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WHY DISABILITY SHOULD BE INCLUDED IN THE PROFESSIONAL EDUCATION OF GENERAL PRACTICE MEDICAL DOCTORS.

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ABSTRACT:

This paper presents arguments for why it is important to include disability in the undergraduate medical curriculum. I, the first author am currently involved with my doctoral thesis proposal titled "Proposing clinician competency guidelines for the inclusion of disability in the undergraduate medical curriculum of South Africa. An exploratory study." As part of my research, I conducted a literature search and developed arguments to strengthen the reasons why the research I propose in my thesis is necessary. It is important that I position myself in this research. I am a South African, Caucasian, female medical doctor, with an interest in physical rehabilitation medicine and I am a person with a physical disability. Although this research study will be conducted in South Africa, I am hopeful that the findings will be transferable to medical schools across the world.

KEY WORDS: disability, inclusion, medical education

BACKGROUND:

The transition from the 20th century to the 21st century has brought with it a shift in the focus of global health conditions from acute to chronic conditions. However, the training of healthcare workers has stayed aligned with what was the focus of healthcare in the 20th century: acute conditions. As a result, medical doctors are well versed in the traditional models of acute care but those will not equip them with the knowledge and skills, needed to treat and manage the current pressing world health problem of chronic conditions [1]. If chronic conditions are being highlighted as the most prevalent global health issue, it stands to reason that disability should also receive increased global acknowledgement and attention. This is because many (but not all) chronic conditions can lead to disabilities [2].

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Both the United Kingdom's General Medical Council and the South African Government have explicitly stated the need to prioritise disability education for medical doctors [3, 4, 5]. There are however no specific details as to how educators should teach medical doctors about disability. How, and even if, disability is taught is very dependent on a lecturer's personal interest and enthusiasm for the subject [3, 6]. Consequently, disability is easily overlooked by educators who are already teaching a very full curriculum.

Why should medical doctors know about disability?

In both South Africa and the rest of the world, there is limited published literature which addresses why disability should be included in undergraduate medical curricula. The World Report on Disability reminds us that persons with disabilities constitute approximately 15% of the world's population [7]. In South Africa, the 2011 census found that persons with disabilities make up 7.5% of the South African population [8]. It is therefore very likely that medical doctors will treat and manage people with disabilities, during their years of providing society with healthcare [3]. In other words, it is an undeniable reality that medical doctors need to be practicing disability inclusive healthcare. Therefore, in order to provide persons with disabilities, with healthcare equal to the healthcare which is afforded to rest of society (able-bodied people), medical doctors need to be equipped with sufficient knowledge and skills pertaining to disability practice. It is an inescapable fact that health disparities exist between persons with disabilities and the general (able-bodied) population [9].

In an attempt to address these disparities, The UN Convention for the Rights of People with Disabilities (UNCRPD) stressed the need for equality within healthcare in 2006 [10]. Sadly, the reality is that the vast majority of medical doctors receive very limited disability education [11, 3]. Medical doctors (who are typically able bodied) report that they often feel hampered by insufficient knowledge and skills relating to disability and are therefore unable

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to provide persons with disabilities with quality healthcare [3]. Medical students added their voices to this feeling of there being a knowledge and skills gap by describing a feeling of often being ill at ease with patients with disabilities [12]. Bowleg [13] reminds us that the contextual basis for all knowledge and understanding of disability must stem from people living with disabilities and not from how persons with disabilities deviate from "the norm" of able-bodied people. Labelling a human being as only disabled is reductionist and it disregards the full range of complexities of being human.

The above statement brings to mind the important issue of intersectionality. Johnson [9] reminds us that persons with disabilities identify with many other dimensions of being human over and above that of simply having a disability. Persons with disabilities may be of varied gender, race, socioeconomic, linguistic and geographical backgrounds. These characteristics intersect and can create further health disparities for persons with disabilities.

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 disabilities face. These barriers are firstly, a pervasive ignorance by society about disability and secondly, negative societal attitudes towards disabilities [6]. For healthcare to be truly equal and fully inclusive, we need to first address all the barriers (many which are created by society) facing persons with disabilities [14]. Therefore, in order to address these barriers, societal views and attitudes about disability need to be challenged. In the aspiration for equality, society needs to be encouraged to critically analyse and hopefully change the way that disability is seen by many.

Medical doctors among many other professionals are well placed within society to address these barriers. Campbell [3] noted, the manner in which medical doctors treat persons with disabilities, can be extremely influential on how society views disability. It's clear from this

last statement, that not only is it important that medical doctors know about disability, but that they know enough to ensure that persons with disabilities have a positive healthcare experience. Johnson [9] suggests that another reason persons with disabilities may have negative healthcare experiences is because of the fact that few persons with disabilities are employed as healthcare personnel. Medical doctors therefore have limited exposure to persons with disabilities in roles such as a colleague/peer or a manager. This limited exposure means that medical doctors' have little to no experience of persons with disabilities as their (medical doctors') equals or as functioning members of society. This lack of exposure may further perpetuate any preconceived notions medical doctors have with regards to persons with disabilities.

If medical doctors are to lead successfully by example and address the many societal barriers faced by persons with disabilities, the traditional medical model (which the majority of medical doctors use as the reference which underpins their clinical practice) needs reconceptualization. The focus of the medical model is very much on a person's impairment /health condition and on the curative or treatment options that medical interventions can offer. Before there is any further discussion about the medical model of disability, I want to differentiate between impairment and disability. These two words are often confused and used incorrectly. An impairment arises through the dysfunction of an organ or a system within the human body. A disability occurs when the impairment has a causal effect of limiting human body activity [15]. For example, the condition muscular dystrophy, has the effect of weakening muscles in the body (impairment), consequently activities such as walking and even talking become difficult (disability). In other words, 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.

Returning our attention to the medical model of disability, when there can be no more medical interventions, medical professionals tend to withdraw and the person with a disability is left on their as own to try and figure out their lives. Given the fact that many of the barriers facing persons with disabilities are societal ones, we can't only be asking, "what is wrong with the person with the disability and can medical interventions help?" We should also be asking, "What are the needs of the person with a disability?" (i.e. viewing the person with a disability holistically). The narrow focus of the medical model is very limiting to everyone (general society and persons with disabilities) because without addressing the second question we run the risk of relegating persons with disabilities to the side-lines of society [16]. The medical model tends to portray persons with disabilities as being dependent, weak and vulnerable. This portrayal perpetuates rather than challenges any preconceived negative values and beliefs that persons with disabilities and society at large may have. The medical model also gives the medical doctor (more often than not, a non-disabled person) the label of being the expert, with far better knowledge and understanding of disability than their patient (person with a disability). In other words, because they (medical doctors) are the expert, they know what is needed by a person with a disability and make the decisions in the doctor/patient relationship. The social model of disability on the other hand places the insider's (person with a disability) life experience as having an important contribution to make to our understanding of disability issues [17].

The social model of disability suggests that society is responsible for 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 model focusses more holistically on a person with a disability. It takes into consideration the needs that a person with a disability has, in order for such an individual to live as full a life as they

can. The social model of disability is preferred by persons with disabilities as well as disability activists, but the medical model of disability cannot be completely ignored. Medical care will always be needed but the values, beliefs and the approach of medical doctors need to change. It is my opinion that 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 disabilities. According to Shakespeare [18] placing all the focus and emphasis on the social model of disability, is as disabling to persons with disabilities as a focus on only the medical model is. Impairments resulting in disabilities arise from certain medical pathologies or dysfunctions in human physiology. No matter how much we desire it, we cannot simply employ a social modelist redefinition and wish the impairment away. Persons with disabilities need to 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 a distinct dichotomy between the medical and social models of disability. We need to instead ensure the harmonious existence of both models in society [18]. 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 the approach) such medical care is being delivered by medical doctors that is being challenged (by the social model) and needs to change.

It is therefore vital that medical doctors are fully educated and 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). This education will assist in ensuring that the different approaches to disability are both integrated into doctors' future medical practice with persons with disabilities. Medical students are society's future medical doctors which means it is very important that medical students are taught to

understand disability as being wider than just the health condition that lead to impairments [19]. The many different models and approaches to disability (medical, social, charity, human rights etc) are constantly being revised which challenges us to engage with disability in various ways. It is not the existence of the medical model of disability that needs challenging but its dominance, particularly in the realm of medicine.

Kessi [20] suggested that the education received (all around the world) at higher education institutes assists in the construction of the views and ideals held by society at large. It is clear that if we hope to achieve a more disability inclusive society, medical doctors need to be afforded adequate disability education by their higher education institutes (medical schools). Medical doctors are powerful professionals who form a significant part of societies workforce and it has already been stated that medical doctors' behaviour towards disability can influence societies behaviour. Therefore, by affording medical doctors a chance to interrogate and challenge widely held views and attitudes towards persons with disabilities, the way can be paved for the rest of society to examine their own thoughts and attitudes that they might have about disability.

Thomas [21] urges that we should be, and more importantly need to be, turning our focus towards elevating disability to a place alongside other world issues, such as sexism and racism. Disablism is explained as being a form of social oppression which involves the discrimination and societal exclusion of a person because of their impairment [19]. We must bear in mind though that the nature of oppression of any kind (e.g. between race groups, religious groups or disabled and non-disabled people), is intrinsically two-directional and dynamic [22]. The weight and responsibility of disablism does not therefore lie entirely with general society but with persons with disabilities too. Increased education about disability will allow us a better understanding of how best to address the issue of disablism.

Is there a recognised need for the inclusion of disability in medical curricula?

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 practice as a doctor. 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 practice disability inclusive medicine. Lastly my being a person with a disability has afforded me unique insights into health and disability. I began my medical training without a disability. I went on to graduate from medical school and then practice clinical medicine as a medical doctor with a disability. I have been both patient and doctor. This experience has taught me some invaluable lessons about disability and the importance of inclusivity, which I have used to shape my practice as a medical doctor. A better understanding of disability can therefore be a catalyst for curriculum change and review.

Pruitt & Epping-Jordan [23] claim that educating medical students by using the traditional hegemonic ways will be insufficient to ensure that graduates are equipped with the knowledge and skills which 21st century doctors need to adequately management and treat the patients of today. Frenk et al [1] add to this claim by describing the current undergraduate medical curriculum as antiquated and fragmentary. New medical discoveries are being made constantly. These new medical discoveries result in pressure being placed on the medical curriculum. As a result of this pressure, the curriculum needs to be under constant review. Sadly, medical education has not kept pace with medical advancements and the current medical challenges. This lag has resulted in medical school graduates who are unable to

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adequately meet the needs of both the population and the patients. These needs are not being met because of incongruent competencies. Thus, there is a world-wide move towards the development of competency-based curricula. This move by medical education towards the attainment of core competencies would prove very helpful in assisting graduates to meet the medical needs of patients in this new millennium [1]. Pillay & Kathard [24] 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. The global call for the redressing of the undergraduate medical curriculum is therefore sounding loud and clear. The inclusion of disability into the curriculum presents us with an opportunity to engage with a way to begin the reconceptualization of the undergraduate medical curriculum. Medical education has also not kept up with current political and societal challenges which have been brought about by the fact that disabled people have become more vocal about their position in society.

CONCLUSION:

This article has provided a number of arguments which advocate strongly for why disability should be included in the professional education of general practice medical doctors. Frenk et al [1] made perhaps the most compelling argument in saying that the medical doctors of today (the new millennium) are inadequately equipped to meet the current most pressing global health issue: chronic conditions. This is because the focus of medical education is still on acute conditions, which dominated the global health stage in the 20th century. Chronic

conditions share a close link with disability. The inclusion of disability into medical curricula would therefore encourage more focus on chronic conditions.

It does not feel enough to simply know about why disability should be included in medical education. Further investigation of the literature needs to be done, to explore if and how disability is being taught to medical students. Further research could help address how a competency-based curriculum facilitates disability inclusion in the education of the general practice medical doctors of today.

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