Inequities in Healthcare Provision Between Indigenous and non-Indigenous Australians

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Rare diseases (RD) are multi-systemic, complex conditions that cause disability and dysfunction. For 70% of RD, the signs and symptoms begin in childhood and continue throughout life. As such, specialist and ongoing care are often necessary in the management of RD.[1] To adequately address the inequities in healthcare provision for RD, meeting the needs of people from diverse backgrounds is pivotal. In Australia, there is a significant disparity in health outcomes between Aboriginal and Torres Strait Islander (hereafter respectfully referred to as Indigenous) people and non-Indigenous people.[2] Indigenous Australians represent 3% of the total population. It is estimated that 43,000-58,000 Indigenous Australians are living with a RD and as Indigenous populations have a younger age structure (median age is 21.6 years compared to 37 years for the Australian population as a whole), over a third of Indigenous people with RD will be children. Historically, and with a legacy that continues, Indigenous Australians face substantial challenges accessing healthcare in comparison to non-Indigenous people.[3] This essay offers a comparison of experiences between Indigenous and non-Indigenous populations and serves to highlight the inequities impeding the diagnosis and treatment of RD in Australia.

The diagnosis of RD is often referred to as an odyssey and if one is familiar with Homer's rendition, these journeys are long, arduous and riddled with obstacles. Compared to non-Indigenous Australians, Indigenous people face even greater barriers in seeking a diagnosis. To begin with, 65.2% of the Indigenous population live in remote or regional areas.[3] As some of these communities can be hundreds, if not hundreds of thousands, of kilometres from major cities, generalist healthcare is often provided by visiting doctors who may only attend every 3-6 weeks. In these settings, RD may be less likely to be recognised as the most urgent or acute conditions are prioritised.[4] Where the signs and symptoms of RD may be vague or subtle, presentation may be delayed. Moreover, as 80% of RD are genetic in origin, patients are likely to require access to clinical genetic services to diagnose their conditions.[3] Due to limited facilities outside of major cities and referral bias (lack of referral from general practitioners to

specialist services), Indigenous people face greater difficulties in accessing these services. Additionally, Indigenous genomic reference data is limited in size and representation so the benefit of genetic services is less likely to be experienced by Indigenous patients.[3]

Aside from the physical barriers that have been discussed, discriminatory behaviour and inherent biases in clinical practice extend diagnostic odysseys for Indigenous patients. In training, medical practitioners are taught, or develop, 'mental shortcuts' to diagnose and recognise patterns of diseases. These are usually related to defining traits or population-specific conditions. For example, medical students are taught to be suspicious of Ricket's disease in children with bow-legs even though there are many other reasons a child may present with this sign. Where this becomes problematic for Indigenous populations is when clinicians misdiagnose RD due to inherent biases in the recognition of diseases. A key example is Fetal Alcohol Spectrum Disorder (FASD). Due to the falsely-held belief that rates of alcohol consumption are higher in Indigenous populations, an Indigenous child may be misdiagnosed with FASD. Misdiagnosis may then inappropriately prevent further investigation into other signs and symptoms or genetic testing that may indicate RD. On a similar note, negative attitudes towards Indigenous people may hinder the insight and tenacity required to diagnose RD. In fact, 3 out of 4 Indigenous patients have reported experiencing race-based discrimination and healthcare practitioners have been found to be less proficient in their performance, deliver less information, and be less supportive of Indigenous patients.[5,6] Accordingly, a culmination of clinician behaviour and difficulties in accessing healthcare heightens barriers to diagnosis of RD in Indigenous Australians.

Upon diagnosis, RD patients are faced with the next part of their journey: treatment and management. Due to the nature of RD, multiple specialists and regular appointments are often required. A study conducted in Western Australia found that RD patients had, on average, 24% longer hospital stays and 110% more hospital discharges in comparison to the general population.[7] Although Australia has a universal healthcare system that is supported by the public sector, many procedures and services are only partially covered.[8] Accordingly, RD patients may be faced with higher healthcare costs.[7] However, Indigenous populations are disproportionately affected by cost factors as they are more likely to experience disadvantage across socioeconomic indicators (such as education, employment and income) and are more likely to live in rural areas where travel-related costs are very high and infrequent transport schedules make journeys long and inconvenient.[3, 9]

Aside from cost factors, the ongoing management of RD is complex and the co-ordination of various appointments and treatment plans prescribed by different clinicians is often left to the patient or primary carer. As such, patient adherence, understanding of procedures, and development of a strong therapeutic bond are significant aspects of care in RD. Indigenous people may face more difficulties in this respect due to a lack of culturally appropriate care – an area of unmet need in Australia's healthcare system. While there are many aspects to culturally appropriate care, the physical hospital environment and behaviour of clinicians are particularly relevant to RD management. Many Indigenous patients have described hospital and clinic environments as alienating; Indigenous men, in particular, have found the hospital regime and dependency disempowering.[6] This translates directly into patient outcomes as Indigenous patients are 6 times more likely to discharge themselves from hospital against medical advice.[2] A source of discomfort arises from hospital referrals that usually arise unexpectedly. In Indigenous culture, regions, referred to as countries, belong to different subsets of Indigenous people and travelling through country in a respectful and responsible way is important. Stepping into another country without being welcomed or invited may bring some uneasiness to Indigenous patients.[6] Building upon the previous point, country is a spiritual, physical, social and cultural concept that is central to Indigenous culture and encompasses the idea that there is an interdependent relationship between people and their ancestral lands. However, the importance of country is often ignored in a clinical setting thereby subjugating Indigenous values, attitudes, and beliefs to the hegemonic Western biomedical model at the expense of Indigenous people's health.[2] In this manner, ongoing management necessitated by RD is frequently rendered unpleasant and unsuitable.

As mentioned, clinician proficiency and behaviour contributes to the challenges faced by Indigenous Australians when accessing treatment. In the provision of culturally appropriate care, a lack of understanding of Indigenous patients' contextual and cultural backgrounds poses communication barriers.[6] Moreover, inadequate information and the use of jargon and technical terms means that patients leave without proper understanding of their treatment. Communication is pivotal to developing a strong therapeutic bond, encouraging adherence to therapy, understanding treatment risks and reducing patient anxiety – aspects that are central to the long-term care of RD. Without good communication, health-damaging behaviours persist and Indigenous patients may delay their attendance or be reluctant to continue treatment.[6]

Clearly, the diagnosis and treatment of RD are disproportionately hindered in the Indigenous population. We observe that the diagnostic odyssey is lengthened by lack of access to services and biases in clinical practice. Subsequently, treatment and management pose prohibitive cost factors and are impeded by a lack of culturally appropriate care. Addressing the inequities faced by Indigenous Australians comes hand in hand with improving care for RD. On the ground, healthcare providers may encourage change by rejecting normalised policies and practices that discriminate against Indigenous patients. Ergo, assessing the different experiences of Indigenous and non-Indigenous Australians serves to highlight inequities in the healthcare system and provide areas of focus to improve care for RD.

(Words: 1266)

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