DETERMINANTS OF MEDICATION ADHERENCE IN SICKLE CELL DISEASE USING THE WORLD HEALTH ORGANIZATION MODEL

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BACKGROUND

- Over 100,000 individuals in the United States are affected with sickle cell disease.
- Sickle cell disease has great prevalence among those with healthcare and healthcare information technology disparities.
- Many individuals with sickle cell disease have poor adherence to medications.
- In 2003, the World Health Organization (WHO) described a model that organized determinants of medication adherence into five interacting dimensions.
- There is limited data that explores the barriers and promoters of medication adherence in sickle cell disease, and none have analyzed these determinants in the context of the WHO model.

OBJECTIVES

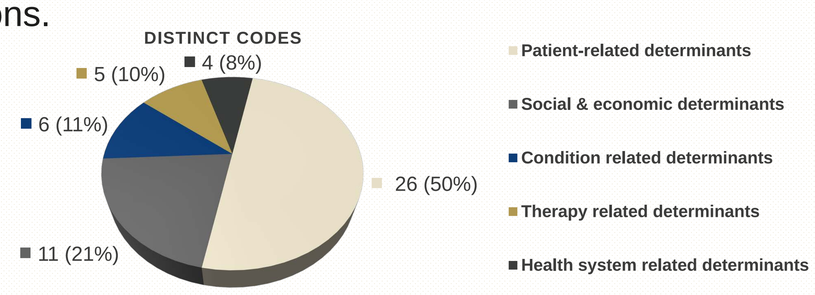
To identify determinants of medication adherence in patients with sickle cell disease using the World Health Organization Model.

METHODS

- Participants selected via convenience sampling from patients seen at outpatient clinics affiliated with the Vanderbilt-Meharry Center for Excellence in sickle cell disease.
- Demographic data collected through surveys.
- Semi-structured interviews conducted between September
- 2016 – July 2017. Interviews were audio recorded, transcribed, and analyzed using Dedoose Version 8.1.8.
- Analysis was done with an open coding grounded theory approach to discover barriers and promoters.
- These determinants were developed into a codebook to identify promoters and barriers of medication adherence.
- The WHO model was subsequently used to fit codes into the different categories of determinants.
- Codes were reviewed by two independent coders, and categorization done via consensus of three authors (KEO, CS, and RMC).

RESULTS

- Forty-six participants with sickle cell disease were interviewed, all participants carried a diagnosis of sickle cell disease.
- The median age was 28.5, and a majority were female (n=24). Most self-identified as Black or African American (n=42).
- Fifty distinct codes were applied with 38 barriers, and 14 promoters.
- Twenty-six were categorized into patient-related determinants.
- Eleven social & economic determinants.
- Six condition related determinants.
- Five therapy related determinants.
- Four health system related determinants.
- Several codes fit multiple dimensions, such as *sense of responsibility* – a barrier in younger ages, but a promoter in older ages, and *stigma*, both a barrier and promoter, and categorized into both social/economic and patient related dimensions.



"… but you got to risk someone stealing the medication…They can see prescription bottles and they don't have time to read them so they stick everything, you know..."

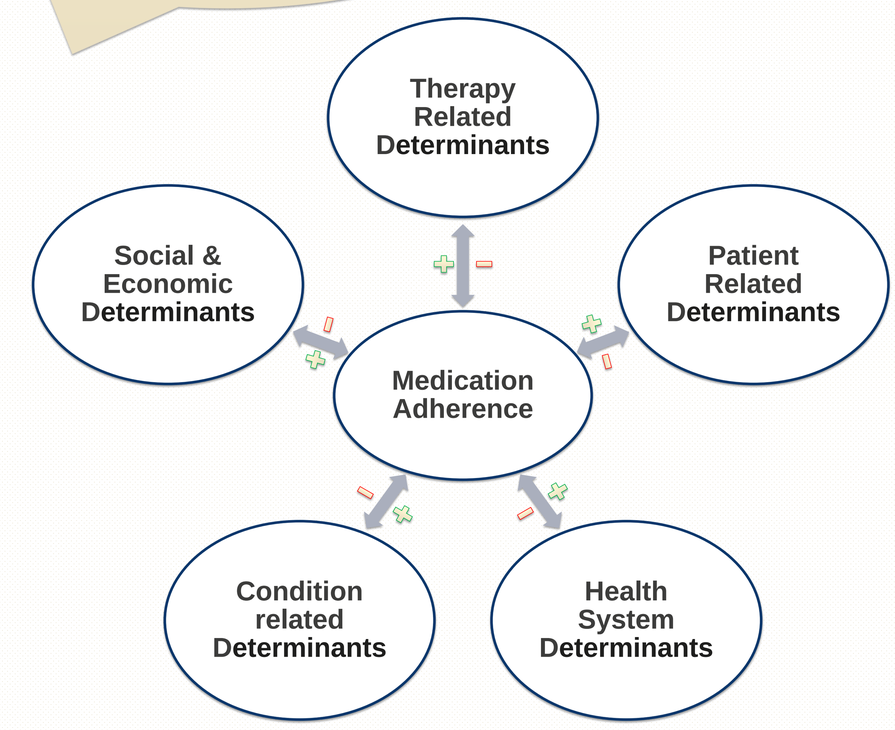
Social & Economic Determinants – Theft

Patient Related Determinants – Responsibility

I just have to take the meds…I just have to do what I can do while I'm here…I have a good life. I have a nice house, nice car, I work hard... That's why I take my meds everyday. I got a lot to live for."

"If you have a certain time you're supposed to take it then that's probably during school then some people might ask, "Why you have to take this?"… Then you kind of like not want to explain or just don't want everybody to know…"

Patient Related Determinants / Social & Economic Determinants - Stigma



CONCLUSIONS

- Most determinants were patient-related in nature, and about half came from other dimensions, showing the multi-dimensional nature of medication adherence in sickle cell disease.
- We also discovered unique determinants in this population, such as the barrier of medication theft.
- Limitations to this study include being performed at a single center with a convenience sampling method of individuals from clinic – this may have led to lack of generalizability and selection bias.
- Using the WHO framework to understand medication adherence determinants in sickle cell disease, a disease affecting those with healthcare and healthcare information technology disparities, can provide input to personal and system informatics solutions that could cross the digital divide.

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