

# EXAMINING THE PREVALENCE OF CHRONIC DISEASE AMONG INFORMAL CARERS TO AIDS-AFFECTED ORPHANS IN KWAZULU-NATAL

JESSICA CASIMIR

I had the opportunity to travel to Nairobi, Kenya in March 2017 to attend at the Africa Health Agenda International Conference, one of the largest public health gatherings on the continent, in which I presented a systematic review on renal disease and dialysis rationing in South Africa. To continue my initial project, I conducted preliminary fieldwork for my dissertation proposal in the summer of 2017. I was fortunate to receive funding from the Center of African Studies for both these research-related trips. I was situated in Durban for three months to explore the difficulties and obstacles of managing the co-morbidity of HIV/AIDS and renal disease (HIV-associated nephropathy). Additionally, I wanted to examine the role of their caregivers in patient adherence and health outcomes. Shortly following my arrival to Durban, informal interviews and conversations with medical professionals and researchers revealed that due to the socioeconomic climate, many South Africans with HIV-associated nephropathy were often in the advanced stages of AIDS such that conducting a qualitative project would be unfeasible and ethically questionable.

My justification for selecting Durban as the primary research hub for this project is due to the current state of the HIV/AIDS epidemic in South Africa. The KwaZulu-Natal province has the highest prevalence of HIV/AIDS in the country at nearly 26% compared to the national percentage of 18.9%. Much of the epidemic is concentrated in low-income areas such as townships, informal settlements, and rural expanses with poor infrastructure; in these vicinities of KZN, the prevalence can range from 40% to 60%. Due to being at the epicenter of the disease, Durban is known as an international hub for global health in which there are a multitude of resources directed on combating HIV/AIDS such as research institutes, academic conferences,



prevention campaigns, activist communities, and NGOs.

Due to the vibrant public health community, I received the opportunity to volunteer at the Hillcrest AIDS Centre Trust, a HIV/AIDS clinic that provides a plethora of services and resources to the Valley of a Thousand Hills, a peri-urban/rural area outside of Durban. One of their hallmark programs, the Granny Support Groups, became of great interest to me. Presently, there are an estimated 3.7 million orphans in South Africa, half of whom have lost one or both parents to AIDS with thousands of grandmothers (*gogos*) becoming the primary carers of their grandchildren. Due to a plethora of social problems, they fail to become recognized as legal guardians, hence preventing them from receiving vital resources from the government. To alleviate many of the day-to-day struggles that many of these carers experience, 58 support groups have been installed throughout the Valley of a Thousand Hills. I was tasked to undertake the data analysis of a programme

assessment survey from 2016. From the findings, the data reported that one of the greatest benefits of the program was that the participants observed the reversal of chronic disease, such as hypertension and diabetes. These findings have allowed me to explore a facet of informal caregiving that I had not originally examined. I am interested in further exploring: How does the caregiver strain and burden affect the prevalence and management of chronic disease among older women in KwaZulu-Natal, South Africa? I intend to return to Durban in the fall of 2018 for twelve months to conduct the data collection phase for my dissertation project.

*Jessica Casimir is a McKnight Doctoral Fellow in the Department of Sociology and Criminology where she is pursuing her PhD in medical sociology. Her project is funded by the Florida Education Fund, the Center for African Studies, the Office of Research, and the Office of Graduate Diversity Initiatives.*