Chronic care experiences and practices in Ghanaian Transnational Families in Ottawa, Canada and Ghana: assessing need and developing practical interventions

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Background

Individuals living with chronic illnesses and family members providing care for chronically ill relatives navigate complex challenges.

Chronic illness disrupts the body and life trajectory, and individuals must make sense of these disruptions and develop practical responses to them over a lifetime. The disruptions include medical, psychological, financial, livelihood, social and spiritual dimensions, and these often intersect in complex ways.

Caregivers also experience similar disruptions and navigate the same challenges. When care is needed, and provided, across national borders these challenges deepen for all concerned.

Take for instance Valerie[1], a professional woman in her forties, married with children, living with her family in London, but having to care for her elderly mother in Accra who is recovering from a stroke and has early stage Parkinson's Disease. Valerie has the finances to pay for local medical care in Accra, and for a live-in carer, although the cost of care increases exponentially each year. But she monitors her mother's daily care needs (feeding, cleaning, leisure) from afar and she worries about intermittent crises that occur with her mother's conditions. She also has to deal with additional family dynamics of siblings and relatives in Ghana and elsewhere who offer conflicting medical and life advice that might undermine her mother's wellbeing. Valerie lives with the daily stress of caring for her mother, as well as the stress of caring for her own family and for herself. She struggles with sleep and her mental health.

There are several stories like Valerie's circulating in Ghanaian diaspora communities in Europe and North America. In many families, adult caregivers also have health conditions of their own, or develop serious health conditions as a result of caregiving. Emerging research on chronic illness and care in African diaspora communities is aligned with these Ghanaian experiences (see de-Graft Aikins et al, 2023). This speaks to a growing crisis of care in transnational African families.

The aim of this study is to gather empirical evidence on chronic care experiences, practices and challenges in Ghanaian transnational families and to use the evidence to develop practical interventions for families with care needs. The focus is on Ghanaian families living between Ghana, UK, USA and Canada, who are affected by chronic physical and mental health conditions.

In the UK, data has already been gathered in London as part of the British Academy funded *Chronicity and Care in African Contexts* Project, which is led by Professor Ama de-Graft Aikins. The methodology of the London Study, which focused on chronic care experiences and practices among Londoners of West African heritage, will inform the US and Canadian studies.

In Canada, we aim to conduct a pilot study in Ottawa, where Dr Yaa Amankwah, the study co-investigator, lives and practices as an Obstetrician-Gynaecologist in the Division of General Obstetrics

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[1] Based on an amalgamation of case studies from the *Chronicity and Care in African Contexts* Project.

and Gynaecology at the Ottawa Hospital, and where she offers professional advice and support to the Ghanaian Association of Ottawa.

Methods

The study will focus on experiences of a wide range of chronic physical conditions. In London, we have interviewed individuals living with, or caring for relatives living with, diabetes, hypertension, post-stroke conditions, sickle cell disease, multiple sclerosis, motor neurone disease, mental health conditions and reproductive health conditions. We hope to replicate the same comprehensive approach in Ottawa.

We will gather data from:

a) primary caregivers (living in Ottawa) who are caring for individuals living with chronic conditions in Ghana (any city or town);
b) the care recipient in Ghana; and
c) secondary caregivers or individuals who form part of the broader support system of caregivers and care recipients (in Ottawa or Ghana). The support system can include healthcare professionals providing treatment services at the time of data collection, or relatives and friends providing social care (e.g church members providing psychosocial or financial support).

At the pilot stage we will aim to focus on a maximum of 10 family case studies. Case studies will include the three sets of participants outlined above. For example a family case study might include one Ottawa resident (of Ghanaian heritage) who is a caregiver, a Ghanaian resident who is a care recipient, and one or two participants based in Ottawa or Ghana who provide healthcare or social care. Other family case studies may have more participants, based on the unique set of care circumstances in the life of the initial caregiver who is recruited.

Data will be gathered through individual interviews, dyadic interviews (individual with a chronic condition and caregiver) and group discussion (when the numbers are too large for small scale conversations). We will use a blend of narrative and semi-structured interviewing approaches.

All interviews will be recorded, transcribed and analysed. Transcripts and analysis will be shared and discussed with participants through dissemination events, prior to the development of interventions and preparation for academic publications.

The *Chronicity and Care in African Contexts* Project has ethical approval from University College London and University of Ghana. We will seek local consent from the Ghanaian Association of Ottawa to recruit Association members, as well as from other local Ghanaian organisations. All participants will complete and sign consent forms that will protect them, the study team and the local organisations from research harms. Interviews will be held at locations of participants choosing and each participant will be given a store voucher worth CAD$50 to compensate for their time.

Results and Applications

This study has intervention and research goals. From the intervention end, we want to create a practical resource for families in need of information and support, whether they are in Canada or Ghana. The study will answer practical questions on how to make sense of the growing prevalence of chronic conditions in Ghanaian communities at home and abroad, what services exist for chronically ill individuals in Ghana, the cost of services, how to access services, and how to manage the psychosocial stresses that come with lived experiences and caregiving. Other forms of practical support will emerge through insights from the Ottawa pilot study.

From the research end, we want to contribute to the literature on healthcare and social care in African diaspora communities (see de-Graft Aikins et al al, 2023), and to the development of healthcare policies in the UK, US and Canada that include the needs of African diaspora communities.

Timelines

- **June 2023**: Pilot data collection in Ottawa (12th – 20th) and Ghana (19th – 30th)
- **September 2023**: Dissemination of initial findings to research participants (Hybrid events in Ottawa and Accra)
- **October 2023**: Study report to be shared; Resource platform to be created on the Chronicity Care Africa website (www.chronicitycareafrica.com) and social media accounts (Facebook, Instagram, Twitter, LinkedIn); Helpline to be established.
- **November - December 2023**: Preparation of academic papers.

Reference

de-Graft Aikins, A., Sanuade, O.A., Baatiema, L., Adjaye-Gbewonyo, K., Addo, J., Agyemang, C. (2023). How chronic conditions are understood, experienced and managed within African communities in Europe, North America and Australia: a synthesis of qualitative studies. *PLoS ONE* 18(2): e0277325.