Also, through more extensive telling and active listening, mutual trust is built.[93] Rita Charon, in her book '*Narrative Medicine: Honoring the Stories of Illness,'* says that through narratives, patients feel welcomed to talk more about their life; thus enabling their practical reason capabilities. When empathy is lacking, mistrust sets in and the

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[87] Charon, *Narrative Medicine: Honoring the Stories of Illness*.

[88] Richard M. Zaner, "Power and Hope in the Clinical Encounter: A Meditation on Vulnerability," *Medicine, Health Care and Philosophy* 3, no. 3 (2000), 263-273.

[89] Rhonda J. Moore and James Hallenbeck, "Narrative Empathy and how Dealing with Stories Helps: Creating a Space for Empathy in Culturally Diverse Care Settings." *Journal of Pain and Symptom Management* (2010).

[90] Charon, *Narrative Medicine: Honoring the Stories of Illness*.

[91] John GS Goldie, "The Ethics of Listening and Responding to Patients' Narratives: Implications for Practice," *Br J Gen Pract* 61, no. 585 (2011), 306-307.

[92] Karin Dahlberg, Les Todres and Kathleen Galvin, "Lifeworld-Led Healthcare is More than Patient-Led Care: An Existential View of Well-Being," *Medicine, Health Care and Philosophy* 12, no. 3 (2009), 265-271.

[93] Charon, *Narrative Medicine: Honoring the Stories of Illness*.

relationship is weakened.[94] Therefore, if the physiotherapist cannot accomplish the necessary narrative roles, patients in persistent pain will not feel heard and might not consider asking those questions that haunt them most.[95] Consequently, the physiotherapy assessment will be misled and the proper diagnosis missed; also leading to non-compliance and shopping around for other opinions. As a result, clinical care will be more expensive than necessary, not to mention the loss of trust in professional competence. Therefore, consideration of the patient's narrative requires an honest search for the person's meaning so that patients are empowered to construct stories that will co-create meaning and eventually lead to better decision-making. However, this is at odds with the clinical scenario where efficiency and evidence are prioritised, since the positive outcomes of narratives cannot be directly measured and can be viewed as time consuming.[96] Nonetheless, it is only with this approach that patients are viewed holistically and empowered to maximise their potential of having those central capabilities listed in Appendix B and discussed in Chapter Two for a flourishing life.

Narrative empathy, therefore, incorporates the mutual understanding of how those life events and sufferings disclosed in the clinic, fit into the larger narrative of life.[97] Having narrative empathy, thus, not only ensures access to quality treatment but provides patients with those choices based on their preferences, cultural beliefs and values. Therefore, when the physiotherapist is empathic, the patient's preferences are understood better. For example, in chronic pain, patients may fear to resume work and might fear losing disability benefits. Unless the patients' fears and expectations are realised and openly discussed in a robust relationship, physiotherapy will be at odds with the patient's treatment priorities.[98] Therefore, the identity of physiotherapists, should not only reside in the contents and size of their toolbox, but also in their unique, responsible and empathic relationships with their patients in pain.

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[94] Moore and Hallenbeck, "Narrative Empathy and how Dealing with Stories Helps: Creating a Space for Empathy in Culturally Diverse Care Settings."

[95] Charon, "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust," 1897-1902.

[96] Goldie, "The Ethics of Listening and Responding to Patients' Narratives: Implications for Practice," 306-307.

[97] Moore and Hallenbeck, "Narrative Empathy and how Dealing with Stories Helps: Creating a Space for Empathy in Culturally Diverse Care Settings."

[98] Rollin M. Gallagher, "Empathy: A Timeless Skill for the Pain Medicine Toolbox," *Pain Medicine* 7, no. 3 (2006), 213-214.

Conclusion and Recommendations

This concluding chapter will review and discuss the key points of this dissertation and explain their relevance to physiotherapy for chronic pain patients.

At the end of this chapter, recommendations will also be made from the viewpoints gleaned from the reflections made vis-à-vis the arguments discussed in this literature review.

Conclusion

Physiotherapy for patients in chronic pain empowers the patient to be autonomous and achieve health. This is done by actively listening to a narrative process within the biopsychosocial and existential concerns relevant specifically to the patient's unique situation. This will enable the patient to develop a robust physiotherapeutic relationship and thus maximise his/her potential to pursue meaningful personal activities that render a dignified life.

Physiotherapists have a huge contribution to make in the field of chronic pain, and their input can ultimately be life-changing. The crucial added value here is not merely in minimising pain or adding years to life, but in enabling the patient in chronic pain to achieve a dignified life. This resonates with the Declaration of Montreal (Appendix A), which states that to acknowledge the intrinsic dignity of the patient in pain and assure the human right to adequate management of pain it is: "the obligation of all healthcare professionals in a treatment relationship with a patient … to offer to a patient in pain the management that would be offered by a reasonably careful and competent healthcare professional in that field of practice."[1]

Recognising that the management of pain is a fundamental human right, expands the obligation to all healthcare professionals, including physiotherapists. This is because failing to provide adequate care will not solely make physiotherapists liable to professional misconduct, but as stated in the Declaration, the physiotherapist will effectively and passively be breaching the patient's human rights. Contrary to patient

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[1] International Pain Summit of the International Association for the Study of Pain, "Declaration of Montreal: Declaration that Access to Pain Management is a Fundamental Human Right," *Journal of Pain and Palliative Care Pharmacotherapy* 25, no.1 (2011), 29-31.

rights which are rooted in a consumer framework, this concept of human rights in the care of patients with chronic pain derives from intrinsic human dignity and applies human rights principles that are legally recognised around the globe. Consumer rights differ from human rights in that they are not inherent in patients because of them being human, but rather due to patients being considered as participants in a consumer transaction, thus resembling contractual rights.[2]

On the other hand, the Declaration affirms the dignity of human beings to be the guiding principle that legitimates adequate care of patients in chronic pain. This centrality given to patients in the Declaration is aimed to address disparities in care by securing such patients as ultimate beneficiaries of the healthcare service, and agents of their own care. As discussed in Chapter One, this also opens space for the legitimation of the right to health in the chronic pain domain. However, as Chapter One argues, any attempts to ameliorate the management of chronic pain cannot be made before understanding the complexity of this phenomenon and the ideologies surrounding it.

Chronic pain challenges the biomedical paradigm and medical knowledge since here there is no cure, and relevant investigations cannot always explain the patient's symptoms. The strong biomedical focus in terms of managing pain such as imaging and anatomical structures serves only to reinforce those negative beliefs about pain and encourages hypervigilance, fear of movement and dependency on healthcare. All of these are also strong predictors of disability. Thus, the uncertainties and gaps in medical knowledge make living with chronic pain a suffering experience and undermine the patients' dignity, since patients continually struggle for their credibility. As discussed in Chapter Two, the pain experienced is not only biological, but also psychological, social, and existential; with the *self* being eroded over time. Patients in chronic pain cut off from those activities that were once a source of meaning. As discussed in Chapter Three, this explains why patients are more satisfied and function better when attention is given to the impact of pain on their daily lives.

Thus, the physiotherapeutic encounter in chronic pain cannot be grounded in a recipe-like guide to communication, nor to systematic assessments and the evidence-base, which is devoid of the human socially embedded element. In this manner, the principle of human dignity would not constitute an ethical cornerstone in the physiotherapeutic

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[2] Jonathan Cohen and Tamar Ezer, "Human Rights in Patient Care: A Theoretical and Practical Framework," *Health Hum Rights* 15, no. 2 (2013), 7-19.

relationship since the individual is not recognised as unique with those specific capabilities and resources to master his/her own life. Such encounters do not focus on the particularity of the individual as they place medical explanations on the forefront. This attitude weakens the physiotherapeutic relationship as it leads to distrust, insecurity, and fear, where the patient's personal competence is questioned, and his/her integrity and right to adequate care are undermined. When physiotherapists, represent themselves predominantly within the biomedical paradigm in chronic pain (as discussed in Chapter One) there is the risk of neglecting the full picture when making the necessary judgements. This gives physiotherapists and their patients a plethora of unrealistic expectations. Moreover, with this view, there is no answer as to why chronic pain manifests diversely among different people and different cultures.

Patient-centred physiotherapy in chronic pain is not merely satisfying patient's preferences and acceding to the patient's demands, such as having short bouts of passive treatment designed to relieve symptoms temporarily. Such an attitude enhances dependency and encourages patients to adopt the sick role. Also, the nature of this physiotherapeutic relationship mirrors the consumerist version of healthcare, ultimately leaving patients responsible for their care with the physiotherapist offering choices. Consequently, this prohibits the physiotherapist from adopting an actual beneficent role in the patient's care. Those essential skills and virtues of the physiotherapist working with patients in chronic pain (discussed in Chapter Three) are vital to assimilate previous experiences and medical facts in an intimate understanding of the patient's perspective. Henceforth, measures are to be tailored in accord with recommendations from his/her unique experience. Within the predominant biomedical philosophy, the identity of the physiotherapist in chronic pain is distorted. The high tech-diagnostic instrumentation deprives the physiotherapeutic relationship of its ethical value in terms of actively listening to all the biopsychosocial and existential dimensions of the patient's unique concerns. Therefore, human rights in the care of chronic pain patients and as stated in the Declaration, move away from the biomedical model to uphold the dignity of patients, so that intrinsic human dignity and freedom is protected and fostered.

A robust physiotherapeutic relationship is constructed around mutual respect and participation without vesting moral authority and power in decision-making. The physiotherapeutic relationship within the biomedical model is founded on a flawed view of autonomy. In chronic pain, patient autonomy, cannot be reduced to merely being free to choose the preferred option from a comprehensive list of available modes of action. This way of understanding autonomy should not shape the physiotherapeutic relationship. The version of personhood this type of relationship is predicated upon, is the patient who is self-ruling and capable of making informed medical decisions. Also, within this paradigm, the patient’s ability to face reality, impairment, and express his/her values to discern his/her best interests is diminished. Here, chronic pain is not viewed as a reality of the human condition and a unique kind of suffering is created as argued in Chapter One.

As discussed throughout the three chapters of this thesis, at its root, physiotherapy for chronic pain is a moral practice, that cannot use only technical skills to achieve the end of caring for the chronic pain patient. This artificial divide between caring and curing, still reflective of the Cartesian dualistic model, confines the human being to simply a materialistic view. It fails to implicate how the patient experiences his/her pain, what it means, and how this meaning determines other relationships. These variables are all integral factors of the pain experience. The profession’s keystone philosophy in the field of chronic pain, thus, needs revision and physiotherapists need to reflect on what are the goals to be achieved in chronic pain. Physiotherapy practice in the theme of chronic pain necessarily demands consistency with the biopsychosocial and existential concerns of patients. As such, this is tantamount to an opportunity for those capabilities to help flourish life. This evinces core humanistic values and adheres to higher ethical standards, as it treats the patient as a person with dignity and respects his/her right to health.

In chronic pain, another way of configuring the physiotherapeutic relationship is essential. As discussed in Chapter Two, the physiotherapist must, therefore, engage with the patient to revive those passions and identify those things that are worth doing for their own sake. There is consequently considerable value in the physiotherapy profession where patient autonomy can be supported by being in control despite the pain. Here the concept of patient autonomy differs from that in acute pain, and the patient is empowered to consider health-related values through moral development. Physiotherapy for chronic pain, thus, enhances the self-actualisation of these patients who are often on the precipice of human predicament and therefore respects their right to health by upholding their dignity. These patients yearn to feel valued again in society in which they feel that they belong.

The principle of human dignity and the right to health can only assume value in physiotherapy for chronic pain when physiotherapy aims to motivate patients and empower them to develop self-management skills and self-efficacy within shared decision-making to live a life as independent as possible. With the attention given to all domains, the physiotherapist promotes the patient's health and autonomy, by enhancing his/her capacity to achieve those personal life goals to move forward in life on his/her own terms. Here, the patient's voice and perspective in clinical decisions are significant during shared decision-making processes to promote active participation in achieving meaningful goals. In this way, both agendas of the physiotherapist and patient are acknowledged in a robust physiotherapeutic relationship. These open negotiated treatment decisions instil feelings of commitment in patients and maximise their potential to achieve the maximum possible threshold of those capabilities to pursue a flourishing life. Ultimately, this is what gives the patient dignity, respects his/her autonomy and right to health, and transforms the suffering individual back into a person. Minimising pain can be the initial step, the last step or it might not be incorporated at all.

This approach does not disregard the importance of the physical body but opens the space to acknowledge the significance of the patient's *lived* experience within the broader contexts by acknowledging personhood as narrative and relational (as discussed in Chapter Three). The objective reality of the patient's pain is still acknowledged (e.g. physiological, anatomical and pathological facets of osteoarthritis), but there is also an orientation to the subjective meaning that the patient in chronic pain gives to his/her lived experience. Also, the social institutions (social, political, structural), mediating the patient's behaviours and experiences are scrutinised. The full richness of human life is, thus, embraced while acknowledging human diversity.

The challenge in physiotherapy within the field of chronic pain is, thus, not around the technical skills but in the quality of the physiotherapeutic relationship, of which empathy and trust are crucial components. As discussed in Chapter Three, the physiotherapeutic relationship has a significant role in identifying and bringing about the necessary behavioural changes. In chronic pain, these changes are brought about by empathy, trust, self-efficacy, setting goals, empowerment, fostering hope etc. To pursue this moral practice and abide by the obligation it entices, the physiotherapist has, according to the Declaration, to give vital importance to the patient's narrative process. Through this process, the physiotherapist accompanies the patients through the pain experience and guides them to reconfigure their sense of the future, and as their capabilities and values change, enable them to reorient themselves. As discussed in Chapter Three, the physiotherapist is, therefore, the primary therapeutic tool that is brought to the encounter, whereas the moral virtues and skills (such as self-reflection, interdisciplinary, working with cultural and individual differences) are crucial to implementing change.

Narratives, in physiotherapy for chronic pain, thus, rehumanise physiotherapy in this field and counterbalance those difficulties arising from the predominant biomedical model. The narrative process (as discussed in Chapter Three), recognises, absorbs, and interprets the pain experience, thus restoring the dignity of the patient when the meaning and significance of these unique stories are heard. Physiotherapy for chronic pain patients, hence, deals with emotions, social interactions and relationships around various cultural scenarios. The biopsychosocial-existential approach through narratives necessitates a robust physiotherapeutic relationship, which must, therefore, be built to serve as the foundation of the whole treatment process that understands the meaning of the patient's unique story. Narratives offer an approach to the physiotherapeutic relationship that stands in opposition to the biomedical model, as it recognises the patient as a social and existential being embedded in a culture and relationships. Thus, the patient is approached as a person with dignity, where his/her unique story of the chronic pain experience is privileged and is the central point for the healing therapeutic relationship. Here, the physiotherapist seeks the personal meaning to the pain in an empathic relationship and upholds the patient's rights to adequate care and health, by confirming his/her dignity.

Recommendations

Therefore, the first step in the whole treatment process and this technological era is for the physiotherapist to be present and actively listen to those patient stories in the clinics that reveal personal meaning-related concerns**. On this basis, it is recommended that the biopsychosocial-existential approach is adopted in physiotherapy for chronic pain through narratives.**

The narrative process, thus, taps into the physiotherapist's desire to have more meaningful relationships with the patients in chronic pain and enhances his/her overall system of humanitarian values. No technical advances will change how physiotherapy is practised in the field of chronic pain from the ethical enterprise that it primarily is. **It is therefore recommended that the physiotherapy profession engages in the pursuit of those methods grounded in the therapeutic relationship to seek better care and uphold the rights and the dignity of the patient in pain, as stated in the Declaration.** Physiotherapy for patients in chronic pain should give more significance to harnessing of relational skills, the capacity to respond to the complex health needs of the patient, the ability to collaborate with colleagues in interprofessional teams, restoring autonomy to patients, goal-setting principles, and supporting family and friends.

However, to make the right ethical judgements, and fully understand the pain experience, the physiotherapist necessitates more than just the knowledge of the ethical principles and the common-sense view of what is existentially right. This understanding does not suffice to satisfy the obligation the physiotherapist has for adequate care of the patient in chronic pain. **It is therefore recommended that physiotherapists possess narrative competency to decipher the patient's storyline and that these are taught at undergraduate levels in universities.** The medical reality in the clinics needs to be depicted by choosing real case scenarios for students to develop those necessary skills that better equip them for ethical decision-making as future physiotherapists. These incorporate various abilities such as active listening, recognising patterns of meaning, empathy, the understanding of diverse religious, social and cultural perspectives, growth in self-criticism and self-awareness. The physiotherapist, thus, needs also those cognitive, emotional and reflexive skills complementary to the technical ones. The moral sensitivity to the particularity of the patient's story is essential, together with that willingness for a deeper understanding of what gives the patient meaning to ameliorate and achieve emotional health. Thus, with adequate narrative competence on the part of the physiotherapist, the former has the potential to expand clinical reasoning and is not only confined to epistemic technical knowledge. Using this tool creates physiotherapists capable of *accompanying* patients through their pain experience, and allows them to respond better to the ethical dilemmas and contextual complexities of different patients. It is only when the patient in chronic pain is approached narratively that practical reasoning can be made since it is in those specific details of the patient's unique experience that the physiotherapist is informed to make the right judgement.

It is therefore also recommended that topics related to the essence of humanity are introduced at the university level to allow physiotherapy students to

appreciate the complexity of the human being and the many variables affecting the physiology, function, meaning, and participation of the patient. Phenomenological dimensions of chronic pain and the unique pain experiences that give pain their unique character are essential learning topics. Social set-ups supporting chronic pain management (e.g. legislation regulating controlled drugs like opioid, analgesics), and the prevailing discourses around pain (e.g. sick roles, stigma, malingering), are fundamental topics to be studied in physiotherapy if the chronic pain phenomenon is to be understood and those capabilities fundamental to the flourishing life enhanced.

The expertise of the physiotherapist developed in clinical relationships is closely aligned to principles of leadership. These skills, underpinned by a humanistic approach and moral transparency, can be eminently transferred to leading roles in physiotherapy and contribute to public debate by enhancing political insights. The potential to forge links in the community will help to effect necessary changes. Policies and outcome measures in healthcare are mainly focused on mortality rates rather than on the capabilities that patients have to live the flourishing life. In policies and other initiatives, focus on enhancing the supportive relationships with physiotherapists and other broader services seems to be absent. Thus, their relevance in empowering the patient to participate in his/her care is underestimated and practically unavailable. Enhancing the self-care capabilities of patients increases patient satisfaction and lessens doctor visits. Consequently, waiting times and referrals decrease, resulting in fewer investigations and fewer drug prescriptions. Physiotherapy can, therefore, not only alleviate suffering in this population but can also break up the cycle of spiralling costs in healthcare. All this has a strong correlation with those changes required to lessen the global burden of chronic pain, which, as discussed in the initial chapter, is a global health priority. The physiotherapy profession in the field of chronic pain, thus, has a unique value. **It is, therefore, highly recommended that physiotherapists also upgrade the skills that equip them to advocate passionately for improving patients' pain experience. The factors that regard those specific interests of the individual patient and cultivates the capabilities attributed to the concept of person are of central importance.**

The general concern behind the implementation of the Declaration of Montreal is an ethical one, where patients must be treated with dignity and respect their right to health. Moral reasoning and clinical decision-making are, thus, closely related. **It is, therefore, also recommended for the ethical role of the physiotherapist in chronic pain to be**

researched further. Only scant significance is given to those fundamental humanitarian aspects inherently associated with chronic pain, and the main body of documentation and evidence is mostly devoted to the ongoing studies on the pain pathophysiology. However, the busy schedule of physiotherapists can pose significant challenges for them to reflect on their philosophy of practice that can ultimately guide them to further research.

Analysing the *why we do of what we do,* can help the physiotherapist be critically aware of his/her role in chronic pain management. Thus, this can provide insights into alternative treatment approaches, teaching topics, budgeting, and will also guide the direction for further research. **Therefore, the last but most significant recommendation will be that for the physiotherapy profession to revisit its philosophy of practice in chronic pain.** The chronic pain crisis beckons for this update in the working philosophy of physiotherapy that takes account of the biopsychosocial and existential domains of the patient in chronic pain. As discussed throughout this thesis, physiotherapists have a central role in the health of this population of patients. Physiotherapists, driven by the desire to make a difference in the lives of their patients should have the confidence to reflect on questions such as: Why cannot we do things better? Why cannot we develop new ways of thinking?

Final Thought

It is only through narratives that the patient in chronic pain is given the voice to be heard and empowers all patients irrespective of their socio-economic status since it takes an interest in the patient as a whole. It acknowledges that chronic pain has meaning for the suffering patient and that discerning this meaning through the narrative process is fundamental to respecting the right to health in the chronic pain domain. The relief of suffering in chronic pain is, therefore, not to be understood in terms of a cure, but suffering in chronic pain is the loss of the patient’s ability for meaningful action and relation with others. At face value and when putting the biomedical philosophy into practice, the latter is found untenable. However, through the narrative process, and with due consideration to the biopsychosocial and existential concerns of the patient in pain, the physiotherapeutic relationship is taken to another level, and it satisfies the obligation of the healthcare professional stated in the Declaration of Montreal. With the narrative process, the burden of the suffering patient is shared by creating a partnership and a caring agreement with patients and their families with the common ultimate goal to restore health and respect it as a fundamental human right.

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Appendix A: Declaration of Montreal

Declaration That Access to Pain Management Is a Fundamental Human Right

International Pain Summit of the International Association for the Study of Pain, "Declaration of Montreal: Declaration that Access to Pain Management is a Fundamental Human Right," *Journal of Pain & Palliative Care Pharmacotherapy* 25, no. 1 (2011), 29-31.

We, as delegates to the International Pain Summit (IPS) of the International Association for the Study of Pain (IASP) (comprising IASP representatives from Chapters in 64 countries plus members in 130 countries, as well as members of the community), have given in-depth attention to the unrelieved pain in the world,

Finding that pain management is inadequate in most of the world because:

- There is inadequate access to treatment for acute pain caused by trauma, disease, and terminal illness and failure to recognize that chronic pain is a serious chronic health problem requiring access to management akin to other chronic diseases such as diabetes or chronic heart disease.
- There are major deficits in knowledge of health care professionals regarding the mechanisms and management of pain.
- Chronic pain with or without diagnosis is highly stigmatized.
- Most countries have no national policy at all or very inadequate policies regarding the management of pain as a health problem, including an inadequate level of research and education.
- Pain Medicine is not recognized as a distinct specialty with a unique body of knowledge and defined scope of practice founded on research and comprehensive training programs.
- The World Health Organization (WHO) estimates that 5 billion people live in countries with low or no access to controlled medicines and have no or insufficient access to treatment for moderate to severe pain.

- There are severe restrictions on the availability of opioids and other essential medications, critical to the management of pain.

And, recognizing the intrinsic dignity of all persons and that withholding of pain treatment is profoundly wrong, leading to unnecessary suffering which is harmful; we declare that the following human rights must be recognized throughout the world:

Article 1. The right of all people to have access to pain management without discrimination (Footnotes 1–4).

Article 2. The right of people in pain to acknowledgment of their pain and to be informed about how it can be assessed and managed (Footnote 5).

Article 3. The right of all people with pain to have access to appropriate assessment and treatment of the pain by adequately trained health care professionals (Footnotes 6–8).

In order to assure these rights, we recognize the following obligations:

1. The obligation of governments and all health care institutions, within the scope of the legal limits of their authority and taking into account the health care resources reasonably available, to establish laws, policies, and systems that will help to promote, and will certainly not inhibit, the access of people in pain to fully adequate pain management. Failure to establish such laws, policies, and systems is unethical and a breach of the human rights of people harmed as a result.
2. The obligation of all health care professionals in a treatment relationship with a patient, within the scope of the legal limits of their professional practice and taking into account the treatment resources reasonably available, to offer to a patient in pain the management that would be offered by a reasonably careful and competent health care professional in that field of practice. Failure to offer such management is a breach of the patient's human rights.

Note: This Declaration has been prepared having due regard to current general circumstances and modes of health care delivery in the developed and developing world. Nevertheless, it is the responsibility of: governments, of those involved at every level of health care administration, and of health professionals to update the modes of implementation of the Articles of this Declaration as new frameworks for pain management are developed.

Footnotes

1. This includes, but is not limited to, discrimination on the basis of age, sex, gender, medical diagnosis, race or ethnicity, religion, culture, marital, civil or socioeconomic status, sexual orientation, and political or other opinion.
2. International Covenant on Economic, Social and Cultural Rights (ICESCR) (1966). The State parties of the ICESCR recognize "the right of everyone to the highest attainable standard of physical and mental health" (Art. 12), creating the "conditions which would assure to all medical service and medical attention in the event of sickness."
3. Universal Declaration of Human Rights (1948): Rights to Health (Article 25); Convention on the Rights of a Child (Article 24); Convention on the Elimination of All Forms of Discrimination Against Women (Article 12); Convention on the Elimination of All Forms of Racial Discrimination (Article 5(e) (iv)).
4. The Committee on Economic, Social and Cultural Rights. General Comment No.14, 22nd Session, April-May 2000 E/C 12/2000/4. "Core obligations" of all signatory nations included an obligation to ensure access to health facilities, goods, and services without discrimination, to provide essential drugs as defined by WHO, and to adopt and implement a national health strategy.
5. Committee on Economic, Social and Cultural Rights. General Comment No.14, 22nd Session, April-May 2000, E/C 12/2000/4, para. 12. General Comment No. 14 stated that health accessibility "includes the right to seek, receive and impart information and ideas concerning health issues."
6. Appropriate assessment includes recording the results of assessment (e.g., pain as the "5th vital sign," can focus attention on unrelieved pain, triggering appropriate treatment interventions and adjustments). Appropriate treatment includes access to pain medications, including opioids and other essential medications for pain, and best-practice interdisciplinary and integrative nonpharmacological therapies, with access to professionals skilled in the safe and effective use of these medicines and treatments and supported by health policies, legal frameworks, and procedures to assure such access and prevent inappropriate use. Given the lack of adequately trained health professionals, this will require providing educational programs regarding pain assessment and treatment in all of the health care professions and programs within the

community for community care workers delivering pain care. It also includes establishment of programs in pain medicine for the education of specialist physicians in pain medicine and palliative medicine. Accreditation policies to assure appropriate standards of training and care should also be established.

7. Failure to provide access to pain management violates the United Nations 1961 Single Convention on Narcotic Drugs declaring the medical use of narcotic drugs indispensable for the relief of pain and mandating adequate provision of narcotic drugs for medical use.
8. The UN Universal Declaration of Human Rights (1948) (Article 5) states: “No one shall be subjected to torture or to cruel, inhuman or degrading treatment...” Comment: Deliberately ignoring a patient’s need for pain management or failing to call for specialized help if unable to achieve pain relief may represent a violation of Article 5.
9. The UN Special Rapporteur on the Right to Health and the UN Special Rapporteur on the question of torture and other cruel, inhuman, and degrading treatment stated: “The failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment.”

Appendix B: Central Human Functional Capabilities

Listed here is the list of Central Human Functional Capabilities, along with a brief description of each capability; quoted from Martha Nussbaum’s book *Women and Human Development: The Capabilities Approach* and found on pages 78-80.

1. **Life.** Being able to live to the end of a human life of normal length; not dying prematurely, or before one’s life is so reduced as to be not worth living.
2. **Bodily Health.** Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.
3. **Bodily Integrity.** Being able to move freely from place to place; having one’s bodily boundaries treated as sovereign, i.e. being able to be secure against assault, including sexual assault, child sexual abuse, and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.
4. **Senses, Imagination, and Thought**. Being able to use the senses, to imagine, think, and reason – and to do these things in a ‘‘truly human’’ way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing self-expressive works and events of one’s own choice, religious, literary, musical, and so forth. Being able to use one’s mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to search for the ultimate meaning of life in one’s own way. Being able to have pleasurable experiences, and to avoid non-necessary pain.
5. **Emotions.** Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one’s emotional development blighted by overwhelming fear and anxiety, or by traumatic events of abuse or neglect. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)

6. **Practical Reason.** Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience.)

7. **Affiliation.**

    A. Being able to live with and toward others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another and to have compassion for that situation; to have the capability for both justice and friendship. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.)

    B. Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails, at a minimum, protections against discrimination on the basis of race, sex, sexual orientation, religion, caste, ethnicity, or national origin. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.

8. **Other Species.** Being able to live with concern for and in relation to animals, plants, and the world of nature.

9. **Play.** Being able to laugh, to play, to enjoy recreational activities**.**

10. **Control over One's Environment**.

    A. Political. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association.

    B. Material. Being able to hold property (both land and movable goods), not just formally but in terms of real opportunity; and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure.