

Review of: "The Plight of Rare Diseases in Southern Africa: Health and Social Services Policy Recommendations"

Helen W. Hernandez

Potential competing interests: No potential competing interests to declare.

This is an excellent paper describing the plight of individuals with rare diseases in sub-Saharan Africa as well as the current barriers that health systems have in supporting them.

The authors describe the need to cooperatively address those barriers and aligns that need with larger initiatives such as the push for universal health coverage and non-communicable diseases. I would suggest the authors take a little time to expand on the unique nature of rare disease through these specific lenses. For example, if ongoing efforts in UHC and NCD were tremendously successful in the next 2-5 years, persons living with rare diseases would still have remaining challenges. While these challenges are absolutely described in several places throughout the paper, an example or two from the rare diseases mentioned (e.g. Pompe, MPS, NMOSD) could be valuable to the readers to emphasize how things like diagnosis and access to information and care, including treatment, differ from the more common conditions that likely dominate the NCD conversation.

I'll add that, in terms of the specific recommendations, these authors seem to have thoroughly studied and considered what strategies have been implemented with success in other contexts and have incorporated them into their recommendations and I'm hopeful that their efforts are impactful for their community members and that lessons that come from this collaboration will be shared in future publications.

Qeios ID: AZTC7Y · https://doi.org/10.32388/AZTC7Y