Proposing clinician competency guidelines for the inclusion of disability in the undergraduate medical curriculum of South Africa - an exploratory study.

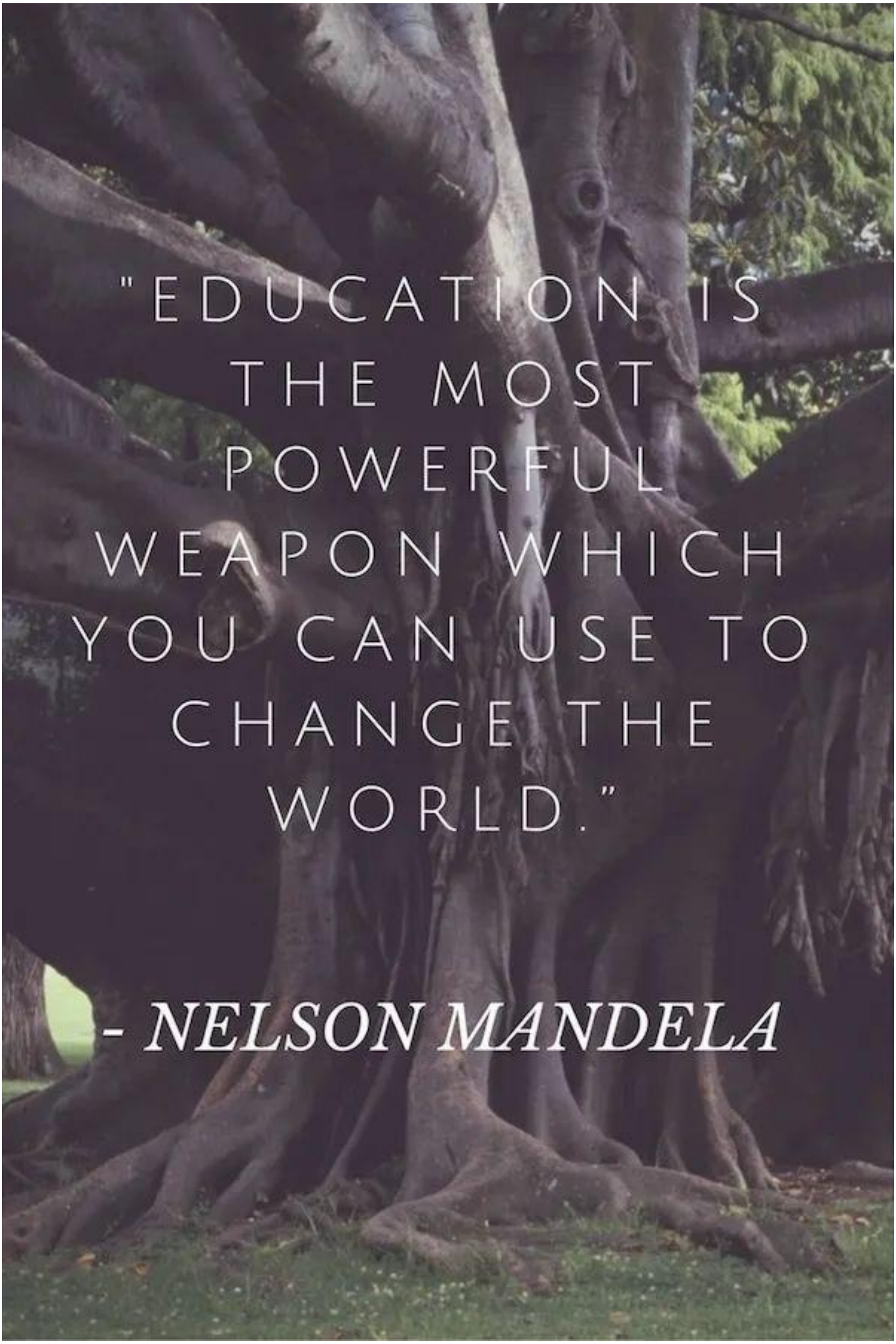
By Dr Sarah Nicole Whitehead
(WHTSAR002)

SUBMITTED TO THE UNIVERSITY OF CAPE TOWN
In fulfilment of the requirements for the degree

PhD in Health Sciences Education

Department of Health Sciences Education
Faculty of Health Sciences
University of Cape Town
November 2022

Supervisor: Professor Harsha Kathard
Co-supervisor: Professor Theresa Lorenzo



"EDUCATION IS THE MOST POWERFUL WEAPON WHICH YOU CAN USE TO CHANGE THE WORLD."

- NELSON MANDELA

Declaration

I, Sarah Nicole Whitehead, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signed by candidate

Sarah Nicole Whitehead

Date signed: 12 April 2023

Acknowledgements

Over the course of this degree – which began as an MPhil, which I upgraded to a PhD – and especially in the last few months, I have learnt to appreciate the phrase “it takes a village!” My name might be the one on the front cover, but this was by no means a solo feat. There is a long list of people that have contributed to me getting to this point. In the interest of time, I unfortunately cannot mention everyone, but there are a few people that I definitely want to acknowledge:

To my parents, John and Frances, I am so grateful to have had you both by my side on this journey to my thesis submission. There have been many ups and downs along the way and individually and collectively you have celebrated the ups and helped me get through the downs. My heartfelt thanks to you both.

To my brother, Sean and his partner Taneill, thank you for all your supportive cheerleading over the years!

To my supervisors Prof. Harsha Kathard and Prof. Theresa Lorenzo, thank you for your expert guidance, knowledgeable assistance and patience over the years. A big thank you to **Prof. Dele Amosun** who joined the supervisory team just a few months before submission and was instrumental in getting me over the finish line of this ultra-marathon aka my PhD.

A special thanks to **my editor, Dr Nadia Hartman** for expertly editing and ensuring I communicate my research processes and outcomes appropriately.

I have been very fortunate in the support I have received from numerous people over the years, but I would particularly like to thank **Ilana Sebastian, Cornell Peek, Brent Erasmus, Mandhir Ramruthan and Tory Madden.**

A big thanks to the **Zimele team** for all the support you have given me and for the faith and trust in my ability. On that note, I want to single out **Kimberly Brennan**. You have been a constant hard-working, enthusiastic, fun and supportive colleague and friend. I don’t know how I would have managed the juggling act of starting a non-profit company whilst doing a PhD, without you!

Lastly, I owe each of **my research participants** a depth of gratitude – beyond measurement. To my Phase one participants, your rich contributions were a major contributing factor to my upgrading from a Master's degree to a PhD. To my Phase two participants, your thoughtful, considered and meaningful contributions were invaluable. Your voices are all adding to disability inclusion.

Table of Contents

Declaration 3

Acknowledgements 4

Lists of Tables and Figures 16

Abbreviations 19

Glossary of Terms 20

Abstract 23

Chapter One – Introduction 25

1.1 Overview of the chapter 25

1.2 The researcher and the research 25

1.3 Problem statement 28

1.4 Purpose and focus of study 28

1.5 Context of the study 29

1.6 Aims and Objectives 32

1.7 Overview of all chapters in this thesis 33

1.8 In summary 35

Chapter Two – Literature review 36

2.1 Overview of the chapter 36

2.2 Literature Review 36

    2.2.1 What is this problem as it relates to this study? 36

    2.2.2 How is disability being included in global undergraduate medical curricula? 47

2.2.3 Which competencies are required in disability education for medical students? 53

2.3 In summary 56

Chapter Three – Conceptual Frameworks 57

3.1 Overview of the chapter 57

3.2 Conceptual Frameworks 57

3.2.1 The International Classification of Functioning, Disability and Health (ICF) 57

3.2.1.1 Why the ICF? 59

3.2.1.2 How exactly does the ICF contribute to curriculum? 59

3.2.2 Establishing a conceptual basis for curriculum change. 60

3.2.3 What does curriculum mean to this study? 61

3.2.3.1 Part A: The curriculum development process – goal setting for generating a curriculum. 62

3.2.3.2 Part B: Competency based medical education (CBME) 63

3.2.3.2.1 How to plan a CBME curriculum 64

3.2.3.2.2 The criticism surrounding CBME 65

3.2.4 Critical Disability Studies 67

3.2.5 A decoloniality lens 69

3.3 In summary 72

Chapter Four – Methodology and Ethical Consideration 73

4.1 Overview of the chapter 73

4.2 My paradigmatic positioning 73

4.2.1 Introduction 73

4.2.2 The generation of knowledge 74

4.2.3 The influence of my paradigmatic positioning 74

4.2.4 My paradigmatic assumption 75

4.3 Study Aims and Objectives 75

4.4 Research Design (2-phase study) 76

4.4.1 Phase one 76

4.4.1.1 Objectives 76

4.4.1.2 Research design for Phase one 77

4.4.2 Phase two 77

4.4.2.1 Objectives 77

4.4.2.2 Research design for Phase two 77

4.5 Procedure 77

4.5.1 Phase one 77

4.5.1.1 Participants (inclusion, exclusion and recruitment) 77

4.5.1.2 Data collection instruments 85

4.5.1.3 Data collection processes 85

4.5.1.4 Data analyses 92

4.5.2 Phase two 95

4.5.2.1 Participants (inclusion, exclusion and recruitment) 95

4.5.2.2 Data collection instrument 99

4.5.2.3 Data collection process 100

4.5.2.4 Data analyses 102

4.6 Ethical considerations (including data security) 103

4.7 Conflicts of Interest 109

4.8 In summary 109

Chapter Five – Phase one Findings 110

5.1 Overview of the chapter 110

5.2 Document analysis 110

5.3 Findings from focus groups and in-depth interviews 114

- 5.3.1 Phase one participants 115
- 5.3.2 Participant profiles 115
- 5.3.3 Generation of themes from focus groups and interviews 119

5.4 Theme One - Experience of disability 119

- 5.4.1 Early and varied exposure 120
  - 5.4.1.1 Exposure to persons with disability 120
  - 5.4.1.2 Theoretical versus practical exposure 122
  - 5.4.1.3 Reminder: Individual people within one group 123
- 5.4.2 Quality of clinical interactions 124
  - 5.4.2.1 Mechanical versus holistic approach 124
  - 5.4.2.2 Role confusion 125
  - 5.4.2.3 Fear of the unknown 126
  - 5.4.2.4 Too much focus on the impairment and disability 126
  - 5.4.2.5 Communication 128
  - 5.4.2.6 Creating a comfortable space 129

5.5 Theme Two - Attitudes towards disability 130

5.5.1 Medical omnipotence 131

5.5.1.1 Arrogance creates a power differential 131

5.5.1.2 Arrogance prevents further learning 131

5.5.1.3 Arrogance prevents knowledge sharing 132

5.5.1.4 Ways to combat arrogance 132

5.5.2 Medical knowledge superiority 133

5.5.2.1 Know your knowledge limits 133

5.5.2.2 Be openminded about knowledge sharing 134

5.5.2.3 Really listening 134

5.5.3 Blinkered assumptions 135

5.5.3.1 Disability = weak or vulnerable 135

5.5.3.2 Any disability = reduced mental capacity 136

5.5.3.3 Rendering a person with a disability invisible 136

5.5.3.4 No visible disability therefore no disability 137

5.5.3.5 Desexualisation of persons with disability 137

5.6 Theme Three - Knowledge about Disability 138

5.6.1 Knowledge constructs 138

5.6.1.1 Basic knowledge about Disability 138

5.6.1.2 The same medical conditions affect able-bodied and disabled people 139

5.6.1.3 Know what questions to ask 139

5.6.1.4 More knowledge needed about psychosocial disabilities 140

5.6.1.5 Ways of imparting knowledge 141

5.6.1.6 Medical knowledge about Disability vs lived experience of disability 141

5.6.1.7 Multidisciplinary knowledge is important 142

5.6.2 Empowered through knowledge 143

5.6.2.1 Claiming autonomy 143

5.6.2.2 Evidence of positive shifts 144

5.7 Theme Four - Life beyond the disability 144

5.7.1 Self-centred vs Person-centred 145

5.7.1.1 What does the patient with the disability want? 145

5.7.1.2 What is the cultural context of the person with the disability? 146

5.7.1.3 Value the humanity of persons with disability 147

5.7.2 Limited beliefs and expectations 147

5.7.2.1 Disability is just a part of diversity 147

5.7.2.2 Disability does not automatically disqualify one from other roles 148

5.7.2.3 The right interventions can improve quality of life 149

5.8 Summary of competencies generated from each theme 149

5.8.1 Theme One – Experience of disability 149

5.8.2 Theme Two – Attitude towards disability 150

5.8.3 Theme Three – Knowledge about Disability 150

5.8.4 Theme Four – Life beyond the disability 150

5.9 What is missing from Phase one data? 150

5.10 In summary 151

Chapter Six – Phase two Findings 152

6.1 Overview of chapter 152

6.2 Aims and objectives addressed by the generation of the initial competency set 152

- 6.2.1 Relationship between competencies 159
- 6.2.2 Relationship between competencies and their sub-competencies 160

6.3 Modified Delphi Method 161

- 6.3.1 Expert panel 161
- 6.3.2 Round one of the modified Delphi 163
  - 6.3.2.1 Question 1 163
  - 6.3.2.2 Question 2 163
  - 6.3.2.3 Question 2.1 164
    - 6.3.2.3.1 Who are the competencies for? 164
    - 6.3.2.3.2 For consideration only? 165
    - 6.3.2.3.3 Advocating for valuing humanity and autonomy 165
    - 6.3.2.3.4 More information needed 166
    - 6.3.2.3.5 Increase mental health awareness 167
    - 6.3.2.3.6 Contextual grounding 167
  - 6.3.2.4 Points of contention 168
- 6.3.3 Round two of the modified Delphi Method 169
  - 6.3.3.1 The expert panel 169
  - 6.3.3.2 Repeat of question 2 from round one 176

6.3.3.3 Question 2.1 (the same as question 2.1 in round one) 177
6.3.3.3.1 Respecting the heterogeneity of persons with disability 177
6.3.3.3.2 Inclusivity 177
6.3.3.3.3 Clinical significance 177
6.3.3.3.4 Are medical doctors superior health professionals? 178
6.3.3.3.5 Understanding and appreciating cultural context 178
6.3.3.3.6 Advocating for valuing humanity 179
6.3.3.3.7 Correct terminology 179
6.3.3.3.8 Clarification needed 180
6.3.3.4 Points of contention 180
6.3.4 Generation of final competency set 180
6.4 In summary 190
Chapter Seven – Discussion and Synthesis 192
7.1 Overview of chapter 192
7.2 Comparing competency sets 192
7.3 Overlapping elements (knowledge, attitudes and skills) in the data 193
7.3.1 Phase one data 194
7.3.2 Phase two data 195
7.3.3 Advocating for integrative competencies 199
7.4 Exploring ableism 200
7.4.1 What is ableism? 200

7.4.2 How this study's competencies challenge ableism 201

7.4.3 Introducing ableism as an epistemic schema 204

7.4.4 The four mechanisms of the epistemic schema of ableism 205

7.4.4.1 Combating Testimonial injustice 206

7.4.4.2 Overcoming Epistemic overconfidence 208

7.4.4.3 Avoiding Epistemic erasure 210

7.4.4.4 Recognising Epistemic derailing 211

7.5 In summary 213

Chapter Eight – Conclusion 214

8.1 Overview of the chapter 214

8.2 Conclusion of this study 214

8.2.1 What this study is offering 214

8.2.2 Common interests and goals, tension and challenges 216

8.2.3 The significance of this study 217

8.2.4 How my study is different 218

8.2.5 How this study contributes to decoloniality 219

8.3 Implications 220

8.4 Limitations 221

8.4.1 Use of research assistants 221

8.4.2 Absence of participants with psychosocial disability in Phase one 221

8.4.3 Variations between South African provinces 221

8.5 Further engagement and research 222

8.6 In summary 222

References 223

Appendices 254

Appendix 1: Information sheet for Phase one participants of the first focus group (Persons with disability) session 254

Appendix 2: Information sheet for Phase one participants of the second focus group (Medical Doctors) session 258

Appendix 3: Information sheet for Phase one participants of the third focus group (Rehabilitation Therapists and Nurses) session 262

Appendix 4: DSA100 form approval letter 266

Appendix 5: Information sheet for Phase one participants of the fourth focus group (Medical Students) session 267

Appendix 6: Questions for the focus group with Persons with disability 271

Appendix 7: Questions for the focus group with the Medical Doctors 271

Appendix 8: Questions for the focus group with the Rehabilitation Therapists and Nurses 271

Appendix 9: Questions for the focus group with Medical Students 271

Appendix 10: HREC MPhil approval 273

Appendix 11: HREC approval for upgrade to DPhil 274

Appendix 12: Information sheet for Phase two participants 275

Appendix 13: Consent form for Phase one participants 278

Appendix 14: Consent form for Phase two participants 280

List of Tables and Figures

Table 2.1: Singh *et al* (2020) Competencies: An Indian medical graduate should be able to…

Figure 4.1 shows a traditional 5-point Likert Scale (Recurve Blog post)

Figure 5.1: This image illustrates some of the various types of impairments which can cause different types of disabilities (google images: esri.com).

Figure 5.2: Illustrated by this image showing how damage is done by forcing a square peg into a round hole (google images: aboundingsolutions.com).

Figure 5.3: The above picture shows how the more exposure someone has to someone else, their preference for that other person increases (google images: conversion-uplift.co.uk).

Figure 5.4: As this image illustrates this subtheme looks at barriers or factors that positively or negatively influence interactions (google images: playbuzz.com).

Figure 5.5: An illustration showing how individual/impairment focused the medical model can be (google images: slideplayer.com).

Figure 5.6: An image showing how attitudes can result in barriers for persons with disability (google images: endthecycle.info).

Figure 5.7: An image showing an example of non-verbal communication (google images: nurseswritingservices.com).

Figure 5.8: This image visually represents basic knowledge (google images: alamy.com).

Figure 5.9: An image) depicting the different knowledge (puzzle pieces) members of a team can add (google images: medbriefnamibia.com).

Figure 5.10: An image showing some of the different goals that might be important to any individual regardless of ability (google images: dreamstime.com).

Figure 5.11: An image depicting the equal (balanced scale) treatment of persons with disability and able-bodied persons (google images: canstockphoto.com).

Table 6.1: Initial competency set in questionnaire one

Figure 6.1 illustrates how data from the 4 main themes of Phase one (reported in Chapter Five) contributed to the generation of certain competencies in the initial competency set.

Figure 6.2 illustrates the interwovenness of the three clusters of competencies of the initial competency set - i.e., most of the competencies and sub-competencies contain elements of more than one of the clusters.

Figure 6.3 illustrates the progression of this study's modified Delphi Method.

Table 6.2: demographic data of each expert. The order of the table is according to the order in which the round one questionnaires were analysed.

Table 6.3: percentage rankings for each competency and sub-competency for the question of importance.

Table 6.4: percentage rankings for each competency and sub-competency for the question of language clarity.

Table 6.5: Experts who participated in round two

Table 6.6: Revised competency set used in round two

Table 6.7: percentage rankings for each revised competency and sub-competency for the question of language clarity.

Figure 6.4 shows the division and overlap - between the knowledge, attitudes and skills clusters – of the competencies in the final set.

Figure 7.1 shows the comparison between the HPCSA competency set – HPCSA undergraduate medical competencies are divided into the seven coloured word headings – **and this study's competencies** – represented by numbers.

Figure 7.2 represents the overlapping elements that will be discussed in this section.

Table 7.1: The first three objectives

Table 7.2: The other/fourth objective addressed by Phase one data

Table 7.3: The objectives addressed by Phase two data

Table 7.4: Competency key for the entire final competency set

Figure 7.3 shows the four mechanisms of ableism as an epistemic schema and which of this study's competencies contribute to each mechanism – the details of their contributions follow in the below text.

Figure 8.1: A flow diagram of the research study. A reminder that the 4 main themes (mentioned in the second block of the diagram) are: Experience of disability, Attitudes towards disability, Knowledge about Disability and Life beyond the disability. The image (google images: communitycare.co.uk) represents the fact that this study is a step towards increasing disability inclusion in medical student education/curricula**.**

Abbreviations

AIHW	Australian Institute of Health and Welfare
ASSAf	Academy of Science of South Africa
CBME	Competency Based Medical Education
CDC	Centre for Disease Control
CEE	Central and Eastern Europe
DoH	Department of Health (South Africa)
DSD	Department of Social Development (South Africa)
HPCSA	Health Professions of South Africa
HREC	Human Research and Ethics Committee
ICIDH	International Classification of Impairment, Disability and Handicaps
ICF	International Classification of Functioning, Disability and Health
LGBTQI	lesbian, gay, bisexual, transgender, queer (or questioning), and intersex
SA	South Africa
SANC	South African Nursing Council
UCT	University of Cape Town
UCT FHS	University of Cape Town, Faculty of Health Sciences
UK	United Kingdom
UK GMC	United Kingdom General Medical Council
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
US	United States
WFME	World Federation on Medical Education
WHO	World Health Organization
WHO WRD	World Health Organization World Report on Disability
WONCA	World Organisation of Family Doctors

Glossary of terms

Curriculum

The HPCSA defines curriculum as “the comprehensive teaching programme required to meet the exit level outcomes and includes but is not limited to content, teaching-learning and assessment.” (Department of Health Government Gazette, 2014, page 3)

Disability

According to the Centre for Disease Control (CDC) in their Disability and Health overview 2020, disability is explained as “*any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).”*

Simply put a disability occurs when the impairment (dysfunction of an organ or a system within the human body) has a causal effect of limiting human body functioning/activity within the individual’s context (Carter, 2018).

The United Nations Convention on the Rights of Persons with disability (UNCRPD) 2006 goes a step beyond the purely impairment/limitation (medical model) focus of the CDC definition above and defines disability thus, *persons with disability include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*

I have included both these definitions because they highlight one of the goals of this study, which is to shift the focus of medical education from a dominance of the traditional medical model of disability towards a more balanced focus which incorporates the medical and social model of disability, as well as any other contextually relevant models.

Disability adjusted life years (DALYS)

“The overall burden of disease is assessed using the disability-adjusted life year (DALY), a time-based measure that combines years of life lost due to premature mortality (YLLs) and years of life lost due to time lived in states of less than full health, or years of healthy life lost due to disability (YLDs).” (www.who.int visited 23/06/2022)

Health Professions Council of South Africa (HPCSA)

This is the professional board that all health professionals – except nurses - must be registered with, to work clinically in South Africa.

Persons with disability

This term stems from the person language movement which began in 1974. Crocker and Smith (2019) argue that despite person first language being the status quo in many health professional teaching programs and by many scholarly journals, person first language is often not used by healthcare practitioners. This disconnect between academia and practice in something seemingly insignificant as the language used in disability context can actually lead to significant influences on the quality of the healthcare persons with disability receive (Crocker & Smith, 2019).

I decided that because this study aims to ultimately improve the quality of healthcare of persons with disability, I would intentionally use the term throughout my thesis to contribute towards healthcare practitioners having a better understanding of why such language is important.

South African Nursing Council (SANC)

This is the professional board that all nurses must be registered with, to work as nurses in South Africa.

Undergraduate medical degree

This is the university qualification that allows an individual to graduate as a medical doctor.

Undergraduate medical curriculum

This forms the education and training medical doctors receive as part of the university degree that allows them to graduate as general practice medical doctors.

Abstract

Introduction

Persons with disability make up the largest minority group in the world yet there is a dearth of research both internationally and nationally on how disability is included in professional training curricula for medical doctors.

Aim of the study

The purpose of this study is to add to the body of knowledge that would facilitate the inclusion of disability in the undergraduate medical curriculum in South Africa.

Methods

This is a mixed method, sequential study – Phase one followed by Phase two. Phase one, data was collected - via focus groups and in-depth interviews - from Medical Doctors, Medical Students, Physiotherapists, Occupational Therapists, Speech and Language Therapists and Persons with disability. Phase two used a modified Delphi Method with an expert panel of disabled and abled Disability Studies Academics, Medical Educators, Disability Rights Activists and Medical Doctors. The experts were asked to rate – using a 5-point Likert Scale - each competency according to its importance and language clarity. They were also asked in open-ended questions, to make any suggestions relating to the language of each competency and whether any competencies could be combined.

Findings

Four main themes emerged from Phase one data: Experience of disability, Attitudes towards disability, Knowledge about Disability and Life beyond the disability. Data from these four themes contributed to the generation of an initial competency set – 17 competencies and 13 sub-competencies. In Phase two the initial competency set was presented to an expert panel as part of a modified Delphi Method. In the first iteration consensus was regarding the importance of each competency. In the second iteration consensus was reached regarding the

language of each competency and a final competency set – containing 13 competencies and 9 sub-competencies - was generated. Competencies and sub-competencies 1-6 are clustered as knowledge competencies, 7-10 as attitudes and 11-13 as skills.

Conclusion

This study sets an important precedent for the inclusion of the subject of disability in undergraduate medical curricula. It proposes an approach to teaching and learning about disability inclusion for medical students. The list of disability specific competencies set forth by this study are a steppingstone in the process of curriculum transformation. The use of this guideline to improve the understanding of disability, and as a catalyst for undergraduate medical curriculum review is recommended.

Chapter One

Introduction

1.1 Overview of the chapter

To begin this chapter, I discuss my lived experience and highlight the personal, international and national factors that motivated this research. I then discuss the problem statement, followed by the purpose and focus of this study. Next, I contextualise where this study was done, followed by an outline of the study's aims and objectives. Finally, an overview of all the chapters of this thesis and a summary of this chapter is presented.

1.2 The researcher and the research

I graduated from the University of Cape Town (UCT) medical school in Cape Town, South Africa in 2010. I am also a Person with a (physical) disability. However, I began my medical training in 2005 after one year (2004) of a BSc Occupational Therapy at UCT without a disability. I went on to graduate from medical school though my impairment and subsequent disability began to manifest physically in the fifth and final year of my medical degree (2009). On graduation, I started practising clinical medicine as a medical doctor with a disability. I have a Symptomatic Pontine Developmental Venous Anomaly (DVA), described as "variations of venous vascular anatomy related to an underdevelopment of either the superficial or deep venous -emissary system, resulting in a dilated transmedullary vein fed by multiple smaller venous radicles responsible for drainage of normal brain parenchyma" (Rinaldo, *et al.* 2020, page 1115), typically resulting in a compressive neuropathy or obstructive hydrocephalus (Rinaldo *et al* 2020; page 1116).

I spent my community service year working as a medical doctor at the Western Cape Rehabilitation Centre (WCRC) in Mitchells Plain in Cape Town, South Africa. This is a centre for the physical rehabilitation of physically disabled individuals (e.g., patients with spinal cord injuries, strokes and traumatic brain injuries). I developed an interest and a passion for that work. From 2014-2018, I worked as a permanent part time medical doctor at Vincent Pallotti Hospital Acute Neurorehabilitation Unit, also in Cape Town, South Africa. This unit is also for the rehabilitation of physically disabled patients.

Through being both a doctor working exclusively with patients with disabilities and being myself a person with a disability, I have gained a unique perspective and understanding of the interaction between medical doctors and their patients with disabilities. I am aware of the influence doctors have in the lives of persons with disability. I have noted that this influence is not always a positive one and can greatly impact their (persons with disability) lives. As a result, I have become passionate about educating society, including medical doctors, about disability. I am aware of my unique position and the voice I have, being a female clinical doctor with a physical disability. I hope to use my position and voice to challenge any preconceived ideas that society has regarding medical doctors and persons with disability**.**

In my opinion, the best way to ensure that medical doctors practice disability inclusive medicine is to educate them on disability during their training for their first professional qualification, which enables them to practise as a medical doctor. Kathard *et al.* (2020) describe disability inclusive healthcare practices as those which enable disability inclusion at all levels within healthcare. Even though I view myself as an advocate of disability inclusion, I'm aware that I am a novice. I do, however, believe that my opinion is important for a number of reasons.

Firstly, I have personal experience of medical curricula from when I was a medical student. Secondly, my professional experience of being a medical doctor working with physically disabled individuals has allowed me to see first-hand the importance of a medical doctor's ability to practise disability inclusive medicine. Lastly, my being a person with a disability has afforded me unique insights into medicine, health and disability. I have been both a patient and a medical doctor. This experience has taught me some invaluable lessons about disability and the importance of inclusivity, which I have used to shape my practise as a medical doctor. A better understanding of disability can be a catalyst for curriculum change and review.

I have introduced certain elements of my lived experience that served as motivation for me to do this research. Various other international and national factors also influenced my motivation for and interest in this research:

- **International factors**

In 2010 (the year that I graduated from medical school) America marked the centenary of the 1910 Flexner Report - which revolutionised 20th century medical education - with the launch of a Commission, aimed at developing a shared global vision and strategy for 21st century medical education. This Commission - comprising of twenty experts from diverse backgrounds and countries - was launched in recognition of the fact that the medical education reforms of the 20th century are no longer adequate for the complexity of 21st century medicine (Frenk *et al.* 2010). This Commission not only sparked my interest in the need for the transformation of medical education, but it also brought forth the issue of decolonisation because it highlighted the fact the 20th century medical education reforms which originated in the global north had not been successfully transferred and adopted by many global south countries. This raised the question of why it had not been a simple transfer and thus the challenge of decolonisation took a more central position in my thought process (Frenk *et al.* 2010).

- **National factors**

Three factors at national level have stirred my interest in this research. They are the National Development Plan 2030 for South Africa (South African Government National Planning Commission 2012), the 2007 ratification of the United Nations Convention on the Rights of Persons with disability (UNCRPD) by South Africa (UN 2006; Visagie, Scheffler, & Schneider, 2013), and the HPCSA Core competencies for undergraduate students in clinical associate, dental and medical teaching and learning programmes in South Africa, developed by the Undergraduate Education and Training Subcommittee of the Medical and Dental Professions Board in collaboration with training institutions and the South African Committee of Medical and Dental Deans (2014). [Core competencies* for undergraduate students in clinical associate, dentistry and medical teaching and learning programmes in South Africa. 1-14).]

These international and national factors highlighted the glaring health disparities that still exist for persons with disability. This strengthened my resolve to do this research to propose a potential step towards remedying this situation.

1.3 Problem statement

There is a dearth of research both internationally and nationally on how disability is included in professional training curricula for medical doctors. There are a few published examples of attempts by several international universities to include more disability focussed teaching into their undergraduate medical curricula. These attempts are however ad hoc, often elective subjects and lack uniform structure and focus. Details of these examples will follow in the literature review chapter. This lack of exposure results in some medical graduates knowing a little about disability and others nothing at all. Consequently, medical graduates are not uniformly equipped to adequately meet the healthcare needs of persons with disability, which perpetuates the struggle of many medical doctors to practise in a disability inclusive way. In fact, what we know about doctors practice with disability is also relatively unexplored and therefore a critical issue.

Emerging studies in South Africa such as Ohajunwa (2012) and Nwanze (2016) show that disability is in its early stages of being included in the undergraduate medical curriculum at the University of Cape Town (UCT). McKinney's (2016) study investigated the inclusion of disability issues into the curriculum of the Engineering Faculty at UCT. McKinney's study found that disability inclusion was absent in the engineering curriculum. This study also highlighted a need for greater multidisciplinary collaboration to ensure a fully Disability inclusive engineering curriculum (McKinney, 2016). These early studies reveal a minimal published understanding of what disability is, and why and how disability should be included in the undergraduate medical curriculum. I argue that disability inclusion in the undergraduate medical curriculum is similar to the abovementioned findings of McKinney (2016).

While the inclusion of disability into medical curricula is an international challenge, this study intends to begin the process of investigation into what will inform how disability could be included in a South African medical undergraduate curriculum.

1.4 Purpose and focus of study

The purpose of this study is to add to the body of knowledge that would facilitate the inclusion of disability in the undergraduate medical curriculum in South Africa. Curriculum development is an ongoing process. This ongoing process has various stages to it – e.g., information generation, teaching, learning, assessment and evaluation. I chose to focus on the initial stage of curriculum development through the generation of disability competencies for inclusion in the undergraduate medical curriculum. Competencies are important in any curriculum development process because they help ensure that the needs of an intended target population are met (Ankam, *et al.* 2019).

In this study I used a two-phase approach to generate competencies. In the first phase, I asked Medical Doctors, Rehabilitation Therapists, Nurses, Medical Students and Persons with disability to describe what is currently done and what should be done in medical doctors' practice with persons with disability. I used this Phase one data as a basis for generating competencies (knowledge, skills and attitudes - encompassing values, beliefs and feelings) that should enable medical doctors to have a disability inclusive medical practice. In the second phase of this study, I presented the list of competencies I generated from the Phase one data to an expert panel. Through a modified Delphi Method, the expert panel reached consensus on the list of disability competencies to propose for inclusion in the undergraduate medical curriculum. The two-phase methodology will be described in greater detail in Methodology chapter.

1.5 Context of the study

This study took place at the University of Cape Town's (UCT) medical school in Cape Town South Africa.

- The establishment of UCT medical school

The medical faculty at UCT was established in 1912 in partnership with Groote Schuur Hospital, Cape Town, South Africa, the first medical school in Sub-Saharan Africa (Sanders & Berman, 2012; de V van Niekerk, 2012). South Africans at the time had to go abroad for medical education and the strong call to establish a national medical school was countered by concerns that no school equal to the standard required by recognised universities of Great Britain could be established in the Cape Colony, which lacked staff and facilities for adequate clinical instruction (Jacobs, 2012). After decades of requesting United Kingdom (UK) universities to recognise that the medical fraternity of South Africa had enough gravitas to their name and that South African medical education should be allowed to stand on its own two feet, this was finally granted in 1920 (Louw, 1979). The curriculum for the six-year degree was modelled on the Edinburgh university curriculum and the first three clinical professors came out from Dublin to teach the medical school (Louw, 1979).

It is evident that the UK was extremely influential in the establishment of UCT’s medical school.

- More than a century later

Through personal communication it was confirmed by Harsha Kathard as Acting Head of Health Science Education at The University of Cape Town (UCT) and Nadia Hartman and Vanessa Burch, all three are employees in Faculty of Health Sciences at UCT (email correspondence 30 May 2016) that, disability is not systematically included in the undergraduate medical curriculum. This is also evident by its absence from the literature that reflected on the achievements in the faculty during the centenary celebration of the medical school. (Saunders, 2012; Hartman *et al.* 2012; Hussey & Hawkridge, 2012).

UCT’s Faculty of Health Sciences (FHS) has some very clear points in its mission that provide a contextual framework for this study:

The Faculty’s mission is to:

- *Respond to the health care needs of South Africa and beyond.*
- *Educate health professionals, educators and scientist for life.*
- *Undertake research that is relevant to the needs of our country and beyond.*
- *Promote health equity through promoting health professional standards in the delivery of quality health care.*
- *To be socially responsive to the needs of the people of our country and beyond.*
- *To develop interventions to reduce the risk of ill health, disability and mortality.*

(The UCT FHS mission as it appears on their website visited 23/08/2021)

South Africa has a long history of colonial rule until it became a republic in 1961. As such medical education in South Africa has a long tradition of being rooted in colonialist schools of thought.

Whitehead (2016) explains that colonialism was suffused with the belief that colonisers brought with them - to the lands they colonised - notions of civilisation and enlightenment.

The assumed superior quality of the colonisers' ideas and models, in areas such as religion and medicine, were simply taken as given.

Colonial theories about medicine were a focal point of the colonial effort (Bala, 2015). This key element of colonialism involved the exportation of colonial medical education approaches and the subsequent adoption of said educational approaches by colonised countries.

Consequently, a former colony such as South Africa, continued to train its medical doctors with education methods reminiscent of the colonial era.

South Africa also bears the legacy of the apartheid regime, which has contributed to the creation of many socio-political and socioeconomic divides and injustices. Meiring, Kannemeyer and Potgieter (2018) argue that it was the racial segregation and marginalisation of South Africa's majority population by the apartheid regime that greatly contributed to the socioeconomic inequalities evident in South Africa today.

In Africa during the 1950s and 1960s the call to decolonise higher education first emerged amidst decolonising struggles against colonial rule (Fataar, 2018).

Christie (2020) explains that for several decades, the South African government ignored these decolonisation struggles because they were focused on strengthening the grip of apartheid on the country.

The undoing of the apartheid regime beginning in 1990 and ending with the major political changes of 1994 signified the end of colonial rule and was when South Africa's decolonisation efforts really gained momentum (Christie, 2020).

In the early 2000s, the Health Professional Council of South Africa (HPCSA) began developing a process by including certain new competencies (ethics, human rights and health law) amongst its accreditation criteria for the successful graduation and registration of all healthcare professionals (London *et al.* 2007). Therefore, as this study is aiming to offer new competencies specific to medicine and disability, the present competencies specified by the HPCSA will be considered and this study will further develop these.

1.6 Aims and Objectives

Before I list this study's aims and objectives, I need to clarify what is meant by my use of the term equitable practice with persons with disability. This term speaks to a medical practice which is equal to that afforded to persons without disability.

Aims 1: To describe what constitutes doctors' approach to disability inclusive practice.

Objectives

1.1. To critically analyse and describe the attitudes/values to the clinical encounter which characterises equitable practice with persons with disability.

1.2. To identify and describe the critical behaviours and skills of doctors which contribute to equitable practice with persons with disability.

1.3 To identify and describe key knowledge constructs which underpin equitable practice with persons with disability.

Aim 2: Describe the competencies related to knowledge, skills and attitudes, (feelings, beliefs and values) required for equitable disability practices.

Objective

2.1. Describe basic competencies (knowledge, skills and attitudes - feelings, beliefs and values) that graduate medical students should have in order to deliver a quality healthcare service to persons with disability.

Aim 3: To develop an initial competency framework that could contribute to developing the undergraduate medical curriculum, with the aim of providing a quality healthcare service to persons with disability.

Objectives

3.1 Identification of initial set of competencies through various data sources.

3.2 Refine the competency framework through expert analysis.

1.7 Overview of all chapters in this thesis

- **Chapter One**

To begin this chapter, I discuss my lived experience and highlight the personal, international and national factors that motivated this research. I then discuss the problem statement, followed by the purpose and focus of this study. Next, I contextualise where this study was done. An outline of the study's aims and objectives follows. Finally, an overview of all the chapters of this thesis and a summary of this chapter is presented.

- **Chapter Two**

This chapter focusses on an in-depth literature review guided by three main questions:

What is the problem related to this study?
How is disability being included in global undergraduate medical curricula?
Which competencies are required in disability education for medical students?

I searched Google Scholar as it has a wide range of articles from many different journals and PubMed. The search terms were: **medical profession; undergraduate medical education; 21st century medicine; health needs of persons with disability; models of disability; International Classification of Functioning; Disability and Health; disability inclusion in undergraduate medical curricula; competency generation; Global south; Persons with disability in South Africa; intersectionality; health disparities; power dynamics in healthcare and healthcare equity and equality.** I was also pointed in the direction of interesting and relevant articles by my supervisors, fellow PhD candidates and UCT librarians. I end with a brief summary of the chapter.

- **Chapter Three**

This chapter begins by discussing the important concepts and theories that were used to frame the study. The process of selecting and refining the conceptual framework has been continuous since commencement in 2016 of my Master's degree followed by an upgrade to

Doctoral studies in 2019. Additions and refinements were aided by further reflections throughout the study. The chapter ends with a brief summary.

- **Chapter Four**

I begin this chapter by detailing my paradigmatic position, followed by an explanation of how I view the generation of knowledge in this study and my paradigmatic assumption for this study. This explanation of my paradigm through which I viewed this study is followed by an explanation and a discussion regarding the methodological aspects of this study - this includes research design, identification, and recruitment of research participants for both phases of this study, data collection methods and procedures and finally the analytical procedures followed in both phases. I then record the ethical considerations for this study, as well as the ways that I ensured the trustworthiness and rigor of this study and data security. I end this chapter with a section on conflicts of interest and a summary of this chapter.

- **Chapter Five**

This chapter records the findings from Phase one of this study. I begin by presenting the findings of the document I analysed and then present the findings from the data gathered from focus groups and in-depth interviews with Medical Doctors, Occupational Therapists, Physiotherapists, Speech Therapists, Nurses, Medical students and Persons with disability. Data from the focus groups and in-depth interviews addresses the first and second aim and their respective objectives. I end with a summary of this chapter.

- **Chapter Six**

In this chapter, I start by describing the aims and objectives of this study that were addressed by the initial competency set. I then describe the modified Delphi that I used in Phase two of this research and report the findings. I then record the final competency set that emerged following consensus being reached by the expert panel of the modified Delphi Method. I end this chapter with a summary of this study’s findings.

- **Chapter Seven**

In this chapter, I begin by comparing my final competency set to the HPCSA core competencies (HPCSA core competency document analysed in Chapter Five). I then discuss other important issues raised by the Phase one and Phase two data findings. I first discuss the overlap of knowledge, attitudes and skills evident in the two phases, then discuss ableism in medicine in general, followed by more detail using a framework by Pena-Guzman and Reynolds (2018). It views ableism in medicine as an epistemic schema divided into four mechanisms: epistemic injustice, epistemic overconfidence, epistemic erasure and epistemic derailing. I will unpack these four mechanisms with reference to the data from both phases. My arguments focus on attitudinal competences that will lead to knowledge and skills being applied in a manner that facilitates equity in medical practice and inclusivity of persons with disability that protects dignity and restores their humanity.

- **Chapter Eight**

This chapter begins with a conclusion of the study unpacked in five sections: What this study offers is: common goals, tension and challenges; the significance of this study; how my study is different – through the use of the term persons with disability, descriptors and examples in the final competency set - and how this study contributes to decoloniality. I then discuss the implications followed by limitations of this study. I finish by suggesting options for further research and engagement and with a summary of this chapter.

1.8 In summary

In this Chapter One, I gave important contextual information about myself as the researcher and information surrounding where and why this study is positioned where it is - that being The University of Cape Town in the Western Province of South Africa. I also recorded the aims and objectives this study intends to address. This chapter provided background for this study and served as introduction to the detailed literature review which follows in the next chapter.

Chapter 2

Literature review

2.1 Overview of the chapter

This chapter focusses on an in-depth literature review guided by three main questions:

What is the problem related to this study?
How is disability being included in global undergraduate medical curricula?
Which competencies are required in disability education for medical students?

I searched Google Scholar as it has a wide range of articles from many different journals and PubMed. The search terms were: **medical profession; undergraduate medical education; 21st century medicine; health needs of persons with disability; models of disability; International Classification of Functioning; Disability and Health; disability inclusion in undergraduate medical curricula; competency generation; Global south; Persons with disability in South Africa; intersectionality; health disparities; power dynamics in healthcare and healthcare equity and equality.** I was also pointed in the direction of interesting and relevant articles by my supervisors, fellow PhD candidates and UCT librarians. I end with a brief summary of the chapter.

2.2 Literature Review

2.2.1 What is this problem related to this study?

The World Health Organisation (WHO) World Report on Disability reminds us that persons with disability constitute approximately 15% of the world's population (WHO WRD, 2011). In South Africa, the 2011 census found that persons with disability make up 7.5% of the South African population (Lehohla, 2011). Notably, Ankhan *et al.* (2019) stated that medical doctors (regardless of their specialty) will inevitably treat patients with disabilities.

The transition from the 20th century to the 21st century has brought with it the need for a shift in the focus of global health conditions from acute to chronic conditions, necessitated by a rise in the prevalence of chronic conditions. The rise was brought about by factors such as increased longevity, urbanization and unhealthy lifestyles (Whelan, 2002; Cieza *et al.* 2018). More specifically, in developed and developing countries, non-communicable, maternal, neonatal and nutritional diseases have dominated the global burden of disease for many years. The 2019 Global Burden of Disease study showed that in developing countries - such as South Africa - there is evidence of an increase from 37.8% of total disability adjusted life years (DALYS) as a result of non-communicable/chronic diseases (e.g., cerebrovascular disease and diabetes) and injuries in 1990 to 66% in 2019 (Emadi, Delavari & Bayati, 2021).

This notable increase in non-communicable/chronic diseases can give rise to greater disability prevalence. In other words, it is an undeniable reality that medical doctors need to be practicing disability inclusive medicine – i.e., medical doctors need to give disability more consideration (Cieza *et al.* 2018).

In order to therefore provide persons with disability with healthcare equal to the healthcare which is afforded to the rest of society (able-bodied people), medical doctors need to be equipped with sufficient knowledge and skills related to disability practice. However, the training of medical doctors has stayed aligned with the 20th century healthcare focus on acute conditions. As a result, medical doctors are well versed in the traditional models of acute care, but that will not equip them with the knowledge and skills needed to treat and manage the current pressing world health problem of chronic conditions (Frenk *et al.* 2010) and consequential increase in disability prevalence (AIHW, 2018).

The increased disability prevalence requires that medical students - society's future medical doctors - are taught about disability and to understand disability as being wider than just the health conditions that lead to impairments (Goodley, 2014).

- **The models of disability in relation to medical education**

A deeper understanding of disability requires knowledge of the two well-known models of disability and what they can individually and collectively contribute to medical education (Jenson, 2018). The medical model of disability has been a predominant framework in medical education for decades. It has underpinned most medical doctors' clinical practice and needs to be reconceptualized (Ohajunwa *et al.* 2014). The focus is very much on a person's impairment/health condition and on the curative or treatment options that medical interventions can offer which results in medicalisation of disability (Jenson, 2018; Franklin, Brady & Bradley, 2020). When no further medical interventions for treatment or cure are feasible, medical professionals tend to withdraw and the person with a disability is left either on their own or is sometimes referred by the treating doctor to a therapist to work out the way forward in life.

The medical model also affords the medical doctor (often, an able-bodied person) the label and power of being the expert, with assumed superior knowledge and understanding of disability than the person with a disability (Pena-Guzman & Reynolds, 2018). A result is the expert doctor alone makes decisions in the doctor/patient relationship.

Cieza *et al.* (2018) argue that medical doctors need to look beyond the medicalisation of disability - and the assumption that, as doctors, they know best – and should be more cognisant and appreciative of the lived experience of persons with disability. The social model of disability can aid this broader perspective (Swartz, 2017). The United Nations Convention on the Rights of Persons with disability (UNCRPD) provides a definition of disability which focusses more on the social model of disability and has been accepted and also critiqued by many globally. The UNCRPD states that, “Persons with disability include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UNCRPD, 2006).

In other words, the social model of disability believes that disability occurs when there is an interaction between a person’s impairment and the social environment which affects the functioning of that person in that social domain/environment.

The social domain of the world that we live in, is geared almost entirely towards the valuing of able-bodiedness. This ableist view of the world’s social domain places numerous barriers (e.g., architectural and attitudinal) in the lives of persons with disability, which contribute to disablement (Loja *et al.* 2013).

An example – from my professional experience - which clearly illustrates this interaction between a person’s impairment and the social environment, is when a patient with behavioural or psychosocial disabilities seeks health care, they are often immediately labelled as difficult, perhaps even aggressive. This labelling is often due to a lack of understanding and awareness of behavioural and psychosocial disabilities. Franklin, Brady and Bradley (2020) argue that labelling of any kind but especially when it’s founded in ignorant assumptions can be profoundly limiting with respect to healthcare. This type of limiting behaviour can result in healthcare being aimed at treating the label (e.g., aggressive) rather than the individual, a quintessential feature of the medical model of disability. This deindividualized treatment could ultimately lead to these patients receiving substandard or in a worst-case scenario, no healthcare (Franklin, Brady & Bradley, 2020).

The social model of disability suggests that society contributes to disabling an individual. For example, if a medical clinic has only stairs and no wheelchair friendly ramps, a person with a mobility impairment will probably be unable to access the building. People with mobility impairments are therefore disabled by the building's inaccessibility.

This is just one example, focusing on physical inaccessibility. Earlier on an example was given which described how people with behavioural and mental disabilities might struggle with health care accessibility.

Individuals with intellectual impairments, visual impairments or hearing impairments often experience lack of access to information and communication methods. The social model of disability focuses on addressing the environmental barriers to participation for a person with a disability in their unique context. It takes into consideration their needs in order for them to live as full a life as they can.

- **A helpful tool**

The International Classification of Functioning, Disability and Health (ICF) has provided a categorization of the environmental factors that can greatly (positively or negatively) influence the lives of persons with disability. These environmental factors include products and technology, the natural environment, support and relationships, attitudes, services, systems and policies, and will be discussed in more detail in Chapter Three.

The social model implies a holistic view and re-orients the focus away from asking "what is wrong with the person with the disability, and can medical interventions help?" to "what are the needs of the person with a disability in their everyday environments?". The narrow focus of the medical model is very limiting to everyone (general society and persons with disability) because without addressing the second question, we run the risk of relegating persons with disability to the side-lines of society (Albert, 2004; Cieza *et al.* 2018).

- **Which model of disability is better?**

Perhaps one of the biggest benefits to the medical model’s focus is the fact there is no avoidance of dealing with the impairment which is an important part of the life of a person with a disability. Avoidance of dealing with the impairment is one of the disadvantages of the social model of disability (Twardowski, 2019).

Medical care will always be needed but the values, beliefs and the approach of medical doctors need to change. The threat posed by an isolated view of either model (medical or social), is that we will end up significantly limiting the lives of persons with disability.

According to Shakespeare (2006) placing all the focus and emphasis on the social model of disability is as disabling to persons with disability as a focus on only the medical model. Impairments resulting in disabilities do arise from certain medical pathologies or dysfunctions in human physiology; a fundamentalist social model neglects the necessity of treating the impairment.

What should happen is that as a society, we need to shift the focus of power from the medical profession back to persons with disability. It is necessary that persons with disability have their needs related to their health condition or impairment addressed. At the same time their need to be able to participate and be included in social life of their families and communities must also be addressed.

If we are to create a world which is more inclusive of disability, we need to move away from the view that there is, to some, a distinct dichotomy between the medical and social models of disability. We need to ensure instead the harmonious existence of both models in society (Shakespeare, 2006; Shandra, 2018).

As stated above, what needs to change is not the actual medical care - the treatment and management of the impairment. Rather it is how (the values, beliefs and approach) such medical care is being delivered by medical doctors, that is being challenged by the social model and needs to change.

A potential step towards achieving the goal of the harmonious existence of both the medical and social models of disability, is to ensure that the two models are incorporated into medical education in such a way that they coexist in collaborative harmony (Jenson, 2018).

- **How to achieve this?**

The emergence of other models such as the Critical Social model (Kruse & Oswal, 2018) and the African/Ubuntu model (Mugumbate, 2020) pose further considerations for medical education change which will be elaborated on in Chapter Three.

Briefly, there needs to be a review and transformation of current medical curricula followed by the incorporation of disability competencies. Dambal *et al.* (2021) describe these as competencies that will equip medical doctors with the knowledge, attitudes and skills that will enable them to provide quality healthcare to persons with disability in a holistic way.

It is therefore vital that medical doctors are educated to understand the importance of a holistic approach to disability (i.e., addressing needs related to the impairment and removing societal barriers, especially shifting stereotypes and biases about disability).

- **All health needs of persons with disability**

Thus far, the focus of discussion has been the necessity of reconceptualising the relationship between the medical and social models of disability and their integration into medical education in ways that address the power imbalance between the two models, as the medical model continues to predominate. The reconceptualization needs to include the fact that persons with disability cannot be classified homogenously and are distinct individual beings.

Labelling a human as only disabled is reductionist and disregards the complexities of being human, which brings forth the important issue of intersectionality, which is also rooted in equity (Abes & Wallace, 2018).

Sabatello (2018) reminds us that persons with disability identify with many other dimensions of being human over and above that of simply having a disability. Seeing disability as just a health issue (Heroux, 2017) can result in oversight of varied gender, race, socioeconomic, linguistic and geographical backgrounds (Abes & Wallace, 2018). These characteristics intersect and can create further health disparities and inequities for persons with disability (Shandra, 2018).

South Africa, characterised by significant variations in socio-economic status and diversity in cultural, linguistic and geographical backgrounds (‘a ‘Rainbow Nation’) epitomises the necessity of foregrounding the individuality and variability of persons with disability (Mkabile & Swartz, 2020).

Health disparities refer to preventable differences in the burden of disease, injury, violence, or the opportunities to achieve optimal health. In the context of persons with disability, health disparities also can arise because of a variety of factors such as poverty levels, environmental threats, inadequate access to health care, individual and behavioural factors and educational inequalities (Mkabile & Swart, 2020; Fortune, Madden & Clifton, 2021). Sabatello (2018) noted that persons with disability in America make up the largest health disparity population.

This American citation seems to belie a global issue need recognised by the UNCRPD and evident in article 25 which stresses equality in health care: that the healthcare received by persons with disability should be of the same range, standard and quality as that of the able-bodied population (UNCRPD, 2006).

The strategy of equality in health care needs to be complemented by equity in health care if fairness within health care is to be promoted. Equity in health refers to equal opportunities to access quality healthcare that meets all persons' specific health and rehabilitation needs (Eide *et al.* 2015; Cieza *et al*, 2020) – a levelling of the playing field. Health inequities are closely linked to social disadvantage and/or marginalization. They are often unfair and unnecessary differences (Orach, 2009).

There is an on-going international effort to create health equity for persons with disability. Healthcare disparities between able-bodied and disabled populations are being addressed in many countries (across Europe and Australia) by the adoption of policies aimed at correcting health inequities between these two population groups (Fortune, Madden & Clifton, 2021).

In a developing country such as South Africa with its history of racial oppression and segregation, the challenges to correcting healthcare inequities are greater due to the intersection of race, poverty and disability (Mkabile & Swartz, 2020). Grut *et al.* (2012) add to these challenges by noting that poor persons with disability in South Africa tend to have little knowledge about or ideas on the health services available to them.

Ensuring accessible health care for persons with disability could be beneficial to society in practical terms since they can become functioning members of society. For example, if persons with disability health needs are met timeously, then protracted and expensive treatment plans and hospital admissions (for the individual or the government) could be avoided and the likelihood of their joining the labour market is greater.

The 2013-2017 research brief on disability and equality in South Africa breaks down the concept of equality into formal and substantive equality (South African Human Rights Commission, 2013-2017). Formal equality promotes equal treatment for all regardless of their identities and substantive equality strives for equal outcomes for all by treating everyone differently, according to their specific needs. This idea of taking into account everyone's specific needs is more in line with how Orach (2009) notes health equity to be an ethical commitment towards ensuring social justice.

Persons with disability do however require both forms of equality to be addressed when it comes to health. However, many often avoidable barriers to health exist for persons with disability. These barriers make the attainment of health equality difficult. Eide *et al.* (2015) remind us that if we hope to address such barriers, we need to take a stance in health which emphasizes equity to reach equality.

One such barrier is the quality of care that health professionals afford persons with disability (Hashemi *et al.* 2022). The reality is that the vast majority of medical doctors receive very limited disability education (lezzoni, 2006; Campbell, 2009; Ankhan *et al.* 2019; Bowen *et al.* 2020). This was confirmed in a recent paper by Borowsky, Morinis and Garg (2021).

In a low to middle income country such as South Africa, the UNCRPD's call for equality within healthcare is met by two significant barriers that persons with disability face. Firstly, there is pervasive ignorance in society about Disability and secondly, the negative societal attitudes towards disabilities (Ohajunwa, McKenzie & Lorenzo, 2013).

The concept of ableism contributes to critically analysing these attitudes. Borowsky, Morinis and Garg (page 2, 2021) provide this definition, "Ableism values independence over interdependence, and perceives physical capability, able-bodiedness, and neurotypicality as the norm. This paradigm treats disabilities as deficits to be ideally overcome. Unfortunately, ableism can lead to significant prejudice, and its ideas have been deeply embedded in conventional understanding of disability." In the aspiration for equality, a reconceptualization of Disability is essential. However, the contextual basis for all knowledge and understanding of Disability must stem from persons with disability and not from how persons with disability deviate from "the norm" of able-bodied people (Bowleg, 2012).

Mogenson and Hu (2019) suggest that that few persons with disability are employed as healthcare personnel which may influence the healthcare experiences of persons with disability. Medical doctors therefore have limited exposure to persons with disability in roles equal to or above them, such as a colleague/peer or a manager. Hence, they have little or no experience of persons with disability as their equals or as functioning members of society. Mogenson and Hu (2019) argue that having more medical doctors with disability will help with the development of medical doctors' empathy towards persons with disability.

The typical power relationship, which stems from the traditional medical model between a doctor and any patient, places the doctor as the expert over the patient (Nimmon & Stensfor-Hayes, 2016). When combined with the lack of exposure an even bigger power differential between doctors and persons with disability may arise, which in turn could result in the latter finding the relationship with doctors very challenging. This lack of exposure may also further perpetuate any preconceived notions medical doctors have with regards to persons with disability (Pena-Guzman & Reynolds, 2018).

- **A call to action**

Bines and Lei (2011) note that up until the early 2000s, curricular inclusion of Disability in the global south was largely absent from discussions. Hence the difficulty in finding accessible literature before the year 2000. It was therefore decided to start with early literature from the global north.

1991 was used as a starting date of reference in the literature for two reasons. Firstly, an important and globally well-known organisation, the UK General Medical Council (GMC), recognised that Disability should be included in undergraduate medical studies (Hall & Hollins, 1996). Secondly, the final write up of this thesis in 2021 meant that I was able to rely on 30-years of evolution in the literature.

While the UK GMC suggested in 1991 that Disability be included in undergraduate medical school curricula, it was noted that the subject of Disability required more time being allocated (Hall & Hollins, 1996).

In 2005 The US Surgeon General's Call to Action to Improve the Health and Wellness of Persons with disability made mention of the fact there was increasing evidence that persons with disability had a health status worse than those without disabilities. Ineffectual medical education was highlighted as the main cause for this inequality (Kirschner & Curry, 2009).

It was six years later that the call to address this issue within medical education was sounded on a global scale. In 2011 the World Health Organization World Report on Disability (WRD) mandated that the education of health professionals must include Disability (WHO & World Bank, 2011).

- **More recently**

Bowen, Havercamp and Bowen (2020) note that since the first Surgeon General's report in 2005, there have been at least four other US reports emphasising the need to educate healthcare professionals about Disability.

The need to include Disability in medical education was recognised more recently in the Delhi declaration of the 15th WONCA World Rural Health Conference (2018) and by the UN flagship report (2018) to examine disability and the Sustainable Development Goals of the 2030 agenda (Singh *et al.* 2020).

In South Africa both the White Paper on the Rights of Persons with disability (DSD, 2016) as well as the Framework and Strategy for Disability and Rehabilitation Services in South Africa (DoH, 2015) stipulate that all health care providers with medical doctors being included in this term, must be trained to adequately serve persons with disability.

However, they merely state that this training should happen and do not give clear instructions as to how it should happen and who should be responsible (DSD, 2016; DoH, 2015). As a result, there seems to be a conflict between South African strategic policies and operational structures surrounding the health care services for persons with disability. Such a conflict only serves to increase the gap between policy and practice (Dayal, 2012).

In my experience learning about rehabilitation in healthcare as a medical doctor requires knowledge about Disability.

In their recent literature search, Joseph and Nishker (2020) found very few medical education curricula devoted to persons with disability. How, and even if, Disability is taught is dependent on a lecturer's personal interest and enthusiasm for the subject (Campbell, 2009; Iezzoni, 2006).

Consequently, Disability is easily overlooked by educators who are already teaching a very full curriculum. This dependence on the passion and enthusiasm of individual advocates is cited by Bowen, Havercamp and Bowen (2020) as a major barrier for disability inclusion in healthcare professional education.

Low numbers of health care professionals, especially doctors, trained in Disability presents a crisis for health care delivery services. According to Cieza *et al.* (2020), globally, 2.41 billion people, (one in three), will need rehabilitation. The main aim of rehabilitation is to improve limitations on everyday functionality caused by underlying health conditions or aging due to a variety of health conditions.

They argue that available rehabilitation services need to be strengthened. A way to assist with this strengthening – particularly in low to middle income countries (e.g., South Africa) - is to incorporate rehabilitation services into a primary care setting. This incorporation has two important implications.

Firstly, those individuals who form part of the traditional workforce in primary care settings (e.g., General Practitioners, Nurses and Community Health Workers) must be trained/educated in assessing rehabilitation needs and delivering rehabilitation interventions that address common health problems. Secondly rehabilitation practitioners (e.g., Physiotherapists and Occupational Therapists) should be included in the primary care workforce (Blose *et al.* 2021).

The Covid-19 pandemic 2020-2021 also highlighted the need for there to be greater understanding of and attention given to Disability in relation to healthcare practices. Ned *et al.* (2020) argue that persons with disability are at high risk of contracting Covid-19 due to inaccessible health systems and underlying health conditions. They claim that post-contracting the virus, persons with disability are vulnerable to the risk of severe illness and death, due to the interaction between the impairments of persons with disability and personal as well as environmental barriers that exist at multiple levels.

The resulting impact of the Covid-19 pandemic is therefore a profoundly negative one for persons with disability. This pandemic has also resulted in a particular increase in the prevalence of psychosocial disabilities (Santomauro *et al.* 2021).

2.2.2 How is disability being included in global undergraduate medical curricula?

- **A call for a new healthcare professional for the 21st century**

Medical education has not kept pace with the disruptive forces of change that began in the early 21st century and this has resulted in antiquated and fragmentary curricula (Frenk *et al.* 2010; Samarasekera *et al.* 2018). New medical discoveries are being made constantly which result in pressure being placed on the medical curriculum. Consequently, the curriculum needs to be under constant review.

Samarasekera *et al.* (2018) postulate that the lack of reform in medical education might be due to a sense of complacency amongst medical educators. This complacency is perhaps born of knowledge that 1910 medical education reforms resulted in almost doubling of the human lifespan.

This lag in 21st century medical education reform has resulted in medical school graduates being unable to adequately meet the needs of all in society due to incongruent limiting competencies. There is a world-wide move towards the development of competency-based curricula, with a focus on core competencies, which would assist graduates to meet the medical needs of all patients in this new millennium (Frenk *et al.* 2010).

Competencies could assist in closing the gap between the traditional approach to medical education - which Leung (2002) reminds us has been found lacking - and the current needs of the population for competencies that focus on what doctors should be doing in medical practice to provide healthcare that meets the needs of the population (Leung, 2002).

In other words, the focus of competencies is on the outcomes one is wanting to achieve with each competency (Leung 2002, ten Cate & Billet, 2014). Therefore, insights into what outcomes are desirable in 21st century doctors require attention being given to current population needs. This attention to current needs in order to drive the development of necessary competencies will become a facilitator when reviewing the traditional medical education approach.

Pillay and Kathard (2015) argue that curricular reform is urgently needed in South Africa. Historical links to, as well as the combined forces of imperialism, colonialism and apartheid have strongly influenced the education of healthcare professionals. The result is a practice by South African healthcare professionals which fails to address the health needs of the majority population and the most marginalised: those persons at the intersection of poverty, race, gender and disability (Pillay & Kathard, 2015).

The slowness to change undergraduate medical education will be further discussed in Chapter Three. In the specific context of Disability, similar calls to reform health professional curricula have been limited, as many healthcare professionals in 2020 still feel ill-equipped to adequately meet the health needs of persons with disability, according to Bowen, Havercamp & Bowen (2020).

The inclusion of disability into the curriculum presents an opportunity to reconceptualise an undergraduate medical curriculum that is responsive to changed economic, political and social challenges and related health conditions, as well as to the advocacy by persons with disability.

The need for a 21st century reform of medical education was well illustrated by the Corona virus pandemic of 2020, which highlighted the need for medical doctors to understand and be appreciative of the potential of a person with a disability's quality of life.

The pandemic raised an important ethical question of whose life is more important? For the purpose of this research, I will focus on the importance of able-bodied people's lives versus disabled people's lives. Doctors faced this difficult decision in this period when global health resources were stretched to their limits. This allocation of available potentially life-saving resources is an unenviable decision to have to make but in the context of this pandemic, where needs far outstripped resource availability, it was inevitable that doctors would have to make such hard decisions.

Although there is no absolutely right or wrong way of making such a decision, there is an ethical way. The ethical way involves making an educated decision based on sound knowledge and a good understanding of persons with disability' value and worth.

The unethical way is for doctors to let the widespread belief that a life with a disability is without much or any meaning or worth, and to make the decision for them. Doctors need to be well prepared for such decision-making before they have to actually make such decisions. Ensuring that medical students (our future doctors) receive adequate disability education that includes specific decision-making competencies would make a considerable difference.

- **What should a disability inclusive medical practice be?**

As mentioned in Chapter One, Kathard *et al.* (2020) describe disability inclusive healthcare practices as those which enable disability inclusion at all levels within healthcare.

Important to note here is that the engagement of students with persons with disability early on in their medical education helps to remove many stereotypes and prejudices. This kind of engagement is thought to be beneficial for when students encounter patients with disability in their medical careers (Symons, Mcguigan & Akl, 2009; Coret *et al.* 2018).

- **Current pedagogy of disability inclusion in medical curricula**

Attempts to include disability into undergraduate medical curricula are focussed on an ad hoc or elective approach.

According to Vlak *et al.* (2004) a few universities in Central and Eastern Europe (CEE) have begun adding disability and rehabilitation related courses to their undergraduate medical curricula. Three universities in Hungary (Budapest, Pecs and Debrecen) offer a few hours of rehabilitation principles, which are included into their courses in orthopaedics, paediatrics and psychiatry.

At the University of Budapest there is also a whole day seminar in rehabilitation offered to final year medical students. At the University of Szeged in Hungary two departments (neurology and psychiatry) have combined to offer a fifteen-hour elective program on disability and rehabilitation. There are two medical schools in Prague which offer a one-week long program to fourth and fifth-year medical students on disability and rehabilitation, which includes both lectures and practical sessions (Vlak *et al.* 2004).

The subject of disability and rehabilitation has also been integrated into the clinical teaching of various courses at the Vienna University Medical School. Students are also given the option to spend two weeks in the Department for Physical Medicine and Rehabilitation (Vlak *et al.* 2004).

Many, if not most of the disability courses in CEE medical schools are optional. However, in Southern Europe, Ljubljana Medical School in Slovenia has incorporated an obligatory disability education course into its curriculum for fifth year medical students. This course is run independently by the Department of Physical and Rehabilitation Medicine. It consists of fifteen hours of lectures and fifteen hours of practical sessions (Vlak *et al.* 2004).

Similarly, Zagreb University in Croatia has added a mandatory forty-five-hour course teaching disability and rehabilitation in the medical curriculum. The inclusion of this disability program was driven by a 2001/2002 reform of the undergraduate 5th year medical students' teaching of Physical and Rehabilitation Medicine (Vlak *et al.* 2004). The purpose was to better equip medical students to satisfactorily me*et al*l the health needs of persons with disability in the community. The breadth and the depth of the course content met its objectives and was well received by the students, according to Vlak *et al.* (2004). The authors suggested the course be introduced to other European countries – the focus of the article is Europe.

Turning attention to America, Sarmiento *et al.* (2016) report that at the University of Michigan Medical School, a disability curriculum for first and second-year medical students was implemented in 2013/14. Disability-focused content was included in a pre-existing two-year program called the Family-Centred Experience. Through individual and small group discussions with persons with disability and their family members, students are taught to appreciate the lived experience of persons with disability. This appreciation encourages both an empathetic and reflexive approach to their future interactions with persons with disability.

A disability curriculum has also been incorporated into the primary care clerkship at the University of South Florida School of Medicine which involves lectures, home visits as well as clinical interactions with persons with disability. It aims to assist students developing an empathic approach towards persons with disability (Sarmiento *et al.* 2016). There is no mention of any competencies underpinning this disability curriculum, but the approach is very similar to the University of Michigan Medical School as it looks to increase awareness and appreciation for the lived experience of persons with disability.

More recently Singh *et al.* (2020) noted that many medical schools across America and the University of Sydney's Health Sciences Faculty in Australia still maintain the approach of disability being optional rather than integral part of the medical curriculum.

- **Despite the ad hoc approach**

Although there seems to be a worldwide ad hoc approach to the teaching of disability and rehabilitation to medical students, the importance of including disability is at least being recognised. This increased awareness is noted in some creative endeavours happening in several universities, aimed primarily at changing the attitudes of students towards disability (Vlak *et al.* 2004).

One such creative idea suggested that students would benefit from visiting the homes of persons with disability to witness these people in their own context and to become more aware of what their capabilities are (Shakespeare, lezzoni & Groce, 2009).

In addition, Shakespeare, lezzoni and Groce (2009) noted that talks from or group discussions with persons with disability provide students with subjective insights into disability. These subjective insights combined with ‘hard science’ assists in strengthening students’ knowledge and understanding of disability (Shakespeare, lezzoni & Groce, 2009).

The focus of the teaching methods mentioned by Shakespeare, lezzoni and Groce (2009) and other authors cited in this section, is aimed at educating and making medical students think about the interaction between a person with an impairment and the environment; a re-orientation to the social dimension of disability. An example is the theoretical and practical courses on the social dimension of disability introduced in the early 2000s at Ege University’s Faculty of Medicine in Turkey (Sahin & Akyol, 2010). A forty-hour elective which is a non-compulsory module entitled “Disability and Me” is one of the practical courses. Theoretical presentations on the social dimensions of disability are delivered; and discussion is further facilitated by books and films aimed at increasing awareness of disability (Sahin, 2015).

These teaching methods are aligned with the UNCRPD’s definition of Disability – see page 38 of this chapter - which in turn is more aligned with the social model of disability. Owens’ (2015) interpretation is that Disability is a product of society and were it not for the various attitudinal and environmental barriers that society imposes (on a person with an impairment), there would be no disability. This perspective has been challenged by Sally French and Carol Thomas who are prominent UK-based, female academics with disabilities. They argue that not all the issues persons with disability face can be addressed with social solutions.

- **Another creative teaching method**

An approach which has been adopted by some Canadian Medical Schools is a pseudo-immersion method. It is aimed at increasing students' feelings of empathy towards persons with disability. Medical students are required to wear vision distorting goggles, walk with swimming flippers or use wheelchairs with the intention of giving them more insight into the lives of persons with disability (Joseph & Nishkar, 2020).

- **Locally**

In South Africa, the University of Cape Town's (UCT) Faculty of Health Sciences (FHS) offers a first-year course to all first-year health professional students, including medical, entitled 'Becoming a Health Professional'. One of the course objectives is: "Have a basic understanding of disability as an equity issue" (General overview: Becoming a Professional (PPH1001F)/ Becoming a Health Professional (PPH1002S); page 2).

Further inclusion of disability issues within the undergraduate medical curriculum at UCT FHS occurs in the second year Clinical Skills course as well as in fourth year Psychiatry (Ohajunwa, McKenzie & Lorenzo, 2013). The method of inclusion entails community interaction with persons with disability which allows a mutual 'giving' between the students and the patients. The students 'give' to the patients, but the patients 'give' back equally in letting the students experience their world (Ohajunwa, McKenzie & Lorenzo, 2013).

A compulsory Disability and Rehabilitation Programme has been incorporated into the medical undergraduate curriculum at Stellenbosch University Medical School (Sammons, 2012). It is spread across the third, fourth, fifth and sixth years of the degree via lectures, practical sessions and engagement with persons with disability. Importantly, an equal share of lectures is given by medical doctors and disability experts.

Whilst these initiatives are promising, there is still no readily available published South African literature on what doctors' practice with persons with disability currently is and what competencies they require, in order to provide them with a quality health care service.

- **What is absent?**

Despite these positive attempts to include disability in undergraduate medical curricula and change teaching methodologies, it is still unclear what competencies such programmes are trying to develop.

Competencies must be geared towards the outcome one aims to achieve. A clear framework of competencies can better guide the development of new pedagogies. Swanick (2018, page 5) suggests a very important question that medical educators should be asking themselves is “what are we educating for?” In the cases of the new teaching methods mentioned in this review, this question is a pertinent one.

2.2.3 Which competencies are required in disability education for medical students?

The published literature on this topic is extremely limited.

An American-based study documented the competencies needed by all healthcare professionals (medical doctors, nurses and allied healthcare professionals) to afford persons with disability quality health care (Havercamp *et al.* 2020). They noted this to be globally the first study of its kind.

The key objective of the study was to establish a national consensus of what knowledge would equip healthcare professionals across disciplines with the ability to deliver quality healthcare to persons with disability.

They used a consensus building technique to evaluate and refine in an iterative process a draft set of competencies. They do not specify the technique. The Alliance of Disability in Health Care Education, an interprofessional non-profit organisation of health educators and multidisciplinary healthcare professionals undertook the project. Participants included persons with disability, disability advocates, family members of persons with disability, disability and health professionals and inter-disciplinary health educators. After two iterations, consensus was reached. This study produced a final set which comprised of six competencies, 49 sub-competencies and 10 principles and values. The final set included topics such as respect, person-centered care and awareness of physical, attitudinal and communication health care barriers (Havercamp *et al.* 2020).

This literature review has revealed that to date, there is still only one published study on the specific competencies for doctors that can inform disability inclusion in medical curricula. It was undertaken in India by Singh *et al.* (2020). They focused on what doctors do (their disability practice) as a basis for generating disability specific competencies - knowledge, skill and attitudes (i.e., values, beliefs and feelings) - for medical curricula development in India.

My study will be the second which begins to address this issue systematically.

Singh *et al.* (2020) adopted a generative process using focus group discussions that included disability rights activists, doctors with disabilities and health profession educators. They worked within the Human Rights model of disability and took cognizance of the competencies defined by the US and Canadian accreditation boards (Singh *et al.* 2020).

The outcome of the multi-stakeholder deliberations was twenty-seven disability related competencies (see table 2.1) that a medical doctor should have mastery in so that they could afford persons with disability quality healthcare (Singh *et al.* 2020).

Table 2.1: Singh *et al.* (2020) Competencies: An Indian medical graduate should be able to…

1	Describe disability as per United Nations Convention on the Rights of Persons with disability while demonstrating acceptance of and respect for the differences and capacities of persons with disability as part of human diversity and humanity.
2	Understand the human rights model of disability and compare and contrast it with the medical and social models of disability.
3	Provide for and encourage genetic testing and counselling for families, where there may be suspected genetically-related disability issues.
4	Make an early diagnosis and suggest methods to prevent the common disabilities present in the community, using a lifecycle approach.
5	Identify the additional healthcare needs of a patient with disability including sexual and reproductive health needs.
6	Demonstrate awareness of the range of assistive devices for patients with disabilities and counsel them to choose the appropriate one.
7	Assess and document disability on a functional basis.
8	Interpret and critically analyze a disability certificate.
9	Discuss long-term management of the common disabilities in the community.
10	Demonstrate respect for inherent dignity and autonomy of patients with disabilities and their caregivers.
11	Demonstrate commitment to give priority to patients or caregivers with disabilities in outpatient departments of health facilities.

12	Demonstrate non-discriminatory behaviour towards patients or caregivers with disabilities and a commitment to provide them care of the same quality as to others.
13	Demonstrate integrity in treating patients with disabilities who are vulnerable to physical, mental, sexual, social and financial exploitation.
14	Promote a patient-centred, supported decision-making approach involving family members in delivering effective healthcare to patients with disabilities.
15	Build an understanding of the concept and practical application of reasonable accommodation in healthcare, both in in-patient and out-patient departments.
16	Engage healthcare staff and all members of an interprofessional team to collaborate towards multidisciplinary assessment and management of patients with disabilities to provide disability-inclusive compassionate care.
17	Advocate social inclusion by raising awareness of the human rights of persons with disability through training and the promulgation of ethical standards for public and private healthcare.
18	Demonstrate the use of verbal and non-verbal empathetic communication techniques while communicating with patients with disabilities and their caregivers in a manner acceptable to the specific disability culture.
19	Assess the capacity of a patient with a disability to give informed consent and demonstrate the ability to take informed consent from a patient with disability.
20	Explain the need for referral and the referral procedure to a patient with disability.
21	Check the understanding of the medical advice related to treatment, prognosis, follow-up, and/or referral given to patients with disabilities.
22	Provide health education to patients with disabilities, their caregivers, their families, and at the community level in a culturally appropriate manner.
23	Demonstrate awareness of the disabilities included in the Rights of Persons with disability Act, 2016 and keep abreast of updates.
24	Demonstrate an understanding of accessible healthcare settings for patients with disabilities, including universal design to ensure physical accessibility and accessible formats of information and communication.
25	Demonstrate familiarity with government-run programs, schemes, legislation and legal services available for persons with disability, and keep abreast of updates.
26	Demonstrate awareness of rights-based and disabled people's organizations in the community.
27	Encourage research on disabling conditions, their prevalence, and their management, so as to add to the body of knowledge on the issue.

- **What about the resistance?**

Resistance to curricula reform is frequent among academics given their many challenges and already heavy workloads (Cerimagic & Hasan, 2018) and can be fuelled by perceptions of existing overloaded curricula (Havercamp *et al.* 2020). Nevertheless, exclusion, discrimination, health and disability inequities in South Africa cannot remain unchallenged. Curricular change is necessary for removing these practices.

Despite the absence of available evidence in South Africa, there seems to be an increasing awareness that the goal of higher education institutions should not only be to provide access to students with disabilities. They should also aim to improve and extend the knowledge of disability in all academic disciplines, as well as graduate students equipped with the skills to deal with and understand disability issues in their professional lives (Ohajunwa, McKenzie & Lorenzo, 2015). Furthermore, disability inclusion appears to be dependent on lecturer(s) interest rather than a systematic response to policy in the South African context (Ohajunwa, McKenzie & Lorenzo, 2013).

2.3 In summary

This literature review indicates that medical practice is located within an exclusionary health system unable to treat persons with disability equitably. The situation is exacerbated by the very limited engagement with Disability in undergraduate medical curricula, internationally and in South Africa. Having established this significant gap in the field and confirmed the necessity of my study, the next chapter will discuss the key conceptual frameworks that underpin my study.

Chapter Three

Conceptual frameworks

3.1 Overview of the chapter

This chapter begins by discussing the important concepts and theories that were used to frame the study. The process of selecting and refining the conceptual framework has been continuous since commencement in 2016 of my Master's degree followed by an upgrade to Doctoral studies in 2019. Additions and refinements were aided by further reflections throughout the study. The chapter ends with a brief summary.

3.2 Conceptual Frameworks

3.2.1 The International Classification of Functioning, Disability and Health (ICF)

In 1980, the World Health Organization (WHO) published The International Classification of Impairments, Disabilities and Handicaps (ICIDH) (Rosenbaum & Stewart, 2004). The classification was created to guide health professionals in looking beyond just the disease and disorder to their possible impacts on individuals, in the sense of impairments, disability and handicaps.

Although the intention of the ICIDH was rooted in the desire to broaden the scope of medical practice beyond the traditional biomedical model, it was not adopted as widely as WHO had hoped. In fact, it received criticism for still being too biomedical in its approach (Rosenbaum & Stewart, 2004).

Schwartz and Wiggins (1985) expressed the need to combine both the traditional biomedical approach and the newer biopsychosocial approach into the practice of medicine since either approach, if used in isolation, does not sufficiently cover all the aspects of human health and disease (Schwartz & Wiggins, 1985).

The lack of engagement with the ICIDH by health professionals and increasing calls for the reformation of medical practice led to a review of the ICIDH by the WHO in the 1990s. The outcome was that nine years later The International Classification of Functioning, Disability and Health (ICF), was published (Rosenbaum & Stewart, 2004).

The ICF focusses on the biopsychosocial approach to healthcare practice in that it encourages health professionals to recognize the many components of health, rather than focus on the consequences of disease - i.e., the ICF proposes a classification aimed at synthesising the individual impairment focused medical, social and other non-impairment focused models (Reindal, 2010).

Rosenbaum and Stewart (2004) observed that the ICF does not exclude what the biomedical approach can contribute to the practice of medicine. Mitra and Shakespeare (2019) elaborate that the ICF looks at the interaction between an individual's health condition and environmental and contextual factors for a holistic understanding of Disability.

According to Jefferson (2020) the ICF also aims to address the power relationships in health care through the development of a shared language to improve communication between healthcare workers, researchers, policymakers and all of society, abled and disabled. However, Owens (2015) argues that implementation of the ICF is still limited in that the focus remains on impairment and the individual due to insufficient attention being given to power dynamics. A result is that services and systems remain exclusionary.

In a medical context, the ICF is a universal classification which means it can be applied by doctors not only to their medical practice with persons with disability but also to their medical practice with society at large (WHO 2001; Rosenbaum & Stewart, 2004). The ICF aims to promote holistic medical practice.

It is important to remember that while other frameworks and classifications which employ a similar interactional stance on Disability do exist, the ICF is most widely accepted (Mitra & Shakespeare, 2019). However, it has also been the focus of criticism. Mitra and Shakespeare (2019) argue that the ICF has not kept pace with our developing understanding of Disability, on the grounds that health conditions appear to manifest in isolation which is not consonant with our expanded knowledge and understanding of socioeconomic determinants of health conditions.

Furthermore, our understanding of wellbeing and quality of life has grown, whereas the focus of the ICF on activities and participation appears limiting. Owens (2015) argues it is still too focused on the individual/medical model. Mitra and Shakespeare (2019) posit that the ICF needs to be more reflective of the totality of the lived experience of people with health conditions.

Moreover, when the ICF model is put into practice as a classification, a policy or an intervention, it offers a normative metric and is therefore not neutral, according to Mitra and Shakespeare (2019). Reindal (2010) argues the ICF model uses a social deviance norm, which can be overcome if it changes how, it measures the effects of health conditions on lives, according to Mitra and Shakespeare (2019). The depth and breadth of the effect needs to be taken into account.

3.2.1.1 Why the ICF?

The ICF framework and classification is appropriate for this study as it is a globally recognised and accepted way of understanding and viewing Disability. In addition, it aligns with one of the main arguments of this study, that a better balance between the medical model and the social model of disability is necessary.

An extension of this above-mentioned main argument (I allude to this in Chapter Two, page 39) is necessary as it will be shown that an investigation of the economic, political and power dimensions are necessary for deepening our understanding of and thinking about Disability. It is not only the increased presence of the social model of disability that will assist with the facilitation of disability inclusion in medical education. I will elaborate on this paragraph in sections 3.2.4 and 3.2.5.

3.2.1.2 How exactly does the ICF contribute to curriculum?

Moran *et al.* (2020) acknowledge the current overload of health professional curricula (the medical curriculum included) but argue the value of incorporating the ICF. It could assist in ameliorating a dependence on uni-professional teaching modules, increasing interprofessional learning opportunities and the development of a common language across healthcare professions. The ability to share communication effectively is critical for interprofessional education and collaboration.

They further suggest it would facilitate a shift from an exclusive focus on the medical condition and impairment diagnosis and treatment to an assessment and treatment/management plan that includes maximising the person with a disability's participation in society (Moran *et al.* 2020).

3.2.2 Establishing a conceptual basis for curriculum change

This study builds on previous UCT studies: Ohajunwa (2012), Ohajunwa, McKenzie and Lorenzo (2013), McKinney (2016) and Nwanze (2016). It analyses how Disability should be included in the undergraduate medical curriculum. It aims to influence change in the existing curriculum. The grounds for doing so are that regular reviews are required in order for curricular to keep abreast of advances in knowledge, according to Harris *et al.* (2010).

In furtherance of the argument for undergraduate medical curriculum change, attention is drawn to the distinction made by the World Federation of Medical Education (WFME), between mandatory and non-mandatory basic global standards (WFME, 2015). The former refers to standards any medical school must meet, and the latter, to those standards that will further the quality development of the individual medical school that strives to meet those standards. These are encapsulated in Chapter Seven relating to "Programme Evaluation", which has four sub-themes:

7.1. Mechanisms for programme monitoring and evaluation

7.2. Teacher and student feedback

7.3. Performance of students and graduates

7.4. Involvement of stakeholders

Each subtheme has a number of basic standards to be met by all medical schools, and a number of quality development standards that should be met by a medical school. The framework informs how medical curricula should be reviewed and is noted for purposes of this study.

In theory, a curriculum review should promote curriculum change as strengths and weaknesses can be identified, which then presents an opportunity for change.

As I mentioned in the literature review, there seems to be global resistance from medical educators to change in the current medical curriculum. Cerimagic and Hasan (2018) argue that the major reason for resistance is the fact that implementing successful curriculum change is not an easy or straightforward process. Successful curriculum change requires considerable planning and preparation. Structural changes are necessary to ensure the delivery of the new curriculum and assessment methods. Equally important is the creation of a culture where the need for change is accepted and understood (Cerimagic & Hasan, 2018).

It is hoped that this study will add to the creation of that culture. The WFME Basic Medical Education Global Standards relating to Programme Evaluation provide a basis for reviewing the curriculum while subthemes 7.3 (performance of students and graduates) and 7.4 (involvement of stakeholders) inform this study that seeks to generate Disability competencies for inclusion in the undergraduate medical curriculum. The adoption of these two subthemes is amply supported in literature discussing medical graduates' under-preparedness for meeting the healthcare needs of persons with disability (see Chapter Two).

As per the subtheme relating to stakeholder participation, this study will engage with persons with disability for their participation in the generation of disability specific competencies to be included in the undergraduate medical curriculum.

It was mentioned that there is only one published study by Singh *et al.* (2020) in India, which describes competencies necessary for a doctor to equitably treat persons with disability. It is vital we obtain this information, about what is needed to enable this equitable treatment before it can be decided what should be included about Disability in an undergraduate medical curriculum. The key concepts and process guiding the study are described below.

3.2.3 What does curriculum mean to this study?

The HPCSA definition of curriculum (see Glossary of terms) was used in this study.

There are two parts to this study. Firstly, the need to generate knowledge about what doctors' medical practice with persons with disability should be. Secondly, based on findings, to identify the competencies - for inclusion in the undergraduate medical curriculum - required to fulfil this practice. These two phases constitute a generative process that will be addressed in distinct sections: Part A will cover curriculum development and Part B will cover curriculum content.

3.2.3.1 Part A: The curriculum development process – goal setting for generating a curriculum.

The end goal of the study is to generate competencies to inform and influence a curriculum which will empower medical doctors with the knowledge, attitudes and skills that will enable them to have a disability inclusive medical practice. I have chosen to focus on the undergraduate medical curriculum and the inclusion of competencies - knowledge, skills, attitudes - to assist with attainment of this goal. This choice of focus stems from my professional and personal experience of being a medical doctor with a disability and noting the importance of medical students graduating from their undergraduate medical degrees, being equipped with good knowledge, attitudes and skills about disability.

Symon, McGuigan and Akl's (2009) American study on the development and implementation of a curriculum to teach medical students how to care for persons with disability provides a useful framework. They set three goals which are adopted for use in this study: 1) building the required knowledge; 2) instilling the appropriate attitudes; and 3) fostering the needed skills to care for persons with disability.

While their study was not aimed at competencies specifically, the three goals – which are geared towards a specific outcome - are of particular importance to bear in mind throughout this study's competency-based curriculum generative process. The teaching of knowledge, skills and attitudes is central to any competency-based curriculum. Their study addresses the 'how' component of this research question. In other words, this framework is very useful for the generation of competencies.

The next section of this chapter focuses on the process of identifying competencies, which varies across studies but usually follows a sequential process, according to Calhoun *et al.* (2002). They describe the following sequence:

1. Purpose or goal identification and clarification: This process entails the identification of current expectations, needs and gaps in the area. In this study the identified gap is that little is documented about medical doctors' practice specifically with persons with disability. Given this orientation a stakeholder description of what a doctor's practice entails or should entail is necessary before competencies can be determined. The process requires multiple perspectives of stakeholders, particularly persons with disability, who are closely involved in what doctors do.

2. Potential identification of a pool of competencies through literature review, document analysis and benchmarking with other professions.

3. Stakeholder analysis and expert input by practitioners, academics who are closely aligned with the curriculum process.

4. Formulation of a draft set of competencies through expert panel and focus groups.

The process as outlined serves only as a guide given the typically creative and generative nature of curriculum development. Steps 1-4 in the sequence were tailored to the specific study interest. Additionally, step 2 relating to identification of a pool of competencies, provided a useful framework for Phase one of this study.

This study focused on what relevant stakeholders believe constitutes a medical doctor competent enough to approach the clinical engagement of persons with disability, no different to those persons without disability: what knowledge, skills and attitudes (i.e., values, beliefs and feelings), should they possess? The development of these competencies into a framework for inclusion in undergraduate medical curriculum will help medical education to produce graduates equipped to meet the healthcare needs of all their patients equitably.

3.2.3.2 Part B: Competency based medical education (CBME)

World-wide, the call for CBME has been sounding for many decades but it has only recently begun receiving focussed attention and gaining dominance in some higher education health care programmes (Schilling & Koetting, 2010; Frank *et al.* 2010). According to Ross, Hauer and van Melle (2018), CBME has been adopted within medical education across Canada, the United States as well as in certain parts of Europe and the UK.

Frank *et al.* (2010) argue that traditional medical education which is organised by knowledge outcomes, is excessively focussed on the instructional process at the expense of the final product. CBME a form of Outcomes Based Education (OBE) allows all curricula decisions to be based on the desired outcomes (Frank *et al.* 2010). The paradigm shift to CBME has occurred due to external factors, such as evolving health care systems, patient care needs and major advances in medical knowledge and technology (Schilling & Koetting, 2010; Dagnone, Bandiera & Harris, 2021). Moreover, an increase in preventable medical errors is seen as proof that the traditional medical educational model is failing to equip medical graduates with the ability to navigate the complex new world of medical practice (Ross, Hauer & van Melle, 2018).

The focal question of CBME is *"what can graduates do?"* CBME's focus is on learner outcomes, i.e., the demonstration of competence in the work environment, whereas the traditional medical education model emphasises the attainment of medical knowledge and focuses on what and how much the graduate knows. This focus on learner outcomes provides the crucial connection between CBME and societal health needs. It implies that CBME is well suited to the training of 21st century medical doctors to enable them to meet evolving societal needs (Ross, Hauer & van Melle, 2018).

An exclusive focus on what graduates can do is potentially limiting in the development of the medical student into a medical doctor. Competencies which address professional identity formation of medical students into medical practitioners are essential to avoid this limitation (Cruess *et al.* 2014). These competencies encourage a medical student to start thinking, behaving and feeling like a doctor in order to provide quality healthcare.

The point above regarding the professional identity formation of a medical doctor is an important reminder that attitudes, thoughts, beliefs and feelings, are shaped through the education process and most often through role modelling.

3.2.3.2.1 How to plan a CBME curriculum

There is still much debate and uncertainty about how planning a CBME curriculum should be approached (Frank *et al.* 2010). Frank *et al.* (2010) set out a six-step approach to the generation of healthcare competencies:

1. Identify the abilities needed of graduates.

2. Explicitly define the required competencies and their components.

3. Define milestones along a development path for the competencies.

4. Select educational activities, experiences and instructional methods.

5. Select assessment tools to measure progress along the milestones.

6. Design an outcomes evaluation of the program.

However, the limitation of this framework is it assumes one has a well-defined outcome. In this instance the assumption is that we know what a medical doctor’s practice is or should be with persons with disability, yet we do not know enough about such a medical practice. As part of the curriculum generative process this research will start with stakeholders to determine what the current Disability medical practice is and what it should be.

This information will then be used to facilitate the generation of competencies relating to knowledge, skills and attitudes. This study adopted steps 1 and 2 of the Frank *et al.* (2010) 6-step approach in order to identify the competencies needed by a medical doctor in their Disability practice. These in turn will contribute to the development of a Disability inclusive curriculum for undergraduate medical students.

3.2.3.2.2 The criticism surrounding CBME

CBME might be embraced by many globally, but it has also garnered plenty of criticism. The CBME framework involves a dramatic transformation to the way that medical education has traditionally been approached which poses challenges to many (Ross, Hauer & van Melle, 2018).

A major criticism is that CBME is too reductionist. Critics feel that the practice of being a good doctor is broken down into individual checklists which disregard the whole experience of practice (Ross, Hauer & van Melle, 2018). Touchie and ten Cate (2016) suggest that this criticism claims that CBME results in the desire to train and assess only the component parts of each competency whilst ignoring the holistic nature of the whole doctor.

The criticism has validity, and the issue of possible reductionism must be closely monitored during the implementation of CBME (Ross, Hauer & van Melle, 2018). Others have questioned the word ‘competence’, saying that educators should be training students for excellence in their future medical practice and not just competence. CBME is criticised by some for having lowered standards.

Touchie and ten Cate (2016) make an important point that none of the critics of CBME offer an alternative educational approach. It is evident though from the literature that medical education needs to undergo a transformation and CBME is well positioned to assist with this (Ross, Hauer & van Melle, 2018).

South Africa has designed an approach to CBME which seeks to ameliorate the criticism about CBME being too reductionist. South Africa uses an ‘applied competence” approach which “takes into account not only skills but knowledge, thinking, reasoning, justifying, prioritising and adapting as part of the learning process” (ASSAf, 2018, p 135).

The following three points stated by ASSAf (2018, page 135-136) provide more details on what applied competence includes:

A	Practical competence: demonstrated ability to distinguish between a range of possibilities for action or intervention, and to make decisions about such actions and to perform the action or intervention.
B	Foundational competence: demonstrated understanding of the knowledge and thinking that informs action or intervention.
C	Reflexive competence: demonstrated ability to integrate actions and decision-making with understanding; it includes justification for actions and decisions, and adaptability to changed circumstances.

Holmboe *et al.* (2017) state clearly that the transformation of medical education is not about choosing one new educational theory to replace the traditional medical education approach. Rather we should be moving forward blending multiple educational theories (CBME included), maintaining flexibility, and using constant review processes to best help educators prepare students for 21st century medical practice.

The above argument is similar to the point I made in Chapter Two about the best Disability model. There is no one model through which medical doctors should view disability just like there is not one perfect approach that must be used in medical education transformation. In both instances it is not the existence of the medical model of disability or the traditional medical educational approach which is being challenged. It is the seemingly rigid and inflexible dominance of this traditional model and traditional educational approach that is under scrutiny.

Despite international and national shifts towards embracing CBME, there is no readily available evidence of the notion of competencies focused on the health of persons with disability being formally included as a core competency anywhere in the world. Joseph and Nishkar (2020) noted this lack of disability related competencies in Canada; and a similar lack was found in the US.

This recorded absence of disability specific competencies highlights the need for my study, where the focus is to generate specific competencies that will enable disability inclusive practice for formal inclusion in the undergraduate medical curriculum.

Joseph and Nishkar (2020) stress the fact that any disability competencies for undergraduate medical education., should be designed and taught by persons with disability – their assertion is justified by Iezzoni and Long-Bellil (2012). In keeping with the scope of this research (design stage), I made sure to adhere to the above point. I included persons with disability in both phases of my research.

3.2.4 Critical Disability Studies

I viewed this study through the lens of Critical Disability Studies. Furthermore, I chose to use it as a theoretical framework rather than a set subject. Minich (2016, page 3) defined Critical Disability Studies as follows: “it involves scrutinising not bodily or mind impairments but the social norms that define particular attributes as impairments, as well as the social conditions which stigmatise attributes in particular populations.”

I am mindful that Minich (2016) is defining Critical Disability Studies with a Global north mindset (she is based in America). The Centre for Disability Studies at Stellenbosch University in South Africa would argue that Critical Disability Studies focuses on the power relations between abled and disabled people that influence policy processes and systems. I use elements from both definitions in my study.

Despite these different definitions, the principle of Minich’s (2016) argument resonated with me as it allows the extension of the principles that underpin Disability Studies into contexts which are not immediately identifiable with Disability. Examples of such contexts are domestic violence, race and gender.

Taking this stance of Critical Disability Studies encourages the subject to maintain the focus of its origin in Social Justice work (Minich, 2016). Theorising Disability Studies as attuned to the systemic devaluation and often subsequent disablement of non -normative bodies and minds (Kim, 2017) helps us remember the intersectional nature of Disability.

Minich (2016) proposes embracing her stance of critical disability studies as a pedagogical approach, a mode of instruction, as this should encourage a transformation of the world view of students (Schalk, 2017). This idea is affirmed by Kim (2017) who also argues that Critical Disability Studies as a theoretical framework, should additionally be embraced as a mode of instruction.

I agree wholeheartedly with Schalk (2017) that Critical Disability Studies is not only aimed at increasing students' knowledge about persons with disability. Critical Disability Studies also intends to shift the way that the students are in their daily lives, their perceptions and their interpretation of the world around them.

The use of a Critical Disability Studies framework as a teaching approach is consonant with this study's intention. The process of generating competencies is aimed at informing and influencing change of the undergraduate medical curriculum. I hope to produce competencies which not only equip students with sound knowledge about persons with disability but also encourages students to reflect, interrogate and challenge their own thoughts and perceptions, as well as those of the world in which they live with particular emphasis on thoughts and perceptions relating to power and privilege.

The Critical Social Theory of Disability is closely related to Critical Disability Studies. It places the experience of Disability in social context with the intent of promoting transformative change for the historically marginalized and disadvantaged disabled community (Meekosha, Shuttleworth & Soldatic, 2013).

In Chapter Two and in the beginning of this chapter, I referred to the social model of disability. According to Berghs *et al.* (2016), the difference between it and Critical Disability Studies model of disability is unclear.

My understanding is that the social model of disability looks entirely to socio-political causes for disability and drawing on Berghs *et al* (2016) elaboration of Critical Disability Studies model, the latter seeks to question the duality of impairment and disability and also looks to understand disability from sociocultural and sociolinguistic perspectives. Lorenzo (2022) reminds us that an important additional feature of the Critical Disability Studies view/model, is the fact that it can also provide a chance for the interrogation, reflection and challenge of power and privilege as they relate to disability inclusion – this feature is in line with how The Centre for Disability Studies at Stellenbosch University in South Africa views Critical Disability Studies (see the beginning of 3.2.4).

Sadiki *et al.* (2022) add another important feature to what Critical Disability Studies does. Critical Disability Studies has the ability to create a space for knowledge reciprocity with the intention of enhancing disability inclusion (Sadiki *et al.* 2022). I intend to emphasise this idea of knowledge sharing in my study's competencies.

The ideas of contextualizing the experience of Disability, knowledge reciprocity and exploring power relations link well with another important lens I used for this study which was the decoloniality of both disability and medicine.

3.2.5 A decoloniality lens

The majority of persons with disability live in the global south (southern hemisphere countries) but despite this the attention and focus of disability studies is in the global north (northern hemisphere countries) (Grech, 2011). Literature about Disability seems to come mainly from northern countries (such as Europe and USA) and has resulted in tendencies to universalise and totalise such writings (Meekosha, 2010).

The major question that arises from this dominance is: do persons with disability in southern countries (such as Africa and South America) share the same issues and ideas as persons with disability in northern countries? (Meekosha, 2010)

Grech and Soldatic (2014) suggest that quite often the theory of disability is founded within theories of knowledge of the global north and is all too quickly passed down to the global south with very little thought given to cultures, context or histories.

Equally prevalent is the fact these global north grounded disability theories hardly ever take into account the possibility that voices, perspectives and theories from the global south might be developing as counter discourse (Grech & Soldatic, 2014).

Global south countries are countries which have been conquered or controlled by northern powers, especially European countries such as England, France and Spain as well as the USA. This conquering and controlling is often done through invasion and war, which leaves behind poverty, dependence and disabled and upset people (Meekosha, 2010).

Meekosha (2010) suggests that disabled people of southern countries do and will have very different ideas and issues as compared to those in northern countries.

This dominance driven by northern countries may result in an unequal view of disability, a 'one size fits all' view. This study takes place in South Africa in the global south and looks to add to the correction of this 'one size fits all' stance on disability – i.e., this study's competencies intend to emphasise the individuality of persons with disability.

Decolonisation assists transformation and vice versa. At UCT, South Africa, the location of this study, issues of decolonisation and transformation at higher education institutions are becoming more and more vocal with the recent #RhodesMustFall and #FeesMustFall protests in 2015-2018. Both issues argue for a need for change and a need to challenge existing hegemonies; and signal that issues of previously marginalised people need to be incorporated in curriculum processes.

The above-mentioned #RhodesMustFall and #FeesMustFall protests in 2015-2018, introduces the other focus of this decoloniality lens which is the decolonisation of medicine.

Globally, medicine – education and practice - is still rooted in the colonial worldview (Eichbaum *et al.* 2021). In my own undergraduate education, we followed a dominantly Eurocentric curriculum. Many conditions, diseases and other health issues manifest in the same way whether you are in the global north or south but there many that are specific to the contexts of individual global south countries. For example, in South Africa there is a much higher TB rate and a multitude of unique manifestations of it compared to Europe and the UK. This example highlights the different global health knowledge needs in countries in post-colonial times.

The core principles of the medical profession include the prioritisation of patient welfare, promotion of patient autonomy and the promotion of social justice (Goddard & Patel, 2021). If South Africa in the global south remains largely dependent on a Eurocentric curriculum to train its medical doctors, it will struggle to enact these core principles for a patient population which has many differences in healthcare needs and issues – i.e., differences in race, gender, disability, class, religion and sexuality - compared to a global north patient population (Eichman *et al.* 2021).

In my opinion the decoloniality of medicine and disability are linked rather closely through the various models which are used to understand disability.

The medical model's view of disability can be traced back to the colonial civilising mission which framed disability as pathology/disease and weakness/vulnerability - i.e., disability was seen as something negative, and a disabled person seen as an inferior being (Grech, 2015). This view resulted in a desire by many western medical practitioners to remedy or cure persons with disability. This is noted as the point that gave western medical doctors unyielding power over persons with disability (Grech, 2015). Proposing ways to correct this major power imbalance is a main objective of this study's final competency set.

Grech (2015) explains that in pre-colonial times, disability was understood from the individual experiential context (culturally, spiritually) of the individual person with an impairment. This understanding of disability is more aligned with the contemporary holistic social model of disability. The social model of disability seeks to prioritise the social, political, economic and environmental factors that create the experience of disability (Shakespeare, 2006). The inclusion of this model to balance out the dominance of the medical model is being called for in global medical education (Joseph & Nishkar, 2020).

Unlike the colonial medical model which was imposed on the global south by the global north, the social model must look at the societal context of where it is being applied. In order for this to happen, Eichman *et al.* (2021) argue previously colonised societies like South Africa need to decolonialise beyond just the physical removal of colonial powers and reclaim South Africa's autonomy or Afrocentricity. To assist with a better understanding of the word Afrocentricity, according to Omar (2020, page 2), Afrocentricity was defined by Molefe Kete Asante "as a frame of reference wherein phenomena are viewed from the perspective of the African person rooted in the cultural image and interest of African people."

In keeping with the sentiments of the above paragraph, the competencies that I aim to generate in this study will, where appropriate, be cognisant of the South African context in which this study is situated. By making the competencies contextually relevant, I intend to increase awareness around the issue of decolonising medical education.

Dirth and Adams (2019) note a key decolonial strategy with respect to disability involves "relocating pathology from inside individuals to the cultural and ecological context" (page 2, table 1). This strategy links well with the call of medical education to redress the dominance of the medical model of disability in their curricula (Boxall, 2018).

It is necessary to point out that these are but two of the models used to understand Disability. There are quite a few other models such as the Human Rights model (Berghs *et al.* 2019) and the Political/relational model (Brilmyer, 2018). There is also the contextually relevant African/Ubuntu model of disability (Bergh, 2017). The latter embraces the South African ideology of Ubuntu and emphasises the need to understand and appreciate the essential shared humanity of Persons with and without disabilities (Bergh, 2017). I am aware that I have discussed the medical and social models in greater detail as they are the two most widely applied in medical education. However, with my use of a Critical Disability Studies lens and this decoloniality lens, I aim to incorporate elements in my competencies to assist in expansion of medical doctors' knowledge and understanding of Disability and persons with disability.

3.3 In summary

The key concepts which underpin this study are:

1. ICF
2. Establishing a conceptual basis for curriculum change.
3. Curriculum development process
4. CBME
5. Critical Disability Studies
6. Decolonisation of disability and medicine

In this chapter I detailed the conceptual frameworks that underpin this study. This chapter – like Chapter Two - strengthened the grounding of this study through engaging international and national literature. This grounding provides a platform from which to begin an in-depth look into the methodological aspects and ethical considerations of this study that follows in the next chapter.

Chapter Four

Methodology and Ethical Considerations

4.1 Overview of the chapter

I begin this chapter by detailing my paradigmatic position, followed by an explanation of how I view the generation of knowledge in this study and my paradigmatic assumption for this study. This explanation of my paradigm through which I viewed this study is followed by an explanation and a discussion regarding the methodological aspects of this study - this includes research design, identification, and recruitment of research participants for both phases of this study, data collection methods and procedures and finally the analytical procedures followed in both phases. I then record the ethical considerations for this study, as well as the ways that I ensured the trustworthiness and rigor of this study and data security. I end this chapter with a section on conflicts of interest and a summary of this chapter.

4.2 My paradigmatic positioning

4.2.1 Introduction

Kivunja and Kuyini (2017) explain that a paradigm is a researcher's unique worldview - made up of a set of basic assumptions (i.e., beliefs and ideas) and norms that guide research actions.

My paradigm is made up of several factors. Importantly, I am a medical doctor and a person with a disability. Just as relevant is the fact that I am female and white. Of note is the fact that I live in South Africa, a global south country, and received my undergraduate medical training from a South African university. The Eurocentric medical curriculum was a legacy of colonialism as outlined in Chapter One. I cited a 1979 article as this information source – see Chapter One - but more recently Hirsch (2018) confirmed that South African university curricula (this includes UCT medical school) are still predominantly Eurocentric.

4.2.2 The generation of knowledge

Rather than seeing myself as the producer of first-hand knowledge in this research, I want to clearly state that my position is more of an interpreter of the knowledge my participants have shared. My role was to interpret and shape the participants' knowledge contributions into an acceptable and formal academic format.

My decision to select Rehabilitation Therapists, Nurses, Medical Students and Persons with disability in Phase one of this study aligns with the conceptual position I have taken in this study. I consciously chose to give value to and elevated the voices of those who have typically had less influence/power in the realm of medicine and medical education. Singh *et al.* (2020) report this as being particularly pertinent to persons with disability. On page 77 of this chapter, I will elaborate on the rationale for including each participant in Phase one.

This alignment with my conceptual framework of decoloniality, a concept held by Sharma (2018), is particularly true of my selection of persons with disability in both phases of this study. On page 78 of this chapter, I provide a rationale for their inclusion from a decolonial perspective. This rationale speaks to both phases of this study. This inclusion highlights a major difference between my study and various others.

4.2.3 The influence of my paradigmatic positioning

These factors all influenced my paradigm, i.e., the way I view the world. In turn, my paradigmatic positioning influenced my selection of decoloniality of both medicine and disability as one of the conceptual frameworks for this study. Naidu (2021, page 1) defines decoloniality as a "theoretical perspective from which to interrogate sociohistorical, geopolitical and economic perspectives on gender, race, and heteropaternalistic influences in medicine emanating from a basis in colonially developed systems of knowledge production." My paradigm also acted as a conceptual lens through which I viewed my decisions with regards to the methodological aspects recorded in this chapter (Kivunja & Kuyini, 2017).

4.2.4 My paradigmatic assumption

One of my paradigmatic assumptions in this study was that, through the use of this study's methodology (described in this chapter), I would be able to show that there is close link between epistemology and ontology in relation to disability and persons with disability.

4.3 Study Aims and Objectives

Aims 1: To describe what constitutes doctors' approach to disability inclusive practice.

Objectives

1.1. To critically analyse and describe the attitudes/values to the clinical encounter which characterises equitable practice with persons with disability.

1.2. To identify and describe the critical behaviours and skills of doctors which contribute to equitable practice with persons with disability.

1.3 To identify and describe key knowledge constructs which underpin equitable practice with persons with disability.

Aim 2: Describe the competencies related to knowledge, skills and attitudes, (feelings, beliefs and values) required for equitable disability practices.

Objective

2.1. Describe basic competencies (knowledge, skills and attitudes - feelings, beliefs and values) that graduate medical students should have in order to deliver a quality healthcare service to persons with disability.

Aim 3: To develop an initial competency framework that could contribute to developing the undergraduate medical curriculum, with the aim of providing a quality healthcare service to persons with disability.

Objectives

3.1 Identification of initial set of competencies through various data sources.

3.2 Refine the competency framework through expert analysis.

4.4 Research Design (2-phase study)

This study set out to explore medical doctors’ current practice with persons with disability as a basis for determining what competencies a doctor needs to provide persons with disability with quality health care. This study is of a complex nature and focussed within the realm of health sciences which makes a mixed methods approach well suited to this study, hence the adoption of two phases. Creswell and Creswell (2017) state that mixed methods are well suited to health sciences research because of the often-complex nature of such research. This research formed a sequential study as well, with Phase one followed by Phase two. The case under study, or unit of analysis, was what do doctors currently do (i.e., their current practice) and what are the competencies that would assist doctors in delivering a quality healthcare service to persons with disability, that should be included in any South African undergraduate medical curriculum. Importantly this study was viewed as a bounded unit. The study was a single case (detailed above) with embedded units (the participants of both phases of this study) (Fabregues & Fetters, 2019).

4.4.1 Phase one

4.4.1.1 Objectives

1.1. To critically analyse and describe the attitudes/values to the clinical encounter which characterises equitable practice with persons with disability.

1.2. To identify and describe the critical behaviours and skills of doctors which contribute to equitable practice with persons with disability.

1.3 To identify and describe key knowledge constructs which underpin equitable practice with persons with disability.

2.1. Describe basic competencies (knowledge, skills and attitudes - feelings, beliefs and values) that graduate medical students should have in order to deliver a quality healthcare service to persons with disability.

4.4.1.2 Research design for Phase one

This phase was purely qualitative in design.

4.4.2 Phase two

4.4.2.1 Objectives

3.1 Identification of initial set of competencies through various data sources.

3.2 Refine the competency framework through expert analysis.

4.4.2.2 Research design for Phase two

This phase involved quantitative and qualitative research.

4.5 Procedure

4.5.1 Phase one

4.5.1.1 Participants (inclusion, exclusion and recruitment)

I used purposeful sampling for both phases in this study which helped me to ensure that the participants that I selected could deliver rich information and insights about the topics raised in this study (Palinkas *et al.* 2015).

In qualitative research the goal is to describe the nature and contents that make up the phenomenon under study in as much detail and depth as possible. Bansal, Smith and Vaara (2018) suggest that qualitative research affords us with critical tools which allow long-held and often taken-as-a-given thoughts and ideas to be interrogated and challenged. These tools also assist in fostering new theoretical paths. Qualitative researchers are not focussed on determining incidence and prevalence (Moser & Korstjen, 2017). Therefore, smaller numbers of participants were applicable to this study. Small groups ensured that all participants got a chance to contribute. Smaller participant numbers also allowed the research assistants to probe quite deeply into a participant’s contribution.

The sample for Phase one consisted of:

1) Persons with disability:

Inclusion criteria	**Rationale for each criterion**
- Persons with any disability, e.g., psychosocial, physical, intellectual or sensory disability. Disability was determined using the UNCRPD definition as recorded in the glossary of terms at the beginning of this thesis.	These participants were chosen because they add a unique voice to the topic and have knowledge from their lived experience of disability. It was noted by Symons, McGuigan and Akl (2009) that persons with disability often reported that they had to teach their medical doctors about the fundamentals of their disabilities. From a decolonial perspective, it was important to include this group. Through the inclusion of persons with disability, I aimed to follow the slogan “nothing about us, without us” which according to Franit (2005) has its origins in South Africa’s Disability Rights Movement. Medicine is full of complex imbalances which are a colonial legacy and the inclusion of these voices which have traditionally been excluded from discussions/decisions about things that affect them, is my contribution to the addressing of these power imbalances (Lokugamage, Ahillan & Pathberiya, 2019).
- Participants in this group must be comprised of a mixture of persons with disability who make use of the private and public	Given the known disparities between the private and public health care systems in South Africa, I wanted to make sure that I

healthcare system in South Africa.	included perspectives based on experiences from both systems.

Exclusion criteria	**Rationale for each criterion**
• under the age of eighteen.	Persons with disability under 18 years were not a necessity for this research. Both persons with disability who are under 18 years old and those unable to give independent informed consent due to their disability, pose extra ethical challenges to research.
• unable to give independent informed consent due to their disability.	

There are numerous types of disabilities and I had hoped to recruit participants with a variety of disabilities. However, the most available and accessible/reachable participants for this group were Persons with physical disability and sensory (visually-impaired) disability.

I was limited in my selection of the different types of disabilities because of several factors: time constraints, i.e., the need to start collecting data within a given timeframe; and non-response to participation request emails. I emailed several public and private institutions for persons with psychosocial, other sensory (e.g., hearing impaired) and intellectual disability. I sent a follow up email after one week and waited another week for a reply but received none. A person with a disability’s age (must be over eighteen years to give independent consent) and a person with a disability’s ability to give informed consent (difficult in many psychosocial and intellectual disabilities) also played a role in limiting my selection pool.

- **Recruitment**

I emailed individuals that I knew would be able to contribute richly to the questions. Initially I briefly explained the research and asked if they were able to be part of the research. Once each participant confirmed their willingness to be in the research, I emailed a more detailed information sheet about the research (appendix 1).

I recruited five persons with disability who had all had numerous clinical interactions with medical doctors. The number involved in the group was small enough to ensure that each participant was able to contribute.

In Chapter Five, I provide a detailed description of the participants included in this group.

2) Qualified medical doctors (completed the national community service):

Inclusion criteria	**Rationale for each criterion**
• Medical doctors registered as general practitioners with HPCSA.	The phenomenon under question relates to medical doctors' current practice when treating persons with disability. It was therefore important to include the voices of medical doctors with practical experience of this phenomenon.
• minimum of five years' work experience post-graduation.	These doctors are in a good position to share rich insights into the topic, based on their personal work experiences of medical practice.
• treated at least one persons with disability or have routinely treated persons with disability during their careers.	This first-hand knowledge would contribute to the richness of the data that they could provide.

Exclusion criteria	**Rationale for each criterion**
- Medical doctors who are not registered as independent medical practitioners with the HPCSA (i.e., have not completed community service).	Such doctors have under three years work experience of clinical medical practice post-graduation. My inclusion criteria states that they must have a minimum of five years work experience.
- no work experience with persons with disability.	These doctors would have no first-hand insights to share.
- Medical specialist in a particular field of medicine.	This study looks to propose competencies for inclusion into the undergraduate medical curriculum, aimed at a General Practitioner (i.e., a doctor with no specialist qualifications post-graduation from their undergraduate medical degree). Therefore, insights from specialists would not be appropriate.

- **Recruitment**

I initially approached two General Practitioners who over years of practice have had some exposure to persons with disability and one General Practitioner who has extensive experience of working with people with physical disabilities. All three doctors confirmed their willingness to be involved and I followed up on this by sending a detailed information sheet about the study (appendix 2). However, a few weeks before their focus group, the first two doctors pulled out of the research due to conflicting time commitments. Using my contacts in Physical Rehabilitation Medicine, I was able to recruit two General Practitioners who have worked for years with persons with disability. I sent these two new doctors information sheets (appendix 2) as well.

In selecting only three medical doctors, I ensured that all three participants received ample opportunity to contribute to the focus group setting. Often one or two people can dominate a larger group, allowing others who might be shyer to participate less. A group of three medical doctors meant that not only was each participant able to contribute, but it also allowed more time to explore a participant's contribution in more depth.

The profiles of the included medical doctors are reported in detail in Chapter Five.

3) Qualified Occupational Therapists, Speech Therapists and Physiotherapists (completed national community service) and Registered Nurses

Inclusion criteria	**Rationale for each criterion**
• Occupational Therapists, Speech Therapists and Physiotherapists that have completed their community service year and are registered with the HPCSA as allied healthcare professionals. These therapists must have all worked with persons with disability with medical doctors - i.e., they either work closely with medical doctors (in a hospital setting) or receive referrals from medical doctors (outpatient setting).	I selected therapists from these particular professional groups because they are well known as the traditional therapeutic disciplines involved in the treatment and management of persons with disability.
• Registered Nurses/RN (i.e., carry the title Sister and registered with the South African Nursing Council/SANC). These nurses must have all worked with persons with disability with medical doctors, i.e., they either work closely with medical doctors (in a hospital setting) or receive referrals from medical doctors (outpatient setting).	My inclusion of Registered nurses/RNs relates to their vital position in healthcare (i.e., nurses interact closely with both doctors and persons with disability, particularly in a hospital setting). They were chosen to provide another view on the current practices of doctors when treating persons with disability.

Exclusion criteria	**Rationale for each criterion**
- Therapists - Occupational Therapists, Speech Therapists and Physiotherapists - who have not completed community service and are not registered with HPCSA.	Such therapists have less than one year work experience post-graduation and would therefore have limited insights into working with persons with disability with medical doctors, i.e., they either work closely with medical doctors (in a hospital setting) or receive referrals from medical doctors (outpatient setting).
- Nurses not registered with SANC as RNs.	From my professional experience, nurses with a rank lower than RN are unlikely to work as consistently closely with medical doctors as RNs.
- Therapists - Occupational Therapists, Speech Therapists and Physiotherapists - and Nurses with no experience of working with persons with disability with medical doctors.	These healthcare professionals could offer no first-hand experiential insights into the topic of this study.

- **Recruitment**

I approached a few appropriate individuals via an introductory email. I also relied upon the snowball effect of word of mouth. From my professional experience of working with therapists and nurses in Physical Rehabilitation Medicine, I could discern their appropriateness for the research. I then sent a more detailed information sheet (appendix 3) about the study to those individuals who expressed an interest in participating.

I recruited two Occupational Therapists, two Speech Therapists, two Physiotherapists and two Registered Nurses. Data from these participants was very valuable to the study as they provided an objective experience and perception of the focus of the study. In total I selected eight participants. By keeping the number under ten, I hoped to allow each participant equal opportunity to contribute. The recruiting of two participants per profession listed had to do with the depth of the data. Having two participants per profession allowed for a deeper exploration of the contributions per profession.

A detailed summary of the profiles of the participants included in this group is reported in Chapter Five.

4) Medical students:

Inclusion criteria	**Rationale for criteria**
• Medical students in the clinical years of their medical degree (i.e., years four, five and six), preferably but not an absolute must, with personal experience of disability.	The end goal of this study was to generate a competency-based curriculum focussing on disability, for possible inclusion in the undergraduate medical curriculum. It was therefore very important that medical students were included as participants in this research. It was important to get first-hand insights into the current curriculum around the topic of disability. Students in the clinical years would be able to answer questions and have discussions about their curriculum, having had interactions with patients and potentially with persons with disability, in the clinical years of their medical school education.

Exclusion criteria	**Rationale for criteria**
• Medical students not in the clinical years of their medical degree (i.e., years one, two and three).	These students would have limited insights to share because they have had no clinical interactions.

- **Recruitment**

I decided to include medical students from the three clinical years (fourth, fifth and sixth year). I first sought permission from the Department of Student Affairs at UCT to involve students in my research (approval reference: WHTSAR002 / Dr Sarah Whitehead, 21 June 2019 – appendix 4). I then recruited a fifth-year medical student who I knew was very involved in curriculum transformation and asked for help in recruiting other medical students. I sent her an information sheet to give to potential participants that she identified (appendix 5).

She recruited four others - a sixth year medical student, two fifth year medical students (she was the third fifth year student) and a fourth-year medical student.

A detailed summary of the profiles of the included medical students is reported in Chapter Five.

4.5.1.2 Data collection instruments

Phase one of this study involved generating data on medical doctors' current practices with persons with disability and suggestions as to what competencies could be useful in assisting doctors in delivering a quality healthcare service to persons with disability (i.e., what do doctors do and what should they do when treating persons with disability). I used document analysis, focus groups and in-depth interviews to obtain data.

4.5.1.3 Data collection processes

1) Document analysis

Documents contain information which has been objectively recorded, without the intervention of the researcher of this study (Bowen, 2009).

Document selected	**Why this document?**
Core competencies for undergraduate students in clinical associate, dental and medical teaching and learning	I chose to review a national document which is contextually relevant to this study because of its location (South Africa) and

programmes in South Africa. (HPCSA, version: February 2014) I reviewed the Health Professional Council of South Africa's (HPCSA) documented guidelines (the education and training guidelines specified by the Medical and Dental board of the HPCSA) as to what a doctor does and what they should be able to do to adequately treat any patient (i.e., the practice and the competencies of a doctor).	connection to the competencies a medical doctor must have upon graduation.

According to Bowen (2009), there are five key reasons why document analysis is useful in qualitative research. This reference is thirteen years old, but I chose to include it because it provides very clear and succinct information about document analysis.

The five reasons Bowen (2009) gives which I apply here to this study's context are:

Firstly, review of the document provided contextual data of some of the research participants (e.g., the HPCSA provides data on the context within which a medical doctor operates). Secondly, information contained in the document guided the questions that need to be addressed during the research. Thirdly, the data gathered from document provided vital additions to the knowledge base of the study. Fourthly, document analysis/review was used to assess any changes or developments which occur over the course of the study. Finally, the document was also useful as a means of verifying or substantiating findings from other data sources.

2) Focus Groups

This method of data collection was employed because it is particularly well-suited to the exploratory nature of this study (Stewart & Shamdasani, 2014). The focus groups allowed for participants to discuss and come up with ideas collectively (i.e., a collective brainstorming of ideas) and by using their own terms (Guest *et al*. 2017).

Furthermore, it was noted by Guest *et al.* (2017) that focus groups are useful for debating and discussing in detail the social construction of issues which might be considered sensitive, which aligns with a key focus of this study to interrogate and challenge the social construction of disability.

The focus groups were of a semi-structured format with a flexible agenda. This format allowed ideas (not anticipated by me) to emerge from participants which added to the richness of the data gathered.

I enlisted the assistance of two research assistants from The Department of Health and Rehabilitation Sciences at UCT. Due to being a medical doctor working with persons with disability as well as a person with a disability, research assistants were used in an attempt to limit answers that the participants think I would like to hear (socially desirable) and to contribute to creating a more comfortable environment for participants.

I was and am fully aware that my subjectivity in relation to this study played a role in many aspects of data generation. Through using research assistants in this phase, I hoped to minimise the influence of subjectivity. Regular reflection in my journal assisted to address the role my subjectivity played throughout this study.

My first research assistant conducted the majority of the focus groups and in-depth interviews. Shortly thereafter she left the study (for unknown reasons) and I found my second assistant, who facilitated the final focus group. Both research assistants were familiar with disability studies and curriculum transformation. The research assistants were experienced in conducting focus groups as well as in-depth interviews.

Before they conducted any focus groups, I met with each research assistant for roughly two hours. We discussed the study and the best process for the focus groups.

I made sure that I was present to greet and thank all the participants before each focus group and to say goodbye after the group. I provided beverages and snacks, and the research assistants oversaw their distribution. All of these actions were intended to cultivate a close relationship of trust with the participants. I discuss the rationale for this close relationship in the credibility section of this chapter.

All the Phase one participants took part in the focus groups.

The first research assistant conducted four focus groups. The third participant group was split into two groups because certain participants could not attend the focus group on the date chosen by the majority in that participant group. The focus groups consisted of three to five participants and were of one to one-and-a half hours duration. The first focus group was made up of Persons with disability participants.

At the start of each focus group, the participants were welcomed and thanked for volunteering their expertise and time. The research assistant explained the study, the purpose of the focus groups, the role of myself and research assistant and why the participants were chosen. The research assistant then ran through the rules and responsibilities of the group and importantly reminded participants that individual anonymity will be upheld as much as possible (Smithson, 2007).

There could not be a guarantee of a hundred percent anonymity or confidentiality amongst the participants. Nevertheless, the research assistant requested that each participant respect the rights of the other participants in this regard. The participants were also informed that should they wish to leave at any time, they were free to do so, without the fear of any future negative consequences.

The research assistant followed the proposed agenda (leading questions generated by me on the topic - see appendix 6-9) as closely as possible but with some flexibility as the aim of the focus group was to find out information on the topic from the participants' own frames of reference (Guest *et al.* 2017). The semi-structured format of the focus group meant that based on the answers provided by the participants, new questions (not part of the original agenda) could be asked of them to explore their previous answers in more detail. The research assistant did her best to ensure that each participant got an equal chance to participate during the group. The research assistant took notes during the session and the sessions were audio recorded with the participants' consent.

After an initial analysis of the focus group data done by the research assistant and me, six participants were selected and invited to an in-depth interview – three participants from the first focus group and two participants from the third focus group and one participant from the fourth focus group. The criterion for selection was that the participants' contributions during the focus groups by the first research assistant was rich enough that it warranted more detailed exploration during the interview. The details of the in-depth interview procedure will be described in the next sub-section of this chapter. No participants were selected for an interview from the focus group facilitated by the second research assistant.

Data from the focus group was transcribed verbatim by a professional transcriber. I attempted the transcription but quickly realised how slow and inadequate I was. I really struggled having to listen to the audio recording of the focus group or interview and at the same time, correctly type what was being said.

In discussion with my supervisors, we decided that hiring a professional transcriber – who signed a confidentiality agreement – was the best course of action. An information sheet given at the recruitment stage (appendices 1-3 and 5) and if requested at the beginning of the focus groups, informed participants of what would be done with the data.

The second focus group consisted of qualified Medical Doctors and followed the same procedure as the first group.

The third and fourth focus group consisted of qualified Occupational Therapists, Speech Therapists, Physiotherapists and Registered Nurses. This participant group was divided into two focus groups of four participants:

Third focus group	Two Physiotherapists (PT1 and PT2) One Speech Therapist (SLT1) One Registered Nurse (RN1)
Fourth focus group	Two Occupational Therapists (OT1 and OT2) One Speech Therapist (SLT2) One Registered Nurse (RN2)

This division was done to accommodate the time constraints of several the participants. These two focus groups followed the same procedure as the first two.

The fifth focus group was facilitated by my second research assistant and consisted of medical students in the clinical years of their undergraduate degree, with personal experience with persons with disability (i.e., a family member) or curriculum transformation and followed the same procedure as the previous four groups.

The time and venue for each group was decided according to suitability for the participants.

In 2016 the ethics committee approved my MPhil proposal for this research study (846/2016 – see appendix 10). Once I had this approval, I conducted the focus groups of the first three participant groups. I upgraded my research to a DPhil in 2018. After receiving ethical approval for the upgrade in early 2019 (043/2019 – see appendix 11), I continued with the fourth participant group of Phase one and then the modified Delphi Method of Phase two.

In both the focus groups and in-depth interviews, the research assistants were made aware (by me) that they needed to try to mediate any power dynamics that could arise between themselves and the participants, as well as between the participants themselves.

They did this by facilitating and guiding conversation rather than controlling it. In the groups they were careful to allow each participant a chance to contribute.

3) In-depth interviews

To extract rich detailed data, in-depth interviews need to be well planned and of a semi-structured nature (Eppich, Gormley & Teunissen, 2019). The questions for this study's interviews related to the information and insights which the chosen participants contributed during the focus groups and provided me with scope to delve deeper into my investigation of what doctors do and what should they do when treating persons with disability.

Some participants may not have felt comfortable enough or not had enough time to give detailed responses in the focus group environment or might feel safer and more able to do so in an individual in-depth interview. Participants who provided rich insights in the focus groups that warranted further exploration were selected for an in-depth interview; they were from focus groups one, three and four (the third participant group was split into the third and fourth focus groups). The selection was done in consultation with my research assistant. On page 89 of this chapter, I detail which participants were selected for in-depth interviews.

Based on the focus groups from which interviewees were selected, the first research assistant was most suitable for conducting the interviews. Six participants were selected for one interview each. The interviews lasted an hour. The questions were based on the contributions the selected participants made during the focus groups and were open-ended. This allowed the research assistant to explore these contributions in more detail and achieve a greater depth of understanding of what the participant meant. I did not conduct the interviews for the same reasons I gave on page 87 as to why I used research assistants to conduct the focus groups.

The interviews were conducted in the choice of language of the participant. All interviews were conducted in English. The interviews were audio-recorded with the consent of the participant. Like the focus groups, the time of and venue for the interviews was decided upon at the convenience of the participants.

4) Reflective Journal

A reflective research journal was kept in both phases of this study which brought transparency to the research. This journal meant that my personal experiences and insights into the entire research design and process, as well as how these might have influenced the data, are clearly visible to both the reader and me (Ortlipp, 2008).

A critical reflection journal afforded me the opportunity to revisit insights written in the journal throughout the research process and question, as well as alter elements of the research design with the benefit of more knowledge gained (e.g., further readings done post the proposal development).

A reflective journal was also a useful way to reflect on the experiences during data collection and the participants' responses to questions used to collect data. It is not possible for the interpretation of the data not to be influenced by me, but a reflective journal helped diminish the weight of this influence. Reflective journaling allowed me the chance to be reflexive and to actively engage with my positionality throughout this study. I was therefore acutely aware of how much of the analysis interpretation was influenced by my own experiences, thoughts and perceptions.

This journal contains a record of my personal thoughts, experiences, decisions and choices throughout the entire research process.

I chose to use a critical reflection process. Fook (2015) explains that the essence of critical reflection is about the ability to create transformation. A critical reflection approach aims to achieve transformation, through the in-depth interrogation of entrenched assumptions and by creating awareness of how power operates.

The interrogation of assumptions and existing power dynamics fits extremely well with the topic of this study.

Apart from reflection on the above mentioned two points, I regularly reflected on my positionality and what role it played in different parts of this study.

The end point of Phase one was when I had sufficiently rich data to allow progress to Phase two with confidence. On pages 94 and 95 of this chapter, I describe how I generated my initial competency set from my Phase one data.

4.5.1.4 Data analyses

- **Document analysis**

The HPCSA guidelines was reviewed with particular attention to any mention of the practice and competencies required of a doctor, to adequately treat persons with disability.

In addition, I used critical discourse analysis (CDA) to analyse the document. Van Dijk (2008) explains that CDA looks to explore how social injustices are produced or perpetuated by text or discourse.

Amoussou and Allagbe (2018) provided me with a useful framework of eight points to consider when applying CDA to a document of text. They provide questions (Amoussou & Allagbe, 2018, page 16) which relate to and explain each of the following eight points and helped guide my analysis:

- **Transitivity:** what patterns of transitivity are found? Who is depicted as Agent (and therefore empowered), and over whom (the affected)? What is the degree of nominalization? How does it background the process itself by omitting information about agents of power? Do passive verbs also delete agents of power? What is the ideological function?
- **Mood and Modality:** How is mood enacted? Declarative, imperative or interrogative? Which values express choices of modality?
- **Vocabulary:** How are words used to show ideology? What aspects of reality are overworded? How are overwording, synonymy, antonymy and hyponymy used to construct ideology? Are there euphemisms or metaphors? What connotations do they convey?
- **Interactional control features**: Which are the interactional control features of the text? Turn-taking? Control of topics? Topic change? Opening and closing of interactions?
- **Topicality**: Which topics are chosen to fill theme position in the clause (initial position) or which are foregrounded?

- **Presuppositions**: Are there presuppositions or assumptions made by a speaker or writer which are not explicitly stated and which the author appears to take for granted?
- **Vagueness**: Which expressions are unclear because they do not give enough information or they do not say exactly what they mean?
- **Implication:** Which implicit information can be deduced or inferred from discourse on the basis of pragmatic contexts?

I carefully addressed each of these eight points in relation to the document. I included examples from the document in my Chapter Five report of the document analysis to add depth to my writing under each point.

The final point **implication** was where I was able to provide a final overview of the document analysis relative to the topic of this study.

- **STEP 1: Thematic analysis**

This data consisted of transcriptions of the focus groups and in-depth interviews held with the Phase one participants. The transcriptions of the data were given to an external person for checking and verification.

After the transcribed data had been verified, thematic analysis was the analytic approach I selected for Phase one. It was chosen for two reasons; as an approach or method it is both accessible and flexible (Braun & Clarke, 2012).

Braun and Clarke (2006) describe six stages a researcher should follow when using thematic analysis:

In the first stage I aimed to become as familiar with the data as possible. This was achieved by reading through all the transcriptions multiple times. Whilst these readings were happening, I made notes of initial thoughts and ideas that arose.

The second stage involved the generating of initial codes by me. This was done by coding features of interest across the whole dataset and then organizing the data relevant to each code.

In the third stage I started identifying themes. The codes initially generated were organised into potential themes and I then searched for and matched all relevant data with the themes.

The fourth stage involved reviewing the themes. This was done through the creation of a thematic map. The themes were compared with the coded extracts from the whole dataset.

The themes were defined and named in the fifth stage. I did this by the ongoing analysis and review of the themes initially identified in stage three. This ongoing analysis allowed me to generate clear definitions for the themes and name them.

The sixth and final stage is where I produced the report of the data. This stage is seen as the final opportunity for analysis (Braun & Clarke, 2006). I had by this stage selected the most information-rich extract examples. These examples were put through a final analysis by relating them back to the research question as well as to the literature reviewed.

- **STEP 2: Generation of initial set of competencies**

Whilst analysing the data from Phase one, I asked myself what the knowledge, attitude, and skill was that the data was asking doctors to be competent in. I recorded these findings as a summary of each theme in Chapter Five.

I became aware of how my Phase one data brought the issue of ableism in medicine to the fore. Pena-Guzman and Reynolds (2018) provided a helpful framework relating to ableism for the generation of the initial competencies. They break down ableism into four separate mechanisms: testimonial injustice, epistemic overconfidence, epistemic erasure and epistemic derailing.

I bore these mechanisms in mind and focussed on generating competencies that could address these mechanisms. In Chapter Seven I will explore these four mechanisms in detail and how the competencies proposed by this study address them.

I also used other data sources, which included the document I analysed in Chapter Five, relevant literature I had read, the analysis of my reflection journal (Braun & Clarke, 2006) and my own personal and professional experience of disability. I combined these other data sources with competencies I had written at the end of each theme reported in the findings of the Phase one data and compiled an initial set of competencies.

I added a descriptor to each competency to help explain the competency.

This initial set of competencies constituted the round one questionnaire given to the expert panel in the modified Delphi of Phase one. It contained a list of 17 competencies and 13 sub competencies. Table 6.1 in Chapter Six shows the competency list in questionnaire one.

- **Overall, in the analysis of Phase one**

I adopted an attitude of reflexivity throughout both steps of the analysis process. An attitude of reflexivity helped maintain critical self-awareness during the analysis (Engward & Davis, 2015). This meant that I tried to be as mindful as possible about how and when my positionality was influencing my interpretation of the data.

I feel that my position as a person with a disability positively influenced my openness to hearing, accepting, wanting to understand and interrogate the data further. As such, I did not face any dilemmas with the actual content of the data.

My position as a medical doctor posed challenges to do with learning the often messy process of qualitative analysis, which is quite different from my undergraduate medical degree, which has strongly influenced the workings of my mind. I would describe my undergraduate medical degree as quite neat and precise.

The analysis of Phase one was greatly influenced by the decoloniality (medicine and disability) lens I discussed in Chapter Three as part of my conceptual framework. I was very conscious of looking for and gravitating towards data extracts that fitted well with the lens mentioned above. My analysis was also informed by my other conceptual frameworks of the International Classification of Functioning, Disability and Health (ICF) and Critical Disability Studies – see Chapter Three.

4.5.2 Phase two

4.5.2.1 Participants (inclusion, exclusion and recruitment)

I selected individual experts based on the following criteria:

1. **Individuals had to be considered experts in their field.**

The Oxford Dictionary defines an expert as “a person who is very knowledgeable about or skilful in a particular area” and according to Caley *et al* (2013), an expert is an individual who possesses widespread and respected knowledge in a particular field, not possessed by most people. For this study experts were defined as individuals who have special skills and knowledge on the subjects of either disability or medical education, gained either by training or through personal and/or work experience.

2. **The experts needed to be from the following categories:**

Inclusion category	**Rationale for each category**
• **Disability Studies experts (non-disabled).**	These individuals are considered to be experts in the field of Disability Studies because of their extensive teaching and research of disability issues. Their research of Disability Studies has been published extensively (i.e., they have an established track record in disability research). Their knowledge of disability issues and experience as educators (teaching the subject to university students) helped add depth to the topic under study.
• **Disability Studies experts with their own disabilities.**	Although these experts have the same characteristics mentioned in the above rationale, their input was invaluable as the opinions they shared were based on both professional and personal experiences and views. On page 78 of this chapter, I wrote my rationale for including persons with disability in Phase one and the same reasoning is true for Phase two.

- **Medical Educationists with curriculum expertise.**	They are well recognised as having an established track record working with medical undergraduate curricula. They were very important in this group as they helped guide the process of including new elements into an already full curriculum.
- **Medical Doctors who work exclusively in facilities with persons with disability.** **(These doctors could not be the same ones as those in the Phase one participant group.)**	I decided to recruit Psychiatrists - one of whom works with intellectual disability – to ensure that psychosocial and intellectual disabilities had more of a voice in this study. They were able to offer valuable insights based on their personal work experience.
- **Disability Rights Activists with Health Professional backgrounds.**	Their passion and enthusiasm for disability rights activism, as well as their allied healthcare backgrounds (two Physiotherapists) allowed them to bring a diverse perspective to the expert panel. Such professionals are often an integral part of the multidisciplinary team (with doctors and other healthcare professionals) that is involved in the treatment and management plans of persons with disability. It was therefore important to hear their insights into the proposed competency list.

Exclusion Criteria	The only major exclusion criteria related to the medical doctors. The medical doctors

	could not be the same doctors that participated in Phase one of this study.

- **Recruitment**

I requested help from a Disability Studies academic with a disability, in identifying potential experts. She gave me the names of people to approach who fitted the Disability Studies experts only. A fellow PhD student suggested that I contact someone in Durban who has considerable experience in medical curriculum transformation. He in turn advised on who else to approach. Thereafter, I relied on suggestions from the individuals that I contacted until I had enough participants. I emailed each potential expert an information sheet about the research – appendix 12 – and asked if they would be part of the expert panel.

The rationale for my decision to recruit two Psychiatrists - medical specialists – is recorded on page 97 of this chapter. I also decided it was important to include qualified therapists in the panel to add the perspective of other health professionals. In total my panel had thirteen participants, represented in the table below:

Criteria	**Number of participants**
Disability Studies Academics with their own disabilities	4
Disability Studies Academics (abled)	2 – 1 of whom is a Speech Therapist.
Medical Doctors	2 – Psychiatrists
Medical Educationists	3 - 2 Occupational Therapists, one of whom is a staunch mental health advocate, and the 3rd is a medical doctor.
Disability Rights Activists	2 - both of whom are health professionals and are involved in the teaching of medical students.

A detailed summary of the profiles of these participants appears in Chapter Six.

2) Health Professions Council of South Africa (HPCSA): Board of undergraduate medical education

The HPCSA is the main professional board for medicine in South Africa. I initially proposed that I would include members of the HPCSA Board of undergraduate medical education in this study. The reasons for this inclusion are two-fold. Firstly, the HPCSA can offer interesting insights into the topic and secondly, the HPCSA could be extremely influential in advocating for the curriculum this research will attempt to generate.

I was however unable to include the HPCSA because Phase two of this study took place late 2020 – early 2021 when the HPCSA was extremely disrupted by the Covid-19 pandemic, which rendered any attempts to contact them about this study impossible.

4.5.2.2 Data collection instrument

I used a modified Delphi Method. It was modified in that the questionnaire in the first round was of a semi-structured nature based on the data analysis of Phase one. Traditionally the questionnaire in the first round of a Delphi study is open-ended in design. However, as information about the research issue (the analysed data from Phase one) was readily available for use, the application of a modified Delphi Method was appropriate (Hsu & Sandford, 2007). The precise details of this study's modified Delphi Method will be discussed further under the procedure of Phase two.

The Delphi Method is useful in exploratory qualitative research to build consensus on the topic under study. As a method of consensus building, it gave me a way to gather insights and opinions from appropriate experts that allowed decisions to be made (Habibi, Sarafrazi & Izadyar, 2014).

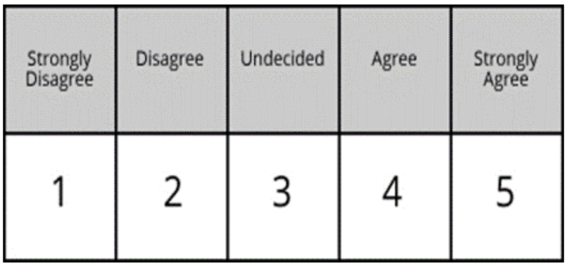
It was a useful method for this study because Phase two was about translating data from the previous phase into competencies to be used in the facilitation of disability into undergraduate medical curricula. Consequently, consensus on the proposed competency list was needed from the relevant experts (Phase two participants).

Although I chose to use this data collection instrument, I would be remiss if I did not acknowledge some of the criticism surrounding the Delphi Method. Afshari (2019) noted the Delphi Method is often too time-consuming and demands a high level of commitment from the experts in the expert panel, and this can lead to a high dropout rate and a low response rate. Another criticism relates to the anonymity of members of the expert panel, meaning they are unable to discuss and debate certain issues as one would in a group setting. This could result in the insights from the experts potentially not being as rich as they could be (Fernandez-Avila, Rojas & Rosseli, 2020).

4.5.2.3 Data collection process

In this phase, the data collection process was held after I had analysed the Phase one data.

I sent potential participants an email briefly outlining the research and what I was asking them to do. Once participants agreed to be on the panel of experts, I sent them a formal information sheet and a consent form. I then put together a questionnaire listing the competencies and sub-competencies that had come out of the Phase one data. I included my analysis under each competency. Before sending the questionnaire to the experts, I sent it to a fellow PhD student in Health Sciences Education. She reviewed the questionnaire and gave peer approval to continue. I then emailed the questionnaire to the experts. I first asked them to rate each competency as to its importance for undergraduate medical students, using a 5-point Likert Scale (see Figure 4.1).



Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1	2	3	4	5

Figure 4.1 shows a traditional 5-point Likert Scale (Recurve Blog post)

Question 1. Is this competency important for undergraduate medical students? (Please answer using the appropriate number: (1) Strongly disagree; (2) Disagree; (3) Neither agree nor disagree; (4) Agree; (5) Strongly agree.

I then asked them to rate the language clarity of each, using a 5-point Likert Scale, and to suggest ways to improve the language.

Question 2. Is the language of each competency, clear and easy to understand? (Please answer using the appropriate number: (1) Strongly disagree; (2) Disagree; (3) Neither agree nor disagree; (4) Agree; (5) Strongly agree.

Question 2.1. Please suggest any ways to improve the language of the competency.

For questions 1, 2 and 2.1, I mimicked what Havercamp *et al.* (2020) (see Chapter Two, page 53, for a review of the study) had asked their Delphi Method participants. At the end of the questionnaire, I asked three questions – questions 3, 4 and 5 were designed after discussions between the PhD student who peer reviewed my initial competency set and myself:

Question 3. Do you feel that any of the competencies don't need to be included in the list? (Please write just the appropriate competency number/s)

Question 4. Do you feel that any of the competencies overlap and could be combined?

Question 5. Do you have any other comments?

I gave the experts three weeks to complete the questionnaire. I sent two reminder emails. Once I had all the questionnaires, I analysed them. In the first-round consensus was reached on the first question. Consensus was not reached with regards to the language of each competency.

I addressed the language suggestions of each competency, giving more weight to similar suggestions from a few experts. I made suggested changes according to the area of expertise of each expert.

I then consulted with my supervisors and reformatted the competencies into a new list and then a second questionnaire. This second questionnaire was then emailed back to all the experts on the panel. The experts were again given three weeks in which to complete the questionnaire. I sent two reminders to each expert during this time.

Following consensus being reached in round two, I compiled a final competency list. The way in which I analysed this Phase two data will be discussed in the next section.

4.5.2.4 Data analyses

- Quantitative data analysis

I collected all the Likert Scale ratings of the competencies. I used an American study by Havercamp *et al.* (2020) as a framework. They had done similar research (to mine) and had made use of a modified Delphi Method. Following their lead, I decided that I would define consensus as having been reached with a 75% or higher score on each Likert Scale (Havercamp *et al.* 2020).

I first added up all the individual Likert scores for each competency. I then divided that score by the number of experts that rated each competency. I then multiplied each number by a hundred to get a percentage. Those competencies with a score of 75% or more were noted to have reached consensus.

- Qualitative data analysis

The qualitative analysis of this Phase two data was by no means a straightforward process, involving much reflection and discussion with my supervisors. In Chapter Six I report the conflicting thoughts and ideas regarding a few of the competencies. These conflicts arose between some of the experts as well as between myself and some of the experts. I discuss in Chapter Eight the main reasons I was challenged by what the experts contributed.

As with the analysis of the Phase one data, the second phase data analysis was influenced and informed by the decoloniality of medicine and disability lens I adopted as part of my conceptual framework, i.e., it was important that the competency list was contextually relevant to South Africa, a country in the global south. The list needed to also be focussed on breaking the traditional dominance of the medical model of disability in medical education, as well as the entrenched power dynamics between medical doctors and persons with disability – these focusses align with my other Chapter Three conceptual frameworks of the ICF and Critical Disability Studies.

The final list of competencies – 13 competencies and 9 sub-competencies - compiled by me after two Delphi rounds was reviewed by my supervisors. The finalised document was sent back to the experts for their approval.

4.6 Ethical considerations (including data security)

Approval for this study was sought from the Faculty of Health Sciences Human Research Ethics Committee (FHS HREC). The FHS HREC approved this proposal in 2016 as an MPhil study (846/2016 – appendix 10). In 2018 approval was sought from the FHS HREC for amendments which had been made to this study in the process of proposing an upgrade to a DPhil study. Approval for the upgrade was granted in early 2019 (043/2019 – appendix 11).

This study was guided by and adhered to the Declaration of Helsinki (2013) which documents what ethical procedures and principles need to be followed in medical research involving human subjects.

As mentioned already, some of participants were persons with disability. Persons with disability are seen as a vulnerable group. The Declaration of Helsinki clearly states that research involving a vulnerable group is only justified in three settings. Firstly, the research must be geared towards meeting the health needs of said group. Secondly, if there is no way that the research can be carried out in a non-vulnerable group and lastly, the vulnerable group in question should stand to gain from the knowledge and insights that come from the research (No. 20, Declaration of Helsinki, 2013).

I carefully considered these three areas pertaining to research using persons with disability in the design of this study. I concluded that the study benefited from their inclusion; it addressed the health needs of persons with disability and persons with disability stand to gain (directly or indirectly) through the study.

Every participant in this study signed an informed consent form (appendix 13 for Phase one participants and appendix 14 for Phase two participants). This consent form was discussed verbally in Phase one, and only via email communication in Phase two, in order to ensure that participants fully understood what was entailed in their participation. Manti and Licari (2018) describe informed consent as the option for participants to use their autonomous rights to voluntarily accept or refuse to participate in the study. The idea that participation was completely voluntarily was emphasised. Participants were made aware that they could choose at any time to no longer participate in the research and that choice would have no negative consequences for them.

In the context of my study, I view my participants with disability as an empowered group. I have explained on page 78 of this chapter that my rationale for including these participants has much to do with the disability rights slogan “nothing about us, without us”. My study is empowering these individuals by giving them a voice in matters where they have traditionally not had one.

I will next address how the ethical issues of confidentiality, autonomy, non -maleficence, beneficence and justice were managed in this study.

- Confidentiality

Surmiak (2018) describes the use of confidentiality in research as a means to protect the privacy of participants of the study, to build a relationship of trust between the study participants and the researcher, as well as to maintain ethical standards and the integrity of the research process.

This study aimed to protect the privacy of its participants with a detailed informed consent form. A consent form was given to each participant at the start of the focus groups, at the start of the interviews and before the modified Delphi Method. The research assistants verbally went through the form with participants to ensure there were no misunderstandings or unhappy feelings regarding contents of the form.

Special considerations to ensure that every participant understood what is in the form and could complete the form, were taken for the participants with disabilities, according to their individual needs.

Most importantly for confidentiality purposes the form explained how I intended to use the data collected, following Surmiak (2018) stressing the importance of an agreement between the participants and the researcher on how data will be used. The form assured the participants of anonymity, and it explained that all identifiers would be removed when data was reported.

I was mindful of assuming that every participant wants complete anonymity, as this had the potential to suppress a participant’s autonomy (Kaiser, 2009). The issue of confidentiality as well as informed consent was continuously revisited during the research to ensure that the principle of autonomy was upheld throughout their participation.

Importantly, at the start of each focus group, the research assistants reminded the group to be respectful of the other members’ confidences and to uphold the confidentiality of the group.

This helped to create a safe space where participants felt comfortable sharing information (Smithson, 2007).

- Non-maleficence

No harm came to any of the participants of this study. Should a participant have become distressed by a sensitive topic at any time during the focus groups or in-depth interviews, a debriefing would have been held. If needed a referral to appropriate counselling would have been made.

- Beneficence

This ethical principle addresses the issue of doing good for others and preventing harm (Bester, 2020). This study was not of direct benefit to the participants. It does however hope to benefit future research into how disability is being included in UCT's undergraduate medical curriculum.

Equally the release of the data will not harm any of the participants but if it arose during the study that such a release would harm a participant in anyway (even if anonymity is maintained), appropriate measures would have been taken by me to minimise this.

- Justice

A very distinctive feature of this ethical principle is that it focuses on avoiding the exploitation and abuse of participants. It looks to maintain an equal share and fairness in the research process (Nnodim & Okigbo, 2020).

Justice was ensured in this study by selecting the participants as fairly as possible, based on how they would best assist the research in producing a meaningful outcome. The outcomes and findings of the research were made available to the participants should they have requested it – only one participant requested the final competency set sent to her after examination of this thesis but I intend to send the competency set to all the participants.

Should any participant have been unhappy with any aspect/outcome of the research, they could contact my supervisors who would have addressed their concerns.

The outcomes of this study will provide a greater societal understanding of the issues under investigation. This study aims to be part of creating a more inclusive society for persons with disability, and thus the outcomes of the study will be made available to anyone requesting the findings, not only the participants of the study. I will also aim to publish the study. This will assist with dissemination of the research.

- **Trustworthiness and Rigor**

Guba (1981) developed a model to ensure trustworthiness and introduce rigor into qualitative research. I used the well-known and widely adopted model that proposes four criteria: credibility, transferability, dependability and confirmability (Guba, 1981). I used the following strategies to make sure that each criterion was addressed:

1) Credibility

Credibility in qualitative research looks at the coherence between the participants' views and the researcher's representation of them (Nowell *et al.* 2017). In this research, aided by research assistants, I aimed for a close relationship with the participants as this facilitates trust. A relationship of trust and understanding between myself, the research assistants and the participants enabled a deeper exploration into issues rather than having to just accept a superficial answer a participant might give if they did not feel safe sharing information. I was mindful that this close relationship could however run the risk of the research assistants and I becoming too enmeshed with the participants' experiences.

I made use of member checking to minimise this risk. In Phase one data analysis I checked my interpretation of what the participants told the research assistants, with the participants, to ensure that I had not clouded what the participants wanted to convey with my own personal experiences. I did this by emailing a draft of my Chapter Five Phase one data report to the participants whose data quotes I used. I asked them to read through and check my interpretations. I also used peer review in the analysis of this data. A fellow PhD student and my supervisors assisted in this regard.

In Phase two I also used member checking through the iterations of the Delphi. After I had produced a final competency list, I sent the list to all the experts involved. They reviewed the guidelines and checked that I had interpreted their responses correctly.

Throughout this study I made use of a reflective journal which was helpful in keeping personal experiences separate from those of the participants. It also helped to reflect on and maintain awareness – i.e., fostered reflexivity - of the multiple roles I hold in this research and how they may influence the study (Engward & Davis, 2015). I discuss this on page 91 of this chapter.

Data gathered from multiple sources allowed me to use the method of triangulation. The triangulation method added to the credibility and validity of this study (Noble & Heale, 2019).

2) Transferability

The study aimed to generate a competency set to guide the inclusion of new competencies into the undergraduate medical curriculum. It is a competency framework/list which could potentially be transferable to any programme which aspires to similar values and approaches to disability inclusion in the curriculum, bearing in mind that particular contexts and philosophies may influence the degree of transferability.

3) Dependability

I kept an audit of all interview recordings, transcripts and analysis to show that the actual study was carried out as it was designed. This audit can and will be checked by colleagues and other research experts (i.e., peer examination and review).

4) Confirmability

A full audit of this study will be kept as mentioned above. The details of what is included in the audit are represented in the table below:

Study plan/design
Implementation

Data recordings and transcripts
Findings – interpretation and analysis

This will allow an external source/moderator to clearly follow and understand why and how certain decisions were made (Nowell *et al.* 2017). Through a reflective journal I maintained awareness of my potential influences on the data. By triangulating the data, I not only ensured the credibility of this study but confirmability as well.

- **Data storage and final disposal**

All written records and audiotapes were kept securely for the duration of the study. The records were stored on a computer with a protected password for security, for the duration of study. Only I had access to the stored data.

The recordings and transcripts of the Phase one data was stored in a separate file on my laptop. The iterations of the Phase two Delphi were stored in yet another separate file. This meant that I could easily access the data I needed during my analysis and didn’t lose or confuse anything.

The transcriptions of the data were password protected and available to my supervisors for verification check when necessary.

Following submission of this thesis, these records will continue to be securely stored for five years. I will then be responsible for the disposal of data.

4.7 Conflicts of Interest

None of the research staff will receive any incentives for recruiting participants or for any other purpose directly related to the study.

No personnel involved in the design, conduct or analysis of the research have any proprietary interests (e.g., royalties, patents, trademarks, copyrights or licensing agreements) involving any agent, device or software being evaluated in the study.

4.8 In summary

In this chapter I detailed the methodology I used for this study – which was greatly informed by following key concepts that I discussed in Chapter Three:

- Establishing a conceptual basis for curriculum change.
- Curriculum development process
- CBME

This included the description of this study, which is a mixed method, sequential study in design - Phase one (involved qualitative research) was followed by Phase two (involved qualitative and quantitative research). Important to note my inclusion of persons with disability as participants in both phases of this study. I also noted that my other conceptual frameworks of the ICF, Critical Disability Studies and my lens of the decoloniality of medicine and disability – see Chapter Three – influenced the analysis of both phases of my research.

The detailed setting forth of the methodological aspects (and the ethical considerations) of this study lay the foundation for the next two chapters, where I will report the findings of this study.

Chapter Five

Phase one Findings

5.1 Overview of the chapter

This chapter records the findings from Phase one of this study. I begin by presenting the findings of the document I analysed and then present the findings from the data gathered from focus groups and in-depth interviews with Medical Doctors, Occupational Therapists, Physiotherapists, Speech Therapists, Nurses, Medical students and Persons with disability. Data from the focus groups and in-depth interviews addresses the first and second aim and their respective objectives. I end with a summary of this chapter.

5.2 Document analysis

The document chosen for critical discourse analysis, using the framework proposed by Amoussou and Allagbe (2018), was:

Core competencies for undergraduate students in clinical associate, dental and medical teaching and learning programmes in South Africa. **(Health Professions Council of South Africa, 2014)**

It was mentioned on pages 85 and 86 of Chapter Four why I chose to include this document. This document was developed by the Undergraduate and Training Subcommittee of the Medical and Dental Professions Board in collaboration with training institutions and the South African Committee of Medical and Dental Deans. The main governing body for this subcommittee and committee is the Health Professions Council of South Africa (HPCSA). The CanMED Physician Competency Framework (property of the Royal College of Physicians and Surgeons of Canada) was used as a reference and guiding tool in the development of this document.

This document speaks to my conceptual framework of decolonisation because of the document’s location within South Africa (the global south). It also is particularly relevant to this study because it is an official document that stipulates the competencies that a generalist medical doctor should have to practice quality medicine in South Africa.

- **Transitivity**

The ideological function of this document is to officially list the competencies that a generalist medical doctor needs to practice medicine in South Africa. A medical doctor is partially depicted as an agent, i.e., has the ability to affect an action over their patients. There is, however, awareness in the text of need to decrease any power differential through constant reminders to a medical doctor to be more inclusive of the patients in the healthcare process, for example:

Enabling Competency 1.1.1d) *Provide compassionate, empathetic and patient/client-centred care.*

The nominalisation of adjectives or verbs *(e.g., perform to performance)* to produce a noun was done only when appropriate in this document and was not excessive.

- **Mood and Modality**

The mood of each key competency is declarative in the sense of only declaring what doctors need to know or they provide a clear instruction, for example:

KEY COMPETENCY 5.2*: Respond to the health needs of the communities that they serve.*

The enabling competencies under each key competency carry with most of them a more inclusive (of patients and other health professionals) mood. Good examples are:

Enabling Competency 2.4.1c) *Encourage discussion, questions and interaction; and* **2.4.1d)** *Engage patients/clients, families, communities and relevant healthcare professionals in shared decision making to develop a plan of care/action.*

- **Vocabulary**

There are no over worded areas in the document. The words used clearly express the ideology of the document.

The examples above of ***Enabling Competencies 1.1.1d and 2.4.1c*** are two of many throughout the document, where the wording reminds the doctor that their relationship with their patients should be one of shared participation in the healthcare process.

The collaborator section is well worded to again remind doctors that within a team of healthcare professionals, they are equal role players, i.e., not superior to other team members. For example:

3.1.1 Enabling Competencies

b) Recognise and respect – irrespective of profession, status, age, gender, race, class or beliefs – the diversity of roles, responsibilities and competencies of other team members. Appreciate diversity and demonstrate the ability to adapt. (Healthcare team members may include other professionals, community workers and practitioners of alternative, complementary and cultural/traditional healthcare practice).

c) Work interdependently and share tasks with others to assess, plan, provide and integrate quality care for individual patients/clients (or groups of patients/clients).

- **Interactional control features**

There is good interaction between the key competencies of each theme and the enabling competencies which help clarify each of the key competencies. Each enabling competency provides a steppingstone towards achieving the corresponding key competency. For example:

1.3 KEY COMPETENCY

Perform comprehensive assessments of patients/clients.

1.3.1 Enabling Competencies

a) Effectively identify and explore issues to be addressed in a patient/client encounter, including the patient/client's context and preferences.

b) Elicit a history of the patient/client that is relevant, concise and accurate to context, for the purposes of disease prevention, health promotion, diagnosis and/or management.

- **Topicality**

This document has seven main themes: **healthcare practitioner, professional, communicator, collaborator, health advocate, leader & manager and scholar**. The healthcare practitioner is foregrounded as the central theme.

- **Presuppositions**

In the document there is no explicit mention of the word disability but ***Enabling Competency 1.2.1h)*** states that doctors must be competent in *"the holistic management of functional and structural impairment, activity limitations and participation restrictions, all with reference to personal and environmental risk factors" (page 3)* which is the International Classification of Functioning, Disability and Health (ICF) definition of disability, but the authors do not state that. The authors assume that readers will connect this term with the word 'disability' and its implications.

- **Vagueness**

There is mention of vulnerable or marginalised population but no clear explanation of which members of society fit into those groups, for example:

Enabling Competency 5.2.1b) *Identify vulnerable or marginalised populations and respond appropriately, with a commitment to equity through access to care and equal opportunities.*

Various forms of the word 'rehabilitative' are mentioned but there is no further explanation of what those words mean. An example is:

KEY COMPETENCY 1.4

Use preventive, promotive, therapeutic and rehabilitative interventions effectively.

None of the enabling competencies that follow this key competency further unpack what is meant by rehabilitative interventions. An example of lack of further information is shown by:

1.5.1 Enabling Competencies

a) Demonstrate effective, appropriate and timely performance of diagnostic, therapeutic and rehabilitative procedures.

There is no explanation given in this enabling competency to address exactly what rehabilitative procedures entail.

- **Implication**

It can be deduced from this document that there is a definite attempt by the HPCSA to ensure that doctors are equipped with competencies which are a balance of the traditional medical model and the social model way of thinking. The latter entails a whole person approach that includes a patient's physical body as well as the environment, be it physical, psychological, social or occupational.

Within the document there are numerous competencies which are focused on what doctors need to know from a biological (disease-oriented) standpoint. These competencies fit with the medical model way of educating doctors.

There are however many other competencies that emphasise the importance of doctors being competent when incorporating into a clinical interaction the psychological and social elements of their patients' lives which align with a social model way of thinking.

However, this implication does not explicitly extend anywhere in the document to disability. The word disability is never used.

5.3 Findings from focus groups and in-depth interviews

- These findings address the following aims and objectives:

Aim 1: To describe what constitutes doctors' approach to disability inclusive practice.

Objectives

1.1. To critically analyse and describe the attitudes/values to the clinical encounter which characterises equitable practice with persons with disability.

1.2. To identify and describe the critical behaviours and skills of doctors which contribute to equitable practice with persons with disability.

1.3 To identify and describe key knowledge constructs which underpin equitable practice with persons with disability.

Aim 2: Describe the competencies related to knowledge, skills and attitudes, (feelings, beliefs and values) required for equitable disability practices.

Objective

2.1. Describe basic competencies (knowledge, skills and attitudes - feelings, beliefs and values) that graduate medical students should have in order to deliver a quality healthcare service to persons with disability.

5.3.1 Phase one participants

Individual participants are referenced in the following way:

PT	Physiotherapist
OT	Occupational therapist
SLT	Speech and Language therapist
RN	Registered nurse
DR	Medical doctor
Student	Medical student
Pseudonyms used	Persons with disability

- **Why pseudonyms for Persons with disability?**

DisabilityRightsWatch of Department of Social Development has asked us not to abbreviate reference to persons with disability, or any derivative thereof (Personal communication, Professor Theresa Lorenzo, August 2022).

5.3.2 Participant profiles

All the participants readily provided me with the following information:

- Persons with disability

Reference category	**Age**	**Gender + Race**	**Narrative about disability**	**Other information relevant to this study**
Delores	38	Female (coloured)	She was diagnosed with fibromyalgia five years ago. She is independently mobile and on a good day at first glance appears 100% able bodied. However, she describes how even on a good day she has to set her alarm for an hour before she has to get out of bed. This is so that she can slowly stretch her muscles and allow blood flow to them, else she is too stiff to even get out of bed. She also describes how touching a metal door handle or a tap can be excruciating. On a bad day, she is crippled with pain and is bed bound.	
Arthur	45	Male (white)	He broke his neck when he was 16 and is a quadriplegic (paralysed from the neck down). He has used an electric wheelchair for 27 years.	He is an active board member of a well-known disability related group in SA.
Marlene	41	Female (white)	She has been severely visually impaired since birth.	She is a trauma counsellor at a private physical rehabilitation unit in Cape Town.
Rose	50	Female (coloured)	She is a tetraplegic secondary to a spinal cord injury. She has been in a wheelchair for 24 years.	She is a successful businesswoman.
Randall	55	Male (coloured)	He is a tetraplegic secondary to a spinal cord injury. He has been a wheelchair-user for 16 years.	He is an active board member of a well-known disability related group in SA.

I am conscious of the fact that the profiles of the Persons with disability participants show limited diversity in the types of disabilities. In Chapter Four, (page 79) I detailed the reasons for this.

This absence of diversity with regards to types of disability (particularly psychosocial disabilities) was potentially limiting to the generation of competencies that are inclusive of all types of disabilities. I therefore prioritised finding several experts with mental health expertise, for Phase two of this study.

- Medical doctors

Reference category	**Age**	**Gender + Race**	**Work experience**	**Narrative detail if relevant to this study**
DR1	58	Male (white)	General Practitioner registered with HPCSA. 40 years working in Physical Rehabilitation Medicine in both the public and private healthcare sectors in SA, Australia and UK.	A wheelchair user.
DR2	51	Female (white)	General Practitioner registered with HPCSA. 35 years working in Physical Rehabilitation Medicine in the public healthcare sector in SA.	
DR3	71	Male (white)	General Practitioner registered with HPCSA. 52 years working in Physical Rehabilitation Medicine in both the private and public healthcare sectors in SA.	

- Physiotherapists, Nurses, Speech Therapists and Occupational Therapists

Reference category	**Age**	**Gender + Race**	**Work experience**	**Narrative detail if relevant to this study**
PT1	25	Female (black)	6 years at a Physical Rehabilitation Unit in the private healthcare sector in Cape Town.	
PT2	65	Female (white)	40 years working in both rural and urban (public and private healthcare) in SA.	
RN1	36	Female (white)	15 years in a Cape Town private hospital Intensive Care Unit.	She is part of her hospital's renal transplant co-ordination team – a multidisciplinary team.
RN2	63	Female (black)	45 years in both the public and private healthcare sectors in Cape Town.	
SLT1	33	Female (coloured)	11 years at a school for physically disabled children – with ties to the	She has an autoimmune disease so has

			public healthcare sector – in a township in Cape Town.	considerable experience interacting with doctors as a patient with a chronic condition.
SLT2	34	Female (white)	10 years at a unit for physical rehabilitation in the public healthcare sector in Cape Town.	
OT1	33	Female (white)	Eight years at a neuro-occupational therapy practise based at a few private hospitals in Cape Town.	
OT2	54	Female (coloured)	27 years as a medico-legal assessment OT in Cape Town.	Most of her clients are disabled. She could offer different insights (not purely clinical) to questions of the group.

- Medical students

Reference category	Age	Gender + Race	Disability	Year of study of degree	Narrative detail relevant to this study.
Student 1	24	Male (black)	No	6th	He has a cousin with a physical disability.
Student 2	23	Female (black)	No	5th	She does not have other personal experience with disability but is part of the UCT curriculum change working group. She is therefore well versed about curriculum reform.
Student 3	24	Male (white)	No	5th	His father is hearing impaired.
Student 4	23	Female (white)	No	5th	She has two cousins with intellectual disability, and she has done quite a lot of work with the deaf community through her church.
Student 5	22	Female (white)	No	4th	She is part of the UCT IQ Ability Group that does a lot of disability rights advocacy.

*All Phase one participants reside in the Western Cape.

5.3.3 Generation of themes from focus groups and interviews

An initial analysis of data from participants in each of the focus groups and the in-depth interviews generated between two and six themes per transcript (a total of ten transcripts). These initial themes were then reviewed altogether, and four main themes were generated.

The four themes were identified to assist in ensuring that I addressed the first aim and its objectives. Within each of these four main themes some of the themes generated from the initial analysis of the data as subthemes was used to better explain them.

THEMES	SUBTHEMES
Experience of disability	➢ Early and varied exposure ➢ Quality of clinical interactions
Attitudes towards disability	➢ Medical omnipotence ➢ Medical knowledge superiority ➢ Blinkered assumptions
Knowledge about Disability	➢ Knowledge constructs ➢ Empowered through knowledge
Life beyond the disability	➢ Self-centred vs person-centred ➢ Limited beliefs and expectations

The data from the four participant groups is referenced as follows: focus group with therapists and a nurse (FGTN), focus group with doctors (FGDr), focus group with medical students (FGMS) or focus group with Persons with disability (FGPD) or as an in-depth interview (IDI) with certain individuals from the focus groups. I have underlined various words or phrases in the findings for emphasis.

5.4 Theme One

Experience of disability

How disability is experienced or perceived not only by medical doctors but by their patients with disability can play a very influential role in whether a clinical encounter between a doctor and a person with a disability is perceived in a positive or negative light.

I use subthemes and categories to provide structure to this theme. The findings that support this theme are from all four participant groups and will be recorded under the following subthemes and categories:

	Subthemes	Categories
5.4.1	**Early and varied exposure**	Exposure to persons with disability
		Theoretical versus practical exposure
		Reminder: Individual people within one group
5.4.2	**Quality of clinical interactions**	Mechanical versus holistic approach
		Role confusion
		Fear of the unknown
		Too much focus on the impairment and disability
		Communication
		Creating a comfortable space

5.4.1 Early and varied exposure

5.4.1.1 Exposure to persons with disability

Participants explored how comfortable they felt regarding the matter of disability as well as what they understand disability to mean. PT2 shared that because she was exposed to persons with disability from a young age, it meant that she felt more comfortable and at ease interacting with persons with disability as a therapist. Although this comment is made by a therapist, anyone (medical doctors included) could feel the same as her given a similar upbringing.

PT2 answered:

Also growing up with two doctors as parents. My mother was a rehab specialist working in a UK rehab unit. I used to go with her sometimes on weekends to see patients. I think it made me very comfortable around any such patients. (PT2, FGTN, 22/4/2017).

Continuing with the idea that early exposure to persons with disability facilitates comfort and ease for anyone interacting with people with disability, is a comment by one of the medical students which relates directly to doctors. Student 1 voiced a thought that the reason why medical practitioners might avoid and be unsure of treating patients with disabilities is because it is an area of medicine with which they are unfamiliar.

My suspicion is that a lot of practitioners (medical doctors) shy away from disability medicine because it's area of medicine that's unknown to many. (Student 1, FGMS, 22/11/2019).

He believes that if doctors are uncomfortable interacting with persons with disability, they might struggle to build a rapport. The source of the discomfort may potentially stem from ignorance with respect to disability medicine and consequently would have difficulty in understanding the nuances and finding relevant solutions for their patients with disabilities. This lack of rapport might result in poor communication between the doctor and the patient with a disability. Poor communication could in this situation result in substandard care/treatment (inequitable practice).

SLT1, DR1 and DR2 raised the fact that because of their work experience with Persons with physical disabilities they feel comfortable treating and interacting with persons with physical disabilities, but they feel inadequately equipped to treat and manage persons with other types of disabilities.

Figure 5.1: This image illustrates some of the various types of impairments which can cause different disabilities (google images: esri.com).

This image emphasizes the point that exposure to all types of disability is important and can potentially foster a more equitable health care experience for persons with disability.

The exposure to persons with disability that the current UCT undergraduate medical curriculum provides students was of particular significance to this study. Student 2 described their exposure as being rather ad hoc with a type of luck of the draw situation. This ad hoc exposure results in an imbalance in the knowledge, skills and attitudes of medical graduates with respect to treating and managing persons with disability. This imbalance could contribute to inequitable practice by doctors towards persons with disability.

… you might experience patients with disabilities in your curriculum or you might not. (Student 2, FGMS, 22/11/2019)

5.4.1.2 Theoretical versus practical exposure

Many participants spoke of the importance of the difference between theoretical and practical exposure to disability. SLT1 explained this clearly. Disability is one of those subjects where she found practical exposure and knowledge to be vitally important.

You can learn a lot from books and things like that but until you're in a real-life situation, you don't really understand. Disability is one of those things that if you're not practically exposed to it, you don't really understand it until it's in your face. (SLT1, IDI, 27/5/2017)

Several other participants advocated for medical education to move away from a predominance of theory-based educational approach for medical students about persons with disability towards a more practical exposure-based educational approach. This aligns with the intention of this study to influence curriculum reform.

In her in-depth interview Delores suggested how medical students' practical exposure to persons with disability could be incorporated into their undergraduate medical studies. She feels that spending time with persons with disability outside a hospital/clinic environment and observing a person with a disability manage their daily lives would help increase the medical students' understanding of a person with a disability. With this suggestion, she offers an important potential educational strategy.

Even if they (medical students) just spend two or three hours in the life of a disabled person on home ground, that'd be really great. (Delores, IDI, 17/10/2017)

Student 2 also suggested a potential educational strategy. She made the point that medical students should be taught about disability by persons with disability or their caregivers. This strategy would expose students to persons with disability in a context where the persons with disability are their educators, rather than just their patients. It would assist in increasing medical students' awareness about the humanity of persons with disability.

> *I don't think it's efficient to have medical doctors teaching us everything about disability. We should be taught by someone who's kind of on the ground dealing with the day to day. I think there are a lot of things able-bodied educationists would miss compared to people who have to deal with it every day. (Student 2, FGMS, 22/11/2019)*

5.4.1.3 Reminder: Individual people within one group

Delores clearly describes that just because a few persons with disability might have the same disability, doctors often seem to assume that all people with the same disability can be treated in the same way and that all will have the same response to the treatment. She feels that by doing this, doctors overlook the individuality of persons with disability. This data addresses an important knowledge construct, that medical doctors need to be very aware that persons with disability are individuals and will present slightly differently, despite having the same impairment and disability.

> *And if you tell them (doctors) that type of treatment is not working for you then they want to know but if it works for the rest of the people with the same disability as you, why not you? The thing is just that we are all individuals and what works for number one won't necessarily work for number six. (Delores, FGPD, 27/5/2017)*

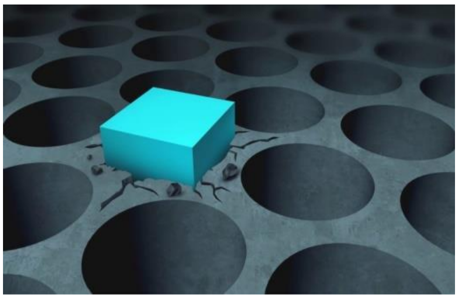


Figure 5.2: This image shows how damage is done by forcing a square peg into a round hole (google images: aboundingsolutions.com).

The other Persons with disability participants voiced strongly that doctors should view those with disability as distinctly different individuals. They were not the only ones to raise this issue. Several of the therapists reiterated the need to remember the heterogenous nature of persons with disability.

Rose then went a step further to explain why she thinks doctors might overlook the individuality of a person with a disability. She describes how she feels that limited exposure to a variety of disabilities results in doctors labelling all persons with disability the same.

I think it's ignorance. I don't think they get exposed to people of various disabilities and therefore have limited labels for disability. (Rose, IDI, 14/10/2017)

The data of this subtheme is building a clear case for the early exposure of medical students to persons with disability and disability as a subject.

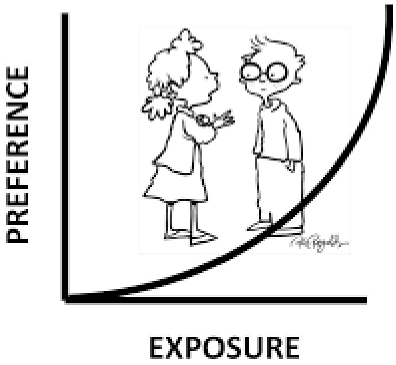


Figure 5.3: The picture shows how the more exposure someone has to someone else, their preference for that other person increases (google images: conversion-uplift.co.uk).

Increased preference will in all likelihood influence behaviour. The potential effect of exposure on behaviour paves the way for the next subtheme.

5.4.2 Quality of clinical interactions

Figure 5.4: As this image illustrates, this subtheme looks at barriers or factors that positively or negatively influence interactions (google images: playbuzz.com).

5.4.2.1 Mechanical versus holistic approach

In response to being asked whether she had had any positive experiences/interactions with a doctor and if so, what made them positive, Rose was very clear in saying that for her, the positive experiences were in the definite minority.

I don’t remember when I had that positive experience with a doctor… (Rose, FGPD, 27/5/2017)

She continued by describing a very mechanical action (script writing) by a doctor as being one of the few positive interactions that she has had with doctor. Such a mechanical action like script writing does not take much time or require the doctor to interact much with the person with a disability. Although she views this action as positive, it in fact speaks to absences/negatives in doctors' attitudes and skills towards persons with disability.

…but sometimes it is good when you go into some clinic saying you need a script for a urine infection and a doctor will just say to you, "Okay, here's a script." (Rose, FGPD, 27/5/2017).

Arthur felt differently. He told his group that he had had quite a few positive experiences/interactions with doctors. He explained the fact that his current GP makes time to get to know him and his lifestyle helps make the experience/interaction a positive one. Every patient (able-bodied and disabled) is likely to find their interaction with a doctor a positive experience if the doctor remains cognisant of the whole patient and values their humanity. This is a significant issue for persons with disability. Persons with disability are often viewed in society as being less than the average human being, and this perception can therefore make it difficult for them to be treated as valuable human beings, with more to their lives than just their disabilities.

I have had quite a few positive experiences with doctors. My GP, he makes time to really know me and my lifestyle. (Arthur, FGPD, 27/5/2017).

5.4.2.2 Role confusion

RN1 raised a different potential barrier to a doctor/person with a disability interaction. She explained that not being sure of her role affects her comfort levels when interacting with a person with a disability. The ensuing interaction is awkward and interrupted by her questioning and second guessing herself. This data is from a nurse, but nurses work very closely with doctors and would have similar interactions with patients.

A hospital can give you context where you feel comfortable because you know what your role (with persons with disability) is and what is expected from you in a purely medical sense. Whereas with the social circumstances, I ask myself, "What is my role?" I feel unsure. It's something that all health professionals should know. (RN1, FGTN, 22/4/2017)

5.4.2.3 Fear of the unknown

PT2 used a personal story to discuss what she viewed as another potential barrier to doctor/person with a disability interaction. She believes this story illustrates the fact that anyone (doctors as well) can be and usually are fearful of beings (e.g., a person with a disability such as her nephew) to which they have had no exposure and therefore do not understand them (i.e., dealing with unknown/other stranger). This data explains how an attitude and behaviour of avoidance can result in a negative, a limited or no interaction with a person with a disability, further perpetuating any stigma attached to disability. If doctors have similar attitudes and behave similarly, these will most likely contribute negatively to the clinical encounter between medical doctors and persons with disability.

I've got a physically and severely mentally handicapped nephew. But I mean – he is quite intimidating to someone that doesn't know him.

But people that know him love him. People that don't know him are fearful because they don't understand him. I think a lot of people - doctors included - are fearful of something (like disability) if they're not exposed to it and they don't understand it. (PT2, IDI, 21/10/2017)

5.4.2.4 Too much focus on the impairment and disability

In response to the question, "What have you observed in how doctors manage or treat persons with disability?" RN2 raised another potential barrier to interactions between a doctor/person with a disability. RN2's response shows that doctors frequently focus only and far too much on the person's actual impairment and disability (e.g., blindness or paraplegia) and not enough on the whole person and their health condition. She raises a key issue here that a more holistic focus could improve quality of care.

Often with doctors, the disability itself is the only thing addressed, not the whole patient. As a result, treatment can be quite limited. (RN2, FGTN, 29/4/2017)

Figure 5.5: An illustration showing how individual/impairment focused the medical model can be (google images: slideplayer.com).

Many of the Persons with disability participants echoed this feeling that many doctors have a narrow focus. However, the Persons with disability participants spoke more about the fact that doctors place too much attention on their disability and what caused them to become disabled in the first place. This meant that the fact that people with a disability are prone to the same general medical conditions as any able-bodied person was often overlooked or there was a delay in them receiving treatment. Randall voiced this clearly,

Yes, you have medical problems related to your disability but you don't always go see the doctor because of your disability. You have other medical conditions just like anyone else. (Randall, FGPD, 27/5/2017)

This data relates to the section in Chapter Two where I review the benefits and limitations of the medical model of disability and to my Chapter Three conceptual framework of the ICF – also mentioned in Chapter Two - which provided my study with a helpful tool through which to view disability.

Rose explained in strong, powerful words that she finds it a very negative experience when doctors focus on her disability too much. In the following data quote from Rose, it is evident, that this doctor seemingly had great difficulty in negotiating the traditional power dynamic that exists between doctors and patients. This is the dynamic that places medical doctors as being above or superior to their patients. This dynamic exists in the relationships many medical doctors have with all their patients (able-bodied and disabled).

There is perhaps a greater power differential in the relationship between doctors and patients with disabilities because of the widespread stereotype that persons with disability are less human/valuable than able bodied people. It is therefore important that doctors are competent in negotiating this power dynamic with persons with disability.

Initially when you visit a doctor they treat you as an imbecile. They first want to know what happened to you? What date? Blah-blah-blah. That's the information they always want to gather first. (Rose, FGPD, 27/5/2017)

The above data quote raises issues similar to the framework of decoloniality I am using for this study. In colonial medicine there has historically been a very firmly established power differential between doctors and patients and in particular patients with disability. Thinking about and challenging these established power dynamics aligns with one of my other Chapter Three conceptual frameworks: Critical Disability Studies.

5.4.2.5 Communication

Student 1 relayed a story to his focus group, that raised yet another potential barrier to a positive and equitable clinical encounter between a doctor and a person with a disability. He described how doctors' inability to communicate adequately with an HIV+ deaf patient meant that she received very limited care and management because none of treating doctors knew sign language or thought to use an interpreter. While it is unfair to expect doctors to be fully competent in all different languages, doctors should be equipped with the knowledge that wherever there is any difficulty in communicating with a patient with a disability, they need to take more time and perhaps think of creative ways to ensure that they communicate effectively with their patient.

During my surgery rotation I saw a patient who was deaf and HIV positive. She hadn't been taking the HIV medication. Nobody had explained it properly to her. (Student 1, FGMS, 22/11/2019)

The awareness (mentioned in the above data) of a doctor's consultation with patients with disabilities needing more time, highlights another potential barrier to persons with disability receiving quality care from medical doctors.

5.4.2.6 Creating a comfortable space

DR2 spoke directly to how a doctor needs be skilled at making a patient with a disability feel like the s/he has as much time for the patient as is needed. She explained that by creating atmosphere of unlimited time, a doctor not only allows the patient with a disability to feel comfortable and safe, but that they (the doctors) are then able to observe the patient better.

When a patient with a disability has a doctor's consultation, you (the doctor) must create an atmosphere that you've got all the time in the world even if you do not have. You must observe. You must create an atmosphere of confidentiality, open communication and comfort for the patient. (DR2, FGDr, 06/05/2017)

In her in-depth interview Delores relayed an experience she had had with a medical doctor. This story illustrates the point the above data makes about a doctor needing to create a non-rushed and comfortable atmosphere for patients with disabilities. This doctor made <u>her feel very rushed, and the resulting interaction was a negative experience for her.</u> This is unfortunately an often-heard story from both abled and disabled patients which is indicative of an overburdened health system.

> *I remember one time when I went to see doctor. My body was extremely sore. I tried to explain to him where in my body the pain was. While I was explaining my head off, doctor was looking everywhere, except at me. When I finished, all doctor did was look at me and then he looked at his watch. All he told me was, "Sorry Mam I only have 15 minutes per person and I still need to get to lunch." He never even looked me in the eye while he's speaking.*
>
> *It was a horrible experience. (Delores, IDI, 17/10/2017)*

This subtheme highlighted several potential barriers to doctors affording persons with disability, quality healthcare. Treating them in an empathetic and holistic manner underpins this subtheme which acts as an important link to the next subtheme.

One of the greatest barriers to interactions between doctors and persons with disability are the attitudes (thoughts and perceptions) of doctors towards disability.

5.5 Theme Two

Attitudes towards disability

When there is a difference present (such as with persons with disability) in any interpersonal interaction, the attitudes (thoughts and perceptions) of the individuals without the difference towards the different Person, can greatly influence whether the interaction is perceived in a positive or negative light by the individuals with the difference. In terms of the interaction between a usually able-bodied doctor and a patient with disability, it is very important to understand more about how certain attitudes might influence a patient with disability’s perception of their clinical encounter with a doctor.

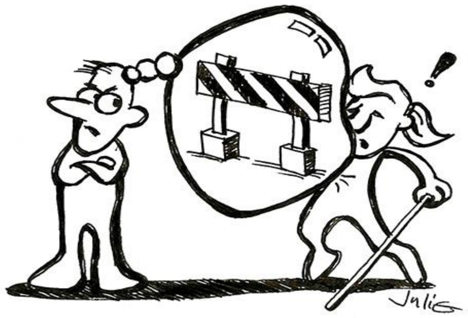


Figure 5.6: An image showing how attitudes can result in barriers for persons with disability (google images: endthecycle.info).

The findings that support this theme are from all four participant groups and will be recorded under the following subthemes and categories:

	Subtheme	Category
5.5.1	**Medical omnipotence**	Arrogance creates a power differential
		Arrogance prevents further learning
		Arrogance prevents potential knowledge sharing
		Ways to combat arrogance
5.5.2	**Medical knowledge superiority**	Know your knowledge limits
		Be openminded about knowledge sharing
		Really listening
5.5.3	**Blinkered assumptions**	Disability = weak or vulnerable
		Any disability = reduced mental capacity
		Rendering a person with a disability invisible

		No visible disability therefore normal
		Desexualisation of persons with disability

5.5.1 Medical omnipotence

5.5.1.1 Arrogance creates a power differential

PT2 was very expressive in telling her focus group that she thinks that many doctors have an attitude of godliness. She feels that this attitude creates a power differential between doctors and patients. This can relate to the relationship between a doctor and all patients (able bodied and disabled). However, this is perhaps particularly pertinent to patients with disabilities because of the stereotypical societal mindset/attitude that persons with disability are of less value and worth than able-bodied members of society. The combination of these two attitudes is likely to increase the power differential in the relationship between doctors and patients with disabilities. This data raises an important issue. Doctors must be competent in the awareness and understanding that they (doctors) are not above everyone else in society.

But I do think there is an attitude of some doctors - they think they're God-like. I think that is a terrible disadvantage for anyone to think that they are superior to anybody else. (PT2, FGTN, 22/4/2017).

5.5.1.2 Arrogance prevents further learning

Arthur agreed with PT2's statement that doctors tend to think that they are God. He thinks that such an attitude is very limiting to a doctor's acquisition of new knowledge. This data describes how a Godlike attitude can negatively impact a doctor's ability to further their own learning. Displaying the commitment to self-learning/ongoing learning requires a certain way of behaving, as well as the skills to acquire further knowledge. Doctors need to therefore develop a competency in this skill.

Disability is a multifaceted and constantly evolving topic. A commitment to self-learning/ongoing learning is therefore vital.

Some doctors think that they are above everyone else, and they think they're God. And they think they know everything. (Arthur, FGPD, 27/5/2017)

5.5.1.3 Arrogance prevents knowledge sharing

Delores expressed her view quite strongly about medical omnipotence. She thinks that doctors think that because they have a medical degree, they know better than the patient what's wrong with the patient. This data speaks to the next sub-theme, which is medical knowledge superiority and addresses the idea of knowledge sharing between doctors and patients with disability. This type of attitude and behaviour from a doctor would clearly contribute negatively towards an ensuing clinical encounter.

Doctors think like this: "I'm the doctor. You're the patient. I went to study for this. I can tell you what is wrong with you".

> *I tell him, "Doctor I have not been to university to study, but it's my body. I know it. I know where my pain is. I know what I'm capable of and what I'm not. So please don't tell me that you know better what's wrong with me." I normally excuse myself then and I'll leave. (*Delores, *FGPD, 27/5/2017)*

5.5.1.4 Ways to combat arrogance

This interaction between the facilitator and Student 2 illustrates the stereotypical societal mindset/attitude that persons with disability are of less value and worth than able-bodied members of society. Student 2 uses the words "more valuable" to describe how society views an able-bodied member of society. This data addresses the very definition of a stereotype, which is a widely held but fixed and oversimplified view or idea about a particular person or thing. This stereotype is one that medical students are likely to have upon entering medical school. This is a good example of why doctors need to develop a competency in the ability to recognise and interrogate any societal stereotypes about persons with disability that may exist within them.

> *Facilitator: Have we created a disability because it's this world that says you need to speak fluently otherwise you are not considered as smart or you know, well rounded, whatever. You could be speaking a lot of nonsense but if you say it very nicely then you come across as being a lot more well-spoken and your ideas mean more.*
>
> *Student 2: You are thought to be more valuable. (Facilitator and student 2, FGMS, 22/11/2017)*

A few participants suggested that doctors must be competent in non-verbal communication. Non-verbal communication skills competence could help combat an attitude of medical omnipotence and build rapport. This idea of rapport-building ties in with the idea of decolonising both medicine and disability. Positive non-verbal communication could help to break the traditional/colonial barriers that maintain the separation between doctors and persons with disability in clinical settings.

Figure 5.7: An image showing an example of non-verbal communication (google images: nurseswritingservices.com).

This subtheme focusses on how many doctors have an attitude of omnipotence/arrogance. This is closely linked to the next subtheme of medical knowledge superiority. An attitude of omnipotence in medical doctors is very likely to result in doctors thinking that their medical knowledge is always superior to patients and even other healthcare professionals.

5.5.2 Medical knowledge superiority

5.5.2.1 Know your knowledge limits

This data from DR3 stresses that a doctor needs to know that their knowledge has limitations. This will hopefully lead to an attitude of "I don't know everything" and to behaviours which emulate that attitude. Medical students need to develop competency in the fact that they as doctors cannot and do not know everything.

Being able to refer to the appropriate specialist doctors when you do not have the answers yourself, is in fact a skill. This skill needs to be developed at medical school so that medical students can competently enter their careers as doctors.

Well, the attitude should be, I don't know everything. The attitude is you must have an open mind and be prepared to refer to somebody who knows more than you. The biggest problem with medics is they do not refer to the appropriate people. (DR3, FGDr, 06/05/2017)

5.5.2.2 Be openminded about knowledge sharing

Arthur added to DR3's data by saying that doctors need to be openminded about how they learn and from whom they learn. He raises the important point that doctors need to be competent in the knowledge that their patients are a valuable knowledge resource.

Be willing to learn and be able to learn from your patients with disabilities and other doctors. (Arthur, FGPD, 27/5/2017)

SLT1 agreed with DR3 and Arthur. She mentions that doctors need to be open to the fact that they (doctors) don't need to make all the decisions or always have the final say. She makes a very important point when she says,

"They can work in a team." (SLT1, FGTN, 22/4/2017).

5.5.2.3 Really listening

OT1's contribution below is a good example of how doctors need to develop a competency in negotiating the power dynamic with their patients, being able to listen to patients in a way that would contribute positively and be armed with the right knowledge and attitude to successfully perform the skill of really listening.

Learning how to listen without pre-empting the answer with what you as a doctor think about how a situation should be and rather listening to what it really is. (OT1, IDI, 24/05/2017)

Arthur agreed with OT1. His group was asked what makes a clinical encounter with a doctor negative. He finds it negative when a doctor doesn't really listen to the patient with the disability and instead does what they (the doctor) think is right.

When the doctor seems to listen to you but does the opposite. (Arthur, FGPD, 27/05/2017)

This subtheme of medical knowledge superiority links well with the next subtheme of assumptions, because if a doctor believes that they know what is best and that they always have the right answer, they are more likely to make assumptions.

5.5.3 Blinkered assumptions

5.5.3.1 Disability = weak or vulnerable

In his in-depth interview Randall described a scenario which illustrates how quickly assumptions can be made about persons with disability. The immediate assumption that just because he was in a wheelchair he needed medical care, made him question his self-perception.

> *I took my daughter to the hospital and upon entering the casualty section the focus was more on me being in a wheelchair and not the fact that she was standing clearly unwell next to me. The staff immediately indicated that she should push me towards the triage area and then she has to go and open a file at reception.*

They should have asked first. Their first thought seemed to be; <u>he's sitting in a wheelchair so she is bringing him in for treatment.</u> I was thinking after, maybe I looked a little bit weak or vulnerable at the time. (Randall, IDI, 19/8/2017)

Randall said that the assumption made him feel "insignificant". This is a strong word. Synonyms for insignificant are unimportant and meaningless. He felt as if he was not allowed to come to the hospital looking the way he did (him being in a wheelchair). He describes very well how such an assumption affected his sense of self-worth. These two pieces of data illustrate the fact that doctors need to be competent in the ability of not making assumptions.

I felt very insignificant. It was as though I had not the right to enter that hospital in my wheelchair. (Randall, IDI, 19/8/2017)

5.5.3.2 Any disability = reduced mental capacity

PT2 mentioned another assumption that she has noticed many doctors make, which is that being disabled in any way is automatically synonymous with reduced mental ability. A key point to note is her saying that "most doctors" behave this way. She is making it clear that there are exceptions. This attitude and behaviour from a doctor is likely to cause feelings of irritation and frustration in the person with a disability, which will negatively impact their clinical encounter with this doctor.

It seems to me that most doctors find it more difficult to treat or speak to disabled patients. They just shout. It's almost -- if you're disabled, you can't mentally comprehend things. (PT2, FGTN, 22/4/2017)

5.5.3.3 Rendering a person with a disability invisible

Arthur finds it extremely rude and offensive when a doctor assumes he has reduced mental capacity.

A doctor has been to university for long enough to know that he should speak to me and not to my assistant. So, in that instance it's very ugly – it's bad. It's actually rude. (Arthur, FGPD, 27/5/2017)

Delores argued that when doctors refer to people with a disability in the third person, they (the doctors) remove the person with a disability's voice. She thinks that this sort of behaviour is sometimes forgivable if it comes from an uneducated person. She sees doctors as educated people and there is therefore no excuse for such behaviour, which shows a disregard for a person with a disability's humanity and renders them invisible.

Why refer to you as the patient in the third person. Our voice is taken away by that. You can excuse sometimes if it's an ignorant person or uneducated person. But when it's the medical profession it's inexcusable because they are not uneducated. (Delores, FGPD, 27/5/2017)

When the facilitator asked the Persons with disability participants how doctors address them, she got some good examples.

> *Rose: The carer is asked... How's she (person with a disability) doing?*
>
> *Randall: Bring her in here.*
>
> *Arthur: Has he been drinking enough water? How's his appetite?*
>
> *Delores: You become the third person. (Discussion between the facilitator and Rose, Randall, Arthur and Delores, FGPD, 27/5/2017)*

5.5.3.4 No visible disability therefore no disability

DR1 shared a story about an ex-colleague who had had a brain haemorrhage and as a result was visually impaired. He makes a very important statement:

You wouldn't think this lady is disabled because she appears completely normal. (DR1, FGDr, 6/5/2017).

He is illustrating that when the disability is not obvious, for example, a person who is not in a wheelchair it is often assumed that a person is not disabled. Such an assumption/approach by a doctor could result in inappropriate or incorrect treatment and management. Doctors need to therefore be competent in the knowledge that not all disabilities are easily visible.

5.5.3.5 Desexualisation of persons with disability

Yet another common assumption made has to do with the desexualisation of disabled bodies. Many able-bodied doctors assume that a person with a disability is not capable of an intimate relationship. Therefore, the doctor will not have any health discussions related to the issue. SLT1 thinks it is foolish to make such an assumption. She also raised the issue of human rights when she states that persons with disability have just as much right as able-bodied people to have sexual health issues discussed with them.

Something silly that people say, "Oh people with special mental, physical or intellectual needs – no one needs to teach them about contraceptives. They don't need to know anything about sexual health." It's silly. They have just as much right as any able-bodied person, to contraceptives etc. (SLT1, IDI, 27/5/2017).

An important potential influencer of an individual's attitude towards disability is the extent of knowledge that they have regarding the subject.

5.6 Theme Three

Knowledge about Disability

The extent of an individual's knowledge about any subject has the potential to influence that individual's attitude and behaviour towards that subject. The societal prejudices about disability are pervasive and might be an additional influencer of a doctor's attitude and behaviour towards disability. A solid arsenal of Knowledge about Disability would hopefully allow doctors to not only challenge these societal prejudices but also contribute to a disability inclusive medical practice.

The findings that support this theme are from all four participant groups and will be recorded under the following subthemes and categories:

	Subtheme	Category
5.6.1	**Knowledge constructs**	Basic knowledge about Disability
		The same medical conditions affect able-bodied and disabled people.
		Know what questions to ask
		More knowledge needed about psychosocial disabilities
		Ways of imparting knowledge
		Medical knowledge about Disability vs lived experience of disability
		Multidisciplinary knowledge is important
5.6.2	**Empowered through knowledge**	Claiming autonomy
		Evidence of positive shifts

5.6.1 Knowledge constructs

5.6.1.1 Basic knowledge about Disability

Figure 5.8: This image visually represents basic knowledge (google images: alamy.com).

Student 2 observes that surely the subject of Disability is no different from the other subjects learnt at medical school. In this context common/basic knowledge refers to the knowledge in the undergraduate medical curriculum aimed at the level of a General Practitioner (GP). It must be remembered that this study's Disability competencies are aimed at the level of a GP. This data recognizes the need for doctors to be competent in basic Knowledge about Disability.

> *I understand that we won't be able to be taught everything. But in med school where people like to say common things are common all the time about diseases etc, well it must be the same for disability surely…. that common things are common. I think that there should be a teaching block allocated. (Student 2, FGMS, 22/11/2019)*

Rose agreed with the idea that GPs should be equipped with basic knowledge about disabilities.

With a GP you wouldn't expect them to have specialist knowledge but basic general knowledge. Things like spinal cord injury, they should know that. They should know when the spinal cord is damaged at a certain point what the extent of it is. (Rose, FGPD, 27/5/2017)

5.6.1.2 The same medical conditions affect able-bodied and disabled people.

DR1 raised an important point. Knowledge and awareness of this point will undoubtedly contribute positively to the quality of healthcare that persons with disability receive from medical doctors.

Medical doctors should be really well trained that there are conditions that don't only develop in disabilities. They develop in abled bodied people as well. (DR1, FGDR, 6/5/2017)

5.6.1.3 Know what questions to ask

DR3 describes how a man who had seemingly recovered from a spinal cord injury received no follow up after discharge and developed secondary complications. DR3 uses this story to stress the importance of knowing that as a doctor, you must be extremely thorough in your history taking with a patient with a disability. As is evident from the story, failure to address such questions can have extensive consequences for the person with the disability. Importantly, doctors need to be competent in creating an environment where the patient feels comfortable enough to share personal information.

> *There was a mine worker who had a lumber spinal injury but he recovered "completely" in inverted commas. He was discharged from hospital but never followed up. He developed secondary complications which caused major marital and occupational problems…*

> *He was luckily referred to a neurologist who had experience in spinal cord injuries, asked the right questions and he made the diagnosis. It's very important that people take a very careful history. You mustn't be worried about asking very personal questions when you're consulting with a disabled person. (DR3, FGDr, 6/5/2017)*

DR3 added that another important question to ask a patient with a disability is, *"Have you consulted any other doctors about your complaint?"*

He thinks this question is particularly relevant to patients with psychosocial disabilities. The knowledge needed here is that doctors must know why it is important to ask these specific questions because of polypharmacy.

> *The reason is especially with psychiatric patients – they shop around, often seeing numerous doctors, and they end up with shopping list of drugs. And you know, so one doctor gives them drugs and the patient goes for a repeat script to another doctor who prescribes more medication – and those might interact. So, you must be very specific and say, "Have you consulted any other doctors about your complaint? (DR3, FGDr, 6/5/2017)*

5.6.1.4 More knowledge needed about psychosocial disabilities

PT1 mentioned to her focus group that she feels that mental disability (she is referring to psychosocial disabilities) is an important issue and considers it a knowledge gap in their university education. Although this data is about the physiotherapy curriculum, it raises the question about whether the medical curriculum – also a health science - has a similar knowledge gap. This data stresses the importance of all health professionals being competent in their knowledge about psychosocial disabilities.

I think mental illness is terribly important. We had no real training about how to deal with mentally disabled patients at all at university. (PT1, FGTN, 22/4/2017)

5.6.1.5 Ways of imparting knowledge

Student 1 answers the question raised by PT1's data above. This will likely result in medical students having a limited view on the treatment modalities for mental health issues.

We get taught a medical approach to a patient with mental illness. In fact, it's very disease orientated only. (Student 1, FGMS, 22/11/2019)

This data quote is in line with traditional teachings of the medical model of Disability which evidently does not equip doctors with sufficient knowledge to adequately treat and manage patients with disabilities. A point supported by my Chapter Two Literature Review.

Aside from addressing a key knowledge construct, this data emphasises the need for doctors to develop competency in a biopsychosocial/holistic approach to mental disability. This approach is in fact important to patients with any disability. Doctors need to also be competent in managing the socio-economic and socio-political aspect of disability, i.e., doctors need to extend their focus beyond just the medical situation.

Interestingly, Student 3 held a different view about the university's teaching of disability as a subject. She feels that the curriculum does teach a more holistic approach to disability.

I came into university seeing disability as only being impairment related. I think the one thing I have really learnt at university partly because of the curriculum is disability is also about the effect that society has on the impairment of persons with disability. (Student 3, FGMS, 22/11/2019)

5.6.1.6 Medical knowledge about Disability vs lived experience of disability

Randall finds it negative when doctors do not value persons with disability's experiential life knowledge. Doctors need to be aware that they (doctors) are not the only owners of worthwhile knowledge (a key knowledge construct). Such a competency should lend itself to a more open-minded attitude by doctors to give the experiential life knowledge of persons with disability due consideration.

It's horrible when doctors disregard the fact that you have some experience. Not medical experience but life experience. (Randall, FGPD, 27/5/2017)

Further on in his group, Randall made a case for why he thinks doctors should really listen to a person with a disability's life knowledge.

Any persons with an impairment causing a disability (any type of disability) would have a similar wealth of experiential life knowledge about their own bodies in relation to their impairments and disabilities.

I'll go because I feel the onset of bladder infection. The doctor will often not listen to me and delay by starting with unnecessary blood tests. I end up wanting to tell the doctor: Listen to me, this has been my complaint/disability for 17 years already, so I know what I'm feeling. (Randall, FGPD, 27/5/2017)

This issue speaks to the need to move away from the traditional colonial view that the medical knowledge of a doctor is superior to any knowledge persons with disability might have.

5.6.1.7 Multidisciplinary knowledge is important

Student 4 raised the important point that medical students need to be better armed with multidisciplinary knowledge and he suggests that multidisciplinary learning be a curriculum priority; essential given that persons with disability often consult various health professional disciplines to appropriately manage their needs.

Figure 5.9: An image depicting the different knowledge (puzzle pieces) members of a team can add (google images: medbriefnamibia.com).

Better knowledge and understanding of multidisciplinary role players will hopefully result in a more equitable medical practice with persons with disability. A strong case is being made here for the fact that doctors need to develop a competency in multidisciplinary knowledge.

We have a program that encourages multidisciplinary interactions. But there isn't enough time to learn how to refer appropriately and what for example Occupational Therapists do. It's a good move that the faculty has done but I think that is worth a more serious engagement. (Student 4, FGMS, 22/11/2019)

DR1 agreed with Student 4's data above. He (DR1) stressed the importance of a doctor having good multidisciplinary knowledge. He described how he taught medical students who rotated through a rehabilitation unit he had worked in.

The medical student needed to be present with the patient whenever the patient would have some sort of therapy. I thought that was also gaining – giving them some insight. (DR1, FGDr, 6/5/2017)

The fact (raised by 5.6.1.6) that people live with disabilities and need to manage by themselves raises the important issue of the next subtheme, which is 'Empowered through knowledge'.

5.6.2 Empowered through knowledge

5.6.2.1 Claiming autonomy

DR1 explained that it is very important that doctors should be empowering patients with disabilities with the knowledge that will allow them to take charge of their disabilities. Sharing a doctor's reasoning behind the treatment plan with the patient should assist in better equipping patients to manage their disability in relation to people that they have regular and often daily interactions with, such as family members.

Medical students need to graduate competent in the knowledge and awareness of why empowerment through knowledge is necessary and important for patients with disabilities, as well as having the skill to do so.

Explain to the patient with a disability why you are doing what you are doing and the reason behind it. I think the patient needs to oversee their own disability and health to manage the people around them. (DR1, FGDr, 6/5/2017)

Student 1 agreed with DR1 that empowerment of patients with disabilities is an important doctor responsibility.

The medical practitioner in that encounter is the person with seemingly more power. Then the onus is on the doctor to try and meet the disabled person where they are and not the other way around. (Student 1, FGMS, 22/11/2019)

5.6.2.2 Evidence of positive shifts

There is evidence of positive change with respect to disability empowerment according to SLT1, who comments that in the recent past, she has observed many patients with disabilities with whom she works, experiencing clinical encounters with doctors with greater knowledge empowerment. Transformational shifts in relationship dynamics between doctors and persons with disability could be at the heart of this shift. These changes in relationship dynamics are not only determined by the doctor but also by the personal agency of the patient.

In the eight years that I've been working, there's a definite difference recently in how patients with disabilities are coming back from their doctors' visits able to give us feedback.

I do feel like people are taking much more responsibility for their own health and disability. I think that's a big strength. (SLT1, FGTN, 22/4/2017)

Equally as important as ensuring that a doctor has a solid knowledge base about disability, is ensuring that doctors can appreciate that persons with disability have lives beyond their disabilities, the focus of Theme Four.

5.7 Theme Four

Life beyond the disability

There is a pervasive societal trend towards focussing intensely on any differences within humanity. As a result, one can forget that these differences are only a small part of an individual's life. This focus prevents us from exploring the rest of a person from their differences in life. This is an extremely limited and limiting approach. Society is full of such differences – religious, cultural and LGBTQI to name a few – but this research focusses on the difference of disability.

In terms of a doctor's medical practice with persons with disability, such a narrow approach is likely to contribute negatively to said medical practice. It is important that the idea that there is 'more to a person with a disability' be explored and brought to the attention of medical doctors.

The findings that support this theme are from all four participant groups and will be recorded under the following subthemes and categories:

	Subtheme	**Category**
5.7.1	**Self-centred vs Person-centred**	What does the patient with the disability want?
		What is the cultural context of the person with the disability?
		Value the humanity of persons with disability
5.7.2	**Limited beliefs and expectations.**	Disability is just a part of diversity
		Disability does not automatically disqualify one from other roles
		The right interventions can improve quality of life

5.7.1 Self-centred vs Person-centred

Self -centred refers to the doctor's attitude, i.e., a self-absorbed doctor and

Person-centred refers to how the doctor should treat their patients with disabilities.

5.7.1.1 What does the patient with the disability want?

SLT1 thinks that quite often doctors overlook the patient's goals. This data addresses the important point that doctors need to develop a competency in a client-centred approach.

> *Doctors don't always look at the patients' goals. For example, with physical rehab of a patient with a disability. Their walking might not great, but because they are mobile, they have achieved some goals according to the doctor. There isn't really the space for the patients to say our goals are bigger… (SLT1, FGTN, 22/4/2017)*

Figure 5.10: An image showing some of the different goals that might be important to any individual regardless of ability (google images: dreamstime.com).

In her in-depth interview SLT1 explained that most doctors focus on functionality only. This focus often fails to acknowledge the patient's needs and desires.

> *I think many doctors get stuck on functional ability and miss the bigger picture of what the patient really wants for their life. For example, I work with learners that have contractions in their hands. Often doctors will say, "That's just cosmetic surgery to straighten the hand and it won't help you use it, so you don't need to do the surgery." However, that individual wants their hand to look a certain way to help them have a better body image and more confidence. (SLT1, IDI, 27/5/2017)*

5.7.1.2 What is the cultural context of the Person with the disability?

OT1 believes it is important to consider a patient with a disability's cultural context. She thinks that an individual's cultural beliefs about medicine and Disability can hugely influence their acceptance of and adherence to treatment and management plans. There is a need for doctors to develop a competency in the knowledge of the intersection of culture, medicine and Disability.

Doctors need to consider different cultural attitudes to medicine and to disabilities. Cultural beliefs can impact treatment success. (OT1, IDI, 24/5/2017)

Cultural competency amongst doctors is a particularly relevant competency in South Africa because of its cultural diversity. Knowledge of cultural context in relation to persons with disability is aligned with this study's frameworks of the ICF, Critical Disability Studies and decoloniality.

5.7.1.3 Value the humanity of persons with disability

Marlene stated that a people's person/empathic approach by a doctor would contribute to a more positive experience for patients with disabilities. In giving them a sense that the doctor is trying to get to know more about their life, the doctor is validating the humanness and worth of the patient with a disability. Often in society at large, persons with disability' humanity is not valued. It is vital that doctors who are held in high regard by society, do value the humanity of persons with disability so that through example, doctors can hopefully educate society. Consequently, doctors need to develop a competency in adopting an empathetic approach. It is also important to advance a competency of understanding of their role as educators (and influencers) in society.

…feeling like this doctor is trying to get to know you and your life better. That's a nice feeling. Just a people's person approach. (Marlene, FGPD, 27/5/2017)

This subtheme paves the way for next subtheme titled 'Limited beliefs and expectations', which can be viewed as an extension of self-centredness (i.e., when the doctor only acknowledges their own opinion and does not give any credence to the opinion of the person with a disability).

5.7.2 Limited beliefs and expectations

5.7.2.1 Disability is just a part of diversity

Randall stated that doctors should treat persons with disability and able-bodied people equally. This also means that the doctor's beliefs and expectations about a person with a disability's life beyond their disability should be no different to their (the doctor) beliefs and expectations about any other patient's life. Doctors need to develop a competency in the ability to not only respect diversity but to also understand and value it.

Disability should also be regarded as a form of diversity. treat disabled people, and able-bodied people equally. (Randall, IDI, 19/8/2017)

Figure 5.11: An image depicting the equal (balanced scale) treatment of persons with disability and able-bodied persons (google images: canstockphoto.com).

5.7.2.2 Disability does not automatically disqualify one from other roles

PT2 strongly expressed how she felt upon hearing what questions other doctors asked a wheelchair-user surgeon friend:

I felt speechless that he was asked questions such as, "Are you really a doctor?" and, "How are you a doctor?" (PT2, FGTN, 22/4/2017)

Oxford Language Dictionary defines speechless as "unable to speak, especially as a temporary result of shock or strong emotion."

The effect of such questions based on limited beliefs and expectations is likely to impact negatively on the individual with a disability's emotional state and in particular their self-belief. This data implies a view that his disability disqualifies him from certain societal roles, which will almost certainly contribute negatively to any medical interaction.

This data quote is an excerpt from a story Randall told about taking his daughter for emergency medical treatment. The medical staff immediately assumed that because he was in a wheelchair, that he was the patient, as first mentioned in subtheme 'Blinkered assumptions' (see page 135). This inability to recognize that he could be a parent (with a disability) with a hurt child, upset him. It demonstrates quite clearly how a doctor's limiting beliefs have a negative emotional impact on the person with a disability.

The attitude seemed to be, he can't be the parent. (Randall, IDI, 19/8/2017)

5.7.2.3 The right interventions can improve quality of life

DR2 feels that doctors have an important role to play in ensuring that their patients with disabilities reach their (the patients') maximum potential in their lives (i.e., the best quality of life possible). She describes numerous interventions which could assist in this regard. Competency in this knowledge will hopefully allow doctors to develop the attitude and the skills needed to practically implement this knowledge in their practice with persons with disability.

There's a lot of things that doctors can do to improve the quality of life of a person with a disability and help them reach their full potential – such as assistive devices, rehabilitation, home adaptations, community integration and helping an individual become financially independent. (DR2, FGDr, 6/5/2017)

5.8 Summary of competencies generated from each theme

5.8.1 Theme One – Experience of disability

Subtheme one:	**suggests several competencies:**
1	Medical students must be knowledgeable of the fact that the **definition of disability is very broad.**
2	Medical students must be skilled in **interacting with a person with a disability.**
3	Medical students must **develop an empathic approach to a person with a disability**.
4	Medical students must have the knowledge and skills, which will enable them to **individualize the treatment and care of persons with disability.**
5	Medical students need to be taught **to value all their patients equally.**

Subtheme two:	**suggests several competencies:**
1	Medical students must be equipped with the knowledge that **persons with disability are susceptible to the same general medical conditions as able bodied people.**
2	Medical students need to be educated about the **common secondary complications of various disabilities.**

5.8.2 Theme Two – Attitude towards disability

Subtheme one	**highlighted an important competency:**
1	Medical students must be aware that they are **not superior to their patients, especially patients with disabilities.**

Subtheme two	**highlighted a few important competencies:**
1	Medical students must be aware that a **medical doctor's knowledge base has its limits**.
2	Medical students need to know that **a patient with a disability's life experience is a valuable knowledge resource**.
3	Medical students need to be able to **actively listen** to their patients with disabilities.

Subtheme three	**highlights an important competency:**
1	medical students must **interrogate societal prejudices and assumptions about persons with disability.**

5.8.3 Theme Three – Knowledge about Disability

Subtheme one	**Highlights important competencies:**
1	Medical students must be equipped with **basic biopsychosocial knowledge about all disabilities.**
2	Medical students need to know that their **knowledge base has limitations.**
3	Medical students must learn to view patients with disabilities as **valuable knowledge resources.**
4	Medical students must have **good multidisciplinary knowledge.**

Subtheme two	**Highlights an important competency:**
1	Medical students must know about the **importance of empowering patients with disabilities with knowledge.**

5.8.4 Theme Four – Life beyond the disability

Subtheme one	**Highlights important competencies:**
1	Medical students must know how to use a **client-centred approach**
2	Medical students need to know about the **intersection between culture, western medicine and disability.**
3	Medical students must be aware of **their future role as societal educators about disability.**

Subtheme two	**Highlights an important competency:**
1	Medical students need to develop a **holistic appreciation of the diverse lives of persons with disability.**

In the third point of 4.5.1.4 of Chapter Four, I explain how I generated the above competencies and how that led me to the generation of an initial competency set (encompassing the above summaries, the document analysis at the beginning of this chapter and other data sources mentioned in the third point of 4.5.1.4 of Chapter Four).

5.9 What is missing from Phase one data?

In the context of South Africa, a country with widespread poverty, unemployment and other inequality issues, there is a muted tone in Phase one with regards to addressing socioeconomic divides or other issues of inequality. I have attempted to correct this muted tone in Phase two of this study in Chapter Six.

5.10 In summary

I reported the findings from Phase one, in this chapter. Through the analysis of Phase one, four main themes emerged - Experience of disability, Attitudes towards disability, Knowledge about Disability and Life beyond the disability - which assisted in the generation of an initial competency set that I could propose to the expert panel in Phase two of this study. The outcomes of this process are reported in the next chapter.

Chapter Six

Phase two Findings

6.1 Overview of chapter

In this chapter, I start by describing the aims and objectives of this study that were addressed by the initial competency set. I then describe the modified Delphi that I used in Phase two of this research and report the findings. I then record the final competency set that emerged following consensus being reached by the expert panel of the modified Delphi Method. I end this chapter with a summary of this study's findings.

6.2 Aims and objectives addressed by the generation of the initial competency set

In the generation of the initial set of competencies, the second aim, its objective as well as objective 3.1 of the third aim, were addressed:

Aim 2: Describe the competencies related to knowledge, skills and attitudes, (feelings, beliefs and values) required for equitable disability practices.

Objective

2.1. Describe basic competencies (knowledge, skills and attitudes - feelings, beliefs and values) that graduate medical students should have in order to deliver a quality healthcare service to persons with disability.

Aim 3: To develop an initial competency framework that could contribute to developing the undergraduate medical curriculum, with the aim of providing a quality healthcare service to persons with disability.

Objective

3.1. Identification of initial set of competencies through various data sources

As mentioned in the methodology (see Chapter Four), the questionnaire for round one contained an initial set of 17 competencies and 13 sub competencies (see Table 6.1). The descriptors proceeding each competency and sub-competency are a combination of my personal and professional experience-based opinions (see 1.2 in Chapter One) and evidence from the literature.

Table 6.1: Initial competency set in questionnaire one

COMPETENCY 1: Medical students should be able to demonstrate an understanding and awareness that the definitions of types of disability are many, often changing and broad. • *Descriptor* *Knowing the broadness of the definition of disability (e.g., visible and invisible disabilities) will help medical students to practice medicine inclusive of all disabilities. Armed with this knowledge medical students will hopefully not discount a disability because it is not obviously visible.*
COMPETENCY 2: Medical students should be able to demonstrate good general knowledge of available resources/options for persons with disability (e.g., rehabilitation options for physical disabilities or technological support for blind/visually impaired people). • *Descriptor* *Doctors are often the most frequently visited healthcare professional for persons with disability. In many instances, doctors together with nurses will be some of the first healthcare professionals to treat a patient in the acute phase of their impairment (e.g., stroke, diabetic foot/amputation or spinal cord injury) which can lead to a disability. There is a very important onus on doctors to be aware of the available resources/options that could greatly enhance their patient's quality of life. In a sense, doctors are responsible for ensuring that a good foundation is in place for the lives of their patients with disabilities.*
COMPETENCY 3: Medical students should be appreciative of the fact that persons with disability are susceptible to the same general medical conditions as able-bodied people. • *Descriptor* *This is a very important competency, because if doctors are not competent in this, the risk of medical harm (e.g., misdiagnosis or mismanagement) increases.*
COMPETENCY 4: Medical students should be able to demonstrate sufficient knowledge about the common secondary complications of various impairments (e.g., renal stones commonly occur in spinal cord injury patients). • *Descriptor* *This is another important knowledge competency doctors must have to ensure that they can give their patients with disabilities quality healthcare.*
COMPETENCY 5: Medical students should be able to work in an interdisciplinary team. • *Descriptor* *This is critical because often a person with a disability will need the services of a number of different healthcare professionals. These professionals need to work well together as a team, as this can positively contribute to the outcome of the patient's treatment.*
SUB-COMPETENCY 5.1: Medical students should have good inter-disciplinary knowledge and understanding.

- *Descriptor*

Good interdisciplinary knowledge will help doctors work effectively and efficiently in an interdisciplinary team.

COMPETENCY 6: Medical students need to show an awareness and understanding of the political aspect of disability.

- *Descriptor*

This is important because current government (political) attitudes and thoughts on and surrounding disability can drive important disability healthcare policy. Doctors need to also be abreast of the political aspect of disability in order to be good advocates for their patients with disabilities and to empower them with knowledge about their rights.

COMPETENCY 7: Medical students need to show the ability to not only respect diversity but to also understand and value it.

SUB-COMPETENCY 7.1: Medical students need to display the knowledge, awareness and understanding about the intersectionality of culture, medicine and disability in a South African context.

- *Descriptor*

The above competency and sub-competency are vital because it is very important that South African doctors are well aware of the rich diversity within South African society because different cultures might have attitudes and beliefs about medicine and disability, which are different to those of the doctor; and can have an influence on the treatment and management outcome.

COMPETENCY 8: Medical students should be able to show that they understand and value the humanness of persons with disability, bearing in mind the South African context in which they live.

- *Descriptor*

This competency is important because if medical students are not taught to value the human essence of persons with disability and regard them as members of society with the same value as able-bodied humans, they are unlikely to afford persons with disability medical treatment equal to that given to able-bodied members of society. The literature emphasises the importance of this competency by reminding us that traditionally medicine is a profession that is meant to treat all human beings/patients equally and without prejudice or bias (Pena-Guzman & Reynolds, 2018). Not being competent in this competency will perpetuate the issue of ableism in medicine. In the context of South Africa, there is a history of devaluation of human lives, through racial oppression (apartheid). Medical students need to be aware of how the intersection of race and disability might be affected by their own implicit biases. Equally, medical students need to appreciate that a Person of colour, living in South Africa who is also disabled, may be struggling with own feeling of unworthiness.

SUB-COMPETENCY 8.1: Medical students should be able to demonstrate an empathic approach based on acknowledgement and valuing of the humanness of persons with disability.

- *Descriptor*

This is important because an empathic approach is needed to help facilitate rapport building and a positive clinical interaction between a doctor and any patient (able-bodied or disabled). It is however difficult for a doctor to be empathic towards a person with a *disability, unless they are taught as medical students, to see persons with disability as valuable members of society.*

SUB-COMPETENCY 8.2: Medical students should be able to demonstrate a client-centred medical management approach.

- *Descriptor*

This is very important. A client-centred approach is similar to a doctor adopting a more empathic approach. It also facilitates rapport building and focusses a lot on the individual needs and wants of each patient.

COMPETENCY 9: Medical students should be able to demonstrate the ability to view a patient with a disability's life holistically (i.e., a biopsychosocial approach).

- *Descriptor*

This is important because being able to appreciate that there is more to a patient with a disability's life than just their medical impairment, will help doctors value persons with disability as human beings. This in turn should assist doctors to be empathic towards persons with disability.

SUB-COMPETENCY 9.1: Medical students should be able to demonstrate the ability to view a patient with a disability's treatment plan holistically (i.e., they need to make sure that it is focussed on the individual needs and support network of each patient).

- *Descriptor*

If a treatment plan is not tailored to meet the individual needs of each person with a disability (i.e., is a generic plan) or if the patient's support structure is not included, there is the potential for decreased or non-adherence by the patient to the plan. It is also important psychologically for the person with a disability to be recognised as an individual with unique needs. It is therefore important that medical students master this competency.

COMPETENCY 10: Medical students should be able to demonstrate an awareness and understanding that practical knowledge and experience (learning from their patients) is just as important as theoretical knowledge.

- *Descriptor*

Practical learning is a very important way to consolidate and add to theoretical learning and disability is no exception. It's an important competency for medical students to grasp.

COMPETENCY 11: Medical students should be able to demonstrate the awareness that they are not more valuable than or superior to their patients.

- *Descriptor*

It is fairly common for doctors to feel superior to their patients. The privilege of studying for so many years at a university medical school can leave a doctor with a sense of entitlement. Biases may be further entrenched by these feelings of privilege and entitlement. An attitude of arrogant superiority is likely to negatively affect an interaction between a doctor and a patient.

COMPETENCY 12: Medical students should be able to create an environment where the patient feels comfortable sharing personal information.

- *Descriptor*

Creating an environment where rapport grows between the doctor and the patient with a disability is critically important in order for patients to feel comfortable sharing personal information. This sharing will enhance the quality of healthcare received by them.

SUB-COMPETENCY 12.1: Medical students should be able to demonstrate the awareness and the ability to ensure that patients with disabilities have more than enough time in their clinical encounters.

- *Descriptor*

Patients with disabilities are often slower than able-bodied patients, in either movement or speech. If a doctor were to rush them due to time constraints, this could lead to miscommunication and a poorer quality of healthcare.

SUB-COMPETENCY 12.2: Medical students must display good non-verbal communication skills and know how to adapt them in the context of a clinical interaction with a patient with a disability.

- *Descriptor*

Positive non-verbal communication can also contribute to rapport building and help a patient feel safe and relaxed.

COMPETENCY 13: Medical students need to be able to demonstrate good knowledge and awareness of why empowerment through knowledge is necessary and important for patients with disabilities. They need to be able to demonstrate the skill of doing so.

- *Descriptor*

This is critically important because a doctor is not with a person with a disability 24 hours a day. If a person with a disability is not empowered with knowledge, to manage their disability, that a person will potentially face many struggles negotiating life.

SUB-COMPETENCY 13.1: Medical students should be able to practice their role as health advocates in any society but particularly in the context of South Africa.

- *Descriptor*

It is very important that medical students are aware of and able to practice this role. Campbell (2009) tells us how doctors treat persons with disability can have major influence on how society at large treats persons with disability. In South African society this is a particularly pertinent competency because of the legacy of apartheid. This legacy has left many implicit and sometimes still explicit biases and stereotypes. It has also resulted in large socioeconomic divides (predominantly between white people and people of colour). It is important that medical students are aware of the potential of the apartheid legacy and disability to intersect and strengthen the feeling of oppression that many persons with disability experience. Educating South African society about disability will help to alleviate of this oppression.

COMPETENCY 14: Medical students should be able to show sufficient skill in interacting (history taking and examination) with persons with disability in a clinical consultation setting.

- *Descriptor*

This skill is critically important and focusses on general interaction with a patient with a disability, as well as the fact that should the patient with a disability have a pre-existing communication difficulty, this can increase the challenge in the interaction. If doctors are unsure of how to interact with their patients with disabilities in clinical setting, then there is the potential for miscommunication between the doctor and the patient, which increases *the patient's risk for medical harm. According to Pena-Guzman and Reynolds (2018), good and clear communication between a doctor and a patient can decrease the patient's risk of medical harm.*

SUB-COMPETENCY 14.1: Medical students should display good listening skills.

- *Descriptor*

Listening without the intention to reply (i.e., really hearing what patients have to say) is a very important skill for a doctor. This skill will greatly assist doctors in the adoption of an empathic approach and facilitate good communication.

COMPETENCY 15: Medical students should be able to demonstrate the ability to continuously be trying to improve patient care through constant reflection, reflexivity and life-long learning.

- *Descriptor*

This is important to minimise the potential of any medical harm. According to Havercamp et al. (2020), persons with disability are twice as likely to report that health professionals are insufficiently equipped with the skills or the equipment to effectively meet their needs, are three times more likely to report mistreatment by healthcare professionals and four times as likely to report being denied healthcare. By adding to their knowledge base, doctors will enhance the standard of healthcare that they give patients.

SUB-COMPETENCY 15.1: Medical students should be able to identify and acknowledge limitations in their knowledge base.

- *Descriptor*

This is important to minimise the potential of any medical harm and to encourage life-long learning.

SUB-COMPETENCY 15.2: Medical students need to be able to utilize the knowledge of other medical professionals through an appropriate referral system.

- *Descriptor*

This is an important competency because effective utilization of the knowledge of other medical professionals can add to a doctor's life-long learning.

SUB-COMPETENCY 15.3: Medical students need to view patients with disabilities as added sources of knowledge.

- *Descriptor*

This is important because although doctors have a vast wealth of book knowledge, they do not have the life knowledge and experience that their patients with disabilities have. Incorporating their patients' life knowledge with their book knowledge could only enhance their medical practice with patients with disabilities. This competency will also add to doctors' life-long learning.

SUB-COMPETENCY 15.4: Medical students should be able to recognise and interrogate the validity of societal assumptions about persons with disability especially those that are within their personal belief systems.

- *Descriptor*

This is very important because doctors are not immune to implicit societal biases about persons with disability. If such biases are left unchecked, they contribute greatly to the *issue of ableism in medicine. This competency is an important way to begin addressing ableism in medicine.*

SUB-COMPETENCY 15.5: Medical students should be able to demonstrate the ability of being able to deal with a feeling of discomfort within themselves.

- *Descriptor*

It is important because if medical students as doctors project their own feeling of discomfort into a clinical interaction with a person with a disability, it is going to potentially result in difficulty in developing good rapport between doctor and patient.

COMPETENCY 16: Medical doctors should be able to demonstrate an ability to adapt physical examination techniques for patients with disabilities if and when needed.

- *Descriptor*

This is an important competency because the ability to think of and be able to implement creative examination techniques will contribute to decreasing the risk of misdiagnosis or mismanagement. (e.g., how one could effectively examine the body, if the patient is physically unable to lie on the examination bed or how to effectively communicate with deaf patient.

COMPETENCY 17: Medical students should be aware of and be able to negotiate the power dynamic with persons with disability.

- *Descriptor*

Persons with disability are faced with pervasive ableist societal views. These views often regard persons with disability as lesser human beings. Being made to feel less of a human is hurtful and can even result in feelings of anger. It is easy to see that if this happened in a clinical setting with a doctor, it would probably result in the person with a disability having a very negative healthcare experience. Society can further perpetuate the marginalisation of persons with disability, if the issue of intersectionality is ignored.

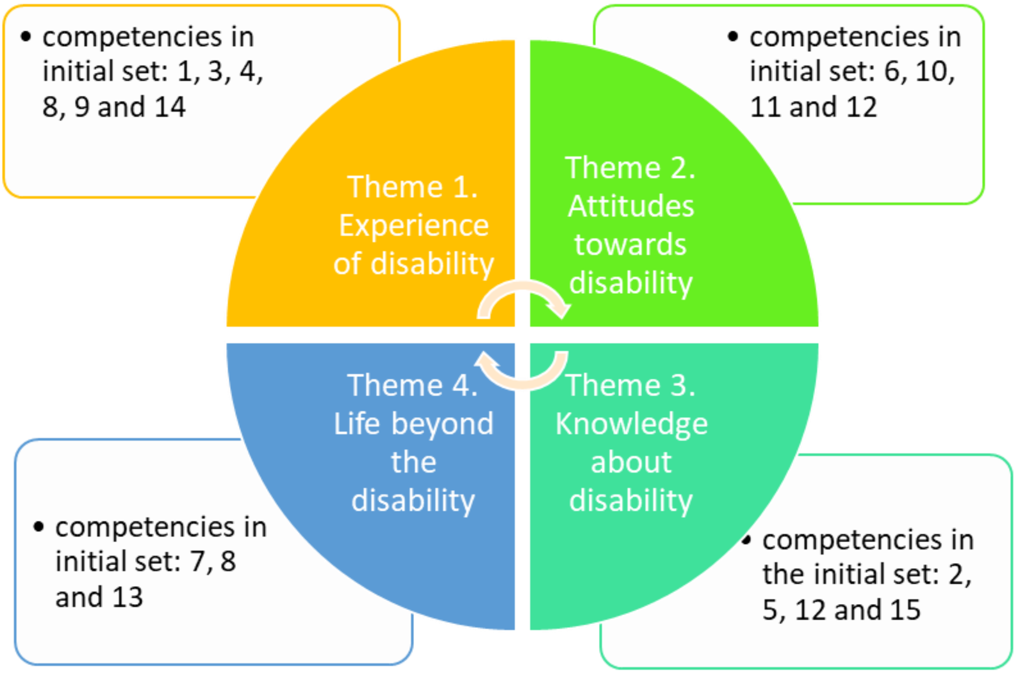


Figure 6.1 illustrates how data from the four main themes of Phase one (reported in Chapter Five) contributed to the generation of certain competencies in the initial competency set.

6.2.1 Relationship between competencies

I organised the competencies and sub-competencies into the following clusters:

- KNOWLEDGE CLUSTER = competencies 1-7 and sub-competencies 5.1 & 7.1
- ATTITUDE CLUSTER = competencies 8-13 and sub-competencies 8.1, 8.2, 9.1, 12.1, 12.2 & 13.1
- SKILLS CLUSTER = competencies 14-17 and sub-competencies 14.1 & 15.1-15.5

Despite having separated the competencies into these clusters to provide structure to the set, I found there was extensive overlap – of knowledge, attitudes and skills - between them (represented in figure 6.2).

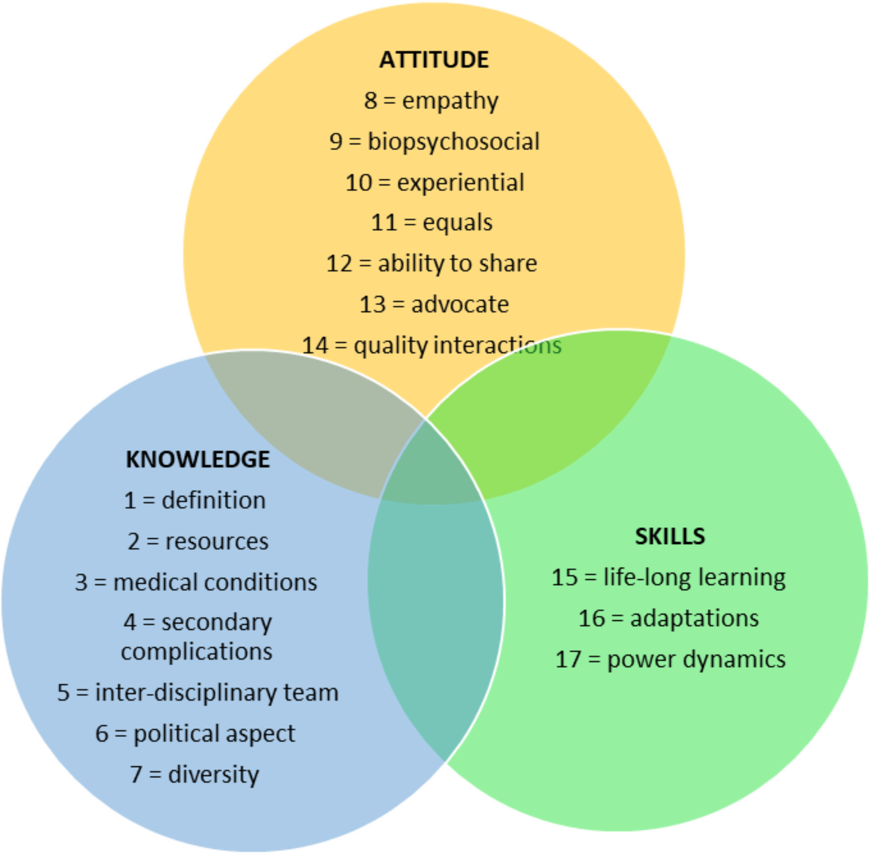


Figure 6.2 illustrates the interwovenness of the three clusters of competencies of the initial competency set - i.e., most of the competencies and sub-competencies contain elements of more than one of the clusters.

6.2.2 Relationship between competencies and their sub-competencies

Sub-competencies were used to further unpack the competencies should they require it. The way the HPCSA Core competency document (analysed in Chapter Five) is structured – with key and enabling competencies – provided me with a basis for the sub-competencies I used.

6.3 Modified Delphi Method

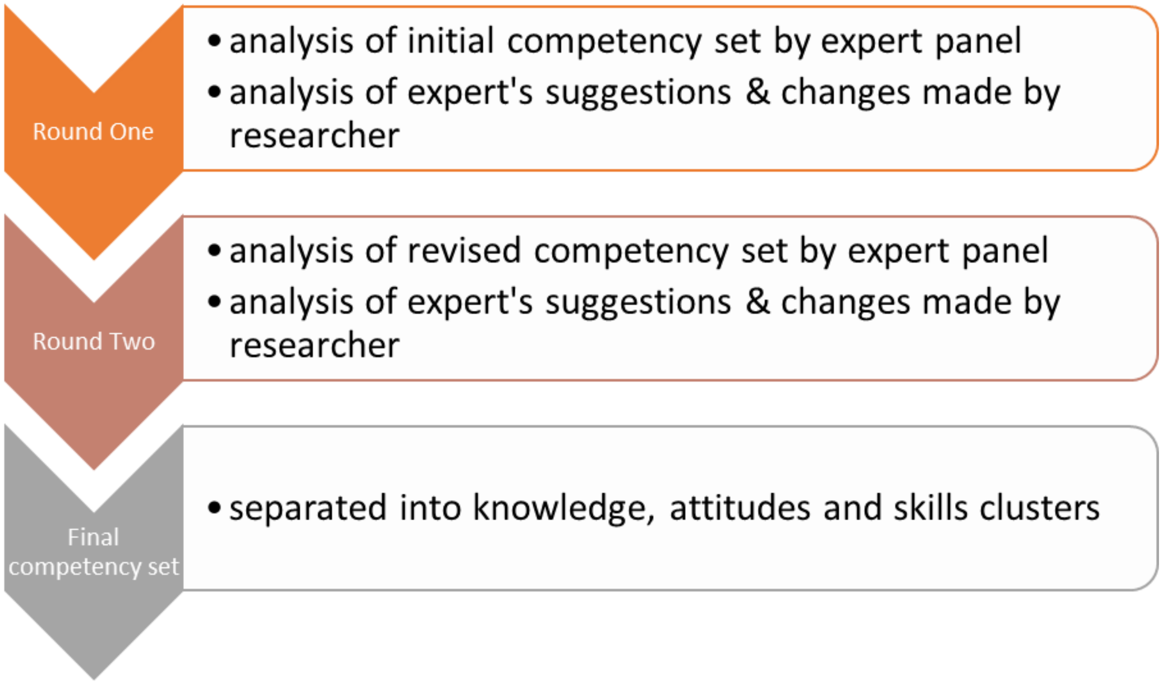


Figure 6.3 illustrates the progression of this study's modified Delphi Method.

These findings of the modified Delphi Method - which led to the generation of the final competency set - address the following aim and objective:

Objective 3.2 of Aim 3: Refine the competency framework through expert analysis.

Objective 3.1 of this third aim was addressed by the generation of the initial competency set (see 6.2, page 152).

6.3.1 Expert panel

Twelve experts participated in this round. Each expert provided me with self-identification data.

Table 6.2: demographic data of each expert. The order of the table is according to the order in which the round one questionnaires were analysed.

***Geographical location abbreviations:**

WC = Western Cape

KZN = KwaZulu Natal

`	**Demographic information**				
Delphi participants	**Race**	**Gender**	**Profession**	**Province**	**Criteria**
NC	White	Female	Clinical Physiotherapist	KZN	Passionate about and advocates for rural & community rehabilitation
DI	White	Female	Psychologist	Gauteng	Achondroplasia causing a physical disability, Disability Studies academic
DD	Coloured	Female	Occupational Therapist	KZN	Mental health advocate, involved in health sciences education
KK	White	Male	Psychiatrist	WC	Practising mental healthcare specialist medical doctor
DP	Black	Female	Disability Studies academic	WC	Non-disabled academic
FN	White	Female	Disability Studies academic	WC	Hard of hearing impairment
XN	White	Male	Disability Studies academic	WC	Quadriplegic causing a physical disability, actively involved in teaching undergraduate medical students about disability
NAX	White	Female	Occupational Therapist	WC	Disability Studies academic, involved in teaching undergraduate medical students about disability
IM	White	Female	Psychologist	Gauteng	Severe visual impairment, Disability Studies academic
QT	White	Male	Psychiatrist	WC	Practising mental healthcare specialist medical doctor, work is focused on mental health intellectual disability

CH	White	Male	Family Medicine Medical Doctor	KZN	Very involved in undergraduate medical curriculum transformation
UD	White	Female	Physiotherapist	WC	Passionate about and advocates for rural & community rehabilitation

6.3.2 Round one of the modified Delphi

6.3.2.1 Question 1

Is this competency important for undergraduate medical students? (Please answer using the appropriate number: (1) Strongly disagree; (2) Disagree; (3) Neither agree nor disagree; (4) Agree; (5) Strongly agree.

Using a 5-point Likert scale, all twelve experts ranked the competencies accordingly. All the competencies and sub-competencies reached consensus with a 75% or higher ranking. The average consensus ranking across the entire set was 95.2%.

Table 6.3: percentage rankings for each competency and sub-competency for the question of importance.

Competencies and sub-competencies			
KNOWLEDGE	**SKILLS**	**ATTITUDES**	**Consensus percentage for QUESTION 1**
1, 5, 5.1	15, 15.1, 15.2, 15.4	9, 10, 12, 12.2, 13	100%
2, 4, 7, 7.1	14, 14.1, 15.3, 15.5, 16	8.1, 8.2, 9.1, 13.1	91%
6	17	12.1	83%
3		8, 11	75%
Average consensus %			95.2%

6.3.2.2 Question 2

Is the language of each competency, clear and easy to understand? (Please answer using the appropriate number: (1) Strongly disagree; (2) Disagree; (3) Neither agree nor disagree; (4) Agree; (5) Strongly agree.

Using a 5-point Likert scale, eleven of the twelve experts ranked the competency set accordingly. NC was the expert who chose not to answer this question. She gave no reason for this. Consensus was not reached with any competency or sub-competency relative to this question. The average consensus ranking (for this question) across the entire competency set was 64.2%.

Table 6.4: percentage rankings for each competency and sub-competency for the question of language clarity.

Competencies and sub-competencies			
KNOWLEDGE	**SKILLS**	**ATTITUDES**	**Consensus percentage for QUESTION 2**
1, 4	14, 14.1, 15.1, 15.2, 15.3, 15.4, 15.5, 16	8.1, 8.2, 9, 12, 12.1, 12.2, 13.1	72%
2, 5, 7, 7.1	17	11	63%
	15	8, 9.1, 13	54%
3, 5.1, 6		10	36%
Average consensus %			64.2%

6.3.2.3 Question 2.1

Please suggest any ways to improve the language of the competency.

The eleven experts who participated in this open-ended question (with the exception of the expert NC, as mentioned above) provided rich and thoughtful suggestions for each competency and sub-competency.

I organised the suggestions into themes/questions that the suggestions made me ask myself about the competency set.

6.3.2.3.1 Who are the competencies for?

- CH gave a suggestion regarding the general structure of every competency and sub-competency on the set. He suggested I use ***medical graduates instead of medical students*** at the beginning of every competency and sub competency.

I agreed with this suggestion because the intention of this study is to propose a competency-based curriculum (for inclusion in the undergraduate medical curriculum) to equip doctors with the ability to afford persons with disability, with quality health care. It sounds better and makes sense that the competencies of this study be aimed at graduates from the undergraduate medical curriculum rather than medical students - a far looser term which could be interpreted as meaning medical students from either the first, second, third, fourth, fifth or sixth year of their undergraduate medical curriculum.

6.3.2.3.2 For consideration only?

- CH also suggested I ***replace the word should with the word must,*** which proceeds medical graduates at the beginning of every competency and sub-competency. CH explained that the word must implied a greater sense of importance (than should) that medical graduates grasp the competency or sub-competency.

I accepted CH’s suggestion. I realized that my use of the word should implied that the competencies were for consideration. Replacing should with must give the competencies an air of necessity and a formality. In my Chapter Two Literature Review as well in my Phase one data, I describe how disability is included in rather an ad hoc manner in many undergraduate medical curricula. As noted in Chapter Two, the subject Disability is often not a mandatory subject.

The use of the word ‘must’ give these competencies a sense of being mandatory.

6.3.2.3.3 Advocating for valuing humanity and autonomy

- DD suggested quite strongly that across the entire set, I change my use of the term ***patients with disabilities to persons with disability.*** She felt this change would give persons with disability a greater sense of autonomy and was more in keeping with the recognition of the humanity of persons with disability.

I wholeheartedly accepted this suggestion. Much of this thesis is dedicated to the valuing of the humanity of persons with disability and many of the competencies asked that doctors be competent in doing just this. This suggestion adds to this idea by reminding doctors that the individual with an impairment resulting in a disability is a person too.

The use of the words ‘patients with disabilities’ also carries a feeling with them of the traditional medical model way of viewing disability. The term ‘patients with disabilities’ could help maintain the perception that individuals with disabilities are always ill and need purely medical intervention. Changing this to ‘persons with disability’ is more in line with my conceptual framework of decolonising disability. Sweet, Dudgeon, McCallum and Ricketson (2014) note that colonial doctors and health care in general, played an important role of perpetuating notion of the colonialised population as inferior victims (i.e., a dehumanising role). In Chapter Three, I discussed this notion with respect to disability. Replacing ‘patients with persons’ is in keeping with looking for ways to minimise this notion by placing doctors and the individuals they treat on more of an equal footing.

The term ‘persons with disability’ is also more in line with the reasons for my selection of Person first language that I chose to use in this thesis (see Glossary of Terms).

- DI, KK, DD and a few other experts suggested that it was important to use the term ***life experience of persons with disability*** instead of just talking about practical education about disability.

I accepted this suggestion because it more affirming of the humanity of persons with disability. It also links directly to some of my Phase one data - specifically 5.6.1.6 (see Chapter Five, page 141) where I speak about the need for doctors to recognise and value the life experience of persons with disability.

6.3.2.3.4 More information needed

- Many of the experts suggested using examples to help with the clarity of many of the competencies and sub-competencies. For example, in one competency I spoke about the importance of empowerment through knowledge for persons with disability. It was suggested that I give examples of what empowerment through knowledge might be for persons with disability.

These suggestions made good sense. I gratefully accepted them because they definitely helped with the clarity and enhanced the accessibility of the competencies.

6.3.2.3.5 Increase mental health awareness

- It was also suggested that I needed to where appropriate, include examples related to mental health.

I accepted this suggestion because I am very conscious of the fact that my Phase one data lacked sufficient mention of mental health issues. I discussed (see Chapter Five, pages 116 and 117) how I wanted to try and correct this insufficiency in this phase and welcomed the suggestion.

6.3.2.3.6 Contextual grounding

- Most experts felt that a number of the competencies and sub-competencies were too generic and needed a stronger ***grounding in a disability context.***

I agreed with this suggestion. Ensuring quality healthcare for persons with disability is the driving factor of this study. With this in mind, I realized upon reviewing the competency set that it was important to place more emphasis on the context of disability.

- UD and a few other experts suggested that where appropriate, I give the competency set more of a ***South African contextual grounding – in terms of race, inequality and poverty.***

I readily accepted this suggestion for two reasons. Firstly, this study was conducted at a South African university by a South African medical doctor (myself). Secondly, in my conceptual framework, I discuss that I will view this study through a decoloniality lens.

Although I am a South African (born, raised and residing in) medical doctor, my undergraduate medical curriculum was very Eurocentric in its focus. I realised that this focus could result in a ‘blind spot’ for me in terms of decolonising both medicine and disability because my thoughts and perceptions arising from training would likely carry an inherent colonial underpinning. Awareness of this potential ‘blind spot’ made me even more open to hearing what the experts had to say.

6.3.2.4 Points of contention

- The very first point of contention was over the first competency. Many of the experts had different suggestions regarding the structure and language that should be used in this competency.

The first competency is focused on doctors knowing and understanding the definition of disability. I decided to give more weight to the suggestions made by the Disability Studies experts with disabilities as I was cognisant of the disability adage, "*Nothing about us without us".*

- Many of the experts suggested that I use the term 'multidisciplinary team' rather than 'interdisciplinary team'.

I initially disagreed with this suggestion when it was first made. However, because this suggestion was repeated by a number of other experts, I thought that I should review the issue closely.

In my professional experience I realized that the term multidisciplinary team is more commonly used and understood. Upon reflection, I was able to see that my initial ambivalence stemmed from my six/seven-year experience of working in physical rehabilitation units where health professionals from different disciplines are in the same building and are able to fulfil both multidisciplinary and interdisciplinary team functions.

In their 2015 review, Clarke and Forster provide a clear explanation of multidisciplinary versus interdisciplinary health care teams. Their explanation helped me realise that term interdisciplinary healthcare team was more appropriate to the in-hospital rehabilitation unit setting (in which I worked), where there is the potential for more collaboration (e.g., goal setting and team meetings) between the healthcare team members. Clarke and Forster (2015) make it clear that an interdisciplinary healthcare team is easier to mention in theory than to implement in practice. In the context of these competencies (i.e., they are for general medical disability practice and not for specific rehabilitation unit medical practice), the term multidisciplinary healthcare team was the most appropriate.

- Two of the male experts, KK and CH made it clear that they thought attitudes (such as empathy) were too difficult to teach and could in fact not be taught.

The rest of the experts did not share these sentiments. I too disagree with KK and CH. Riess (2021) argues that empathy can be nurtured and taught which supports my view.

- DD thought it was unnecessary to have a competency which focused on the fact that persons with disability are susceptible to the same medical conditions as able-bodied people are. DD thinks this should be inherently understood by doctors.

I share her view that it ideally should be inherent in a doctor’s knowledge base however, my personal experience (as a person with a disability), my professional experience as a medical doctor and my Phase one data show that this often not the case. Therefore, it is important to have this competency overtly stated. All of the other experts agreed that this was an important competency.

There were numerous suggestions about the possibility of combining a few of the competencies and sub-competencies – e.g., there were a few experts who felt that competency 8 and sub-competencies 8.1 and 8.2 could be combined.

Many of the experts suggested revising and proofreading my descriptors to improve their clarity and meaning.

I bore these suggestions in mind as I revised the set using the experts’ other suggestions. This revised competency set was presented to the experts for the second round of the modified Delphi Method.

6.3.3 Round two of the modified Delphi Method

6.3.3.1 The expert panel

The first questionnaire (from round one) was revised and a new set of 13 competencies and nine sub-competencies (22 in total and presented in table 6.6) was presented to the same experts as those from round one of this Delphi. Eight of the twelve experts completed round two – a participation rate of 66.7%. This participation rate was acceptable for the following reasons:

- This response is greater than 50%
- All four disabilities studies experts with impairments completed this second questionnaire. Their participation is important because this study looks to highlight the voices of persons with disability.
- Two of the experts who responded have experience with mental health, which was vital as I have flagged the gap in my Phase one data with respect to mental health. Their contribution was important for including mental health in this phase of the study.

Table 6.5: Experts who participated in round two

	Demographic information				
Delphi participants	**Race**	**Gender**	**Profession**	**Province**	**Criteria**
NC	White	Female	Clinical Physiotherapist	KZN	Passionate about and advocates for rural & community rehabilitation
DI	White	Female	Psychologist	Gauteng	Achondroplasia causing physical disability, Disability Studies academic
DD	Coloured	Female	Occupational Therapist	KZN	Mental health advocate, involved in health sciences education
KK	White	Male	Psychiatrist	WC	Practising mental healthcare specialist medical doctor
DP	Black	Female	Disability Studies academic	WC	Non-disabled academic
FN	White	Female	Disability Studies academic	WC	Severe hearing impairment
XN	White	Male	Disability Studies academic	WC	Quadriplegic causing a physical disability, actively involved in teaching undergraduate medical students about disability

IM	White	Female	Psychologist	Gauteng	Severe visual impairment, Disability Studies academic

Table 6.6: Revised competency set used in round two

COMPETENCY 1: Medical graduates must demonstrate an awareness of how the United Nations (UNCRPD 2006) defines persons with disability and an understanding that the many definitions of types of disability (e.g., mental, physical and intellectual to name a few) are not finite, often changing and extensive. • *Descriptor* *Knowing the extensiveness of the definitions of the types of disability (e.g., physical or visible and mental or invisible disabilities) will help medical graduates practise medicine inclusive of all disabilities. Armed with this knowledge medical graduates will hopefully not discount a disability because it is not obviously visible.* *United Nations defines persons with disability as those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may therefore hinder effective participation in society on an equal basis with others (UNCRPD, 2006). It is important to recognise that this definition is by no means finite and may be expanded in various contexts to contain those who experience an impact on the functioning.*
COMPETENCY 2: Medical graduates must demonstrate good knowledge of the services and resources that are available for persons with disability (e.g., the rehabilitation options offered by a multidisciplinary team for all disabilities, technological support for blind/visually impaired people or support groups for people living with mental disability) and understand that the person with a disability must be included in a participatory dialogue about these resources. • *Descriptor* *Doctors are amongst the most frequently visited healthcare professional for persons with disability. In many instances, doctors together with nurses will be some of the first healthcare professionals to treat a patient in the acute phase of their impairment (e.g., stroke, diabetic foot/amputation or spinal cord injury) which can lead to a disability. There is a very important onus on doctors to be aware of the available resources/options that could greatly enhance their patient's quality of life. In a sense, doctors are responsible for ensuring that a good foundation is in place for the future lives of their patients with disabilities.*
COMPETENCY 3: Medical graduates must demonstrate an awareness of the ways in which persons with disability are susceptible to the same medical conditions as their able-bodied peers, in addition to those medical conditions that might be associated with their underlying disability. • *Descriptor* *This is a very important competency, because if doctors are not competent in this, the risk of medical harm (e.g., misdiagnosis or mismanagement) increases.*
COMPETENCY 4: Medical graduates must demonstrate knowledge about the common secondary complications of various impairments which have led to

disabilities (e.g., renal stones commonly occur in spinal cord injury patients or complications of cigarette smoking which is very common in people living with mental disability.)

- *Descriptor*

This is another important knowledge competency doctors must have to ensure that they can give their patients with disabilities quality healthcare.

COMPETENCY 5: Medical graduates must be able to work in a multidisciplinary team and in the context of disability, the graduate must be able to show how other members of the multidisciplinary team might contribute to comprehensive person-centred care.

- *Descriptor*

This is critical because often persons with disability will need the services of a number of different healthcare professionals. These professionals need to work well together as a team, as this can positively contribute to the outcome of the person's treatment plan and ultimately to their quality of life.

Sub-Competency 5.1: Medical graduates must be aware of the roles, skills and potential competencies of allied health professionals in the multidisciplinary team.

- *Descriptor*

Good multidisciplinary knowledge (of allied healthcare professionals) will help doctors work effectively and efficiently in a multidisciplinary team.

Sub-Competency 5.2: Medical graduates must demonstrate the ability to draft appropriate referrals to different members of the multidisciplinary team, showing an awareness of what each member can add at which time, during clinical care.

- *Descriptor*

This is an important competency because inappropriate referrals can waste the time of the healthcare professional receiving the referral and the person with a disability.

Sub-Competency 5.3: Medical graduates must demonstrate an awareness and understanding that a medical doctor is not automatically the leader of a multidisciplinary team.

- *Descriptor*

This is important because it will assist with the facilitation of effective teamwork.

COMPETENCY 6: Medical graduates must understand how persons living with disability (exactly like able bodied people) form part of families and communities, have equal human rights and participate in society in diverse ways including economically and politically (understand disability as a form of diversity within society).

Sub-Competency 6.1: Medical graduates must display the knowledge, awareness and understanding about the intersection of culture, medicine, gender, sexuality and disability in a South African context – for example, in some South African cultures, disability is perceived as a curse.

- *Descriptor* *The above competency and sub-competency are vital because it is very important that South African doctors understand and accept disability as a form of diversity and are aware of the rich diversity within South African society. Intercultural perspectives on health and disability and intervention choices need to be considered as they can have an influence on the treatment and management outcome.*
COMPETENCY 7: Medical graduates must be reflexive and demonstrate that they understand and value the humanity and individuality of persons with disability, bearing in mind the South African context in which they live (i.e. develop an empathic, person-centred approach towards persons with disability). - *Descriptor* *This competency is important because if medical graduates are not taught to value the humanity of persons with disability and regard them as members of society with the same value as able-bodied humans, then they are unlikely to afford persons with disability with medical treatment equal to that given to able-bodied members of society. The literature emphasises the importance of this competency by reminding us that traditionally medicine is a profession that is meant to treat all human beings/patients equally and without prejudice or bias. In the context of South Africa, there is a history of devaluation of human lives, through racial oppression (apartheid) and loss of individual identity through group labelling. Bias and stereotypes towards racial and cultural differences, as well as what is considered a societal norm (e.g., able-bodiedness) still exist. Therefore, medical graduates need to appreciate that a black person, living in South Africa who is also disabled, may be struggling with their own feeling of unworthiness – due to an internalization of South African society members explicit or implicit attitudes regarding such differences.* *An empathic approach helps facilitate rapport building and a positive clinical interaction between a doctor and any patient (able-bodied or disabled). It is however difficult for a doctor to be empathic towards persons with disability, unless they are taught as medical graduates, to see Persons with disability as valuable members of society.*
COMPETENCY 8: Medical graduates must demonstrate an awareness of how understanding the lived experience of persons with disability is key to both the assessment and management approaches to persons with disability. (i.e., During any clinical interaction, medical graduates must regard persons with disability as sources of knowledge and treat them as equal partners in the healing/rehabilitation process.) - *Descriptor* *Disability is multifaceted and affects a multitude of aspects of a person with a disability's life (medically, psychosocially and spiritually etc). It is very important that the graduate's traditional theoretical knowledge (book knowledge) be supplemented by learning from the lived experience of persons with disability. This combining of knowledge will strengthen and deepen medical graduates' understanding of disability. It will assist graduates with the sub-competency below.*
Sub-Competency 8.1: Medical graduates must be able to compile persons with disability contextually relevant treatment and management plans using a holistic approach (i.e., the focus must be on the individual's physiological, psychological, social and occupational needs and inclusive of the support network of each patient, with the intention of promoting community reintegration.)

- *Descriptor*

If a treatment plan is not tailored to meet the individual needs of each person with a disability (i.e., is a generic plan) it could lead to non-adherence by the individual to the plan. It is also important psychologically for the person with a disability to be recognised as an individual with unique needs. It is therefore important that medical graduates master this competency.

COMPETENCY 9: Medical graduates must demonstrate the awareness that a meaningful clinical engagement with persons with disability takes places when the doctor acts and behaves as an equal partner and does not take an authoritarian view.

- *Descriptor*

It is common for doctors to feel superior to their patients. The privilege of studying for so many years at a university medical school can leave a doctor with of a sense of entitlement. This overconfidence in their positions as experts with superior knowledge of the body and health, might also stem from an internalization of the extent to which society tends to view doctors as the ultimate experts of the body and health (Cassam, 2017; Pena-Guzman & Reynolds, 2018). Biases and stereotypes (such as persons with disability are less valuable to society compared with able bodied people) may be further entrenched by these feelings of privilege and entitlement. An attitude of arrogant superiority is likely to negatively affect an interaction between a doctor and a patient.

COMPETENCY 10: Medical graduates must demonstrate good understanding of why empowerment through knowledge (e.g., psychoeducation for mental disabilities or education about pressure care to physically disabled individuals) is necessary and important for persons with disability. They must also demonstrate the skill of doing so.

- *Descriptor*

This is critically important because doctors are not with persons with disability 24 hours a day, to assist with daily life issues. If persons with disability are not empowered with knowledge, to manage their disability, those people will potentially face many struggles negotiating life.

Sub-Competency 10.1: Medical graduates must be able to practice their role as advocates (influencers and game changers) for the rights of persons with disability, in any society but particularly in the context of South Africa.

- *Descriptor*

It is very important that medical graduates are aware of and able to practice this role. Campbell (2009) tells us that how doctors treat persons with disability can have a major influence on how society at large treats persons with disability. In South African society this is a particularly pertinent competency because of the legacy of apartheid. This legacy has left many implicit and sometimes still explicit biases and stereotypes. It has also resulted in large socioeconomic divides (predominantly between white people and people of colour). It is important that medical graduates are aware of the potential of the apartheid legacy and disability to intersect and strengthen the feeling of oppression that many persons with disability experience. Educating South African society about disability will help to alleviate some of this oppression.

COMPETENCY 11: Medical graduates must be able to set clear boundaries and create an environment of trust, where the person with a disability feels comfortable sharing personal information (e.g., some physical disabilities as well as the drug

treatment for some mental disabilities can result in sexual dysfunction and discussing this might be difficult for the person.)

- *Descriptor*

Creating an environment where rapport grows between the doctor and the person with a disability is critically important for the individual to feel comfortable sharing personal information. This sharing will enhance the quality of healthcare received by them.

Sub-Competency 11.1: Medical graduates must demonstrate good skill (this encompasses the skill of active listening, as well as positive non-verbal communication – such as eye contact, nodding, giving the person time and space to talk) in interacting (history taking and examination) with persons with disability in a clinical consultation setting.

- *Descriptor*

This skill is critically important and focusses on general interaction with a patient with a disability, as well as the fact that the patient with a disability may have a pre-existing communication difficulty which can increase the challenge in the interaction. If doctors are unsure of how to interact with their patients with disabilities in clinical setting, then there is the potential for miscommunication between the doctor and the patient, which increases the patient's risk for medical harm. According to Pena-Guzman and Reynolds (2018), good and clear communication between a doctor and a patient can decrease the patient's risk of medical harm.

Listening without the intention to reply (i.e., really hearing what patients have to say) is a very important skill for a doctor. This skill will greatly assist doctors in the adoption of an empathic approach and facilitate good communication. Positive non-verbal communication can also contribute to rapport building and help a patient feel safe and relaxed.

Sub-Competency 11.2: Medical graduates must demonstrate an awareness of the need to assign sufficient/extra time, where possible, to ensure that all the needs of persons with disability are met in their clinical encounters.

- *Descriptor*

Persons with disability are often slower than able-bodied patients, in either movement or speech or where someone with dementia or schizophrenia might take longer to express ideas, or simply to build trust. If a doctor were to rush them due to time constraints, this could lead to miscommunication and a poorer quality of healthcare.

COMPETENCY 12: Medical graduates must demonstrate how in the context of such a multifaceted and evolving subject of disability, the adoption of an attitude of reflexivity, the practice of regular personal reflection – to create awareness of their own knowledge limitations - and a commitment to lifelong learning assists them in providing good care to persons with disability.

- *Descriptor*

Disability is an extensive subject with evolving information. It is not possible for a doctor to know everything about every possible impairment and resultant disability. This is important to minimise the potential of any medical harm. According to Havercamp et al. (2020), persons with disability are twice as likely to report that health professionals are insufficiently equipped with the skills or the equipment to effectively meet their needs, are three times more likely to report mistreatment by healthcare professionals and four times *as likely to report being denied healthcare. By being aware through reflection of their own knowledge limitations and then adding to their knowledge base, doctors will enhance the standard of healthcare that they give patients.*

Sub-Competency 12.1: Medical graduates must demonstrate a willingness to critically evaluate any of their own assumptions, as well as any feelings of discomfort (i.e., things like disability which are different and often unfamiliar, can evoke feelings of discomfort) about persons with disability, how these relate to more broadly held societal attitudes, and how they might impact upon their assessment and management of persons with disability.

- *Descriptor*

This is very important because doctors are not immune to implicit societal biases about persons with disability. If such biases are left unchecked, they can contribute greatly to the issue of ableism in medicine. This competency is an important way to begin addressing ableism in medicine. If medical graduates as doctors, project their own feeling of discomfort into a clinical interaction with persons with disability, it is going to potentially result in difficulty in developing good rapport between doctor and patient.

COMPETENCY 13: Medical doctors must demonstrate a willingness to adapt assessment and examination techniques to meet the needs of persons with disability.

- *Descriptor*

This is an important competency because the ability to think about and to implement creative examination techniques will contribute to decreasing the risk of misdiagnosis or mismanagement. (e.g., how one could effectively examine the body, if the patient is physically unable to lie on the examination bed or how to effectively communicate with deaf patient.)

6.3.3.2 Repeat of question 2 from round one

The experts were again asked to rank each revised competency and sub-competency according to its language clarity. Consensus was reached for each competency and sub-competency on the set. The average consensus ranking across the entire set was 90.9%.

Table 6.7: percentage rankings for each revised competency and sub-competency for the question of language clarity.

Competency and sub-competency	**Consensus percentage for QUESTION 2**
4, 5.3, 8, 9, 10.1,11, 11.1, 11.2, 13	100%
1, 2, 3, 5, 5.1, 5.2, 7, 10, 12, 12.1	87.5%
6, 6.1, 8.1	75%
Average consensus %	90.9%

6.3.3.3 Question 2.1 (the same as question 2.1 in round one)

Many of the suggestions from the experts related to the grammatical structure of the competencies as well to the descriptor paragraphs below each competency and sub-competency. I have again organised the suggestions into important themes/questions.

6.3.3.3.1 Respecting the heterogeneity of persons with disability

- In competency 1, IP felt I needed to make clear that although there are various general categories of disability (e.g., physical and cognitive or psychosocial disabilities), definitions within each category may vary depending on the individual presentation of each disability.

I accepted this suggestion for two reasons. Firstly, IP is a Disability Studies expert with her own disability, and I felt her suggestion on this subject carried significant weight. Secondly, this suggestion links directly with subtheme 5.4.1 of my Phase one data (see Chapter Five, page 120) where the need for doctors to respect and understand the heterogeneity of persons with disability is emphasised.

6.3.3.3.2 Inclusivity

- In competency 2 IP suggested including parents or guardians of children with disabilities in the participatory dialogue about available resources for persons with disability.

I liked and accepted this suggestion. I had been determined to make the competency set as inclusive of the different types of disability as possible. However, I had not focused on that the set should be specifically inclusive of children as well as adults with disabilities. IP’s suggestion allowed for increased inclusivity within the competency set.

6.3.3.3.3 Clinical significance

- Both DD and KK thought I needed to be clearer that the knowledge mentioned in competency 4, relates to both the occurrence and the treatment of common secondary complications.

I accepted this suggestion because it enhances the application of this competency from knowing to knowing and doing.

- In sub-competency 11.1 and competency 13, DD suggested that I add treatment/management to where I mention history and examination.

This suggestion was accepted because it adds clarity and a sense of completeness to the practical implications of the competency and sub-competency.

6.3.3.3.4 Are medical doctors superior health professionals?

- DD stated that in competency 5, I should remove the term allied healthcare professionals and just use healthcare professionals. This is because she strongly believes that the word allied, diminishes these healthcare professionals and puts medicine as a more important profession.

I initially wasn’t sure about this suggestion. Upon reflection I realized that my initial feeling of ambiguity was coloured by the fact that I have trained in the colonial take on medicine. In this view medicine is seen as the more superior health profession.

In my conceptual framework I discuss how this study looks to decolonise medicine. This suggestion helped me explore decolonising the medical curriculum by a levelling of the playing field amongst health professionals. Thus, it was accepted.

6.3.3.3.5 Understanding and appreciating cultural context

- DP was the only expert who strongly disagreed with how I had written in sub-competency 6.1, that in many African cultures, disability was seen as curse. She felt that I was giving a very one-sided example. She strongly suggested that I include that whilst some African cultures might view disability as a curse, other African cultures view disability as spiritual blessing.

DP is a self-identified black African woman, so I accepted her knowledge of this example in African culture. I applied her suggestion because it adds depth to the example. Her suggestion also aligns with Chapter Three definition of Afrocentricity and my other conceptual framework of Critical Disability Studies, which privileges an understanding of the person with a disability's contextual background.

6.3.3.3.6 Advocating for valuing humanity

- DD reiterated her suggestion from round one, that the word 'patient' (still present in some descriptors) be changed to 'person'. She felt that the word patient places too much emphasis on the medical model.

In round one I accepted this suggestion and explained why. I attempted to revise the round one competency set with suggestion in mind because it's value to this study. I therefore accepted this reiteration because it provided me with an opportunity to re-look at the competency set and make sure that I was using more of the social and other models of disability to underpin the competency set. This is in keeping with the points I raised in Chapter Two about the evidenced based need to challenge the dominance of the medical model of disability in medical education. Similarly, this suggestion aligns with my conceptual frameworks of the ICF and Critical Disability Studies, which advocate for less reliance on only the medical model of disability.

- In keeping with the idea of advocating for valuing humanity, DD also suggested that where appropriate, I should use terms such as equal partners and participatory dialogue.

I accepted this suggestion because this links to my Chapter Three intention to challenge hegemonic power dynamics between medical doctors and Person with disability and to encourage knowledge reciprocity between them.

6.3.3.3.7 Correct terminology

- XN and FN both suggested that instead of the words 'mental disability', I should use the words cognitive and/or psychosocial disability. This suggestion is because they both felt that 'mental disability' is too close to the term mental retardation, which is a completely unacceptable term to use.

I accepted this suggestion without hesitation because they are both persons with disability and have doctoral qualifications in disability inclusive research. I have read some of both of their valuable contributions to research in this field. I therefore felt confident in this suggestion.

6.3.3.3.8 Clarification needed

- In competency 11, both IP and XN felt that by just saying 'set clear boundaries', it wasn't clear what I meant. XN suggested adding the word 'professional' in front of boundaries.

I accepted this suggestion because it helps greatly with the clarity of the competency.

6.3.3.4 Points of contention

- There were no points of contention in round two of my modified Delphi Method.

6.3.4 Generation of final competency set

I revised the competency set using the round two suggestions and discussed the findings with my supervisors.

Consensus was achieved in round two which meant that it was the final round. Below is the approved - by the experts - final set of 13 competencies and 9 sub-competencies. I have included a descriptor for each competency and sub-competency, to further explain and highlight the importance of each one.

As mentioned in 6.1.1, I found there to be considerable overlap within many of the competencies and sub-competencies, with respect to knowledge, attitudes and skills. According to what appeared to be more clearly foregrounded, I clustered this final competency set as follows:

- Knowledge cluster = 1-6
- Attitude cluster = 7-10
- Skills cluster = 11-13

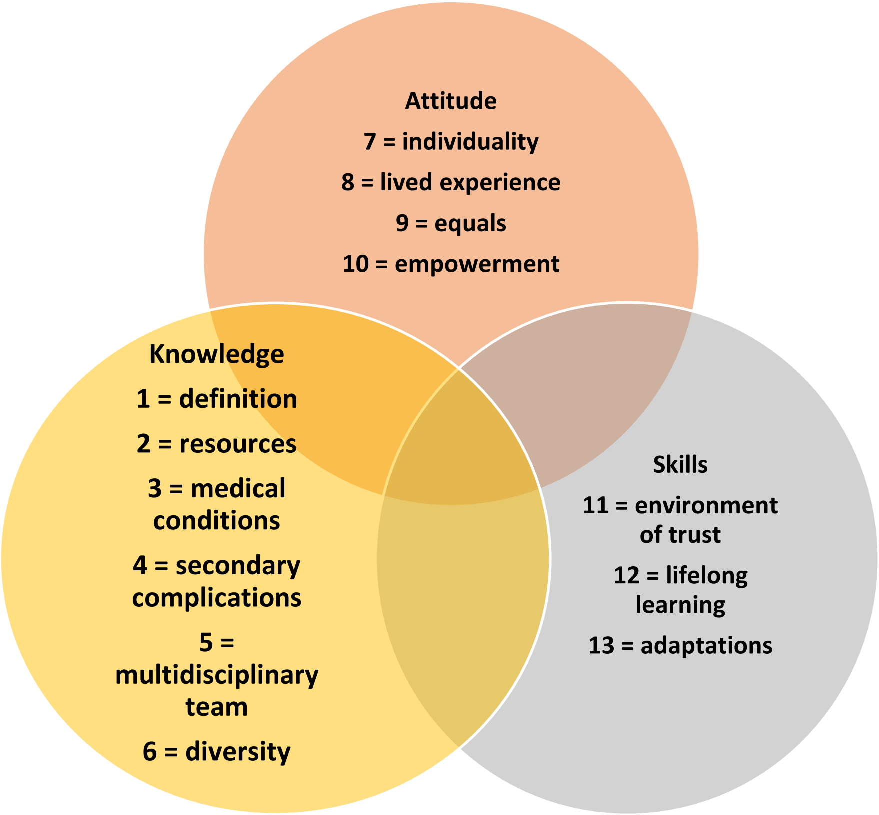


Figure 6.4 shows the division and overlap - between the knowledge, attitudes and skills clusters – of the competencies in the final set.

KNOWLEDGE CLUSTER

COMPETENCY 1: Medical graduates must demonstrate an awareness of how the United Nations (UNCRPD 2006) defines persons with disability as well as an understanding that the many definitions of the types of disabilities (e.g., mental health issues, physical and intellectual to name a few) are not finite, often changing, are extensive and should be interpreted differently for each individual presentation of disability.

- *Descriptor*

The definitions of the types of disabilities (e.g., physical or visible and cognitive/psychosocial or invisible) are extensive. Being knowledgeable about these definitions will assist medical graduates to practice medicine inclusive of all disabilities. Armed with this knowledge medical graduates will hopefully not discount a disability because it is not obviously visible.

The United Nations defines persons with disability as those who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their effective participation in society on an equal basis with others (UNCRPD, 2006). It is important to recognise that this definition is by no means finite and maybe expanded in various contexts to contain those who experience an impact on their functioning.

COMPETENCY 2: Medical graduates must demonstrate knowledge of the resource constraints and context for persons with disability and understand that the person with a disability or the parents/guardians of children with disabilities, must be included in a participatory dialogue about these resources.

- *Descriptor*

Doctors are amongst the most frequently visited healthcare professional for persons with disability. In many instances, doctors together with nurses will be some of the first healthcare professionals to treat a person in the acute phase of their impairment (e.g., stroke, diabetic foot/amputation or spinal cord injury) which can lead to a disability. There is an important onus on doctors to be aware of the available resources/options that could greatly enhance their patient's quality of life. In a sense, doctors are responsible for ensuring that a good foundation is in place for the future lives of persons with disability.

COMPETENCY 3: Medical graduates must demonstrate an awareness that persons with disability are susceptible to the same medical conditions as their able-bodied peers, in addition to those medical conditions that might be associated with their disability (e.g., pneumonia is not associated with a particular disability and everyone is susceptible to it, whereas autonomic hypertension is directly associated with a physical disability caused by a spinal cord injury).

- *Descriptor*

This is an important competency for doctors to have so that the risk of medical harm (e.g., misdiagnosis or mismanagement) can be avoided as far as possible.

COMPETENCY 4: Medical graduates must demonstrate knowledge about the occurrence and treatment of the common secondary complications of various impairments which have led to disabilities (e.g., renal stones commonly occur in spinal cord injury patients or complications of cigarette smoking which is common in people living with cognitive or psychosocial disabilities).

- *Descriptor*

This is another important knowledge competency doctors must have to ensure that they can give their patients with disabilities quality healthcare.

COMPETENCY 5: Medical graduates must be able to work in a multidisciplinary team and in the context of disability, the graduate must be knowledgeable about how other members of the multidisciplinary team might contribute to comprehensive person-centred care.

- *Descriptor*

This is critical because often persons with disability will need the services of a number of different healthcare professionals. These professionals need to work well together as a team, as this can positively contribute to the outcome of the person's treatment plan and ultimately to their quality of life. The use of a person-centred approach is important. In this approach (style of care), the person receiving the care is placed at the centre of the care – i.e., they are seen as a person and not just an impairment or a disability. The individual's unique aspirations and needs drive the direction of care.

Sub-Competency 5.1: Medical graduates must be aware of the roles, skills and competencies of the healthcare professionals in a multidisciplinary team with regards to working with persons with disability.

- *Descriptor*

Good multidisciplinary knowledge (of the healthcare professionals in a multidisciplinary team) will help doctors work effectively and efficiently in a multidisciplinary team.

Sub-Competency 5.2: Medical graduates must demonstrate the ability to compile appropriate referrals to different members of the multidisciplinary team, showing an awareness of the potential contribution of each member, during the course of clinical care.

- *Descriptor*

This is an important competency because inappropriate referrals can waste the time of the healthcare professional receiving the referral and the person with a disability.

Sub-Competency 5.3: Medical graduates must demonstrate an awareness and understanding that a medical doctor is not necessarily the leader of a multidisciplinary team.

- *Descriptor*

This is important because it will assist with the facilitation of effective teamwork and because the outcome being sought is not necessarily biomedical. It could be psychosocial.

COMPETENCY 6: Medical graduates must understand how persons living with disability form part of families and communities, have equal human rights and participate in society in diverse ways (exactly like able bodied people) including educationally, economically and politically.

Sub-Competency 6.1: Medical graduates must display knowledge, awareness and understanding about the intersection of culture, medicine, gender, sexuality and disability in a South African context – for example, in South Africa there are multiple cultural understandings of disability. In some South African cultures, disability is perceived as a curse, some other cultures perceive disability as part of human diversity.

- *Descriptor*

The above competency and sub-competency are vital because it is important that South African doctors understand and accept disability as a form of diversity within a richly diverse South African society. Intercultural perspectives on health and disability and intervention *choices need to be considered as they can have an influence on the treatment and management outcome of persons with disability.*

ATTITUDE CLUSTER:

COMPETENCY 7: Medical graduates must be reflexive and demonstrate that they understand and value the humanity and individuality of persons with disability, bearing in mind the South African context in which they live (i.e., develop an empathic, person-centred approach towards persons with disability).

- *Descriptor*

This competency is of vital importance because if medical graduates are not taught to value the humanity of persons with disability and regard them as having the same value as able-bodied persons, then they are unlikely to treat persons with disability on an equal basis to those without disabilities. The literature emphasises the importance of this competency by reminding us that medicine is a profession that traditionally is meant to treat all human beings/patients equally and without prejudice or bias. Within the South African context there is a history of devaluation of human lives through racial oppression (apartheid) and loss of individual identity through group labelling. Bias and stereotypes towards racial and cultural differences as well as what is considered a societal norm (e.g., able-bodiedness) still exist. Therefore, medical graduates need to appreciate that a black person living in South Africa who is also disabled, may be struggling with their own feelings of unworthiness due to an internalization of explicit or implicit attitudes of other members of society towards them.

An empathic approach is needed to help facilitate rapport building and a positive clinical interaction between doctor and patient (able-bodied or disabled). It is however difficult for a doctor to be empathic towards persons with disability unless they are guided as medical graduates to see persons with disability as valuable members of society.

COMPETENCY 8: Medical graduates must demonstrate an awareness of how understanding the lived experience of persons with disability is key to both the assessment and management approaches to persons with disability (i.e., during any clinical interaction, medical graduates must regard persons with disability as sources of knowledge and treat them as equal partners in the healing/rehabilitation process.)

- *Descriptor*

Disability is multifaceted and affects a multitude of aspects of a person with a disability's life (medically, psychosocially and spiritually etc). It is important that graduates' traditional theoretical knowledge (book knowledge) be supplemented by learning from the lived experience of persons with disability. This combination of knowledge will strengthen and deepen medical graduates understanding of disability. It will assist graduates with the sub-competency below.

Sub-Competency 8.1: Medical graduates must be able to compile contextually relevant treatment and management plans using a holistic approach for persons with disability (i.e., the focus must be on the individual's physiological, psychological, social and occupational needs and inclusive of the support network of each person with a disability, with the intention of promoting community integration.)

- *Descriptor*

A treatment and management plan should be tailored to meet the individual needs of each person with a disability. This will increase the likelihood of the individual adhering to the plan. It is also important psychologically for the person with a disability to be recognised as an individual with unique needs. It is therefore important that medical graduates master this competency.

COMPETENCY 9: Medical graduates must demonstrate the awareness that a meaningful clinical engagement with persons with disability is more likely to take place when the doctor acts and behaves as an equal partner (i.e., does not take an authoritarian view).

- *Descriptor*

It is fairly common for doctors to position themselves as superior to their patients. The privilege of studying for so many years at a university medical school can leave a doctor with a sense of entitlement. This overconfidence in their positions as experts with superior knowledge of the body and health might also stem from an internalization of the extent to which society tends to view doctors as the ultimate experts of the body and health (Cassam, *2017; Pena-Guzman & Reynolds, 2018). Biases and stereotypes (such as persons with disability are less valuable to society, compared with able bodied people) may be further entrenched by these feelings of privilege and entitlement. An attitude of arrogant superiority is likely to negatively affect an interaction between a doctor and a patient.*

COMPETENCY 10: Medical graduates must demonstrate good understanding of why empowerment through knowledge (e.g., psychoeducation for cognitive or psychosocial disabilities or education about pressure care to physically disabled individuals) is necessary and important for persons with disability and their families. They must also demonstrate the skill of doing so.

- *Descriptor*

This is critically important because doctors are not necessarily with persons with disability 24 hours a day to assist with daily life issues. If persons with disability are not empowered with knowledge to manage their disability, they could potentially face many struggles negotiating everyday life.

Sub-Competency 10.1: Medical graduates must be able to practice their role as advocates (influencers and game changers) for the rights of persons with disability in any society, but particularly in the context of South Africa – i.e., extending their medical practice beyond just clinical intervention.

- *Descriptor*

It is important that medical graduates are aware of and able to practice this role. Campbell (2009) tells us that the manner in which doctors treat persons with disability can have a major influence on how society at large treats persons with disability. In South African society this is a particularly pertinent competency because of the legacy of apartheid. This legacy has left many implicit and sometimes still explicit biases and stereotypes. It has also resulted in large socioeconomic divides (predominantly between white people and black people). It is important that medical graduates are aware of the potential of the apartheid legacy and disability to intersect and strengthen the feeling of oppression that many persons with disability experience. Educating South African society about disability will help to alleviate some of this oppression.

SKILLS CLUSTER:

COMPETENCY 11: Medical graduates must be able to set clear professional boundaries and create an environment of trust, where the person with a disability feels comfortable sharing personal information (e.g., some physical disabilities as well as the drug treatment for some mental disabilities can result in sexual dysfunction and discussing this might be difficult for the person.)

- *Descriptor*

Professional boundaries allow for structure in the relationship between healthcare professional and patient. Within professional boundaries there are clearly defined borders that mark the edges between professional relationship and personal relationship. Thus, professional boundaries act by protecting the patient's vulnerability and privacy, allowing the necessary work to take place in a defined space. Creating an environment where rapport grows between the doctor and the person with a disability is critically important in order for individuals to feel comfortable sharing personal information. This sharing will enhance the quality of healthcare received by them.

Sub-Competency 11.1: Medical graduates must demonstrate good skill (this encompasses the skill of active listening, as well as positive non-verbal communication - such as eye contact, nodding, giving the person time and space to talk) in interacting (history taking, examination and treatment/management) with persons with disability in a clinical consultation setting.

- *Descriptor*

This skill is critically important and focuses on general interaction with a patient with a disability, as well as the fact that the patient with a disability may have a pre-existing communication difficulty (e.g., communication impairments, psychosocial difficulties; language proficiency issues) which could make the interaction more challenging. If doctors are unsure of how to interact with their patients with disabilities in a clinical setting, then there is the potential for miscommunication between the doctor and the patient which increases the patient's risk for medical harm. According to Pena-Guzman and Reynolds *(2018), good and clear communication between a doctor and a patient can decrease the patient's risk of medical harm.*

Listening without the intention to reply (i.e., really hearing what patients have to say) is an important skill for a doctor. This skill will greatly assist doctors in the adoption of an empathic approach and facilitate good communication. Positive non-verbal communication can also contribute to rapport building and help a patient feel safe and relaxed.

Sub-Competency 11.2: Medical graduates must demonstrate an awareness of the need to assign adequate time where necessary to ensure that all the needs of persons with disability are met in their clinical encounters.

- *Descriptor*

Persons with disability may be slower than able-bodied patients, in either movement or speech or where someone with dementia or schizophrenia might take longer to express ideas, or simply to build trust. If a doctor were to rush them due to time constraints, this could lead to miscommunication and a poorer quality of healthcare.

COMPETENCY 12: Given the multifaceted and evolving concept of disability, medical graduates must adopt an attitude of reflexivity, the practice of regular personal reflection – to create awareness of their own knowledge limitations - and a commitment to lifelong learning assists them in providing good care to persons with disability.

- *Descriptor*

Disability is an extensive subject with evolving information. It is not possible for a doctor to know everything about every possible impairment and resultant disability. However, reflexivity is important to minimise the potential of any medical harm. This is important in relation to this study because according to Havercamp et al. (2020), persons with disability are twice as likely to report that health professionals are insufficiently equipped with the skills or the equipment to effectively meet their needs, are three times more likely to report mistreatment by healthcare professionals and four times as likely to report being denied healthcare. By being aware through reflection of their own knowledge limitations and then adding to their knowledge base, doctors will enhance the standard of healthcare that they give patients.

The main driving force behind a commitment to lifelong learning is a curiosity for knowledge. This curiosity is encouraged by certain skills, namely, willingness to learn, always seeking improvement, adaptability and being inquisitive.

Sub-Competency 12.1: Medical graduates must demonstrate a willingness to critically evaluate any of their own assumptions, as well as any feelings of discomfort (i.e., impairments which are different and often unfamiliar, can evoke feelings of discomfort) about persons with disability, how these relate to more broadly held societal attitudes, and how they might impact upon their assessment and management of persons with disability.

- *Descriptor*

This is fundamentally important because doctors are not immune to implicit societal biases about persons with disability. If such biases are left unchecked, they can contribute greatly to the issue of ableism in medicine. If medical graduates as doctors, project their own feeling of discomfort into a clinical interaction with persons with disability, it is going to potentially result in difficulty in developing good rapport between doctor and patient.

COMPETENCY 13: Medical doctors must demonstrate a willingness to adapt assessment, examination and treatment/management techniques to meet the needs of persons with disability.

- *Descriptor*

This is an important competency because the ability to think about and to implement creative assessment, examination and management techniques will contribute to decreasing the risk of misdiagnosis or mismanagement (e.g., how one could effectively examine the body, if the patient is physically unable to lie on the examination bed or how to effectively communicate with a deaf patient.)

6.4 In summary

This chapter recorded the findings from Phase two of this study which entailed presenting the initial competency set from Phase one to an expert panel. A modified Delphi Method was used as explained in the Methodology Chapter. Consensus was reached after two iterations and the final competency set was generated.

From the beginning of this study, I have been clear that I intend this study’s final competency set to be proposed as an addition to the pre-existing HPCSA competency set. It is important to discuss a comparison of the two sets in the next chapter.

In addition, the process of Phases one and two highlighted two other issues for me. These issues are the overlap between knowledge, attitudes, skills and ableism in medicine. Both these issues in relation to my study warrant further discussion which takes place in Chapter Seven.

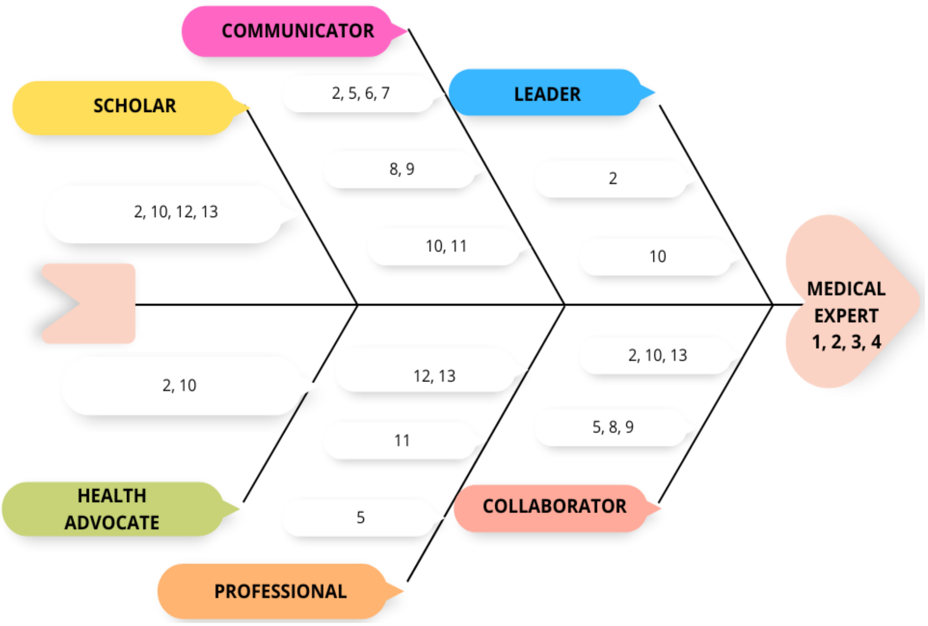
Chapter Seven

Discussion and Synthesis

7.1 Overview of chapter

In this chapter, I begin by comparing my final competency set to the HPCSA core competencies (HPSCA core competency document analysed in Chapter Five). I then discuss other important issues raised by the Phase one and Phase two data findings. I first discuss the overlap of knowledge, attitudes and skills evident in the two phases, then ableism in medicine in general, followed by more detail using a framework by Pena-Guzman and Reynolds (2018). It views ableism in medicine as an epistemic schema divided into four mechanisms: epistemic injustice, epistemic overconfidence, epistemic erasure and epistemic derailing. I will unpack these four mechanisms with reference to the data from both phases. My arguments focus on attitudinal competences that will lead to knowledge and skills being applied in a manner that facilitates equity in medical practice and inclusivity of persons with disability that protects dignity and restores their humanity.

7.2 Comparing competency sets



Competency Key

1 = definition

2 = resources

3 = medical conditions

4 = secondary complications

5 = multidisciplinary team

6 = diversity

7 = individuality

8 = lived experience

9 = equals

10 = empowerment

11 = environment of trust

12 = lifelong learning

13 = adaptations

Figure 7.1 shows the comparison between the HPCSA competency set – HPCSA undergraduate medical competencies are divided into the seven coloured word headings – **and this study's competencies** – represented by numbers.

After comparing this study's competency set to the HPCSA competency set for undergraduate medical students and remembering that the focus of this study is disability related competencies, it can be argued that this study's entire competency set fits fairly neatly into the roles shown by figure 7.1. In fact, in my opinion various competencies from this study's final set fit into a number of HPCSA roles. These noticeable overlaps provide a platform for the next section.

7.3 Overlapping elements (knowledge, attitudes and skills) in the data

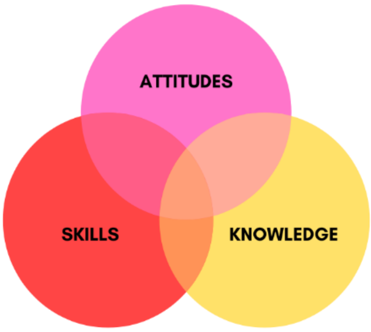


Figure 7.2 represents the overlapping elements that will be discussed in this section.

I have divided this section into a brief discussion of the overlapping elements in the Phase one data followed by a more in-depth discussion of the overlapping elements in Phase two data, with reference to the final competency set that I am proposing. I end this section with a suggestion of what is being advocated based on the contents of the first two parts of this section.

7.3.1 Phase one data

An important observation about the data gathered from the Phase one participants is that most of the data quotes address more than one of the first three objectives of this research. In fact, often all of the first three objectives are addressed by a single data quote (either directly or indirectly) – i.e., there are often elements of knowledge, attitudes and skills. It can be argued that attitudes, skills and knowledge are **interwoven.**

For example, the very first data quote of the subtheme ‘Early and varied exposure’ (Chapter Five, page 120) seems to be addressing objective 1.1 (see table 7.1). However, upon further analysis, it appeared that the development of an attitude of comfort/familiarity interacting with persons with disability has the potential to increase the skills - objective 1.2 (see table 7.1) - of the person who is being exposed in the manner mentioned in the data quote. At the same time, the development of such an attitude would be seemingly very beneficial to acknowledging the importance of learning and understanding about persons with disability – objective 1.3 (see table 7.1).

Table 7.1: The first three objectives

1.1	To critically analyse and describe the attitudes/values to the clinical encounter which characterises equitable practice with persons with disability.
1.2	To identify and describe the critical behaviours and skills of doctors which contribute to equitable practice with persons with disability.
1.3	To identify and describe key knowledge constructs which underpin equitable practice with persons with disability.

It is however difficult to make the claim that there is definite cause and effect pattern between attitudes, skills and knowledge among medical doctors in their clinical practice with persons with disability.

The potential interwovenness of knowledge, attitudes and skills was reiterated when I looked at these Phase one findings with the intention of addressing objective 2.1 (see table 7.2).

Table 7.2: The other/fourth objective addressed by Phase one data

2.1	Describe basic competencies (knowledge, skills and attitudes - feelings, beliefs and values) that graduate medical students should have in order to deliver a quality healthcare service to persons with disability.

7.3.2 Phase two data

The same observation – mentioned in 7.3.1 - applies to Phase two of this study which addresses objectives 3.1 and 3.2 (see table 7.3).

Table 7.3: The objectives addressed by Phase two data

3.1	Identification of initial set of competencies through various data sources.
3.2	Refine the competency framework through expert analysis.

When deciding whether each competency could be labelled as knowledge, attitude or skills, it quickly became clear that it was difficult to separate many of the competencies into one of the three clusters (knowledge, attitudes, skills). Only a handful of competencies could be labelled as (content) knowledge competencies; the remainder contained elements of all three clusters – represented by Figure 6.2 in Chapter Six, page 160. I suggest that this overlap is because different types of knowledge underpin all the competencies.

I identified two types of knowledge: content and interpersonal. Medical students and medical educators need to know why it is important that each competency be mastered. Where a competency feels potentially generic (potentially relevant to a doctor's practice with all patients), medical students (future medical doctors) need to know why these competencies are of particular relevance to patients with disabilities. The more knowledge that a medical student has regarding these competencies, the greater likelihood of their undergoing an attitudinal shift (in hopefully a positive direction) towards patients with disabilities. This attitudinal shift could result in greater efficacy in the mastery and delivery of a skill competency. I argue that more focus must be given to the effects attitudinal shifts can have on the quality of a medical doctor's disability practice.

This is evidenced by the following examples from the generated competency set:

- **COMPETENCY 5: Medical graduates must be able to work in a multidisciplinary team and in the context of disability, the graduate must be knowledgeable about how other members of the multidisciplinary team might contribute to comprehensive person-centred care.**

- **Sub-Competency 5.1: Medical graduates must be aware of the roles, skills and competencies of the healthcare professionals in a multidisciplinary team with regards to working with persons with disability.**

Competency 5 and sub-competency 5.1 are listed as knowledge competencies in the final competency set but I will explain why I feel there is an overlap between knowledge, attitude and skill in these competencies.

Morrison, Goldfarb and Lanken (2010), writing about medical education in the 21st century, emphasised that undergraduate medical curricula need to make an effort to include education around leadership and working in multidisciplinary healthcare teams.

Twelve years later Nakamura (2022) reports that attempts to include multidisciplinary education in medical education are being made but it is a slow process. Nakamura (2022) emphasises the importance of multidisciplinary education to assist with the multidisciplinary teamwork which is critical in meeting the diverse health needs of the 21st century.

A good multidisciplinary knowledge base will help doctors work effectively and efficiently in a multidisciplinary team – i.e., it will contribute to making the skill of teamwork easier to master. I am aware that Disability Studies involves both interdisciplinary and multidisciplinary knowledge but in the context of this study, I use the word multidisciplinary.

A good multidisciplinary knowledge base will also most likely contribute to an attitudinal shift within many doctors. Such a shift would hopefully result in a greater respect and valuing of what health professionals from other disciplines do (their work), as well as for how they can add to a patient with a disability's treatment options.

This idea resonates with my decolonisation of medicine lens I describe in Chapter Three. Wong, Gishen and Lokugamage (2021) suggest that the addition to medical education of perspectives from other healthcare disciplines (other than medicine) that have traditionally been marginalised by coloniality, can be helpful in challenging the traditional biomedical model in medical education.

- **Sub-Competency 8.1: Medical graduates must be able to compile contextually relevant treatment and management plans using a holistic approach for persons with disability (i.e., the focus must be on the individual's physiological,**

psychological, social and occupational needs and inclusive of the support network of each person with a disability, with the intention of promoting community integration).

In the competency set, I have clustered this sub-competency 8.1 as an attitude competency. However, I believe this sub-competency is a good example of the overlapping nature of knowledge, attitude and skill.

A doctor needs the knowledge of why such an approach to drawing up treatment and management plans with persons with disability is important. It is critical that doctors know and understand what it means to be contextually relevant. As sub-competency 8.1 explains, a contextually relevant treatment and management plan is one where the context (physical, psychological, social, occupational and family/primary care network etc) of each person with a disability plays a pivotal and decisive role in how such a plan is compiled. Knowing why this approach is important should translate into the doctor adopting an attitude that complements this knowledge. Armed with the knowledge and attitude pertaining to the importance of this competency will hopefully bring forth the necessity for doctors to be skilled in the clinical implementation of this sub-competency.

An awareness, consideration and understanding of the contextually background of a person with a disability is what two of my conceptual frameworks, the ICF and Critical Disability Studies call for.

- **COMPETENCY 9: Medical graduates must demonstrate the awareness that a meaningful clinical engagement with persons with disability is more likely to take place when the doctor acts and behaves as an equal partner (i.e., does not take an authoritarian view).**

This competency 9 seemed at first glance to fit quite neatly in the attitude competencies category of the final competency set. It is focussed on the repositioning of and equalising of power in the doctor-patient relationship, with applicability to disability. The competency speaks to the need for medical students to acquire an attitude of reciprocity in relating and learning.

However, after a deeper reading, I feel that it demonstrates the knowledge, attitude and skill overlap.

Doctors need to know why this behaviour is important. Knowing the philosophical reasoning behind the ‘why’ should encourage an attitude in doctors that will help in the clinical implementation of this competency. However, to truly be competent in the enactment of competency doctors need to develop the skill in doing so.

- **COMPETENCY 10: Medical graduates must demonstrate good understanding of why empowerment through knowledge (e.g., psychoeducation for cognitive or psychosocial disabilities or education about pressure care to physically disabled individuals) is necessary and important for persons with disability and their families. They must also demonstrate the skill of doing so.**

This competency 10 is an important example of not only the overlap of knowledge, attitude and skill but of the overlap in types of knowledge as well.

Similar to the other examples, doctors need to know why empowerment through knowledge is important for persons with disability. Doctors need to also know about the different ways to empower a person with a disability with knowledge specific to their medical impairment as well as their subsequent disability. Furthermore, through finding out and affirming what the person with a disability already knows is a powerful empowerment tool. Knowledge in these spheres should encourage an attitude to assist doctors in enacting this competency. The effective and efficient clinical implementation of this competency requires the development of a skill of empowerment through knowledge of persons with disability and their families.

- **COMPETENCY 13: Medical doctors must demonstrate a willingness to adapt assessment, examination and treatment/management techniques to meet the needs of persons with disability**.

I included this competency 13 in the skills competency cluster, but I will argue below that it is not a purely skills competency.

It is important for doctors to know why they might need to adapt their assessment, examination and treatment/management techniques for persons with disability. I believe that knowledge can influence attitude. Therefore, the clearer a doctor is regarding why this might be necessary, the easier the adoption will be of an attitude which aids this competency.

However, to clinically implement this competency in an effective and efficient way which maintains the provision of quality healthcare to persons with disability, a doctor needs to develop the skill in doing so – e.g., making use of an interpreter if there are any communication challenges or using writing materials for a person with a hearing disability who is able to read.

7.3.3 Advocating for integrative competencies

I am advocating for the dispensing of the traditional bounds of knowledge, attitude and skill competencies. I suggest that especially in the context of persons with disability, these competencies be labelled integrative (of knowledge, attitude and skill) competencies.

Eftekhar *et al.* (2012) found that knowledge and clinical skills are closely linked. They argue that certain knowledge is needed to produce certain clinical skills. In addition, Groene, Ehrhardt and Bergelt (2022) suggest that attitudes can positively or negatively influence the enactment of certain clinical skills, particularly those that require any communication with patients.

Rather than simply teaching or being taught these competencies, medical educators and medical students should be given the tools that would enable them to analyse and interrogate them. Such exploration would allow them to explore the overlap of knowledge, attitudes and skills for themselves.

The data examples I present in this discussion highlight the critical influence that attitude has on many of the competencies and not just those reported as attitude competencies, i.e., those reported as knowledge competencies and those categorised as skills competencies. Attitudes are often thought to be difficult to teach and assess. Yet I argue that action needs to be taken to ensure that we are teaching and assessing the attitudes of our medical students.

The lens of decoloniality supports my suggestion that greater emphasis must be given to the teaching and learning of attitudes in medicine. Nemutandani, Hendricks and Mulaudzi (2018) argue that the process of decolonisation in healthcare can be very important in causing mindset and attitudinal shifts, moving away from the perceived or assumed superior dominance of colonial thoughts and perceptions to being more open to indigenous (including personal and cultural) thoughts and perceptions about health care. In fact, Nemutandani, Hendricks and Mulaudzi (2018) – writing from a South African context - see decolonisation as a way to challenge and overcome any negative attitudes that decades of colonialism have fostered.

7.4 Exploring ableism

The issue **of ableism** in medicine became apparent when looking for ways to link data from the two phases. In this section, I will first discuss ableism in general using examples from Phase one data to help explain ableism. Thereafter, I will show how the final competency set generated in Phase two challenges ableism. In the final part of this section, I discuss ableism as an epistemic schema.

7.4.1 What is ableism?

An easily understandable definition of ableism describes it as form of social oppression by the able-bodied majority against the disabled minority (Nielson, 2020). The policies and practices of ableism view the embodiment of able-bodiedness as humanity's default setting, rendering persons with disability as less than human (Nielson, 2020).

Janz (2019) makes the assertion that medical doctors are not immune to the ableistic attitudes and understandings of Disability that are held by many in society. This claim by Janz (2019) is evident many times throughout Phase one data. Fergus, Teale, Sivapragasam, Mesina and Stergiopoulos (2018) remind us that medical students do not enter medical school as blank slates. They bring with them an array of different life experiences which can influence their practice of medicine. I argue that it is these claims combined with the influences of the medical model of disability that perpetuates ableism.

In the second and third category of the subtheme 'Blinkered assumptions' (Chapter Five, pages 135 and 136), there is the observation by a therapist of how some doctors automatically talk very loudly to persons with disability because of the pervasive societal belief that all persons with disability have cognitive challenges as well. The participants with disabilities then gave a few good examples of how doctors often address the able-bodied person attending the consultation with the person with a disability (e.g., a family member or a carer) instead of directly addressing the person with a disability.

These ways of communicating strip a person with a disability of autonomy and in fact in that instance medical doctors devalue a person with a disability of their humanity.

The first category of the subtheme, ‘Medical omnipotence’ (Chapter Five, page 131), explains how the combination of an attitude of arrogance from doctors and the ableistic societal view of persons with disability as less valuable humans is likely to increase this power differential. This inequality in power will almost certainly hamper communication even further between able-bodied doctors and disabled patients.

Pena-Guzman and Reynolds (2018) claim that ableism plays a malevolent role in the communication between the patient and the healthcare provider. It does this by altering the communication between an able-bodied physician and a disabled patient. Ableism can alter communication by creating and maintaining a power differential between an able-bodied physician and a disabled patient.

This altering often results in the patient experiencing a variety of forms of epistemic injustices and it also exposes the patient to a higher risk of medical error and/or harm.

7.4.2 How this study’s competencies challenge ableism

Sub-competency 12.1 in the set aims to combat this issue by encouraging medical students and medical educators to become aware of and interrogate their premedical school perceptions and feelings about Disability, as ableism is embedded in programmes. Therefore, the process of unpacking values and prejudices is important for all associated with programme.

- **Sub-Competency 12.1: Medical graduates must demonstrate a willingness to critically evaluate any of their own assumptions, as well as any feelings of discomfort (i.e., impairments which are different and often unfamiliar, can evoke feelings of discomfort) about persons with disability, how these relate to more broadly held societal attitudes, and how they might impact upon their assessment and management of persons with disability.**

The link between my final competency set, ableism and decoloniality is facilitated by Ndlovu’s (2021) argument that decoloniality can assist persons with disability in reclaiming their humanness by “emancipation through consciousness and awareness of oppression and autonomy” (Ndlovu, 2021, page 66). This statement serves as a good reminder that decoloniality is a powerful tool with which to combat the effects of ableism which is often a biproduct of colonialism (Ndlovu, 2021).

The final competency set (summarised via key terms that encapsulate each competency- see table 7.4) looks to challenge ableism in medicine through creating a strong awareness that the perceived other (a person with a disability) is in fact just a modulation of the same fabric of society to which able-bodied people belong and deserve to be equally valued and respected.

Table 7.4: Competency key for the entire final competency set

Competency Key

1 = definition
2 = resources
3 = medical conditions
4 = secondary complications
5 = multidisciplinary team
5.1 = roles
5.2 = referrals
5.3 = team member
6 = diversity
6.1 = intersectionality
7 = individuality
8 = lived experience
8.1 = holistic approach
9 = equals
10 = empowerment
10.1 = advocacy
11 = environment of trust
11.1 = quality interactions
11.2 = extra time
12 = lifelong learning
12.1 = self-reflection
13 = adaptations

Yet another challenge to the entrenchment of ableism by the competency set will come from the influence the competency set will have on both the formal and hidden curriculum. The intention of the competency set is to bring about a much-needed shift in thinking with respect to undergraduate medical education.

This shift required is two-fold: moving the focus away from the individual’s impairment to environmental and societal barriers; and from curing/normalising function to recognising capabilities.

This impairment focus has resulted in a medical culture that views disability as an illness or weakness. This medical culture can lead to a perpetuation of the sense of otherness of persons with disability (i.e., perpetuation of ableism in medicine).

7.4.3 Introducing ableism as an epistemic schema

Ableism is viewed by Pena-Guzman and Reynolds (2018) as an epistemic schema rooted in prejudice. Epistemic schemas are a collection of both implicit and explicit values, biases, norms, impulses, desires, fantasies and assumptions. This collection influences what is seen as knowledge, who is acknowledged as the knower and how knowledge is interpreted, assessed and adjudicated within an epistemic community. Epistemic schemas assist in making sense of the world but may also serve to justify the maintenance and replication of societal inequalities (Pena-Guzman & Reynolds, 2018; Toole, 2019).

As a profession Medicine is ideally supposed to treat every person – regardless of ability - equally without discrimination or prejudice. However, due to many epistemic schemas that are rooted in prejudice – such as ableism –this ideal of equality in medicine is a noble goal which must be striven for (Pena-Guzman & Reynolds, 2018).

Gaede (2021) suggests that a root cause of this inequality is the firmly entrenched (colonial) hierarchy within the hidden curriculum of undergraduate medical education which stems from the colonial legacy of an 18th century way of thinking in medicine. Empathy was overlooked in the pursuit of medical advancement through experimentation and discovery (Lokugamage, Ahillan & Pathberiya, 2019). One of the results is the perpetuation of unjust power relationships between medical students and medical educators; medical students themselves and ultimately medical doctors and patients.

I argue that the continued presence of the above-mentioned hierarchies is a major contributing factor to the complexity entailed in changing doctor-patient relationships towards a more equal power dynamic.

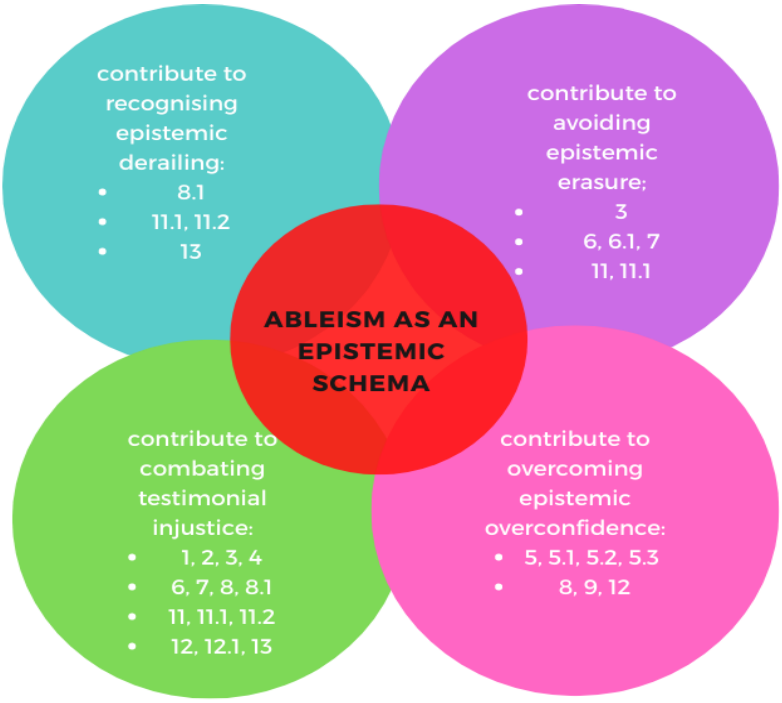
The overarching intention of the entire competency set is an attempt to achieve this ideal of equality in medicine. However, competencies 6, 7 and sub-competency 6.1 are particularly good, clear reminders to medical graduates to keep striving for equality in medical care afforded to able-bodied persons and to persons with disability.

Competency 6	**Diversity**
Sub-competency 6.1	**Intersectionality**
Competency 7	**Individuality**

7.4.4 The four mechanisms of the epistemic schema of ableism

I made mention in 7.1 of the four mechanisms that Pena-Guzman and Reynolds (2018) find useful to further breakdown the epistemic schema of ableism. These mechanisms are testimonial injustice, epistemic overconfidence, epistemic erasure and epistemic derailing.

In this section, I use examples from Phase one data to assist in explaining and discussing each of the four mechanisms. In addition, I use examples from the final competency set to demonstrate what my proposed competencies can contribute (see figure 7.3 on the next page).



Competency Key

1 = definition

2 = resources

3 = medical conditions

4 = secondary complications

5 = multidisciplinary team

5.1 = roles

5.2 = referrals

5.3 = team member

6 = diversity

7.1 = intersectionality

7 = individuality

8 = lived experience

8.1 = holistic approach

9 = equals

11 = environment of trust

11.1 = quality interactions

11.2 = extra time

12 = lifelong learning

12.1 = self-reflection

13 = adaptations

Figure 7.3 shows the four mechanisms of ableism as an epistemic schema and which of this study's competencies contribute to each mechanism – the details of their contributions follow in the below text.

7.4.4.1 Combating Testimonial injustice

Testimonial injustice in a medical setting takes place when a doctor holds and maintains a group-based belief about a particular population group (e.g., black, women or disabled). Through the maintenance of this belief, a doctor devalues what the patient is saying to them. Pena-Guzman and Reynolds (2018) describe it as an unfair invalidation – by the hearer - of what the testifier is saying, based on the social identity of the testifier.

The second category of the subtheme, 'Blinkered assumptions' (Chapter Five, page 135) highlighted a very common and pervasive belief which can lead a testimonial injustice being done to a patient with a disability by a doctor, and that is, if there is one impairment present (e.g., physical, blind, deaf or speech etc) then the person with that disability has a mental or intellectual disability as well. This assumption often causes doctors to downgrade the validity of what a patient with a disability has to say, both unfairly and presumptively. In fact, a common thing that many doctors (and many members of general society) do when interacting with a person a disability, is that they bypass the person with a disability and address the able-bodied person who is with the person with a disability.

This belief implies that the person with the disability is incapable of independent and meaningful discussion. The data from Phase one is rich in examples of this belief.

The Persons with disability participants were rather vocal about how rude and offensive they find the behaviour of doctors that arises as a result of this belief.

A further example of testimonial injustice in the clinical interaction between a doctor and a patient with a disability occurs when a medical doctor focusses almost exclusively on a patient's impairment which caused their disability and seems to ignore the fact that the patient with a disability is, or might be, seeking medical attention for a medical problem that is unrelated to their disability.

This exclusive focus of privileging the body and doctor's sense making of the clinical process disallows the true testimony of the person with a disability from being heard and accepted.

Testimonial injustice is often a result of unfamiliarity with certain social identities. In the context of this study, I argue that testimonial injustice occurs because of able bodied medical doctors' unfamiliarity with persons with disability. This unfamiliarity puts doctors at risk of merely adhering to societal prejudices and biases about disability. This makes it easier for testimonial injustice to take place.

It is important to remember that there is also rife ableism amongst medical doctors themselves. This particular form of ableism was raised in the second category of subtheme 'Limited beliefs and expectations' (Chapter Five, page 148). It is easy to see how such a question of role validity could result in testimonial injustice amongst able-bodied and disabled doctors.

- **What these competencies contribute to combating testimonial injustice**

The overarching intention of most of this study's final competency set (see table 7.4 for competency key, page 202) is to increase the understanding of medical doctors about

Disability and persons with disability. This could contribute to a lowering of the risk of testimonial injustices being done to persons with disability by doctors.

However, each competency has a different approach to increasing a doctor's familiarity with disability. Some do so rather directly and in an obvious sense.

For example, the first four competencies in the final set actively and directly seek to ensure doctors are equipped with the content knowledge to assist them in feeling more familiar about disability.

Competency 1	**Definition**
Competency 2	**Resources**
Competency 3	**Medical conditions**
Competency 4	**Secondary complications**

Whereas competency 6, sub-competency 6.1, competency 7, 8 and sub-competency 8.1, focus more on expanding the interpersonal knowledge of doctors - with specific emphasis on recognising and valuing the humanity of persons with disability.

Competency 6	**Diversity**
Sub-competency 6.1	**Intersectionality**
Competency 7	**Individuality**
Competency 8	**Lived experience**
Sub-competency 8.1	**Holistic approach**

The competencies that are categorised as skills are focused on ensuring that a doctor is comfortable and familiar with what they need to do in a clinical setting to afford quality medical healthcare to persons with disability.

Competency 11	**Environment**
Sub-competency 11.1	**Quality interactions**
Sub-competency 11.2	**Extra time**
Competency 12	**Lifelong learning**
Sub-competency 12.1	**Self-reflection**
Competency 13	**Adaptations**

7.4.4.2 Overcoming Epistemic overconfidence

This is the second mechanism that Pena-Guzman and Reynolds (2018) offer up as a factor contributing to the perpetuation of ableism in medicine. Cassam (2017) posits that epistemic overconfidence by medical doctors has the potential to cause medical harm.

Epistemic overconfidence tends to cause the medical doctor to not seek additional information or not to refer to other healthcare professionals, which could assist them in ensuring they correctly diagnose, treat and manage their patients.

The first category of the subtheme, ‘Medical knowledge superiority’ (Chapter Five, page 133) speaks about how the pride (in their epistemic prowess) of a doctor can often be a barrier to the doctor seeking more information from other healthcare professionals or referring to more appropriate healthcare professionals. It illustrates well the point that Pena-Guzman and Reynolds (2018) make that overconfidence in doctors could stem from the internalization of the many epistemic credits that society attributes to them by virtue of their position as doctors. This overconfidence can result in arrogance which can in turn prevent the self-recognition by the doctor of their knowledge limitations.

In the third category of the subtheme, ‘Medical omnipotence’ (Chapter Five, page 132) a participant from the persons with disability group suggested another way that epistemic overconfidence could arise.

Epistemic overconfidence might also not allow a doctor to acknowledge and appreciate the lived experience of a Person with disability. This is expressed clearly in the sixth category of the subtheme, ‘Knowledge constructs’ (Chapter Five, page 141).

- **What these competencies contribute to overcoming epistemic overconfidence**

Several of the competencies in the final set are potential contributors.

Competency 12 is perhaps the best competency in the set that gives doctors a chance of minimising the occurrence of epistemic overconfidence in their medical practice with persons with disability. The competency reminds doctors quite clearly that due to the *multifaceted and constantly evolving concept of Disability*, it is vital that doctors recognise that they might not know everything (i.e., recognising their knowledge limitations) and why this is important in the context of Disability. The competency offers doctors particular skills to assist with this recognition.

Competency 12	**Lifelong learning**

Competencies 8 and 9 carry with them the intention of making doctors aware that they are not superior beings and persons with disability inferior beings. The creating of this awareness is achieved by both competencies having the words *equal partners* in them.

Competency 8 also specifically mentions the need for doctors to recognise the lived experience of persons with disability as a valuable source of knowledge.

The intentions of competency 5 and the related 3 sub-competencies are similar to competencies 8 and 9 but the focus is on making a doctor cognisant of what the different members of a multidisciplinary team can bring to the healthcare of persons with disability (I.e., helping doctors realise that they do not know everything when offering persons with disability quality healthcare.)

Competency 5	**Multidisciplinary team**
Sub-competency 5.1	**Roles**
Sub-competency 5.2	**Referrals**
Sub-competency 5.3	**Team member**
Competency 8	**Lived experience**
Competency 9	**Equals**

7.4.4.3 Avoiding Epistemic erasure

The third mechanism represents how ableism is viewed as an epistemic schema. Epistemic erasure occurs when a medical doctor omits entire swaths of information in a clinical interaction with a patient. This omission is based purely on the doctor's preconceived notions about the patient because of the patient's social identity. These preconceived notions mean the doctor leaves out information relevant to the patient.

In the third category of subtheme 'Knowledge constructs' (Chapter Five, page 139), we are reminded of the importance of getting the full history of a person with a disability – i.e., do not omit questions simply because you (as the doctor) do not think they are relevant.

This reminder leads into a very common example of epistemic erasure with persons with disability. Ableism tends to portray persons with disability as objects of pity. One way of achieving this is by the desexualisation of disabled bodies. This stereotype shows itself in a medical setting when a doctor makes no mention of sexual health issues nor asks any sexual health related questions when interacting with a patient with a disability. This is done because a doctor assumes the patient with the disability does not and could not have sexual health issues. The fifth category of the subtheme 'Blinkered assumptions' (Chapter Five, page 137) provides a good example of this issue.

- **What these competencies contribute to avoiding epistemic erasure**

A few of the competencies in this study are geared towards addressing the issue of epistemic erasure by doctors in the context of their clinical interactions with persons with disability.

Competency 3 directly addresses this issue through saying that *medical graduates must demonstrate an awareness that persons with disability are susceptible to the same medical conditions as their able-bodied peers…* This awareness will hopefully help remind to not omit asking certain questions because they assume such information is not relevant to a person with a disability.

Competency 3	**Medical conditions**

In a slightly less direct manner, competency 6 and sub-competency 6.1 and competency 7, focus on addressing the issue of epistemic erasure. They do this through creating knowledge, awareness and understanding about the diversity of the humanity and individuality of persons with disability.

Competency 6	**Diversity**
Sub-competency 6.1	**Intersectionality**
Competency 7	**Individuality**

These ideas speak to the issue of decolonisation. Through these competencies which are encouraging medical students (our future doctors) to embrace diversity, this study hopes to add to the many voices that have traditionally been on the receiving end of forms of erasure in the global south. These voices are challenging and protesting the exclusive (white and patriarchal) and exclusionary (non-white, female, disabled and many other minority groups) ethos that colonialism has left in its wake (Behari-Leak & Mokou, 2019).

Armed with this knowledge, awareness and understanding will hopefully mean that doctors are less likely to assume what should and should not be addressed in a clinical interaction.

Competency 11 and sub-competency 11.1, lay foundations for good, clear and open communication between doctors and persons with disability. Such communication should assist in lowering the risk of epistemic erasure.

Competency 11	**Environment of trust**
Sub-competency 11.1	**Quality interactions**

7.4.4.4 Recognising Epistemic derailing

The fourth mechanism that makes up the concept of ableism as an epistemic schema is epistemic derailing. This occurs when the assumed characteristics of a speaker's social identity are used as deciding factors for how knowledge is interpreted in a communication, thereby severely limiting the quality of the communication (Chapman & Carel, 2022).

In the context of disability and medicine – as noted by this study - this can occur when a doctor is unable to look past a patient's impairment and as such believes that all the health issues a patient has, are all related to the patient's impairment. Chapman and Carel (2022) argue that this derailing places a burden of responsibility on the person with a disability to educate doctors and attempt to correct the disruption to communication.

The first data quote in the fourth category of the subtheme 'Quality of the clinical interaction' (Chapter Five, page 126), explains that this focus can result in quite limited healthcare treatment, i.e., when a doctor's dominant and sometimes only approach is through the lens of the medical model of disability. The third data quote in this same category (Chapter Five, page 128) describes how this focus can make persons with disability feel.

Epistemic derailing often indicates that the doctor is not really listening to what a patient is saying. Several other Phase one participants agreed that derailing of this kind often results in the person with the disability's needs, wants and desires not being properly heard and met.

Epistemic derailing is potentially medically harmful because it can cause a doctor not to explore certain topics raised by the patient. Epistemic derailing can also cause a doctor to not pursue certain tests that could be helpful in directing the doctor to a diagnosis and treatment plan.

- **What these competencies contribute to recognising epistemic derailing**

Sub-competency 8.1 provides doctors with a very effective approach to assist in addressing epistemic derailing. This sub-competency emphasises that the treatment and management plan of a person with a disability must take into account the individual needs both from a medical and social model of disability.

Sub-competency 8.1	**Holistic approach**

Sub-competency 11.1, 11.2 and competency 13 give doctors' useful tools which will assist in making sure all the needs of a person with a disability are met, thereby helping to minimise the risk of epistemic derailing. For example, with respect to effective communication, the necessity of extra time in consultations with persons with disability and the necessity of having to adapt assessment, examination and treatment and management techniques.

Sub-competency 11.1	**Quality interactions**
Sub-competency 11.2	**Extra time**
Competency 13	**Adaptations**

In summary, the above discussion – section 7.4 - shows how testimonial injustice, epistemic overconfidence, epistemic erasure and epistemic derailing are closely linked. It also shows how individually and collectively, the competencies in the final competency set of this study address these four mechanisms. The competencies proposed by this study actively address the epistemic schema of ableism in medicine.

7.5 In summary

This chapter began with a comparison of the study's competency set and the HPCSA competency set (from the document analysed in Chapter Five). I then discussed two other key issues that this study highlighted. First was discussed - with reference to examples from my data - the overlap between knowledge, attitudes and skills. I emphasised the critical role of attitudes in medicine, as well as the role that decoloniality can play in shifting attitudes and how more should be done to include the teaching and assessment of attitudes in undergraduate medical education. Then ableism was discussed in medicine - again with reference to my data. A framework provided by Pena- Guzman and Reynolds (2018) helped to do this by viewing ableism in medicine as an epistemic schema comprised of four mechanisms: testimonial injustice, epistemic overconfidence, epistemic erasure and epistemic derailing. The following chapter provides the conclusion to this study.

Chapter Eight

Conclusion

8.1 Overview of the chapter

This chapter begins with a conclusion of the study unpacked in five sections: What this study offers is: common goals, tension and challenges; the significance of this study; how my study is different– through the use of the term persons with disability, descriptors and examples in the final competency set - and how this study contributes to decoloniality. I then discuss the implications followed by limitations of this study. I finish by suggesting options for further research and engagement and with a summary of this chapter.

8.2 Conclusion of this study

8.2.1 What this study is offering

This study sets an important precedent for the inclusion of the subject of Disability in undergraduate medical curricula. It proposes an approach to teaching and learning about disability inclusion for medical students. The list of disability specific competencies set forth by this study are a steppingstone in the process of curriculum transformation. In the first subsection of Chapter Two Literature Review, I provide international and national literary evidence that recognises the need and call for curriculum transformation, thereby further substantiating the importance of what this study is proposing.

These proposed competencies open other parts of the curriculum – i.e., how the proposed disability competencies should be taught and assessed - to be interrogated and addressed through further research.

Through vital stakeholder input, a key feature of this study's competency generation was the inclusion of persons with disability in both phases of this study. Singh *et al.* (2020) argue that disability specific competencies should not be generated without the input of persons with the lived experience of disability. Vergunst *et al.* (2017) argues the despite persons with disability often having high healthcare needs, they are frequently left out of research-based healthcare interventions. By using a competency-based approach, this study has been able to explicitly address many of the healthcare needs of persons with disability. As mentioned in my Methodology Chapter, the conceptual framework around curriculum, greatly informed the curricular processes followed in this study (see Chapter Three, page 60).

This study's competency set hopes to offer a way for the medical, social and various other models of disability to co-exist in a more harmonious manner within medical education - i.e., to minimise the traditional dominance of the medical model of disability (an individual approach focused on the person's health condition and impairment only). This point first raised in Chapter Two Literature Review, provides this offering of this study's competency set with the necessary evidence to support its importance. Two of my Chapter Three concepts, the ICF and Critical Disability Studies, align well with this offering. Equally my choice of a decoloniality lens through which to view this study is supported by this offering (see Chapter Three, page 69).

As mentioned in section 7.3, Chapter Seven, pages 193-199, the competency set also proposes that there be a greater focus given to the teaching and assessment of attitudes.

Chapter Seven, page 199, presents an argument advocating for this greater focus on attitudes given a very close link between knowledge, skills and attitudes. It is supported in the literature by the work of Eftekhar *et al.* (2012) and more recently by Groene, Ehrhadt and Bergelt (2022) - see Chapter Seven, page 199. The data highlighted the influence of attitudes on healthcare that medical doctors provide persons with disability. Lefkowitz, Meitar and Kuper (2021) argue that teaching attitudes - such as professionalism and empathy - is as important as the hard sciences which are already taught in high volumes at medical school. According to these authors an absence on the focus of teaching attitudes can have a major impact on the quality of care by doctors.

Importantly this competency set looks to offer a way to help decrease the traditional power differential - a colonial legacy - between doctors and persons with disability. The competency set does this by focussing attention on the elevation of the humanity of persons with disability to a more equal footing with doctors. This offering links to my decoloniality lens and my Critical Disability Studies lens – see Chapter Three. In Chapter Seven, I explain how decolonisation can assist with challenging of pre-existing power dynamics and Lorenzo (2022) provided this study with clear guidelines relating to Critical Disability Studies' ability to achieve the same objective.

8.2.2 Common interests and goals, tension and challenges

Although all the study participants were united by common interests and goals – through disability experience (personal, professional or academic) and/or the transformation of medical education (see Chapter Four for the inclusion criteria for all participants) – neither phase was without tension or challenges in thoughts and ideas. This tension was higher in Phase two than Phase one – I will elaborate further on.

Phase one data provided vital information about what a doctor needs to know about Disability, and comprised the initial competency set. The data was generated from focus groups and in-depth interviews with Medical Doctors, Rehabilitation Therapists, Nurses, Medical Students and Persons with disability. The expert panel in Phase two helped formulate this study's final competency set (see figure 8.1 below). The panellists participating in the modified Delphi Method were diverse: abled and disabled Disability Studies Academics, Medical Educationists, Medical Doctors and Disability Rights Activists.

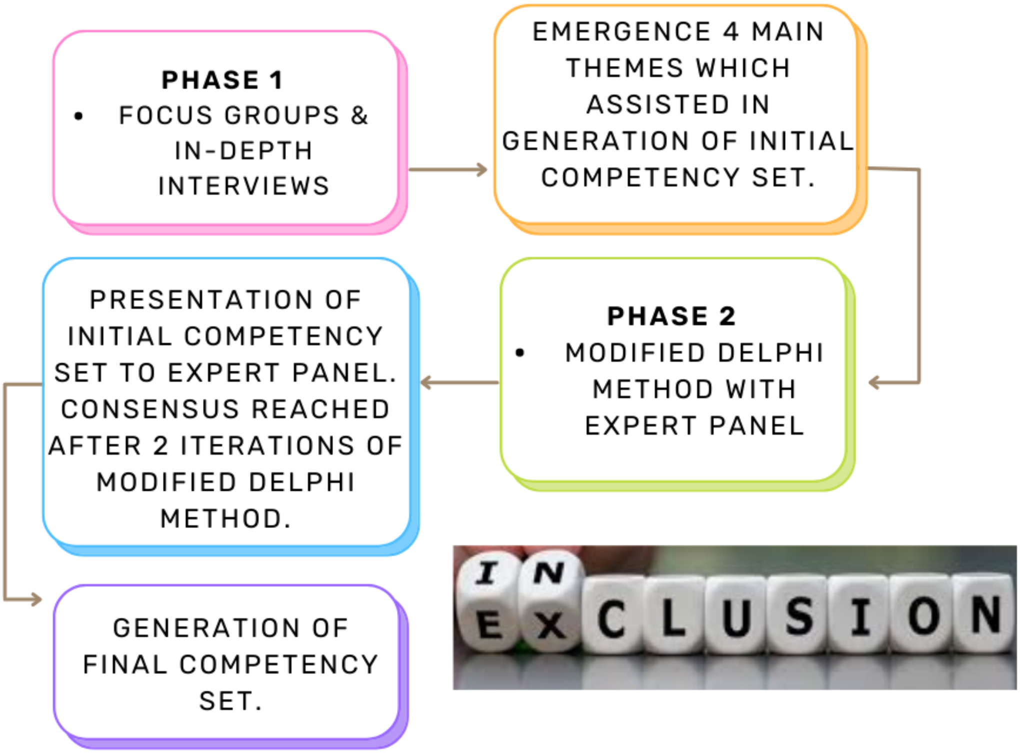


Figure 8.1: A flow diagram of the research study that is a step towards increasing disability inclusion in medical student education/curricula (google images: communitycare.co.uk).

A reminder that the four main themes (mentioned in the second block of the diagram) are: Experience of disability, Attitudes towards disability, Knowledge about Disability and Life beyond the disability.

Although there was no tension amongst the Phase one participants, Phase one challenged me during the data analysis because it was a completely new process. I had to reflect on my positionality to maintain awareness of my objectivity.

Most of the tension in Phase two stemmed from a few of the white male medical doctor experts feeling that attitudes are too difficult to teach and assess and should therefore not be included in the competency set. All the experts with disabilities and a few female experts – white, black and coloured - (qualified Rehabilitation Therapists and Disability Studies Academics) disagreed with this assumption.

The experts challenged me to think about whether I was meeting the intention of proposing competencies that transcended an individual, impairment approach. I was also made aware and challenged on addressing decoloniality. The latter is an attempt to start rectifying the resounding critique (national and international) that 21st century medical graduates are not sufficiently equipped to meet the needs of all their patients (Wartman, 2019). I elaborated on this call in Chapter Two.

Right from the beginning of this study I have shared the same common interests and goals (see the first paragraph of 8.2.2) as all the participants of this study. The process of this study has reinforced these interests and goal. Perhaps most importantly, this study has given a stronger conceptual basis - rooted in evidence from local and international literature – with which to pursue a passion for disability advocacy.

8.2.3 The significance of this study

It is important to highlight that this study is the first learning engagement of its kind in South Africa and possibly second in the world (Singh *et al.* 2020). (See Chapters One and Two)

There is a similar study by Havercamp *et al.* (2020) in the global north. It generated disability competencies relevant to health professionals in different disciplines (e.g., medicine, nursing and other health professionals) – this study is reviewed in Chapter Two. Our respective study approaches are both important to ensure that persons with disability receive quality healthcare. Havercamp *et al.* (2020) remind us that all healthcare professionals will likely engage professionally with persons with disability, and therefore need to be competent in disability inclusive practice.

I suggest that my study and the study in India by Singh *et al.* (2020) (reviewed in Chapter Two) are important additional developments of Havercamp *et al.* (2020)'s work.

In my professional experience as a physical rehabilitation doctor, and personal experience as a person with a disability throughout Phase one data of this study, it has become clear that doctors (along with nurses) are often part of a person with a disability's initial engagement with healthcare services.

This assertion is seemingly supported by Fortune, Madden and Clifton (2021, pages 8-9) who report that "the National Health Survey (2017–18) provides data on the proportion of people who consulted different types of health professionals in the past 12 months. Compared to people without disability aged 18–64 years, a higher percentage of those with disability reported having consulted a GP (92%, compared with 83% of those without disability), a specialist (50%, compared with 29% of those without disability) and an allied health professional (37%, compared with 19% of those without disability)." It is important to note that these numbers are from Australia and might differ amongst countries.

It is therefore evident that doctors play a large role that can either positively or negatively influence a person with a disability's perception of healthcare. It is vital that doctors are competent in disability inclusion to assist in the influence being positive. This statement links to the relevance and significance of study recorded in the first two Chapters of this thesis.

8.2.4 How my study is different

While there are similarities between my competency set, that of Havercamp *et al.* (2020) and Singh *et al.* (2020), there are three critical differences that I believe help make my study novel.

- Both Havercamp *et al.* (2020) and Singh *et al.* (2020) repeatedly use the words *patients with disabilities* in their competency set. One of the experts in my Delphi Method was quite vocal in her suggestion that I replace *patients with disabilities with persons with disability*. Her argument (Chapter Six, page 165) which I chose to support, is that the word patients would be a perpetuation of the dominance of the medical model of disability - minimising this dominance is one of my study's main intentions.
- The other difference is my addition of descriptors to each competency. I suggest that these will help both medical students and medical educators to understand the competency and why it says what it says.
- My inclusion of examples to some of my generated competencies is yet another different aspect of my competency set.

Important to note is that the contextual issues (e.g., socioeconomic status of a developing country, race and gender) that add complexity to the findings are different from the global north study but are likely to be similar to the Singh *et al.* (2020) study in India.

8.2.5 How this study contributes to decoloniality

I spoke in Chapter Three of the intention to use the issue of decoloniality as a conceptual framework for this study. Two ways are mentioned in 8.2.1: that the competencies generated by this study are focused on decreasing the traditional dominance of the medical model of disability in medical education; and they are aimed at lessening the power differential in relationships between doctors and persons with disability. Both the dominance of the medical model of disability in medical education and the perpetuation of a wide power differential in doctors' relationships with persons with disability, stem from a colonial approach to medicine.

Another notable contribution is that my study about disability competencies, viewed through a decoloniality lens, strengthens the paucity of literature on decoloniality and disability (Imada, 2017).

8.3 Implications

From the outset I wanted to situate this study as one which is generating competencies in an existing curriculum that is overloaded. I recognised that engagement with this study's proposed competencies might be met with resistance from some medical educators.

It is suggested that many of the competencies be woven into pre-existing topics. For example, when medical students learn about acute stroke in neurology, multidisciplinary knowledge can be included. Many of the competencies such as empathy and negotiating power dynamics arguably relate to medical practice with all patients and should already be being taught to medical students. Therefore, all that would need to happen is for disability to be specifically mentioned when these topics about certain impairments are taught.

In 7.2 of Chapter Seven, I compared this study's final competency set with that of HPCSA. It was noted that several of this study's competencies seemed to contain combinations of the seven roles the HPCSA has used in categorising their competencies. The implication of this noting of overlaps is to challenge the structure of HPCSA competency document in two ways. Firstly, it should be reviewed to see if all the competencies can really be neatly categorised within those seven roles. Secondly, the Collaborator role in HPCSA document speaks only of competence in collaboration between healthcare professionals whereas my final competency set advocates for a knowledge collaboration between medical doctors and persons with disability. This second point can be traced quite directly back to my Chapter Three citation of Sadiki *et al.* (2022). These authors stressed that fact that Critical Disability Studies has the ability to encourage knowledge reciprocity and I noted my intention in Chapter Three to utilise this ability.

This study's competencies differ from those stipulated by the HPCSA, in that they are specifically underpinned by Disability. These competencies therefore propose a way towards achieving the ideal goal of medicine which is equal medical treatment for all people – see Chapter Seven, page 203.

Although these competencies carry an underpinning of disability, I believe they provide a framework for competencies for other marginalised groups, as evident in sub-competency 6.1 (Chapter Six, page 184) which actively seeks to raise awareness about other aspects of diversity and how they can intersect. However, the extent of transferability can and should be decided by other marginalised groups because it can be argued that other marginalised groups need to recognise the relevance of Disability as an axis of power that intersects with their differences and diversity.

While this study’s disability specific competencies are not a prescriptive method that will solve the challenge of disability inclusion in health sciences education, they are, however, an important initial step towards ensuring a disability competent medical workforce. These competencies pave the way for further engagement and dialogue around the focus of disability inclusion in medical education.

8.4 Limitations

8.4.1 Use of research assistants

In Chapter Four, it was detailed exactly why research assistants were employed in Phase one of this study. I was justified in this action because it ensured that I minimised the introduction of any bias that my presence might have introduced during the focus groups and in-depth interviews. Recognising that research assistants might not delve as deeply as I could, I took every precaution to prepare them for facilitating in-depth engagement: intensive training, writing all the initial questions for the focus groups myself – to ensure relevance to my study, debriefing the assistants after the groups and discussing with the assistants which participants I wanted an in-depth interview with and why.

8.4.2 Absence of participants with psychosocial disability in Phase one

I noted this absence in Chapter Five and tried to mitigate for this lack through the inclusion of psychiatrists in Phase two expert panel.

Despite this attempt I am conscious that this lack may have limited the variety of the Phase one participant contributions.

8.4.3 Variations between South African provinces

This study is proposing disability specific competencies for inclusion in the undergraduate medical curriculum of South Africa. The context of this study is the Western Province of South Africa. It is important to note, there are vast socio-economic, socio-political, sociocultural and socio-geographic differences between South Africa’s nine provinces. These differences could have resulted in differences in participants’ contributions if the same study was replicated in another South African province. This particularly applies to my Phase two participants. In Chapter Six, I list their demographic data and record most of my Phase two experts as being white. The Eastern Cape is a province in South Africa which has a very large population of black South Africans, many living in rural areas. Such South Africans might express different views to my majority white Phase two experts. This potential limitation therefore invites further research to test this hypothesis.

8.5 Further engagement and research

This study’s proposed competencies would require working with professional licensing boards (HPCSA) to embed them into medical education standards.

It would be important to engage in professional development to assist faculty staff in teaching the competencies.

More medical education research is needed to develop assessment and evaluation tools for the competencies, especially those related to the psychosocial construction of attitudes.

8.6 In summary

In this chapter I concluded this study through the consideration of different aspects of it. I discussed the implications of this study and very importantly acknowledged the limitations of this study. I lastly made suggestions for further research and engagement.

References

Abes, E. S., & Wallace, M. M. (2018). " People see me, but they don't see me": An intersectional study of college students with physical disabilities. *Journal of College Student Development*, *59*(5), 545-562. https://doi.org/10.1353/csd.2018.0052.

Academy of Science of South Africa. (2018). Reconceptualising health professions education in South Africa. 1-260. http://dx.doi.org/10.17159/assaf.2018/0021.

Achoki, T., Sartorius, B., Watkins, D., Glenn, S. D., Kengne, A. P., Oni, T., ... & Naghavi, M. (2022). Health trends, inequalities and opportunities in South Africa’s provinces, 1990–2019: findings from the Global Burden of Disease 2019 Study. *Journal of Epidemiology and Community Health*, *76*(5), 471-481. http://dx.doi.org/10.1136/jech-2021-217480.

Aday, L. A. (1994). Health status of vulnerable populations. *Annual review of public health*, *15*(1), 487-509. https://doi.org/10.1146/annurev.pu.15.050194.002415.

Afshari, A. R. (2019). Using the Delphi Method for Futures Studies. In *Proceedings of the International Conference on Industrial Engineering and Operations Management Pilsen, Czech Republic, July* (pp. 23-26). Retrieved from https://ieomsociety.org/.

Amoussou, F., & Allagbe, A. A. (2018). Principles, theories and approaches to critical discourse analysis. *International Journal on Studies in English Language and Literature*, *6*(1), 11-18. http://dx.doi.org/10.20431/2347-3134.0601002.

Anderson, C. (2010). Presenting and evaluating qualitative research. *American journal of pharmaceutical education, 74*(8). https://doi.org/10.5688/aj7408141.

Andrews, E. E., Ayers, K. B., Brown, K. S., Dunn, D. S., & Pilarski, C. R. (2021). No body is expendable: Medical rationing and disability justice during the COVID-19 pandemic. *American Psychologist*, *76*(3), 451. https://doi.org/10.1037/amp0000709.

Ankam, N. S., Bosques, G., Sauter, C., Stiens, S., Therattil, M., Williams, F. H., ... & Mayer, R. S. (2019). Competency-based curriculum development to meet the needs of people with disabilities: a call to action. *Academic medicine*, *94*(6), 781-788. https://doi.org/10.1097/acm.0000000000002686.

Antonio, C. A. T. (2021). Challenges and Pitfalls in the Design and Reporting of Qualitative Research in the Health Sciences: Reflections from a Referee and Reviewer. *Acta Medica Philippina*, *55*(7). https://doi.org/10.47895/amp.vi0.2983.

Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative research*, *1*(3), 385-405. https://doi.org/10.1177/146879410100100307.

Baffoe, M. (2013). Stigma, discrimination & marginalization: Gateways to oppression of persons with disabilities in Ghana, West Africa. *Journal of Educational and Social Research*, *3*(1), 187-187. Retrieved fromhttps://www.richtmann.org/journal/index.php/jesr/article/view/12107.

Bala, P. (Ed.). (2015). *Medicine and colonialism: Historical perspectives in India and South Africa*. Routledge.

Bansal, P., Smith, W. K., & Vaara, E. (2018). New ways of seeing through qualitative research. *Academy of Management Journal*, *61*(4), 1189-1195. https://doi.org/10.5465/amj.2018.4004.

Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: a case of the tail wagging the dog?. *British Medical Journal*, *322*(7294), 1115-1117. https://doi.org/10.1136/bmj.322.7294.1115.

Barnes, C., & Mercer, G. (2001). Disability culture. *Handbook of disability studies*, 515-534. https://doi.org/10.4135/9781412976251.n22.

Batt, A. M., Tavares, W., & Williams, B. (2020). The development of competency frameworks in healthcare professions: a scoping review. *Advances in Health Sciences Education*, *25*(4), 913-987. https://doi.org/10.1007/s10459-019-09946-w.

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The qualitative report*, *13*(4), 544-559. https://doi.org/10.46743/2160-3715/2008.1573.

Bazeley, P. (2009). Analysing qualitative data: More than 'identifying themes'. *Malaysian Journal of Qualitative Research*, *2*(2), 6-22. Retrieved from http://www.researchsupport.com.au/.

Behari-Leak, K., & Mokou, G. (2019). Disrupting metaphors of coloniality to mediate social inclusion in the global south. *International Journal for Academic Development*, *24*(2), 135-147. https://doi.org/10.1080/1360144X.2019.1594236.

Berghs, M. (2017). Practices and discourses of ubuntu: Implications for an African model of disability?. *African Journal of Disability*, *6*(1), 1-8. https://doi.org/10.4102/ajod.v6i0.292.

Berghs, M. J., Atkin, K. M., Graham, H. M., Hatton, C., & Thomas, C. (2016). Implications for public health research of models and theories of disability: a scoping study and evidence synthesis. https://doi.org/10.3310/phr04080.

Berghs, M., Atkin, K., Hatton, C., & Thomas, C. (2019). Do disabled people need a stronger social model: a social model of human rights?. *Disability & Society*, *34*(7-8), 1034-1039. https://doi.org/10.1080/09687599.2019.1619239.

Bester, J. C. (2020). Beneficence, interests, and wellbeing in medicine: what it means to provide benefit to patients. *The American Journal of Bioethics*, *20*(3), 53-62. https://doi.org/10.1080/15265161.2020.1714793.

Betancourt, J. R., Green, A. R., Carrillo, J. E., & Ananeh-Firempong, O. (2003). Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports*, 118(4), 293–302. https://doi.org/10.1016/s0033-3549(04)50253-4.

Bines, H., & Lei, P. (2011). Disability and education: The longest road to inclusion. *International Journal of Educational Development*, *31*(5), 419-424. https://doi.org/10.1016/j.ijedudev.2011.04.009.

Birdsey, B., & Joseph, L. (2021). Plurality of perspective: Doctor-parents of deaf children in a low-to middle-income country. *International Journal of Pediatric Otorhinolaryngology*, *142*, 110610. https://doi.org/10.1016/j.ijporl.2021.110610.

Blose, S. B., Doeraj, S., Padia, S., Pillay, K., Reddy, K., & Chetty, V. (2021). Healthcare professionals’ perceptions of community-based rehabilitation in KwaZulu-Natal, South Africa. *African Journal of Primary Health Care & Family Medicine*, *13*(1), 2461. https://doi.org/10.4102/phcfm.v13i1.2461.

Boet, S., Sharma, S., Goldman, J., & Reeves, S. (2012). Medical education research: an overview of methods. *Canadian Journal of Anesthesia/Journal canadien d'anesthésie*, *59*(2), 159-170. https://doi.org/10.1007/s12630-011-9635-y.

Borowsky, H., Morinis, L., & Garg, M. (2021). Disability and Ableism in Medicine: A Curriculum for Medical Students. *MedEdPORTAL*, *17*, 11073. https://doi.org/10.15766/mep_2374-8265.11073.

Bowen, C. N., Havercamp, S. M., Bowen, S. K., & Nye, G. (2020). A call to action: Preparing a disability-competent health care workforce. *Disability and Health Journal*, *13*(4), 100941. https://doi.org/10.1016/j.dhjo.2020.100941.

Bowen, G. A. (2009). Document Analysis as a Qualitative Research Method. *Qualitative Research Journal,* 9(2), 27–40. https://doi.org/10.3316/qrj0902027.

Boxall, K. (2018). 18 Revisiting the foundations of (critical) disability studies. *Manifestos for the Future of Critical Disability Studies: Volume 1*. https://doi.org/10.4324/9781351053341-18.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa.

Braun, V., & Clarke, V. (2012). Thematic analysis. APA Handbook of Research Methods in Psychology, Vol 2: Research Designs: Quantitative, Qualitative, Neuropsychological, and Biological., 57–71. https://doi.org/10.1037/13620-004.

Brilmyer, G. (2018). Archival assemblages: applying disability studies' political/relational model to archival description. *Archival Science*, *18*(2), 95-118. https://doi.org/10.1007/s10502-018-9287-6.

Britten, N. (1995). Qualitative research: qualitative interviews in medical research. *Bmj*, *311*(6999), 251-253. https://doi.org/10.1136/bmj.311.6999.251.

Burbules, N. C., & Berk, R. (1999). Critical thinking and critical pedagogy: Relations, differences, and limits. *Critical theories in education: Changing terrains of knowledge and politics*, 45-65. https://doi.org/10.4324/9780203826256-11.

Burge, P., Ouellette-Kuntz, H., Isaacs, B., & Lunsky, Y. (2008). Medical students' views on training in intellectual disabilities. *Canadian Family Physician*, *54*(4), 568-571. Retrieved from http://www.cfp.ca/.

Caley, M. J., O'Leary, R. A., Fisher, R., Low-Choy, S., Johnson, S., & Mengersen, K. (2014). What is an expert? A systems perspective on expertise. *Ecology and evolution*, *4*(3), 231-242. https://doi.org/10.1002/ece3.926.

Calhoun, J. G., Davidson, P. L., Sinioris, M. E., Vincent, E. T., & Griffith, J. R. (2002). Toward an understanding of competency identification and assessment in health care management. *Quality Management in Healthcare, 11*(1), 14-38. https://doi.org/10.1097/00019514-200211010-00006.

Campbell, F. K. (2009). Medical education and disability studies. *Journal of Medical Humanities*, *30*(4), 221-235. https://doi.org/10.1007/s10912-009-9088-2.

Carraccio, C., Wolfsthal, S. D., Englander, R., Ferentz, K., & Martin, C. (2002). Shifting paradigms: from Flexner to competencies. *Academic medicine*, *77*(5), 361-367. https://doi.org/10.1097/00001888-200205000-00003.

Cassam, Q. (2017). Diagnostic error, overconfidence and self-knowledge. *Palgrave Communications*, *3*(1), 1-8. https://doi.org/10.1057/palcomms.2017.25.

Cerimagic, S., & Hasan, S. (2018). Changing medical education curriculum: challenges, preparation and implementation of change. In *Sustainable Ecological Engineering Design for Society, International (SEEDS) Conference* (pp. 6-7). Retrieved from https://www.researchgate.net/.

Chapman, E. N., Kaatz, A., & Carnes, M. (2013). Physicians and implicit bias: how doctors may unwittingly perpetuate health care disparities. *Journal of general internal medicine, 28*(11), 1504-1510. https://doi.org/10.1007/s11606-013-2441-1.

Chapman, R., & Carel, H. (2022). Neurodiversity, epistemic injustice, and the good human life. *Journal of Social Philosophy*. Portico. https://doi.org/10.1111/josp.12456.

Christie, P. (2020). *Decolonising schools in South Africa: The impossible dream?*. Routledge. https://doi.org/10.4324/9780367853624.

Cieza, A., Causey, K., Kamenov, K., Hanson, S. W., Chatterji, S., & Vos, T. (2020). Global estimates of the need for rehabilitation based on the Global Burden of Disease study 2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet, 396*(10267), 2006-2017. https://doi.org/10.1016/s0140-6736(20)32340-0.

Cieza, A., Sabariego, C., Bickenbach, J., & Chatterji, S. (2018). Rethinking disability. *BMC medicine*, *16*(1), 1-5. https://doi.org/10.1186/s12916-017-1002-6.

Clarke, D. J., & Forster, A. (2015). Improving post-stroke recovery: the role of the multidisciplinary health care team. *Journal of multidisciplinary healthcare*, *8*, 433. https://doi.org/10.2147/jmdh.s68764.

CoBaTrICE Collaboration UniSecICM@ uhb. nhs. uk. (2006). Development of core competencies for an international training programme in intensive care medicine. *Intensive care medicine*, *32*, 1371-1383. https://doi.org/10.1007/s00134-006-0215-5.

Coret, A., Boyd, K., Hobbs, K., Zazulak, J., & McConnell, M. (2018). Patient narratives as a teaching tool: a pilot study of first-year medical students and patient educators affected by intellectual/developmental disabilities. *Teaching and Learning in Medicine*, *30*(3), 317-327. https://doi.org/10.1080/10401334.2017.1398653.

Cooke, M., Irby, D. M., Sullivan, W., & Ludmerer, K. M. (2006). American medical education 100 years after the Flexner report. *New England journal of medicine*, *355*(13), 1339-1344. https://doi.org/10.1056/nejmra055445.

Couser, G. T. (2011). What disability studies has to offer medical education. *Journal of Medical Humanities*, *32*(1), 21-30. https://doi.org/10.1007/s10912-010-9125-1.

Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries?. *Journal of advanced nursing*, *26*(3), 623-630. https://doi.org/10.1046/j.1365-2648.1997.t01-25-00999.x.

Creswell, J. W., & Creswell, J. D. (2017). *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications. Retrieved from: https://www.researchgate.net/.

Crocker, A. F., & Smith, S. N. (2019). Person-first language: are we practicing what we preach?. *Journal of multidisciplinary healthcare*, *12*, 125. https://doi.org/10.2147/jmdh.s140067.

Cruess, R. L., Cruess, S. R., Boudreau, J. D., Snell, L., & Steinert, Y. (2014). Reframing medical education to support professional identity formation. *Academic Medicine*, *89*(11), 1446-1451. https://doi.org/10.1097/acm.0000000000000427.

Cruess, R. L., Cruess, S. R., & Steinert, Y. (2016). Amending Miller’s pyramid to include professional identity formation. *Academic Medicine*, *91*(2), 180-185. https://doi.org/10.1097/acm.0000000000000913.

Culyer, A. J. (2007). Equity of what in health care? Why the traditional answers don't help policy-and what to do in the future. *HealthcarePapers*, *8*(Special Issue), 12-26. https://doi.org/10.12927/hcpap.2007.19216.

Dagnone, J. D., Bandiera, G., & Harris, K. (2021). Re-examining the value proposition for Competency-Based Medical Education. *Canadian Medical Education Journal/Revue canadienne de l'éducation médicale, 12*(3), 155-158. https://doi.org/10.36834/cmej.68245.

Dambal, A., Gururaj, H., Aithal, K. R., Dharwad, M. K., Sherkhane, R., Siddanagoudra, S., ... & Mulla, S. A. (2021). Delivering disability competencies of MCI's revised competency based curriculum at a medical university in North Karnataka. *medical journal armed forces india*, *77*, S65-S72. https://doi.org/10.1016/j.mjafi.2020.12.029.

Davis, L. J. (2016). *The disability studies reader*. Routledge. https://doi.org/10.4324/9781315680668.

Dayal, H. (2012). Capacity of the SA public health sector to deliver rehabilitation services: an institutional analysis. Retrieved from https://repository.hsrc.ac.za/.

Demby, N., & Northridge, M. E. (2018). Delivering equitable care to underserved communities. *American journal of public health*, *108*(11), 1446. https://doi.org/10.2105/ajph.2018.304701.

Department of Health, South Africa (2000). National Rehabilitation Policy.

Department of Health, South Africa (2014). Government Gazette: Health Professions Council of South Africa.

Department of Health, South Africa (2015). Framework and Strategy for Disability and Rehabilitation Services in South Africa.

Department of Social Development, South Africa. (2016). White paper on the rights of persons with disabilities.

Dirth, T. P., & Adams, G. A. (2019). Decolonial theory and disability studies: On the modernity/coloniality of ability. *Journal of Social and Political Psychology*, 7(1), 260–289. https://doi.org/10.5964/jspp.v7i1.762.

Dolan, B. (2021). The Medical Profession Through History. Retrieved from https://escholarship.org/.

Donoghue, C. (2003). Challenging the authority of the medical definition of disability: An analysis of the resistance to the social constructionist paradigm. *Disability & Society*, *18*(2), 199-208. https://doi.org/10.1080/0968759032000052833.

Eichbaum, Q. G., Adams, L. V., Evert, J., Ho, M. J., Semali, I. A., & van Schalkwyk, S. C. (2021). Decolonizing global health education: rethinking institutional partnerships and approaches. *Academic Medicine*, *96*(3), 329-335. https://doi.org/10.1097/acm.0000000000003473 .

Eftekhar, H., Labaf, A., Anvari, P., Jamali, A., & Sheybaee-Moghaddam, F. (2012). Association of the pre-internship objective structured clinical examination in final year medical students with comprehensive written examinations. *Medical education online*, *17*(1), 15958. https://doi.org/10.3402/meo.v17i0.15958.

Emadi, M., Delavari, S., & Bayati, M. (2021). Global socioeconomic inequality in the burden of communicable and non-communicable diseases and injuries: an analysis on global burden of disease study 2019. *BMC public health*, *21*(1), 1-13. https://doi.org/10.1186/s12889-021-11793-7.

Englander, R., Cameron, T., Ballard, A. J., Dodge, J., Bull, J., & Aschenbrener, C. A. (2013). Toward a common taxonomy of competency domains for the health professions and competencies for physicians. *Academic Medicine*, *88*(8), 1088-1094. https://doi.org/10.1097/acm.0b013e31829a3b2b.

Engward, H., & Davis, G. (2015). Being reflexive in qualitative grounded theory: discussion and application of a model of reflexivity. *Journal of advanced nursing*, *71*(7), 1530-1538. https://doi.org/10.1111/jan.12653.

Ennion, L., & Rhoda, A. (2016). Roles and challenges of the multidisciplinary team involved in prosthetic rehabilitation, in a rural district in South Africa. *Journal of Multidisciplinary Healthcare*, *9*, 565. https://doi.org/10.2147/jmdh.s116340.

El-Islam, M. F. (2017). Person Centered Psychiatric Medicine= شخصنة الطب النفسي. The Arab Journal of Psychiatry, 44(5487), 1-4.

Eppich, W. J., Gormley, G. J., & Teunissen, P. W. (2019). In-depth interviews. In *Healthcare Simulation Research* (pp. 85-91). Springer, Cham. https://doi.org/10.1007/978-3-030-26837-4_12.

Epstein, R. M., & Hundert, E. M. (2002). Defining and assessing professional competence. *Jama*, *287*(2), 226-235. https://doi.org/10.1001/jama.287.2.226.

Fàbregues, S., & Fetters, M. D. (2019). Fundamentals of case study research in family medicine and community health. *Family medicine and community health*, *7*(2). https://doi.org/10.1136/fmch-2018-000074.

Fataar, A. (2018). Decolonising education in South Africa: Perspectives and debates. *Educational Research for Social Change*, *7*(SPE), vi-ix. Retrieved from http://www.scielo.org.za.

Fernández-Ávila, D. G., Rojas, M. X., & Rosselli, D. (2020). The Delphi method in rheumatology research: are we doing it right?. *Revista Colombiana de Reumatología (English Edition)*, *27*(3), 177-189. https://doi.org/10.1016/j.rcreue.2019.04.007.

Fergus, K. B., Teale, B., Sivapragasam, M., Mesina, O., & Stergiopoulos, E. (2018). Medical students are not blank slates: Positionality and curriculum interact to develop professional identity. *Perspectives on medical education*, *7*(1), 5-7. https://doi.org/10.1007/s40037-017-0402-9.

FitzGerald, C., & Hurst, S. (2017). Implicit bias in healthcare professionals: a systematic review. *BMC medical ethics*, *18*(1), 1-18. https://doi.org/10.1186/s12910-017-0179-8 .

Fook, J. (2015). Chapter 26: Reflective practice and critical reflection. Handbook for practice learning in social work and social care: Knowledge and theory, 3. 440-454.

Forester-Miller, H., & Davis, T. E. (1995). *A practitioner's guide to ethical decision making*. Alexandria, VA: American Counseling Association. Retrieved from https://www.counseling.org/.

Fortune, N., Madden, R. H., & Clifton, S. (2021). Health and access to health services for people with disability in Australia: data and data gaps. *International Journal of Environmental Research and Public Health*, *18*(21), 11705. https://doi.org/10.3390/ijerph182111705.

Franits, L. E. (2005). Nothing about us without us: Searching for the narrative of disability. *AJOT: American Journal of Occupational Therapy*, *59*(5), 577-580. https://doi.org/10.5014/ajot.59.5.577.

Frank, J. R., Snell, L. S., Cate, O. T., Holmboe, E. S., Carraccio, C., Swing, S. R., ... & Harris, K. A. (2010). Competency-based medical education: theory to practice. *Medical teacher*, *32*(8), 638-645. https://doi.org/10.3109/0142159x.2010.501190.

Frank, J. R., Snell, L., Englander, R., Holmboe, E. S., & Icbme Collaborators. (2017). Implementing competency-based medical education: Moving forward. *Medical teacher*, *39*(6), 568-573. https://doi.org/10.1080/0142159x.2017.1315069.

Franklin, A., Brady, G., & Bradley, L. (2020). The medicalisation of disabled children and young people in child sexual abuse: Impacts on prevention, identification, response and recovery in the United Kingdom. *Global studies of childhood*, *10*(1), 64-77. https://doi.org/10.1177/2043610619897278.

Frenk, J., Chen, L., Bhutta, Z. A., Cohen, J., Crisp, N., Evans, T., ... & Zurayk, H. (2010). Health professionals for a new century: transforming education to strengthen health systems in an interdependent world. *The lancet*, *376*(9756), 1923-1958. https://doi.org/10.1016/s0140-6736(10)61854-5.

Fricker, M. (2008). On Miranda Fricker’s Epistemic Injustice: Power and the Ethics of Knowing: Précis. *THEORIA. Revista de Teoría, Historia y Fundamentos de la Ciencia*, *23*(1), 69-71. Retrieved from https://addi.ehu.es/.

Gaede, B. (2021). ‘I know my place’-The hidden curriculum of professional hierarchy in a South African undergraduate medical program: A Qualitative Study. https://doi.org/10.21203/rs.3.rs-745000/v1.

Gerstenblatt, P. (2013). Collage portraits as a method of analysis in qualitative research. *International Journal of Qualitative Methods*, *12*(1), 294-309. https://doi.org/10.1177/160940691301200114.

Gervais, J. (2016). The operational definition of competency-based education. *The Journal of Competency-Based Education*, *1*(2), 98-106. https://doi.org/10.1002/cbe2.1011.

Gholamzadeh, S., Khastavaneh, M., Khademian, Z., & Ghadakpour, S. (2018). The effects of empathy skills training on nursing students' empathy and attitudes toward elderly people. *BMC Medical Education*, *18*(1), 1-7. https://doi.org/10.1186/s12909-018-1297-9.

Godat, D. (2010). Time to think: Listening to ignite the human mind. *InterAction*, *2*(1), 144. Retrieved from https://sfwork.com/.

Goddard, A. F., & Patel, M. (2021). The changing face of medical professionalism and the impact of COVID-19. *The Lancet*, *397*(10278), 950-952. https://doi.org/10.1016/s0140-6736(21)00436-0.

Goldhamer, M. E. J., Pusic, M. V., Co, J. P. T., & Weinstein, D. F. (2020). Can Covid catalyze an educational transformation? Competency-based advancement in a crisis. *New England Journal of Medicine, 383*(11), 1003-1005. https://doi.org/10.1056/nejmp2018570.

Goodley, D., & Lawthom, R. (2019). Critical disability studies, Brexit and Trump: A time of neoliberal–ableism. *Rethinking History*, *23*(2), 233-251. https://doi.org/10.1080/13642529.2019.1607476.

Government of South Africa: Office of the Deputy President. (1997, revised 2016). White Paper, Integrated National Disability Strategy, South Africa.

Government of South Africa. (1996). Constitution of South Africa.

Government of South Africa: National Planning Commission, Office of the Presidency (2013). National Development Plan 2030: Our future – make it work: Executive summary. 1-70.

Griebenow, R., Mills, P., Stein, J., Herrmann, H., Kelm, M., Campbell, C., & Schäfer, R. (2020). Outcomes in CME/CPD-Special Collection: How to make the "pyramid" a perpetuum mobile. *Journal of European CME*, *9*(1), 1832750. https://doi.org/10.1080/21614083.2020.1832750.

Grech, S. (2011). Recolonising debates or perpetuated coloniality? Decentring the spaces of disability, development and community in the global south. *International Journal of Inclusive Education*, *15*(1), 87-100. https://doi.org/10.1080/13603116.2010.496198.

Grech, S., & Soldatic, K. (2014). Introducing Disability and the Global south (DGS): We are critical, we are open access. *Disability and the Global south*, *1*(1), 1-4. Retrieved from http://www.dgsjournal.org/.

Grech, S. (2015). Decolonising eurocentric disability studies: Why colonialism matters in the disability and global south debate. *Social Identities*, *21*(1), 6-21. https://doi.org/10.1080/13504630.2014.995347.

Groene, O. R., Ehrhardt, M., & Bergelt, C. (2022). Attitude and communication skills of German medical students. *BMC Research Notes*, *15*(1), 1-6. https://doi.org/10.1186/s13104-021-05901-4.

Grut, L., Braathen, S. H., Mji, G., & Ingstad, B. (2012). Accessing community health services: challenges faced by poor people with disabilities in a rural community in South Africa. *African journal of disability*, *1*(1), 1-7. https://doi.org/10.4102/ajod.v1i1.19.

Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Ectj*, *29*(2), 75-91. https://doi.org/10.1007/bf02766777.

Guest, G., Namey, E., Taylor, J., Eley, N., & McKenna, K. (2017). Comparing focus groups and individual interviews: findings from a randomized study. *International Journal of Social Research Methodology*, *20*(6), 693-708. https://doi.org/10.1080/13645579.2017.1281601.

H3Africa Guidelines for Informed Consent, (2013). Facaulty of Health Sciences, Human Research Ethics Committee at UCT (downloaded from website 13/08/2016).

Habibi, A., Sarafrazi, A., & Izadyar, S. (2014). Delphi technique theoretical framework in qualitative research. *The International Journal of Engineering and Science*, *3*(4), 8-13. Retrieved from http://www.theijes.com/.

Hall, A. K., Rich, J., Dagnone, J. D., Weersink, K., Caudle, J., Sherbino, J., ... & Van Melle, E. (2020). It’s a marathon, not a sprint: rapid evaluation of competency-based medical education program implementation. *Academic Medicine, 95*(5), 786-793. https://doi.org/10.1097/acm.0000000000003040.

Hall, I., & Hollins, S. (1996). Changing medical students' attitudes to learning disability. *Psychiatric Bulletin-Royal College of Psychiatrists*, *20*, 429-430. https://doi.org/10.1192/pb.20.7.429.

Halman, M., Baker, L., & Ng, S. (2017). Using critical consciousness to inform health professions education. *Perspectives on medical education*, *6*(1), 12-20. https://doi.org/10.1007/s40037-016-0324-y.

Hartman, N., Kathard, H., Perez, G., Reid, S., Irlam, J., Gunston, G., ... & Ige, B. (2012). Health Sciences undergraduate education at the University of Cape Town: a story of transformation: forum-education. *South African Medical Journal*, *102*(6), 477-480.

Hashemi, G., Wickenden, M., Bright, T., & Kuper, H. (2022). Barriers to accessing primary healthcare services for people with disabilities in low and middle-income countries, a Meta-synthesis of qualitative studies. *Disability and Rehabilitation*, *44*(8), 1207-1220. https://doi.org/10.1080/09638288.2020.1817984.

Havercamp, S. M., Barnhart, W. R., Robinson, A. C., & Smith, C. N. W. (2021). What should we teach about disability? National consensus on disability competencies for health care education. *Disability and Health Journal*, *14*(2), 100989. https://doi.org/10.1016/j.dhjo.2020.100989.

Hawkins, A. H., & Sacks, O. W. (1993). Oliver Sack's Awakenings: reshaping clinical discourse. *Configurations*, *1*(2), 229-245. https://doi.org/10.1353/con.1993.0009.

Health Professions Council of South Africa: Undergraduate Education and Training Subcommittee of the Medical and Dental Professions Board in collaboration with training institutions and the South African Committee of Medical and Dental Deans. (2014 version). Core competencies* for undergraduate students in clinical associate, dentistry and medical teaching and learning programmes in South Africa. 1-14

Heffernan, A. K. (2021). Disability and political theory. *Contemporary Political Theory*, 1-4.. https://doi.org/10.1057/s41296-021-00493-x.

Heroux, J. R. (2017). Infusing disability studies within special education: A personal story. *Review of Disability Studies: An International Journal*, *13*(1). Retrieved from https://rdsjournal.org/.

Hirsch, J.L. (2018). In South Africa, a push to change Eurocentric university curriculum. Global observatory. Retrieved from http://theglobalobservatory.org.

Holmboe, E. S., Sherbino, J., Englander, R., Snell, L., Frank, J. R., & ICBME Collaborators. (2017). A call to action: the controversy of and rationale for competency-based medical education. *Medical teacher*, *39*(6), 574-581. https://doi.org/10.1080/0142159x.2017.1315067.

Hosking, D. L. (2008). Critical disability theory. A paper presented at the 4th biennial disability studies conference at Lancaster University, UK, Sept. 2-4, 2008. *Journal of*

Consulting and Clinical Psychology, *72*(3), 467-478. Retrieved from https://www.lancaster.ac.uk/.

Hsu, C. C., & Sandford, B. A. (2007). The Delphi technique: making sense of consensus. *Practical assessment, research, and evaluation*, *12*(1), 10. https://doi.org/10.7275/pdz9-th90.

Hussey, G. D., & Hawkridge, A. (2012). The state and future of research at the University of Cape Town's Faculty of Health Sciences: forum-reflections. *South African Medical Journal*, *102*(6), 412-414. https://doi.org/10.7196/samj.5622.

Iezzoni, L. I. (2006). Going beyond disease to address disability. *New England Journal of Medicine*, *355*(10), 976. https://doi.org/10.1056/nejmp068093.

Iezzoni, L. I., & Long-Bellil, L. M. (2012). Training physicians about caring for persons with disabilities: “Nothing about us without us!”. *Disability and health journal*, 5(3), 136-139. https://doi:10.1016/j.dhjo.2012.03.003.

Imada, A. L. (2017). A decolonial disability Studies? *Disability Studies Quarterly, 37*(3). https://doi.org/10.18061/dsq.v37i3.5984.

Jabareen, Y. (2009). Building a conceptual framework: philosophy, definitions, and procedure. *International journal of qualitative methods, 8*(4), 49-62. https://doi.org/10.1177/160940690900800406.

Jacobs, M. (2012). 100 years of UCT's Faculty of Health Sciences. *South African Medical Journal*, *102*(6), 390. https://doi.org/10.7196/samj.5933.

Jamieson, S. (2004). Likert scales: How to (ab) use them?. *Medical education*, *38*(12), 1217-1218. https://doi.org/10.1111/j.1365-2929.2004.02012.x.

Janz, H. L. (2019). Ableism: the undiagnosed malady afflicting medicine. *Cmaj*, *191*(17), E478-E479. https://doi.org/10.1503/cmaj.180903.

Jefferson, R. D. (2020). *Using the International Classification of Functioning, Disability and Health (ICF) to promote biopsychosocial clinical reasoning and person-centred practice (PCP) in two multi-disciplinary teams* (Doctoral dissertation, Brunel University London). Retrieved from https://bura.brunel.ac.uk/.

Jenson, K. (2018). Discourses of disability and inclusive education. *He Kupu The Word*, *5*(4), 52-59. Retrieved from https://www.hekupu.ac.nz/.

Jessup, R. L. (2007). Interdisciplinary versus multidisciplinary care teams: do we understand the difference?. *Australian Health Review*, *31*(3). https://doi.org/10.1071/ah070330.

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational researcher*, *33*(7), 14-26. https://doi.org/10.3102/0013189x033007014.

Jones, J., & Hunter, D. (1995). Qualitative Research: Consensus methods for medical and health services research. *Bmj, 311*(7001), 376–380. https://doi.org/10.1136/bmj.311.7001.376.

Joseph, M., & Nisker, J. (2020). Need for prominent Core curricula designed and taught by persons with disabilities in all levels of medical education. *Canadian Journal of Disability Studies*, *9*(5), 245-264. https://doi.org/10.15353/cjds.v9i5.697.

Jowsey, T. (2019). Three zones of cultural competency: surface competency, bias twilight, and the confronting midnight zone. *BMC medical education*, *19*(1), 1-8. https://doi.org/10.1186/s12909-019-1746-0.

Kaiser, K. (2009). Protecting respondent confidentiality in qualitative research. *Qualitative health research*, *19*(11), 1632-1641. https://doi.org/10.1177/1049732309350879.

Kathard H, Padarath A, Galvaan R & Lorenzo T, (2020). South African Health Review 2020. Durban: Health Systems Trust. 1-13.

Kawshala, H. (2017). Theorizing the concept of core competencies: An integrative model beyond identification. *International Journal of Scientific and Research Publications*, *7*(2), 253. Retrieved from https://www.ijsrp.org/.

Kent, A., & De Villiers, M. R. (2007). Medical education in South Africa–exciting times. *Medical Teacher, 29*(9-10), 906-909. https://doi.org/10.1080/01421590701832122.

Kessi, S. (2015). Time to decolonise our universities. *Black alumni panel discussion. Sunday Independent*.

Kim, J. B. (2017). Toward a Crip-of-Color Critique: Thinking with Minich's' Enabling Whom?'. *Lateral*, *6*(1). https://doi.org/10.25158/l6.1.14.

Kirschner, K. L., & Curry, R. H. (2009). Educating health care professionals to care for patients with disabilities. *Jama*, *302*(12), 1334-1335. https://doi.org/10.1001/jama.2009.1398.

Kivunja, C., & Kuyini, A. B. (2017). Understanding and applying research paradigms in educational contexts. *International Journal of higher education*, *6*(5), 26-41. https://doi.org/10.5430/ijhe.v6n5p26.

Kline, N. (1999). *Time to think: Listening to ignite the human mind*. Hachette UK.

Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American journal of public health*, *105*(S2), S198-S206. https://doi.org/10.2105/ajph.2014.302182.

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American journal of occupational therapy*, *45*(3), 214-222. https://doi.org/10.5014/ajot.45.3.214.

Kruse, A. K., & Oswal, S. K. (2018). Barriers to higher education for students with bipolar disorder: A critical social model perspective. *Social Inclusion*, *6*(4), 194-206. https://doi.org/10.17645/si.v6i4.1682.

Larsen, A. E., Adamsen, H. N., Boots, S., Delkus, E. C. G., Pedersen, L. L., & Christensen, J. R. (2019). A survey on client-centered practice among Danish occupational therapists. *Scandinavian Journal of Occupational Therapy*, *26*(5), 356-370. https://doi.org/10.1080/11038128.2018.1465584.

Lefkowitz, A., Meitar, D., & Kuper, A. (2021). Can doctors be taught virtue?. *Journal of Evaluation in Clinical Practice*, *27*(3), 543-548. https://doi.org/10.1111/jep.13398.

Lehohla, P. (2011). Profile of persons' with disabilities: Census 2011. Statistics South Africa.

Lempp, H., & Seale, C. (2004). The hidden curriculum in undergraduate medical education: qualitative study of medical students' perceptions of teaching. *Bmj*, *329*(7469), 770-773. https://doi.org/10.1136/bmj.329.7469.770.

Leppink, J. (2015). Data analysis in medical education research: a multilevel perspective. *Perspectives on Medical Education*, *4*(1), 14-24. https://doi.org/10.1007/s40037-015-0160-5.

Leung, W. C. (2002). Competency based medical training. *BMJ: British Medical Journal*, *325*(7366), 693. https://doi.org/10.1136/bmj.325.7366.693.

Liberman, R. P., Hilty, D. M., Drake, R. E., & Tsang, H. W. (2001). Requirements for multidisciplinary teamwork in psychiatric rehabilitation. *Psychiatric Services*, *52*(10), 1331-1342. https://doi.org/10.1176/appi.ps.52.10.1331.

Lingard, L. (2015). The art of limitations. Perspectives on Medical Education, 4; 136-137.

Lingard, L. (2015). The writer's craft. *Perspectives on Medical Education, 4*(2), 79-80. https://doi.org/10.1007/s40037-015-0176-x.

Loja, E., Costa, M. E., Hughes, B., & Menezes, I. (2013). Disability, embodiment and ableism: Stories of resistance. *Disability & Society*, *28*(2), 190-203. https://doi.org/10.1080/09687599.2012.705057.

Lokugamage, A. U., Ahillan, T., & Pathberiya, S. D. C. (2020). Decolonising ideas of healing in medical education. *Journal of Medical Ethics*, *46*(4), 265-272. https://doi.org/10.1136/medethics-2019-105866.

London, L., Baldwin-Ragaven, L., Kalebi, A., Maart, S., Petersen, L., & Kasolo, J. (2007). Developing human rights competencies for South African health professional graduates. *South African Medical Journal*, *97*(12), 1269-1270. Retrieved from https://journals.co.za/.

Lorenzo, T. (2022). Section 7: Studying Critical Disability – A Transformative and Inclusive Agenda for Social Change. *Handbook of Disability*. 1-7. https://doi.org/10.1007/978-981-16-1278-7_17-1.

Louw, J. H. (1979). A brief history of the Medical Faculty, University of Cape Town. *South African Medical Journal*, *56*(22), 864-870. Retrieved from https://journals.co.za/.

Ludwig, S., Dettmer, S., Wurl, W., Seeland, U., Maaz, A., & Peters, H. (2020). Evaluation of curricular relevance and actual integration of sex/gender and cultural competencies by final year medical students: effects of student diversity subgroups and curriculum. *GMS Journal for Medical Education*, *37*(2). https://dx.doi.org/10.3205/zma001312.

Martin, J., Lloyd, M., & Singh, S. (2002). Professional attitudes: can they be taught and assessed in medical education?. *Clinical medicine*, *2*(3), 217. https://doi.org/10.7861/clinmedicine.2-3-217.

Makulova, A. T., Alimzhanova, G. M., Bekturganova, Z. M., Umirzakova, Z. A., Makulova, L. T., & Karymbayeva, K. M. (2015). Theory and practice of competency-based approach in education. *International Education Studies*, *8*(8), 183-192. https://doi.org/10.5539/ies.v8n8p183.

Manti, S., & Licari, A. (2018). How to obtain informed consent for research. *Breathe*, *14*(2), 145-152. https://doi.org/10.1183/20734735.001918.

Maribo, T., Petersen, K. S., Handberg, C., Melchiorsen, H., Momsen, A. M. H., Nielsen, C. V., ... & Labriola, M. (2016). Systematic literature review on ICF from 2001 to 2013 in the Nordic countries focusing on clinical and rehabilitation context. *Journal of clinical medicine research*, *8*(1), 1. https://doi.org/10.14740/jocmr2400w.

Mattila, M., & Papageorgiou, A. (2017). Disability, perceived discrimination and political participation. *International Political Science Review*, *38*(5), 505-519. https://doi.org/10.1177/0192512116655813.

Mayat, N., & Amosun, S. L. (2011). Perceptions of Academic Staff towards Accommodating Students with Disabilities in a Civil Engineering Undergraduate Program in a University in South Africa. *Journal of Postsecondary Education and Disability*, *24*(1), 53-59. Retrieved from https://eric.ed.go/.

McColl, M. A., Forster, D., Shortt, S. E., Hunter, D., Dorland, J., Godwin, M., & Rosser, W. (2008). Physician experiences providing primary care to people with disabilities. *Healthcare policy*, *4*(1), e129. https://doi.org/10.12927/hcpol.2008.19989.

McKinley, R. K. (2015). Qualitative and quantitative: the yin and the yang or the light and the dark sides of medical education?. *Perspectives on Medical Education*, *4*(1), 1-3. https://doi.org/10.1007/s40037-015-0162-3.

McKinney, V. J. (2016). An exploratory case study on the preparation of undergraduate civil engineering students at the University of Cape Town to contribute to an inclusive society for people with disabilities. (Doctoral dissertation: University of Cape Town) Retrieved from https://open.uct.ac.za/.

McKinney, V., & Amosun, S. L. (2020). Impact of lived experiences of people with disabilities in the built environment in South Africa. *African Journal of Disability*, *9*(1), 1-11. https://doi.org/10.4102/ajod.v9i0.518.

Meekosha, H. (2011). Decolonising disability: Thinking and acting globally. *Disability & Society*, *26*(6), 667-682. https://doi.org/10.1080/09687599.2011.602860.

Meekosha, H., Shuttleworth, R., & Soldatic, K. (2013). Disability and critical sociology: Expanding the boundaries of critical social inquiry. *Critical Sociology*, *39*(3), 319-323. https://doi.org/10.1177/0896920512471220.

Meeks, L. M., & Moreland, C. (2021). How should we build disability-inclusive medical school admissions?. *AMA Journal of Ethics*, *23*(12), 987-994. https://doi.org/10.1001/amajethics.2021.987.

Meiring, T., Kannemeyer, C., & Potgieter, E. (2018). The gap between rich and poor: South African society’s biggest divide depends on where you think you fit in. Retrieved from https://www.opensaldru.uct.ac.za/.

Meyer, G. S., Potter, A., & Gary, N. (1997). A national survey to define a new core curriculum to prepare physicians for managed care practice. *Academic Medicine*, *72*(8), 669-76. https://doi.org/10.1097/00001888-199708000-00010.

Milota, M. M., van Thiel, G. J., & van Delden, J. J. (2019). Narrative medicine as a medical education tool: a systematic review. *Medical teacher*, *41*(7), 802-810. https://doi.org/10.1080/0142159x.2019.1584274.

Minich, J. A. (2016). Enabling whom? Critical disability studies now. *Lateral*, *5*(1). https://doi.org/10.25158/l5.1.9.

Minich, J. A. (2017). Thinking with Jina B. Kim and Sami Schalk. *Lateral*, *6*(1). https://doi.org/10.25158/l6.1.15.

Mitra, S., & Shakespeare, T. (2019). Remodeling the ICF. *Remodeling the ICF. Disability and Health Journal*, *12*, 337-339. https://doi.org/10.1016/j.dhjo.2019.01.008.

Mkabile, S., & Swartz, L. (2020). Caregivers’ and parents’ explanatory models of intellectual disability in Khayelitsha, Cape Town, South Africa. *Journal of Applied Research in Intellectual Disabilities*, *33*(5), 1026-1037. https://doi.org/10.1111/jar.12725.

Mogensen, L., & Hu, W. (2019). “A doctor who really knows…”: a survey of community perspectives on medical students and practitioners with disability. *BMC medical education*, *19*(1), 1-10. https://doi.org/10.1186/s12909-019-1715-7.

Moran, M., Bickford, J., Barradell, S., & Scholten, I. (2020). Embedding the international classification of functioning, disability and health in health professions curricula to enable interprofessional education and collaborative practice. *Journal of Medical Education and Curricular Development*, *7*, 2382120520933855. https://doi.org/10.1177/2382120520933855.

Morcke, A. M., Dornan, T., & Eika, B. (2013). Outcome (competency) based education: an exploration of its origins, theoretical basis, and empirical evidence. *Advances in Health Sciences Education, 18*(4), 851-863. https://doi.org/10.1007/s10459-012-9405-9.

Morrison, G., Goldfarb, S., & Lanken, P. N. (2010). Team training of medical students in the 21st century: would Flexner approve?. *Academic Medicine*, *85*(2), 254-259. https://doi.org/10.1097/acm.0b013e3181c8845e.

Moser, A., & Korstjens, I. (2017). Series: Practical guidance to qualitative research. Part 1: Introduction. *European Journal of General Practice*, *23*(1), 271-273. https://doi.org/10.1080/13814788.2017.1375093.

Mouton, J. (2001). *How to succeed in your master's and doctoral studies: A South African guide and resource book*. Van Schaik.

Mugumbate, J. (2020). Baba Jairos Jiri’s ubuntu models of charity, disability and rehabilitation. *African Journal of Social Work, 10*(1), 83-88. Retrieved from https://www.ajol.info/.

Mulenga, I. M., & Kabombwe, Y. M. (2019). Understanding a competency-based curriculum and education: The Zambian perspective. Retrieved from http://dspace.unza.zm/.

Murray, C. J., Abbafati, C., Abbas, K. M., Abbasi, M., Abbasi-Kangevari, M., Abd-Allah, F., ... & Nagaraja, S. B. (2020). Five insights from the global burden of disease study 2019. *The Lancet*, *396*(10258), 1135-1159. https://doi.org/10.1016/S0140-6736(20)31404-5.

Naidu, T. (2021). Modern medicine is a colonial artifact: Introducing decoloniality to medical education research. *Academic Medicine, 96*(11S), S9-S12. https://doi.org/10.1097/acm.0000000000004339.

Nakamura, T. (2022). Team Medicine and Multidisciplinary Education. In *Japan Nutrition* (pp. 87-97). Springer, Singapore. https://doi.org/10.1007/978-981-16-6316-1_5.

Ndlovu, S. (2021). HUMANNESS AND ABLEISM: Decolonising the Human, 65–85. https://doi.org/10.18772/22021036512.7.

Ned, L., McKinney, E. L. M., McKinney, V., & Swartz, L. (2020). COVID-19 pandemic and disability: Essential considerations. *Social and health Sciences*, *18*(2), 136-148. Retrieved from https://journals.co.za/.

Neilson, S. (2020). Ableism in the medical profession. *CMAJ*, *192*(15), E411-E412. https://doi.org/10.1503/cmaj.191597.

Nemutandani, S. M., Hendricks, S. J., & Mulaudzi, M. F. (2018). Decolonising the mindsets, attitudes and practices of the allopathic and indigenous health practitioners in postcolonial society: An exploratory approach in the management of patients. *African Journal of Primary Health Care and Family Medicine*, *10*(1), 1-8. https://doi.org/10.4102/phcfm.v10i1.1518.

Nimmon, L., & Stenfors-Hayes, T. (2016). The "Handling" of power in the physician-patient encounter: perceptions from experienced physicians. *BMC medical education*, *16*(1), 1-9. https://doi.org/10.1186/s12909-016-0634-0.

Noble, H., & Heale, R. (2019). Triangulation in research, with examples. *Evidence-based nursing*, *22*(3), 67-68. https://doi.org/10.1136/ebnurs-2019-103145.

Nolan, A. (2018). Creating a thinking culture. *Modern Legal Practice*, *2*(1), 38-45. Retrieved from https://www.ingentaconnect.com/.

Nnodim, P., & Okigbo, A. (2020). Justice as Fairness and Ubuntu: Conceptualizing Justice through Human Dignity. *Ethical Perspectives*, *27*(1), 69-91. Retrieved from https://www.researchgate.net/.

Norman, G., Norcini, J., & Bordage, G. (2014). Competency-based education: milestones or millstones?. *Journal of graduate medical education*, *6*(1), 1-6. https://doi.org/10.4300/jgme-d-13-00445.1.

Nousiainen, M. T., Caverzagie, K. J., Ferguson, P. C., Frank, J. R., & ICBME Collaborators. (2017). Implementing competency-based medical education: What changes in curricular structure and processes are needed?. *Medical teacher*, *39*(6), 594-598. https://doi.org/10.1080/0142159x.2017.1315077.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International journal of qualitative methods*, *16*(1), 1609406917733847. https://doi.org/10.1177/1609406917733847.

Nuwagaba, E. L., & Rule, P. (2015). Navigating the ethical maze in disability research: Ethical contestations in an African context. *Disability & Society*, *30*(2), 255-269. https://doi.org/10.1080/09687599.2014.998333.

Nwanze, I. (2016). *How can we include disability issues in undergraduate curricula at the University of Cape Town?* (Master's thesis, University of Cape Town). Retrieved from https://open.uct.ac.za/.

O Connell, M. T., & Pascoe, J. M. (2004). Undergraduate medical education for the 21st century: leadership and teamwork. *FAMILY MEDICINE-KANSAS CITY-*, *36*(1; SUPP), S51-S56. Retrieved from https://fammedarchives.blob.core.windows.net/.

Ohanunwa, C. (2012). *A study to determine the extent and nature of disability inclusion within the curriculum of the Faculty of Humanities, University of Cape Town* (Master's thesis, University of Cape Town). Retrieved from https://open.uct.ac.za/.

Ohajunwa, E. B. C., & McKenzie, J. (2013). beyond 'if' to 'how': disability inclusion in higher education. *University of Cape Town case study. Disability Catalyst Africa: Series*, *4*. Retrieved from https://vula.uct.ac.za/.

Ohajunwa, C., Mckenzie, J., & Lorenzo, T. (2015). Enabling disability inclusive practices within the University of Cape Town curriculum: A case study. *African Journal of Disability*, *4*(1). https://doi.org/10.4102/ajod.v4i1.157.

Okumura, Y. (2016). Reducing research waste through good reporting practices. *Journal of Epidemiology*, JE20160105. https://doi.org/10.2188/jea.je20160105.

Oliver, M., & Barnes, C. (2013). Disability studies, disabled people and the struggle for inclusion. In *The Sociology of Disability and Inclusive Education* (pp. 20-33). Routledge. https://doi.org/10.1080/01425692.2010.500088.

Omar, M. T. (2020). Afrocentricity and Afrocentric cultural identity: A response to racialization in the African American thought. *The Saharan Journal*, *1*(2), 200-225. Retrieved from https://thesaharan.com/.

Orb, A., Eisenhauer, L., & Wynaden, D. (2001). Ethics in qualitative research. *Journal of nursing scholarship*, *33*(1), 93-96. https://doi.org/10.1111/j.1547-5069.2001.00093.x.

Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The qualitative report*, *13*(4), 695-705. https://doi.org/10.46743/2160-3715/2008.1579.

Osgood, D. W., Foster, E. M., & Courtney, M. E. (2010). Vulnerable populations and the transition to adulthood. *The future of children*, 209-229. https://doi.org/10.1353/foc.0.0047.

Owens, J. (2015). Exploring the critiques of the social model of disability: the transformative possibility of Arendt's notion of power. *Sociology of health & illness*, *37*(3), 385-403. https://doi.org/10.1111/1467-9566.12199.

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and policy in mental health and mental health services research*, *42*(5), 533-544. https://doi.org/10.1007/s10488-013-0528-y.

Peña-Guzmán, D. M., & Reynolds, J. M. (2019). The harm of ableism: Medical error and epistemic injustice. *Kennedy Institute of Ethics Journal*, *29*(3), 205-242. https://doi.org/10.1353/ken.2019.0023.

Pillay, M. & Kathard, H. & Samuel, M. A. (1997). The curriculum of practice: A conceptual framework for speech-language therapy and audiology practice with a black African first language clientele. *South African Journal of Communication Disorders*, *44*(1), 109-117. https://doi.org/10.4102/sajcd.v44i1.232.

Pinney, S. J., & Regan, W. D. (2001). Educating medical students about musculoskeletal problems: are community needs reflected in the curricula of Canadian medical schools?. *JBJS*, *83*(9), 1317-1320. https://doi.org/10.2106/00004623-200109000-00004.

Pohlhaus Jr, G. (2014). Discerning the primary epistemic harm in cases of testimonial injustice. *Social Epistemology*, *28*(2), 99-114. https://doi.org/10.1080/02691728.2013.782581.

Price, M. & Ally, R. (2016). The challenge of decolonisation: UCT's transformation journey. Today’s news (online), 5 April 2016.

Pruitt, S. D., & Epping-Jordan, J. E. (2005). Preparing the 21st century global healthcare workforce. *Bmj*, *330*(7492), 637-639. https://doi.org/10.1136/bmj.330.7492.637.

Pype, P., Pype, K., Rowlands, A., George, R., & Devisch, I. (2021). COVID-19 and touch in medical encounters. *Patient Education and Counseling*, *104*(3), 464. https://doi.org/10.1016/j.pec.2020.10.023.

Ramani, S., & Mann, K. (2016). Introducing medical educators to qualitative study design: twelve tips from inception to completion. *Medical teacher*, *38*(5), 456-463. https://doi.org/10.3109/0142159x.2015.1035244.

Redwood-Campbell, L., Pakes, B., Rouleau, K., MacDonald, C. J., Arya, N., Purkey, E., ... & Pottie, K. (2011). Developing a curriculum framework for global health in family medicine: emerging principles, competencies, and educational approaches. *BMC Medical Education*, *11*(1), 1-8. https://doi.org/10.1186/1472-6920-11-46.

Reindal, S. M. (2010). Redefining disability: a rejoinder to a critique. *Etikk i praksis-Nordic Journal of Applied Ethics*, (1), 125-135. https://doi.org/10.5324/eip.v4i1.1744.

Reynolds, J. M. (2016). Toward a critical theory of harm: ableism, normativity, and transability (biid). *APA newsletter on philosophy and medicine*, *16*(1). https://doi.org/10.4324/9780429266119-10.

Reynolds, J. M. (2018). Three things clinicians should know about disability. *AMA Journal of Ethics*, *20*(12), E1182-1188. https://doi.org/10.1001/amajethics.2018.1181.

Riess, H. (2022). Empathy can be taught and learned with evidence-based education. *Emergency Medicine Journal*, *39*(6), 418-419. https://doi.org/10.1136/emermed-2021-212078.

Rinaldo, L., Lanzino, G., Flemming, K. D., Krings, T., & Brinjikji, W. (2020). Symptomatic developmental venous anomalies. *Acta Neurochirurgica*, *162*(5), 1115-1125. https://doi.org/10.1007/s00701-020-04213-z.

Ross, S., Hauer, K. E., & van Melle, E. (2018). Outcomes are what matter: competency-based medical education gets us to our goal. *MedEdPublish*, *7*(85), 85. https://doi.org/10.15694/mep.2018.0000085.1.

Rotenberg, S., Gatta, R. D., Wahedi, A., Loo, R., McFadden, E., & Ryan, S. (2021). Disability Training for Health Workers: A Global Narrative Systematic Review. *medRxiv*. https://doi.org/10.1101/2021.08.03.21261522.

Sabatello, M. (2018). Precision medicine, health disparities, and ethics: the case for disability inclusion. *Genetics in Medicine*, *20*(4), 397-399. https://doi.org/10.1038/gim.2017.120.

Sadiki, C; Mji, G; Nicholls, L; Franco, L. (2022). Reciprocity in Knowledge Production: A Cornerstone for Disability Inclusion. *Handbook of Disability*. 1-21. https://doi.org/10.1007/978-981-16-1278-7_18-1.

Sahin, H., & Akyol, A. D. (2010). Evaluation of nursing and medical students' attitudes towards people with disabilities. *Journal of Clinical Nursing*, *19*(15-16), 2271-2279. https://doi.org/10.1111/j.1365-2702.2009.03088.x.

Şahin, H. (2015). What Do Medical Students Think About Disability?. *European Journal of Research on Education*, *3*(1), 40-44.

Samarasekera, D. D., Goh, P. S., Lee, S. S., & Gwee, M. C. (2018). The clarion call for a third wave in medical education to optimise healthcare in the twenty-first century. *Medical teacher*, *40*(10), 982-985. https://doi.org/10.1080/0142159x.2018.1500973.

Sammons, H. (2012). *To evaluate and make recommendations for improvement to the MBChB Rehabilitation Programme of the University of Stellenbosch* (Masters thesis, Stellenbosch: Stellenbosch University). Retrieved from https://scholar.sun.ac.za/.

Sandelowski, M. (1998). Writing a good read: Strategies for re-presenting qualitative data. *Research in nursing & health*, *21*(4), 375-382. https://doi.org/10.1002/(sici)1098-240x(199808)21:4%3C375::aid-nur9%3E3.0.co;2-c.

Sanders, H. R., & Kane-Berman, J. (2012). The University of Cape Town's Medical Faculty and Groote Schuur Hospital. *SAMJ: South African Medical Journal*, *102*(6), 394-395. https://doi.org/10.7196/samj.5648.

Sanmiquel-Molinero, L., & Pujol-Tarrés, J. (2020). Putting emotions to work: the role of affective disablism and ableism in the constitution of the dis/abled subject. *Disability & Society*, *35*(4), 542-569. https://doi.org/10.1080/09687599.2019.1650719.

Santen, S. A., Ryan, M. S., & Coates, W. C. (2020). What Can a Pandemic Teach Us About Competency-based Medical Education?. *AEM Education and Training*, *4*(3), 301. https://doi.org/10.1002/aet2.10473.

Santomauro, D. F., Herrera, A. M. M., Shadid, J., Zheng, P., Ashbaugh, C., Pigott, D. M., ... & Ferrari, A. J. (2021). Global prevalence and burden of depressive and anxiety disorders in

204 countries and territories in 2020 due to the COVID-19 pandemic. *The Lancet*, *398*(10312), 1700-1712. https://doi.org/10.1016/s0140-6736(21)02143-7.

Sarmiento, C., Miller, S. R., Chang, E., Zazove, P., & Kumagai, A. K. (2016). From impairment to empowerment: a longitudinal medical school curriculum on disabilities. *Academic Medicine*, *91*(7), 954-957. https://doi.org/10.1097/acm.0000000000000935.

Saunders, S. (2012). Contributions of the University of Cape Town to medical science in the first 100 years: personal reflections: forum-history. *South African Medical Journal*, *102*(6), 391-393. https://doi.org/10.7196/samj.5425.

Schalk, S. (2017). Critical disability studies as methodology. *Lateral*, *6*(1). https://doi.org/10.25158/l6.1.13.

Schilling, J. F., & Koetting, J. R. (2010). Underpinnings of competency-based education. *Athletic Training Education Journal*, *5*(4), 165-169. https://doi.org/10.4085/1947-380x-5.4.165.

Schwartz, M. A., & Wiggins, O. (1985). Science, humanism, and the nature of medical practice: A phenomenological view. *Perspectives in Biology and Medicine*, *28*(3), 331-361. https://doi.org/10.1353/pbm.1985.0008.

Schwarz, M. R., & Wojtczak, A. (2002). Global minimum essential requirements: a road towards competence-oriented medical education. *Medical Teacher*, *24*(2), 125-129. https://doi.org/10.1080/01421590220120740.

Scully, J. L. (2018). From “she would say that, wouldn't she?” to “does she take sugar?” epistemic injustice and disability. *IJFAB: International Journal of Feminist Approaches to Bioethics*, *11*(1), 106-124. https://doi.org/10.3138/ijfab.11.1.106.

Scully, J. L. (2020). Disability, disablism, and COVID-19 pandemic triage. *Journal of bioethical inquiry*, *17*(4), 601-605. https://doi.org/10.1007/s11673-020-10005-y.

Shakespeare, T. (2006). The social model of disability. *The disability studies reader*, *2*, 197-204.

Shakespeare, T., Iezzoni, L. I., & Groce, N. E. (2009). Disability and the training of health professionals. *The Lancet*, *374*(9704), 1815-1816. https://doi.org/10.1016/s0140-6736(09)62050-x.

Shandra, C. L. (2018). Disability as inequality: Social disparities, health disparities, and participation in daily activities. *Social Forces*, *97*(1), 157-192. https://doi.org/10.1093/sf/soy031.

Sharma, M. (2018). ‘Can the patient speak?’: Postcolonialism and patient involvement in undergraduate and postgraduate medical education. *Medical education*, *52*(5), 471-479. https://doi.org/10.1111/medu.13501.

Shokri, M. (2017). What is political power. *Theory of Political Consciousness and Integrated Concept of Power). Arts Social Sci J*, *8*(268), 2. Retrieved from https://www.semanticscholar.org/.

Short, E. C. (1991). Introduction: Understanding curriculum inquiry. *Forms of curriculum inquiry*, 1-25.

Singh, S., Cotts, K. G., Maroof, K. A., Dhaliwal, U., Singh, N., & Xie, T. (2020). Disability-inclusive compassionate care: Disability competencies for an Indian Medical Graduate. *Journal of Family Medicine and Primary Care*, *9*(3), 1719. https://doi.org/10.4103/jfmpc.jfmpc_1211_19.

Smithson, J. (2008). Focus groups. *The Sage handbook of social research methods*, *357*, 370. https://doi.org/10.4135/9781446212165.n21.

Solomon, M. Z., Wynia, M. K., & Gostin, L. O. (2020). Covid-19 crisis triage—optimizing health outcomes and disability rights. *New England Journal of Medicine*, *383*(5), e27. https://doi.org/10.1056/nejmp2008300.

Solvang, P. (2000). The emergence of an us and them discourse in disability theory. *Scandinavian Journal of Disability Research*, *2*(1), 3-20. https://doi.org/10.1080/15017410009510749.

South African Human Rights Commission. (2017). Research Brief on Disability and Equality in South Africa 2013-2017.

Stewart, D. W., & Shamdasani, P. N. (2014). *Focus groups: Theory and practice* (Vol. 20). Sage publications. https://doi.org/10.4135/9781412991841.

Strasser, S., London, L., & Kortenbout, E. (2005). Developing a competence framework and evaluation tool for primary care nursing in South Africa. *Education for Health: Change in Learning & Practice, 18*(2). Retrieved from https://www.researchgate.net/.

Suda, M., Onoe, H., & Harigai, K. (2017). Cases which were treated by giving grounds to delusion: What is client-centered medical care?. *Journal of General and Family Medicine*, *18*(3), 108-113. https://doi.org/10.1002/jgf2.34.

Sun, Y. (2020, December). Research on the Ethical Connotation and Specific Standards of the Justice Principle of Property Right Empowerment. In *Fifth International Conference on Economic and Business Management (FEBM 2020)* (pp. 568-571). Atlantis Press. https://doi.org/10.2991/aebmr.k.201211.097.

Suri, H. (2011). Purposeful sampling in qualitative research synthesis. *Qualitative research journal*, *11*(2), 63-75. https://doi.org/10.3316/qrj1102063.

Surmiak, A. (2018). Confidentiality in qualitative research involving vulnerable participants: Researchers' perspectives. In *Forum: Qualitative Social Research* (Vol. 19, No. 3, pp. 393-418). Freie Universität Berlin. Retrieved from https://www.qualitative-research.net/.

Swanwick, T. (2018). Understanding medical education. *Understanding Medical Education: Evidence, Theory, and Practice*, 1-6. https://doi.org/10.1002/9781119373780.ch1.

Sweet, M. A., Dudgeon, P., McCallum, K., & Ricketson, M. D. (2014). Decolonising practices: Can journalism learn from health care to improve Indigenous health outcomes. *Medical Journal of Australia*, *200*(11), 626-627. https://doi.org/10.5694/mja14.00528.

Symons, A. B., McGuigan, D., & Akl, E. A. (2009). A curriculum to teach medical students to care for people with disabilities: development and initial implementation. *BMC Medical Education*, *9*(1), 1-7. https://doi.org/10.1186/1472-6920-9-78.

Tavakol, M., & Sandars, J. (2014). Quantitative and qualitative methods in medical education research: AMEE Guide No 90: Part I. *Medical Teacher*, *36*(9), 746-756. https://doi.org/10.3109/0142159x.2014.915298.

Tarvainen, M. (2019). Ableism and the life stories of people with disabilities. *Scandinavian Journal of Disability Research*, *21*(1). https://doi.org/10.16993/sjdr.632.

Tederko, P., Krasuski, M., Denes, Z., Moslavac, S., & Likarevic, I. (2015). What medical doctors and medical students know about physical medicine and rehabilitation: a survey from Central Europe. *European Journal of physical and rehabilitation Medicine*, *52*(5), 597-605. Retrieved from https://europepmc.org/.

Ten Cate, O., & Billett, S. (2014). Competency-based medical education: origins, perspectives and potentialities. *Medical Education*, *48*(3), 325-332. https://doi.org/10.1111/medu.12355.

The Council of Europe (2021). Disability and Disablism. 1-22. (www.coe.int visited on 20/07/2021)

Thill, C. (2015). Listening for policy change: how the voices of disabled people shaped Australia's National Disability Insurance Scheme. *Disability & Society*, *30*(1), 15-28. https://doi.org/10.1080/09687599.2014.987220.

Thorne, S. (2000). Data analysis in qualitative research. *Evidence-based nursing*, *3*(3), 68-70. https://doi.org/10.1136/ebn.3.3.68.

Tilley, H. (2016). Medicine, empires, and ethics in colonial Africa. *AMA Journal of Ethics*, *18*(7), 743-753. https://doi.org/10.1001/journalofethics.2016.18.7.mhst1-1607.

Toole, B. (2019). From standpoint epistemology to epistemic oppression. *Hypatia*, *34*(4), 598-618. https://doi.org/10.1111/hypa.12496.

Touchie, C., & ten Cate, O. (2016). The promise, perils, problems and progress of competency-based medical education. *Medical education*, *50*(1), 93-100. https://doi.org/10.1111/medu.12839.

Twardowski, A. (2019). Controversies around the social model of disability. *Kultura-Społeczeństwo-Edukacja*, *16*(2). https://doi.org/10.14746/kse.2019.16.1.

Tyler, I. (2015). Dis/ability studies: theorising disablism and ableism. 23-40.

Unger, J. P., Morales, I., De Paepe, P., & Roland, M. (2020). The physician and professionalism today: challenges to and strategies for ethical professional medical practice. *BMC health services research*, *20*(2), 1-5. https://doi.org/10.1186/s12913-020-05884-1.

United Nations (2006). UN Convention on the Rights of Persons with Disabilities.

University of Cape Town, Faculty of Health Sciences website (visited on 23/08/2021). www.health.uct.ac.za/fhs/about/mission.

University of Cape Town. General overview: Becoming a Professional (PPH1001F)/ Becoming a Health Professional (PPH1002S). PDF version 2020; 1-2.

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & health sciences*, *15*(3), 398-405. https://doi.org/10.1111/nhs.12048.

Vadlamannati, K. C., Cooray, A., & De Soysa, I. (2020). *Healthcare equity and COVID-19: Assessing the relative effectiveness of egalitarian governance and healthcare system capacity on the COVID-19 pandemic* (No. 2020/89). WIDER Working Paper. https://doi.org/10.35188/unu-wider/2020/846-7

Van der Vleuten, CPM. & Driessen, EW. (2014). What would happen to education if we took education evidence seriously? Perspectives on Medical Education, 4; 222-232. https://doi.org/10.1007/s40037-014-0129-9.

Van Dijk, T. A. (2008). Critical discourse analysis and nominalization: Problem or pseudo-problem?. *Discourse & Society*, *19*(6), 821-828. https://doi.org/10.1177/0957926508095897.

Vergunst, R., Swartz, L., Hem, K. G., Eide, A. H., Mannan, H., MacLachlan, M., ... & Schneider, M. (2017). Access to health care for persons with disabilities in rural South Africa. *BMC health services research*, *17*(1), 1-8. https://doi.org/10.1186/s12913-017-2674-5.

Visagie, S., Scheffler, E., & Schneider, M. (2013). Policy implementation in wheelchair service delivery in a rural South African setting. *African Journal of Disability*, *2*(1), 1-9. https://doi.org/10.4102/ajod.v2i1.63.

Vlak, T., Boban, M., Franulovic-Golja, N., & Eldar, R. (2004). Teaching disability and rehabilitation medicine at the Medical School in Split, Croatia. *Croat Med J*, *45*(1), 99-102. Retrieved from https://www.academia.edu/.

Wald, H. S. (2015). Professional identity (trans) formation in medical education: reflection, relationship, resilience. *Academic Medicine*, *90*(6), 701-706. https://doi.org/10.1097/acm.0000000000000731.

Wartman, S. A. (2019). The empirical challenge of 21st-century medical education. *Academic Medicine*, *94*(10), 1412-1415. https://doi.org/10.1097/acm.0000000000002866.

Whelan, J. (2002). WHO calls for countries to shift from acute to. *BMJ*, *324*(1237). https://doi.org/10.1136/bmj.324.7348.1237.

Whitehead, C. R. (2016). On gunboats and grand pianos: medical education exports and the long shadow of colonialism. *Advances in Health Sciences Education*, *21*(1), 1-4. https://doi.org/10.1007/s10459-015-9660-7.

Wolbring, G. (2008). The politics of ableism. *Development*, *51*(2), 252-258. https://doi.org/10.1057/dev.2008.17.

Wong, S. H., Gishen, F., & Lokugamage, A. U. (2021). 'Decolonising the Medical Curriculum ': Humanising medicine through epistemic pluralism, cultural safety and critical consciousness. *London Review of Education*, *19*(1). https://doi.org/10.14324/lre.19.1.16.

World Federation for Medical Education (WFME). World Federation for Medical Education Global Standards for Quality Improvement, The 2015 Revision. WFME Office, Ferney-Voltaire, France, Copenhagen, Denmark.

World Health Organisation (WHO) website (visited on 17/02/2016). www.who.int.

World Health Organization. (2011). World report on disability 2011. World Health Organization.

WORLD MEDICAL ASSOCIATION DECLARATION OF HELSINKI (2013): Ethical Principles for Medical Research Involving Human Subjects. 2013.

Yin, R. K. (1994). Discovering the future of the case study. Method in evaluation research. *Evaluation practice, 15*(3), 283-290. Retrieved from https://journals.sagepub.com/.

Zestcott, C. A., Blair, I. V., & Stone, J. (2016). Examining the presence, consequences, and reduction of implicit bias in health care: a narrative review. *Group Processes & Intergroup Relations*, *19*(4), 528-542. https://doi.org/10.1177/1368430216642029.

Appendices

Appendix 1: Information sheet for Phase one participants of the first focus group (Persons with disability) session

(Should a participant's first language not be English, the researcher will endeavour to get the information sheet translated into a language the participant prefers. The translation will be done by a qualified translator).

My name is Sarah Whitehead. I am conducting this study for my doctoral thesis in Health Sciences Education. This information sheet contains details of the study and will tell you what the data collected from you will be used for.

Title of Study: Proposing clinician competency guidelines for including disability in the undergraduate medical curriculum in South Africa - an exploratory study.

Purpose and focus of study:

The purpose of this study is to assist with disability inclusion in the undergraduate medical curriculum in South Africa. It focuses on the initial process of curriculum generation by aiming to describe what medical doctors do (their practice with persons with disability) and what competencies (knowledge, skills and attitudes) they should have to enable a disability inclusive practice. There will be a focus group discussion with five persons with disability who have frequent contact with medical doctors. Some of you may be invited to an in-depth interview. This interview is to explore your contributions from the focus group in more detail. The aim is to gather data as to the disability competencies a doctor should have.

What the data from the focus groups will be used for:

The data from the focus groups will be audio-taped and transcribed verbatim. To ensure that the information that you provide cannot be identified as coming from you, the researcher will code all the information. This coded information will be categorized into themes. These themes will be presented to an expert panel to reach consensus on the disability competencies which could be included in an undergraduate medical curriculum.

Confidentiality agreement:

All information shared by you in the focus group will remain confidential. The research assistant will remind all the participants that any information shared in the focus group must be treated as confidential by all members of the group. The researcher will also maintain confidentiality through the use of codes or pseudonyms when reporting any of the data.

Selection of participants:

You were selected for this study because it is vitally important to hear the voices of persons with disability regarding this topic.

Recruitment of participants:

The researcher will recruit 5 persons with disability. The first participant group will consist of Persons (who have frequent contact with doctors) with disability. To recruit these participants, the researcher will send a general email request. This request will explain the research and ask if they will participate in it. Once persons with disability have volunteered, they will be sent a personal email containing details of the date, time, venue and proposed agenda for the focus groups, as well as the researcher's contact details.

What is required of participants?

Participation is completely voluntary and all information that you share in the focus groups will be treated with strict confidentiality. The researcher, her supervisor Harsha Kathard and her co-supervisor Theresa Lorenzo will be the only people who are aware of your participation in this study (their contact details are at the end of this information sheet.

The focus group session will last an hour to an hour and a half and will audio-recorded. The date, time and venue for the session will be decided to most convenience you. The audio-recorded data will be transcribed verbatim. It will then be sent to you, so you may check that the researcher has not misinterpreted any of your contributions made during the focus group session. Corrections will be made to any misinterpretations.

You are free to choose to not answer a specific question at any time during the study and do not need to produce a reason why. You are also free to withdraw from the study at any time.

After the focus groups, one or two participants will be invited to an in-depth interview. The purpose of which is explore contributions they made in the focus group in more detail.

Should a participant incur any travel expenses, these will either be reimbursed or covered by the researcher (i.e., if they do not have the money available to travel).

What will the benefit be to the participants?

In taking part in this study, you are actively contributing to a greater understanding and awareness of disability issues within undergraduate medical curricula. There will be no remuneration for participation in this study.

What risks will be involved?

Informational risk:

Any information shared by you in the focus groups will be treated as confidential. You will not be identifiable in any reports or a thesis where the information is used. The researcher, the research assistant, the researcher's supervisor and co supervisor are the only people with whom identifiable data will be shared. However, 100% confidentiality amongst the other participants cannot be guaranteed. But the researcher and research assistant will do their best to ensure that other participants of the focus groups, understand that they may not discuss what is shared and by whom with others outside of the focus group.

Should you have any further queries or want to discuss the focus group process, please contact the researcher's supervisor or co supervisor, on the details listed below.

Researcher:

Dr Sarah Whitehead

+27 82 5842891

Email: se_whitehead@yahoo.com

Supervisor:

Harsha Kathard

Faculty of Health Sciences, University of Cape Town

Interim Head: Department of Health Sciences Education

Professor: Communication Sciences and Disorders

Tel: +27 21 406 6041

Email: harsha.kathard@uct.ac.za

Co-supervisor:

Theresa Lorenzo

Faculty of Health Sciences, University of Cape Town

PhD Convenor, Disability Studies: Department of Health and Rehabilitation Sciences

Tel: +27 21 406 6326

Email: theresa.lorenzo@uct.ac.za

If you have any queries or concerns about your rights or welfare as a research participant please contact the head of the Faculty of Health Sciences, Human Research Ethics Committee, Marc Blockman with the contact details below:

Ethics Committee

Associate Professor Marc Blockman

Chairperson: Faculty of Health Sciences Human Research Ethics Committee

Tel: +27 21 406 6496

Email: Marc.Blockman@uct.ac.za

Appendix 2: Information sheet for Phase one participants of the second focus group (Medical Doctors) session

(Should a participant's first language not be English, the researcher will endeavour to get the information sheet translated into a language the participant prefers. The translation will be done by a qualified translator).

My name is Sarah Whitehead. I am conducting this study for my doctoral thesis in Health Sciences Education. This information sheet contains details of the study and will tell you what the data collected from you will be used for.

Title of Study: Proposing clinician competency guidelines for including disability in the undergraduate medical curriculum in South Africa - an exploratory study.

Purpose and focus of study:

The purpose of this study is to assist with disability inclusion in the undergraduate medical curriculum in South Africa. It focuses on the initial process of curriculum generation by aiming to describe what medical doctors do (their practice with persons with disability) and what competencies (knowledge, skills and attitudes) they should have to enable a disability inclusive practice. There will be focus group discussion with three General Practitioners to get information about your current disability practice and what competencies you think would facilitate this practice. Some of you may be invited to an in-depth interview. This interview is to explore your contributions from the focus group in more detail. The aim is to gather data as to the disability competencies a doctor should have.

What the data from the focus groups will be used for:

The data from the focus groups will be audio-taped and transcribed verbatim. To ensure that the information that you provide cannot be identified as coming from you, the researcher will code all the information. This coded information will be categorized into themes. These themes will be presented to an expert panel to reach consensus on the disability competencies which could be included in an undergraduate medical curriculum.

Confidentiality agreement:

All information shared by you in the focus group will remain confidential. The research assistant will remind all the participants that any information shared in the focus group must

be treated as confidential by all members of the group. The researcher will also maintain confidentiality through the use of codes or pseudonyms when reporting any of the data.

Selection of participants:

You were selected for this study because of your work experience as a General Practitioner, which puts you in a good position to offer rich insights into the topic.

Recruitment of participants:

These participants will be medical doctors who have a minimum of five years' work experience post-graduation and have treated a patient or patients with disabilities in the course of their careers. The participants will be General Practitioner, registered with the HPCSA as independent medical practioners and not specialists in a particular discipline of medicine. The recruitment will be done as follows: an email will be sent to 3 General Practitioners (GP). This email will explain the purpose of study and will invite them to participate in the first group. In this email the researcher will ask if a time can be set up for the researcher to visit the GP and discuss the email directly. An email may seem impersonal but the researcher is mindful that she is approaching busy professionals and therefore wants to proceed at their convenience. Once they have accepted the invitation, the researcher will send them each a personal email containing details of the date, time, venue, the proposed agenda for the focus group as well as the researcher's contact details.

What is required of participants?

Participation is completely voluntary and all information that you share in the focus groups will be treated with strict confidentiality. The researcher, her supervisor Harsha Kathard and her co-supervisor Theresa Lorenzo will be the only people who are aware of your participation in this study (their contact details are at the end of this information sheet.

The focus group session will last an hour to an hour and a half and will audio-recorded. The date, time and venue for the session will be decided to most convenience you. The audio-recorded data will be transcribed verbatim. It will then be sent to you, so you may check that the researcher has not misinterpreted any of your contributions made during the focus group session. Corrections will be made to any misinterpretations.

You are free to choose to not answer a specific question at any time during the study and do not need to produce a reason why. You are also free to withdraw from the study at any time.

After the focus groups, one or two participants will be invited to an in-depth interview. The purpose of which is explore contributions they made in the focus group in more detail.

What will the benefit be to the participants?

In taking part in this study, you are actively contributing to a greater understanding and awareness of disability issues within undergraduate medical curricula. There will be no remuneration for participation in this study.

What risks will be involved?

Informational risk:

Any information shared by you in the focus groups will be treated as confidential. You will not be identifiable in any reports or a thesis where the information is used. The researcher, the research assistant, the researcher's supervisor and co supervisor are the only people with whom identifiable data will be shared. However, 100% confidentiality amongst the other participants cannot be guaranteed. But the researcher and research assistant will do their best to ensure that other participants of the focus groups, understand that they may not discuss what is shared and by whom with others outside of the focus group.

Should you have any further queries or want to discuss the focus group process, please contact the researcher's supervisor or co supervisor, on the details listed below.

Researcher:

Dr Sarah Whitehead

+27 82 5842891

Email: se_whitehead@yahoo.com

Supervisor:

Harsha Kathard

Faculty of Health Sciences, University of Cape Town

Interim Head: Department of Health Sciences Education

Professor: Communication Sciences and Disorders

Tel: +27 21 406 6041

Email: harsha.kathard@uct.ac.za

Co-supervisor:

Theresa Lorenzo

Faculty of Health Sciences, University of Cape Town

PhD Convenor, Disability Studies: Department of Health and Rehabilitation Sciences

Tel: +27 21 406 6326

Email: theresa.lorenzo@uct.ac.za

If you have any queries or concerns about your rights or welfare as a research participant please contact the head of the Faculty of Health Sciences, Human Research Ethics Committee, Marc Blockman with the contact details below:

Ethics Committee

Associate Professor Marc Blockman

Chairperson: Faculty of Health Sciences Human Research Ethics Committee

Tel: +27 21 406 6496

Email: Marc.Blockman@uct.ac.za

Appendix 3: Information sheet for Phase one participants of the third focus group (Rehabilitation Therapists and Nurses) session

(Should a participant's first language not be English, the researcher will endeavour to get the information sheet translated into a language the participant prefers. The translation will be done by a qualified translator).

My name is Sarah Whitehead. I am conducting this study for my doctoral thesis in Health Sciences Education. This information sheet contains details of the study and will tell you what the data collected from you will be used for.

Title of Study: Proposing clinician competency guidelines for including disability in the undergraduate medical curriculum in South Africa - an exploratory study.

Purpose and focus of study:

The purpose of this study is to assist with disability inclusion in the undergraduate medical curriculum in South Africa. It focuses on the initial process of curriculum generation by aiming to describe what medical doctors do (their practice with persons with disability) and what competencies (knowledge, skills and attitudes) they should have to enable a disability inclusive practice. There will be a focus group discussion with 2 physiotherapists, 2 occupational therapists, 2 speech therapists and 2 registered nurses to gain insights into how medical doctors disability practice is perceived by individuals (the therapists and nurses) who form an integral part of the healthcare team. Some of you may be invited to an in-depth interview. This interview is to explore your contributions from the focus group in more detail. The aim is to gather data as to the disability competencies a doctor should have.

What the data from the focus groups will be used for:

The data from the focus groups will be audio-taped and transcribed verbatim. To ensure that the information that you provide cannot be identified as coming from you, the researcher will code all the information. This coded information will be categorized into themes. These themes will be presented to an expert panel to reach consensus on the disability competencies which could be included in an undergraduate medical curriculum.

Confidentiality agreement:

All information shared by you in the focus group will remain confidential. The research assistant will remind all the participants that any information shared in the focus group must

be treated as confidential by all members of the group. The researcher will also maintain confidentiality through the use of codes or pseudonyms when reporting any of the data.

Selection of participants:

You were selected for this study because of your work experience as a therapist who forms an important part of the healthcare team. This puts you in a good position to offer rich insights into the topic.

Recruitment of participants:

This group will contain 2 physiotherapists, 2 occupational therapists, 2 speech therapists and 2 registered nurses. Therapists that have completed their community service year and are registered with the HPCSA as allied healthcare professionals will be asked to participate. These therapists must work with patients with disabilities. They must either work closely with medical doctors (in a hospital setting) or receive referrals from medical doctors (outpatient setting). Participants for the second focus group will be recruited as follows: An email request will be sent to the heads of each therapeutic discipline (occupational therapy, speech therapy and physiotherapy) at a number of Cape Town hospitals. The email will request them to send an email to their therapists which explains the research and invites them to participate in the study. A similar email request will also be sent to the Head of nursing at a number of Cape Town hospitals. This email will ask them to forward the request to their registered nurses, which explains the research and invites them to participate. The therapists and nurses, that volunteer will be sent a personal invitation detailing the date, time, venue and proposed agenda for the focus groups as well as the researcher's contact details.

What is required of participants?

Participation is completely voluntary and all information that you share in the focus groups will be treated with strict confidentiality. The researcher, her supervisor Harsha Kathard and her co-supervisor Theresa Lorenzo will be the only people who are aware of your participation in this study (their contact details are at the end of this information sheet.

The focus group session will last an hour to an hour and a half and will audio-recorded. The date, time and venue for the session will be decided to most convenience you. The audio-recorded data will be transcribed verbatim. It will then be sent to you, so you may check that the researcher has not misinterpreted any of your contributions made during the focus group session. Corrections will be made to any misinterpretations.

You are free to choose to not answer a specific question at any time during the study and do not need to produce a reason why. You are also free to withdraw from the study at any time.

After the focus groups, one or two participants will be invited to an in-depth interview. The purpose of which is explore contributions they made in the focus group in more detail.

What will the benefit be to the participants?

In taking part in this study, you are actively contributing to a greater understanding and awareness of disability issues within undergraduate medical curricula. There will be no remuneration for participation in this study.

What risks will be involved?

Informational risk:

Any information shared by you in the focus groups will be treated as confidential. You will not be identifiable in any reports or a thesis where the information is used. The researcher, the research assistant, the researcher's supervisor and co supervisor are the only people with whom identifiable data will be shared. However, 100% confidentiality amongst the other participants cannot be guaranteed. But the researcher and research assistant will do their best to ensure that other participants of the focus groups, understand that they may not discuss what is shared and by whom with others outside of the focus group.

Should you have any further queries or want to discuss the focus group process, please contact the researcher's supervisor or co supervisor, on the details listed below.

Researcher:

Dr Sarah Whitehead

+27 82 5842891

Email: se_whitehead@yahoo.com

Supervisor:

Harsha Kathard

Faculty of Health Sciences, University of Cape Town

Interim Head: Department of Health Sciences Education

Professor: Communication Sciences and Disorders

Tel: +27 21 406 6041

Email: harsha.kathard@uct.ac.za

Co-supervisor:

Theresa Lorenzo

Faculty of Health Sciences, University of Cape Town

PhD Convenor, Disability Studies: Department of Health and Rehabilitation Sciences

Tel: +27 21 406 6326

Email: theresa.lorenzo@uct.ac.za

If you have any queries or concerns about your rights or welfare as a research participant please contact the head of the Faculty of Health Sciences, Human Research Ethics Committee, Marc Blockman with the contact details below:

Ethics Committee

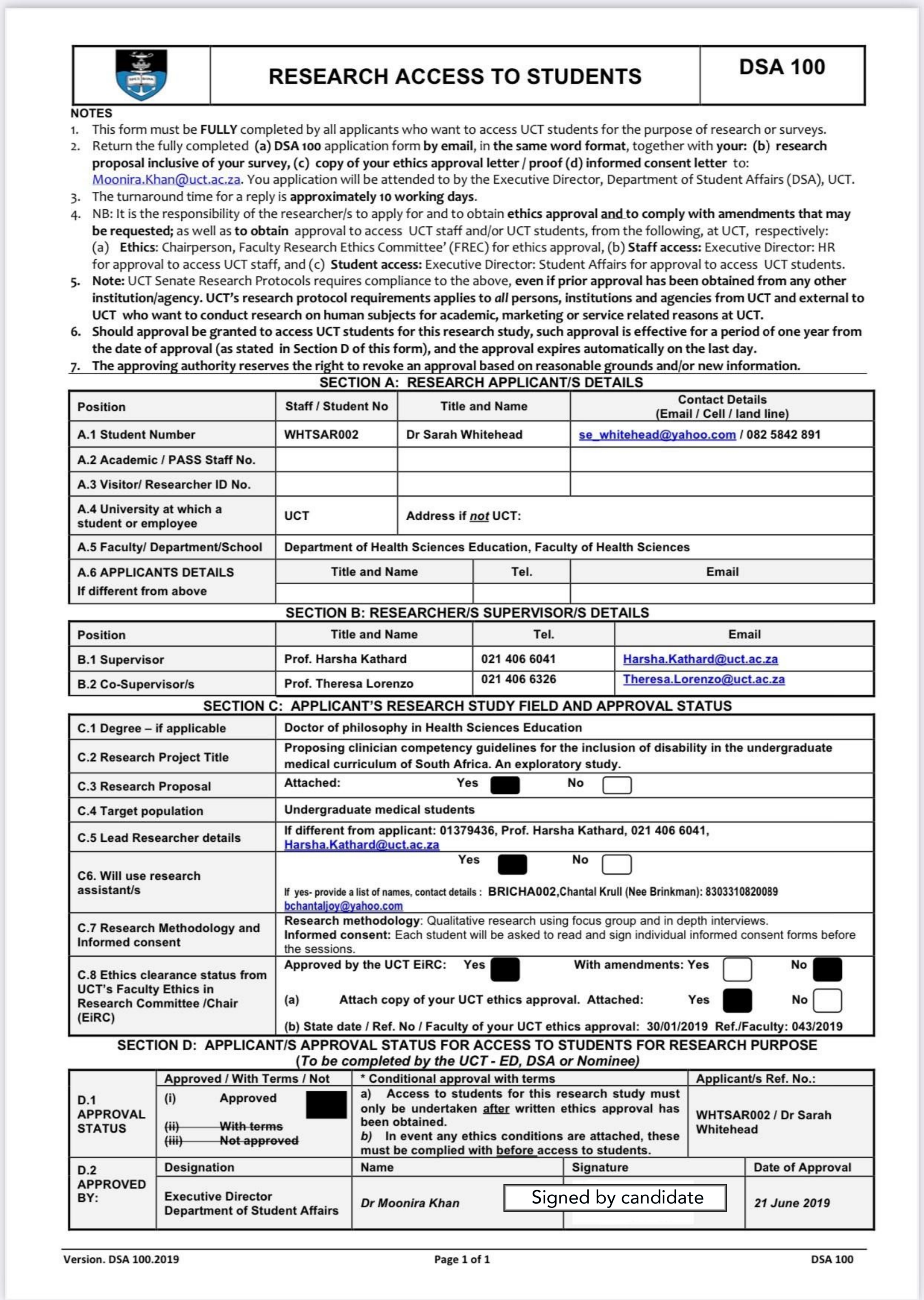
Associate Professor Marc Blockman

Chairperson: Faculty of Health Sciences Human Research Ethics Committee

Tel: +27 21 406 6496

Email: Marc.Blockman@uct.ac.za

Appendix 4: DSA100 form approval letter



RESEARCH ACCESS TO STUDENTS

DSA 100

NOTES

1. This form must be **FULLY** completed by all applicants who want to access UCT students for the purpose of research or surveys.
2. Return the fully completed **(a) DSA 100** application form **by email**, in **the same word format**, together with **your: (b) research proposal inclusive of your survey, (c) copy of your ethics approval letter / proof (d) informed consent letter** to: Moonira.Khan@uct.ac.za. You application will be attended to by the Executive Director, Department of Student Affairs (DSA), UCT.
3. The turnaround time for a reply is **approximately 10 working days**.
4. NB: It is the responsibility of the researcher/s to apply for and to obtain **ethics approval and to comply with amendments that may be requested;** as well as **to obtain** approval to access UCT staff and/or UCT students, from the following, at UCT, respectively: (a) **Ethics**: Chairperson, Faculty Research Ethics Committee' (FREC) for ethics approval, (b) **Staff access:** Executive Director: HR for approval to access UCT staff, and (c) **Student access:** Executive Director: Student Affairs for approval to access UCT students.
5. **Note:** UCT Senate Research Protocols requires compliance to the above, **even if prior approval has been obtained from any other institution/agency. UCT's research protocol requirements applies to *all* persons, institutions and agencies from UCT and external to UCT who want to conduct research on human subjects for academic, marketing or service related reasons at UCT.**
6. **Should approval be granted to access UCT students for this research study, such approval is effective for a period of one year from the date of approval (as stated in Section D of this form), and the approval expires automatically on the last day.**
7. **The approving authority reserves the right to revoke an approval based on reasonable grounds and/or new information.**

SECTION A: RESEARCH APPLICANT/S DETAILS

Position	Staff / Student No	Title and Name	Contact Details (Email / Cell / land line)
A.1 Student Number	WHTSAR002	Dr Sarah Whitehead	se_whitehead@yahoo.com / 082 5842 891
A.2 Academic / PASS Staff No.			
A.3 Visitor/ Researcher ID No.			
A.4 University at which a student or employee	UCT	Address if *not* UCT:	
A.5 Faculty/ Department/School	Department of Health Sciences Education, Faculty of Health Sciences		
A.6 APPLICANTS DETAILS If different from above	Title and Name	Tel.	Email

SECTION B: RESEARCHER/S SUPERVISOR/S DETAILS

Position	Title and Name	Tel.	Email
B.1 Supervisor	Prof. Harsha Kathard	021 406 6041	Harsha.Kathard@uct.ac.za
B.2 Co-Supervisor/s	Prof. Theresa Lorenzo	021 406 6326	Theresa.Lorenzo@uct.ac.za

SECTION C: APPLICANT'S RESEARCH STUDY FIELD AND APPROVAL STATUS

C.1 Degree – if applicable	Doctor of philosophy in Health Sciences Education
C.2 Research Project Title	Proposing clinician competency guidelines for the inclusion of disability in the undergraduate medical curriculum of South Africa. An exploratory study.
C.3 Research Proposal	Attached: Yes ☒ No ☐
C.4 Target population	Undergraduate medical students
C.5 Lead Researcher details	If different from applicant: 01379436, Prof. Harsha Kathard, 021 406 6041, Harsha.Kathard@uct.ac.za
C6. Will use research assistant/s	Yes ☒ No ☐ If yes- provide a list of names, contact details : BRICHA002,Chantal Krull (Nee Brinkman): 8303310820089 bchantaljoy@yahoo.com
C.7 Research Methodology and Informed consent	**Research methodology**: Qualitative research using focus group and in depth interviews. **Informed consent:** Each student will be asked to read and sign individual informed consent forms before the sessions.
C.8 Ethics clearance status from UCT's Faculty Ethics in Research Committee /Chair (EiRC)	Approved by the UCT EiRC: Yes ☒ With amendments: Yes ☐ No ☒ (a) Attach copy of your UCT ethics approval. Attached: Yes ☒ No ☐ (b) State date / Ref. No / Faculty of your UCT ethics approval: 30/01/2019 Ref./Faculty: 043/2019

SECTION D: APPLICANT/S APPROVAL STATUS FOR ACCESS TO STUDENTS FOR RESEARCH PURPOSE

(*To be completed by the UCT - ED, DSA or Nominee)*

D.1 APPROVAL STATUS	Approved / With Terms / Not	* Conditional approval with terms		Applicant/s Ref. No.:
	(i) Approved ☒ ~~(ii) With terms~~ ~~(iii) Not approved~~	a) Access to students for this research study must only be undertaken after written ethics approval has been obtained. *b)* In event any ethics conditions are attached, these must be complied with before access to students.		WHTSAR002 / Dr Sarah Whitehead
D.2 APPROVED BY:	Designation	Name	Signature	Date of Approval
	Executive Director Department of Student Affairs	*Dr Moonira Khan*	Signed by candidate	*21 June 2019*

Version. DSA 100.2019 Page 1 of 1 DSA 100

Appendix 5: Information sheet for Phase one participants of the fourth focus group (Medical Students) session

(Should a participant's first language not be English, the researcher will endeavour to get the information sheet translated into a language the participant prefers. The translation will be done by a qualified translator).

My name is Sarah Whitehead. I am conducting this study for my doctoral thesis in Health Sciences Education. This information sheet contains details of the study and will tell you what the data collected from you will be used for.

Title of Study: Proposing clinician competency guidelines for including disability in the undergraduate medical curriculum in South Africa - an exploratory study.

Purpose and focus of study:

The purpose of this study is to assist with disability inclusion in the undergraduate medical curriculum in South Africa. It focuses on the initial process of curriculum generation by aiming to describe what medical doctors do (their practice with persons with disability) and what competencies (knowledge, skills and attitudes) they should have to enable a disability inclusive practice. There will be a focus group discussion with six final year (6th year) medical students with personal experience with persons with a disability (i.e., a family member with a disability). Some of you may be invited to an in-depth interview. This interview is to explore your contributions from the focus group in more detail. The aim is to gather data as to the disability competencies a doctor should have.

What the data from the focus groups will be used for:

The data from the focus groups will be audio-taped and transcribed verbatim. To ensure that the information that you provide cannot be identified as coming from you, the researcher will code all the information. This coded information will be categorized into themes. These themes will be presented to an expert panel to reach consensus on the disability competencies which could be included in an undergraduate medical curriculum.

Confidentiality agreement:

All information shared by you in the focus group will remain confidential. The research assistant will remind all the participants that any information shared in the focus group must

be treated as confidential by all members of the group. The researcher will also maintain confidentiality through the use of codes or pseudonyms when reporting any of the data.

Selection of participants:

You were selected for this study because you are well placed to give feedback (surrounding the inclusion of disability) on the undergraduate medical curriculum, having nearly completed your degree. Your personal experience with a person with a disability means that you will be able to contribute rich insights on the subject of disability.

Recruitment of participants:

The fourth participant group will consist of medical students from years 4-6 of their undergraduate degree with personal experience of persons with a disability (i.e., a family member with a disability). Once medical students have volunteered, they will be sent a personal email containing details of the date, time, venue and proposed agenda for the focus groups, as well as the researcher's contact details.

What is required of participants?

Participation is completely voluntary and all information that you share in the focus groups will be treated with strict confidentiality. The researcher, her supervisor Harsha Kathard and her co-supervisor Theresa Lorenzo will be the only people who are aware of your participation in this study (their contact details are at the end of this information sheet.

The focus group session will last an hour to an hour and a half and will audio-recorded. The date, time and venue for the session will be decided to most convenience you. The audio-recorded data will be transcribed verbatim. It will then be sent to you, so you may check that the researcher has not misinterpreted any of your contributions made during the focus group session. Corrections will be made to any misinterpretations.

You are free to choose to not answer a specific question at any time during the study and do not need to produce a reason why. You are also free to withdraw from the study at any time.

After the focus groups, one or two participants will be invited to an in-depth interview. The purpose of which is explore contributions they made in the focus group in more detail.

Should a participant incur any travel expenses, these will either be reimbursed or covered by the researcher (i.e., if they do not have the money available to travel).

What will the benefit be to the participants?

In taking part in this study, you are actively contributing to a greater understanding and awareness of disability issues within undergraduate medical curricula. There will be no remuneration for participation in this study.

What risks will be involved?

Informational risk:

Any information shared by you in the focus groups will be treated as confidential. You will not be identifiable in any reports or a thesis where the information is used. The researcher, the research assistant, the researcher's supervisor and co supervisor are the only people with whom identifiable data will be shared. However, 100% confidentiality amongst the other participants cannot be guaranteed. But the researcher and research assistant will do their best to ensure that other participants of the focus groups, understand that they may not discuss what is shared and by whom with others outside of the focus group.

Should you have any further queries or want to discuss the focus group process, please contact the researcher's supervisor or co supervisor, on the details listed below.

Researcher:

Dr Sarah Whitehead

+27 82 5842891

Email: se_whitehead@yahoo.com

Supervisor:

Harsha Kathard

Faculty of Health Sciences, University of Cape Town

Interim Head: Department of Health Sciences Education

Professor: Communication Sciences and Disorders

Tel: +27 21 406 6041

Email: harsha.kathard@uct.ac.za

Co-supervisor:

Theresa Lorenzo

Faculty of Health Sciences, University of Cape Town

PhD Convenor, Disability Studies: Department of Health and Rehabilitation Sciences

Tel: +27 21 406 6326

Email: theresa.lorenzo@uct.ac.za

If you have any queries or concerns about your rights or welfare as a research participant please contact the head of the Faculty of Health Sciences, Human Research Ethics Committee, Marc Blockman with the contact details below:

Ethics Committee

Associate Professor Marc Blockman

Chairperson: Faculty of Health Sciences Human Research Ethics Committee

Tel: +27 21 406 6496

Email: Marc.Blockman@uct.ac.za

Appendices 6 – 9: The following questions were used to guide the focus group process.

Appendix 6: Questions for the focus group with Persons with disability

1) Based on personal experiences, what positive or negative things do the majority of doctors do when treating patients with disabilities?
2) What makes treatment by a doctor a positive experience for you?
3) What makes treatment by a doctor a negative experience for you?
4) What in your opinion are the basic knowledge, skills and attitudes that a doctor should be equipped with in order to adequately treat patients with disabilities?

Appendix 7: Questions for the focus group with the Medical Doctors

1) What is your thinking about disability?
2) How do you know a person has a disability?
3) How do you approach the consultation and treatment?
4) Give examples of your practice with specific cases without mentioning the patient's names
5) Reflect on the basic knowledge, skills and attitudes that a doctor should be equipped with in order to adequately treat patients with disabilities.

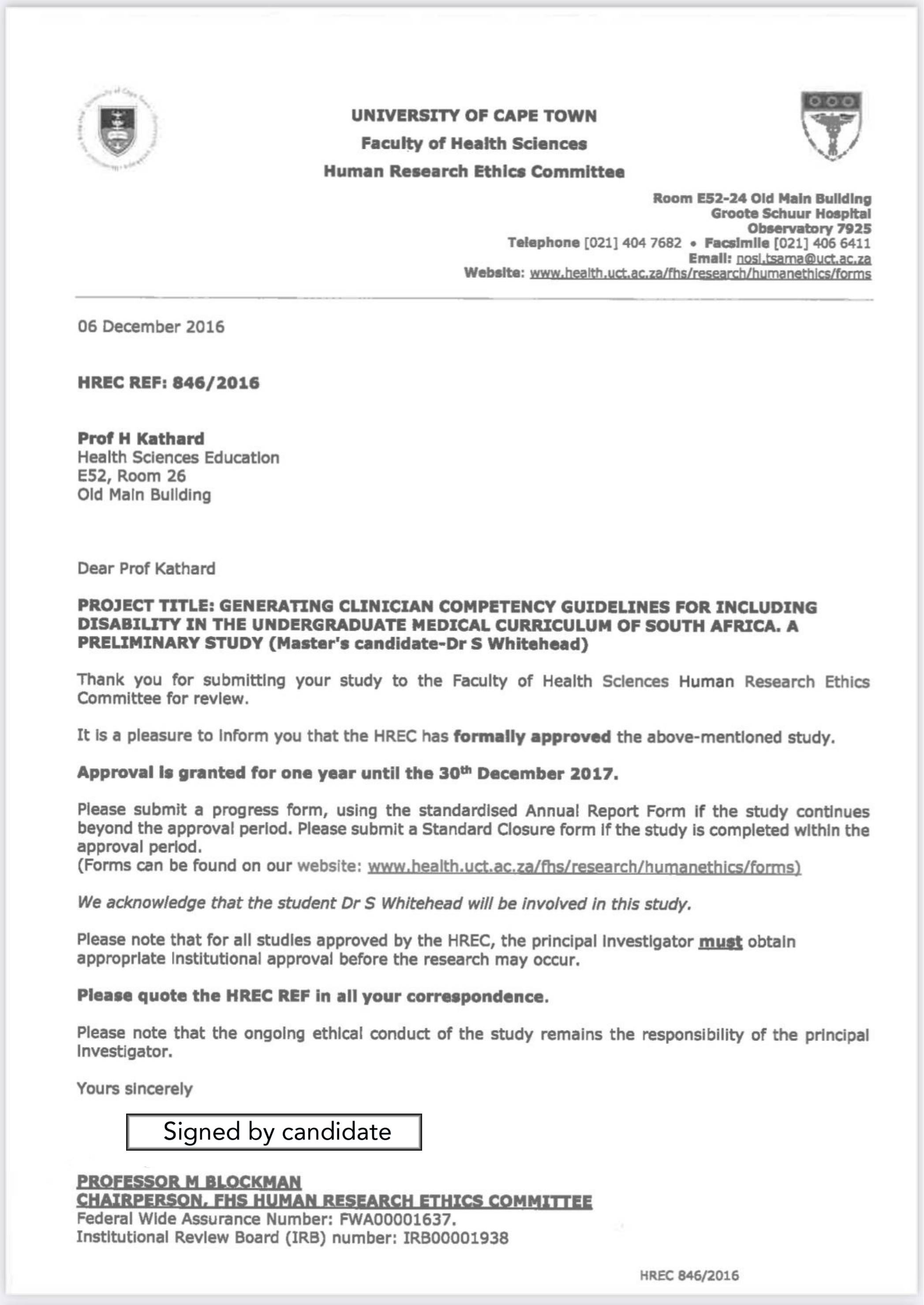
Appendix 8: Questions for the focus group with the Rehabilitation Therapists and Nurses

1) What have you observed in how doctors manage /treat persons with disability?
2) What are the strengths and challenges? How can the practice be developed further?
3) What have been your observations/experiences of doctors managing/treating persons with disability?
4) How do doctors approach their medical treatment with persons with disability?
5) What in your opinion are the basic knowledge, skills and attitudes that a doctor should be equipped with in order to adequately treat patients with disabilities?

Appendix 9: Questions for the focus group with Medical Students

1) Have you had any exposure to disability issues in your undergraduate medical curriculum? If so, what, when and how?
2) Do you think it's important to include disability issues in the undergraduate medical curriculum? Why?
3) Do you feel adequately equipped/prepared by your undergraduate medical curriculum to treat and manage persons with disability appropriately?

Appendix 10: HREC MPhil approval



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 404 7682 • **Facsimile** [021] 406 6411
Email: nosi.tsama@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

06 December 2016

HREC REF: 846/2016

Prof H Kathard
Health Sciences Education
E52, Room 26
Old Main Building

Dear Prof Kathard

PROJECT TITLE: GENERATING CLINICIAN COMPETENCY GUIDELINES FOR INCLUDING DISABILITY IN THE UNDERGRADUATE MEDICAL CURRICULUM OF SOUTH AFRICA. A PRELIMINARY STUDY (Master's candidate-Dr S Whitehead)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30th December 2017.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student Dr S Whitehead will be involved in this study.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

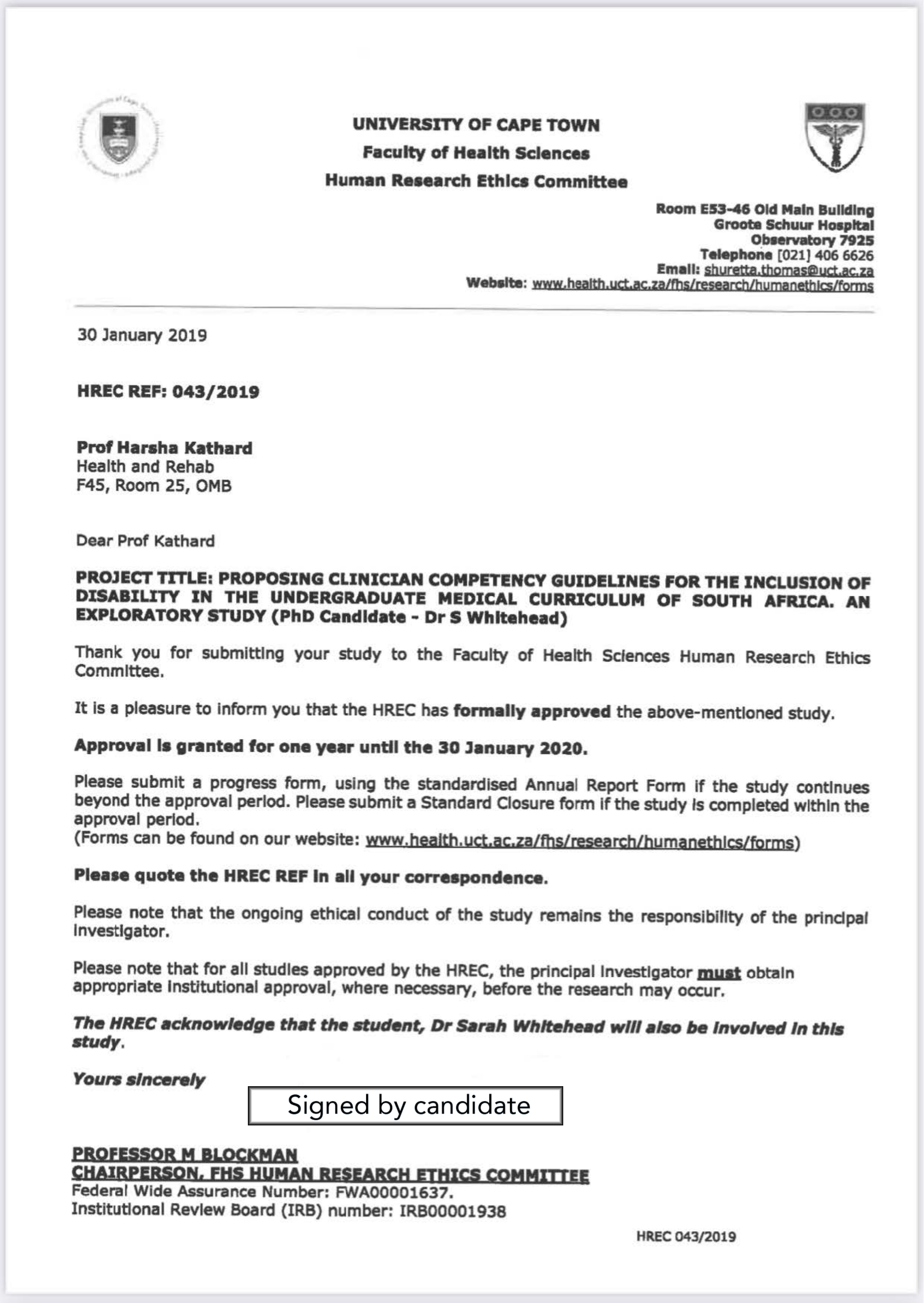
Yours sincerely

Signed by candidate

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HREC 846/2016

Appendix 11: HREC approval for upgrade to DPhil



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6626
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

---

30 January 2019

HREC REF: 043/2019

Prof Harsha Kathard
Health and Rehab
F45, Room 25, OMB

Dear Prof Kathard

PROJECT TITLE: PROPOSING CLINICIAN COMPETENCY GUIDELINES FOR THE INCLUSION OF DISABILITY IN THE UNDERGRADUATE MEDICAL CURRICULUM OF SOUTH AFRICA. AN EXPLORATORY STUDY (PhD Candidate - Dr S Whitehead)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 January 2020.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student, Dr Sarah Whitehead will also be involved in this study.

Yours sincerely

Signed by candidate

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HREC 043/2019

Appendix 12: Information sheet for Phase two participants

My name is Dr Sarah Whitehead. I'm a UCT PhD candidate in health sciences education. My thesis is titled: "Proposing clinician competency guidelines for the inclusion of disability in the undergraduate medical curriculum of South Africa. An exploratory study." My research is split into two phases. In Phase one I gathered data from Medical Doctors, Occupational Therapists, Physiotherapists, Speech Therapists, Nurses, Medical Students and Persons with disability. From this data, I produced a list of competencies, that would assist medical school graduates (I.e., generalist medical doctors) to afford persons with disability quality healthcare.

In Phase two, I plan to use a modified Delphi Method to reach consensus on the list of competencies I have already generated. I'm looking for disability studies academics (preferably with lived disability experience), medical educationists (particularly those involved in curriculum transformation/decolonization), medical doctors and disability rights/social justice activists, to be members of the expert panel for the modified Delphi. Your involvement on the panel is completely anonymous (my supervisors and I are the only people who will know your identity) as the Delphi will be run entirely online and no identifying features will be shared with other experts on the panel. You will be asked via an online survey to rate the competencies using a 5-point Likert scale. There will also be space under each competency for you to add any comments and/or suggestions. After every person on the panel has completed the first online survey, I will analyse and synthesise the results into a new survey, which will be sent back to you. You will be asked to do exactly the same as you did for the first survey. These iterations will continue for four rounds or until 75% consensus is reached.

I will then draw up a final list of disability competencies for inclusion in the undergraduate medical curriculum. This list will be sent to for you to check that you are happy with it.

You are free to choose to not answer a specific question at any time during the study and do not need to produce a reason why. You are also free to withdraw from the study at any time.

What will the benefit be to the participants?

In taking part in this study, you are actively contributing to a greater understanding and awareness of disability issues within undergraduate medical curricula. There will be no remuneration for participation in this study.

What risks will be involved?

Informational risk:

Any information shared by you in the focus groups will be treated as confidential. You will not be identifiable in any reports or a thesis where the information is used. The researcher, the researcher's supervisor and co supervisor are the only people with whom identifiable data will be shared. However, 100% confidentiality amongst the other participants cannot be guaranteed. But the researcher will do her best to ensure that other participants of the expert panel, understand that they may not discuss what is shared and by whom with others outside of the expert panel.

With the above information in mind, please confirm if you are available to commit to this process. I will email you further information and a formal consent form should you be able to commit.

Should you have any further queries or want to discuss the expert panel process, please contact the researcher's supervisor or co supervisor, on the details listed below.

Researcher:

Dr Sarah Whitehead

+27 82 5842891

Email: se_whitehead@yahoo.com

Supervisor:

Harsha Kathard

Faculty of Health Sciences, University of Cape Town

Interim Head: Department of Health Sciences Education

Professor: Communication Sciences and Disorders

Tel: +27 21 406 6041

Email: harsha.kathard@uct.ac.za

Co-supervisor:

Theresa Lorenzo

Faculty of Health Sciences, University of Cape Town

PhD Convenor, Disability Studies: Department of Health and Rehabilitation Sciences

Tel: +27 21 406 6326

Email: Theresa.Lorenzo@uct.ac.za

If you have any queries or concerns about your rights or welfare as a research participant please contact the head of the Faculty of Health Sciences, Human Research Ethics Committee, Marc Blockman with the contact details below:

Ethics Committee

Associate Professor Marc Blockman

Chairperson: Faculty of Health Sciences Human Research Ethics Committee

Tel: +27 21 406 6496

Email: Marc.Blockman@uct.ac.za

Consent documentation (consent form and information sheets) follow H3Africa guidelines for Informed Consent, 2013 (downloaded from Faculty of Health Sciences, Human Research Ethics Committee of UCT website).

Appendix 13: Consent form for Phase one participants

CONSENT FORM

Please tick each box, to indicate that you read, understood and agree to each statement.

Title of the study: Proposing clinician competency guidelines for including disability in the undergraduate medical curriculum in South Africa.- an exploratory study.

I have received an information sheet explaining the research project and I understand all that is written on the sheet. ☐

I have been given the opportunity to ask questions and these questions have all been answered to my satisfaction. ☐

I am aware that I can contact Harsha Kathard or Theresa Lorenzo if I have further queries, concerns or complaints. I have been given their contact details in the information sheet. ☐

I understand that to participate in this study will involve the following:

Attending a focus group session and a possible follow up in depth interview. ☐

The moderator will take notes during the focus group sessions. ☐

My voice will be recorded. ☐

I give consent to the recording of my voice during the data collection. ☐

I understand that although the researcher will be able to identify me, all the information I contribute will be coded, kept confidential, and will only be reviewed and assessed by the researcher, her supervisor and co-supervisor. ☐

I understand that I will remain anonymous in any report, thesis or presentation of the results of this research. ☐

I understand that I can choose to withdraw from this research at any time and that there will be no negative consequences for me. ☐

I freely agree to participate in this research study. ☐

Participants Name & Signature

Date & Place

----------------------*Witness (if needed)*

Date & Place

Appendix 14: Consent form for Phase two participants

CONSENT FORM

Please tick each box, to indicate that you read, understood and agree to each statement.

Title of the study: Proposing clinician competency guidelines for including disability in the undergraduate medical curriculum in South Africa - an exploratory study.

I have received an information sheet explaining the research project and I understand all that is written on the sheet. ☐

I have been given the opportunity to ask questions and these questions have all been answered to my satisfaction. ☐

I am aware that I can contact Harsha Kathard or Theresa Lorenzo if I have further queries, concerns or complaints. I have been given their contact details in the information sheet. ☐

I understand that to participate in this study will involve the following:

Answering an online questionnaire and then attending a group discussion for consensus reaching purposes. ☐

I understand that although the researcher will be able to identify me, all the information I contribute will be coded, kept confidential, and will only be reviewed and assessed by the researcher, her supervisor and co-supervisor. ☐

I understand that I will remain anonymous in any report, thesis or presentation of the results of this research. ☐

I understand that I can choose to withdraw from this research at any time and that there will be no negative consequences for me. ☐

I freely agree to participate in this research study. ☐

Participants Name & Signature
Date & Place

----------------------*Witness (if needed)*
Date & Place