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POSITION PAPER

Community and Informal Care Providers at the Heart of Universal Health Coverage in sub-Saharan Africa: A Position Paper

Ephraim Kisangala[1,2], Etheldreda Leinyuy Mbivnjo[3], Bernard Ojiambo Okeah[4], Mohammed Azhar Khan[5]

[1] African Centre for Systematic Reviews and Knowledge Translation, College of Health Sciences, Makerere University (African Centre MaKCHS) P.O. Box 7072 Kampala, Uganda; ephraim-kis@gmail.com;

[2] Kairos Hospital, P.O. Box 7573 Kampala, Uganda;

[3] Biaka University Institute of Buea, P.O. Box 77 Buea, Cameroon; metheldreda@gmail.com;
[4] School of Healthcare Sciences, Bangor University, LL57 2EF Gwynedd, United Kingdom; bernardokeah@gmail.com;
[5] Dr. M A Khan Dental Practice, Unit B, 10 Barnard Road, Sherwood, Durban 4091, South Africa; mazhar015@gmail.com;

Corresponding Author: Ephraim Kisangala;
Address: African Centre for Systematic Reviews and Knowledge Translation, College of Health Sciences, Makerere University (African Centre MaKCHS) P.O. Box 7072 Kampala, Uganda;
Email: ephraimkis@gmail.com;

Abstract

Globally, increased demand on often scarce healthcare resources and those challenges incumbent in responding to the coexistence of infectious and non-communicable diseases warrant the need to address persistent health inequities. Understanding the complex intersectionality of vulnerability and reaching those in most critical need of healthcare lies at the heart of fostering and sustaining resilient healthcare systems. Harnessing the long-recognised value of Community and Informal Care Providers (CICPs) is instrumental to Universal Health Coverage (UHC). The present COVID-19 context serves as a poignant example of where access to formal healthcare services by many has become increasingly difficult. Here, the value of informal or volunteer-led health services has been a lifeline for many. For several decades, formal reportage has evidenced the established role of CICPs, particularly across Sub-Saharan Africa with quantifiable efficacy across a number of domains, such as, maternal and child health, neglected tropical disease prevention, tuberculosis care and malaria control. CICPs have been sustainable and effective as a conduit between the formal and informal health sectors, and between health facilities and the remotest of communities. Maximising the function of CICPs relies on socio-culturally, geographically sensitive, and bespoke support; psychosocial, practical, and logistical capacitation coupled with situationally and culturally appropriate monitoring and evaluation. The Astana Declaration highlights the centrality of building on existing knowledge, insight and resource. We therefore argue that CICPs are indispensable in Africa's move towards UHC, and hold promise for acceptable, accessible, affordable, and quality healthcare to everyone who needs to get, be and stay healthy**.**

Keywords: Community Health Workers, Informal Caregivers, Universal Health Coverage, sub-Saharan Africa

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Background

Africa's life expectancy is 11 years below global mean levels (1), and hosts three countries (Central African Republic, Lesotho, and Swaziland) with the least life expectancy at birth (<50 years) between 2010 and 2015. In West Africa, the life expectancy at 60 years is 14.1 years for men and 14.7 years for women (2). Sub-Saharan Africa is now facing a dual burden of non-communicable and communicable diseases with an age-standardised disability-adjusted life-years (DALYs) of 21 757·7 per 100,000 population for non-communicable diseases which is comparable to that of communicable, maternal, neonatal and nutritional disorders combined (26 491·6 DALYs) in 2017, highlighting the need for health systems to address these changing tides (3). Managing non-communicable diseases is costly, and poses additional threats for African healthcare systems that have relied heavily on donors and the private sector for healthcare financing while the share of health in public funds is comparatively small (4,5). In addition, out-of-pocket expenditure has put 1.14 billion people below the poverty line, Africa has the poorest access to essential quality health services in the world (1) with inefficient information systems and health inequalities (6) amidst poor governance and inadequate human resources for health (7). Good health and wellbeing is a pre-requisite, measure and consequence of sustainable development, making its universal and equitable access an absolute necessity (6). Consequently, the World Health Organisation (WHO) has established the triple billion agenda with Universal Health Coverage (UHC) for one billion additional individuals by 2023 as one of its targets (8). This comes as a reinforcement to the Tokyo Declaration on UHC (9) and the Astana Declaration on primary health care as the gateway to UHC(10). Also, the Harmonisation for Health in Africa initiative has been revisited and a package for essential healthcare services established to drive the move towards UHC in the African region (1). The Astana Declaration is committed to training, recruiting and retaining health personnel including those providing primary care in the most rural/remote areas with special attention to developing countries (10) which reiterates Community Health Workers' (CHWs) pivotal role in UHC (11). More so, the WHO has developed guidelines to enhance CHW programme design, implementation, performance and evaluation by member states and partners to support the strive towards UHC as a fundamental pillar for achieving the Sustainable Development Goals (SDGs) (12). CHWs are generalist or specialist (13,14) paid or unpaid lay and paraprofessionals who provide culturally acceptable care to communities in which they live and have undergone short standardised training (15). Closely related to them are informal helping or social support networks (family, friends, neighbours, natural helpers, role-related helpers, people with same problems and volunteers) who willingly offer unpaid services and people naturally turn to them for help (16), creating a near balance in care demand and supply. In this position paper, CHWs and informal helping networks will be collectively referred to as Community and Informal Care Providers (CICPs) and excludes medicine sellers identified as informal providers by some studies (17). These CICPs have been in use since the mid twentieth century (13,16) and have proven their worth in the ongoing coronavirus pandemic (18,19). In addition, the Kampala Statement notes the contribution of CHWs to Sustainable Development Goals (SDGs) 1, 2, 3, 5, 6, 10 and 17 (20). Furthermore, SDG 4 is promoted by training/educat-

ing CHWs (13,15), and the relationship between the third SDG (good health and well-being) and all other sixteen SDGs (6), demonstrates CHWs crucial role in both UHC and sustainable development (See Figure 1 and Figure 2 below). Thus, UHC provides a critical linchpin without which attaining the United Nation's health-related agenda may remain elusive. We therefore argue that with appropriate support, monitoring and evaluation, CICPs are indispensable in Africa's move towards UHC and hold promise for acceptable, accessible, affordable, and quality healthcare to everyone who needs to get, be and stay healthy.

Figure 1: CICPs drive sustainable development by ensuring UHC

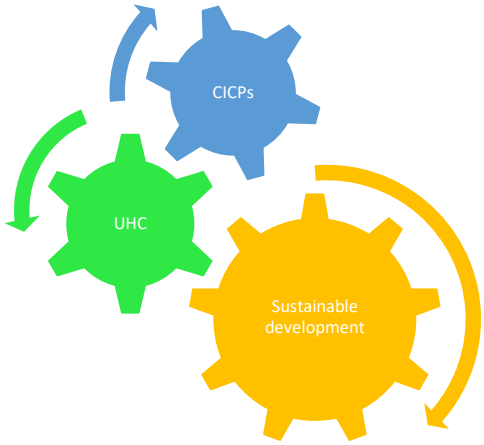

Figure 2: Community and Informal Care Providers (CICPs) at the Heart of Good Health and Well-being (Adapted from the WHO Health in the SDG Era Infographic)

CICPs in accelerating UHC

Health systems in sub-Saharan Africa are grossly underfunded and this has a huge limitation on the extent to which health services are made available to citizens (20). Besides, the available health services may not be easily accessible due to barriers partly occasioned by socio-political contexts. CICPs can potentially expand the reach of healthcare services in hard to reach areas thereby immensely improving UHC. One area that has greatly benefited from the invaluable work of CICPs is HIV management services. Evidence from a multi-country study published by the Community Action Network (CAN) conducted in Ethiopia, Malawi, Zambia, and South Africa revealed how CICPs continue to improve access to universal counselling and testing as well as scaling up anti-retroviral therapy (21). The research further showed that CICPs were actively involved in mobilizing communities for HIV prevention services and providing HIV testing in some instances. Moreover, the CICPs are instrumental in promoting the health-seeking behaviour of communities thus contributing to the uptake of HIV related services such as prevention of mother to child transmission (PMTCT) (21). Other potential areas for the application of CICPs include providing support to HIV patients and directly observed treatment (DOT) for HIV and Tuberculosis. In Uganda, CICPs have been utilized in the provision of home-based care for children living with HIV (22). Although some have argued that CICPs lack the knowledge and skills to deliver quality healthcare services, pre-deployment training and continuous supportive supervision with remote digital support may help bridge this gap. CICPs play a role in the long-term management of chronic illnesses including non-communicable diseases (NCDs). A South African based study recorded the roles undertaken by CICPs (informal caregivers) and the challenges they face while looking after advanced cancer patients in end of life care (23). In such instances, the work undertaken by CICPs complements palliative care services provided by hospices. Undoubtedly, end of life care can be very challenging and distressful even to the best qualified professionals, hence, the need to provide relevant support including stress management services for CICPs undertaking such roles. Some countries lack organized palliative care services, hence, the vital role of CICPs who are the main service providers as evidenced by a Ghanaian study that explored the motivations and experiences for family caregivers for advanced breast cancer patients (24). Delivering essential healthcare services is often complicated in emergency situations including disasters and other catastrophic events. More often, there is limited access to life-saving interventions by extremely vulnerable populations considering the delays as emergency responders undertake risk assessments before accessing the affected persons. A recent publication on the COVID-19 emergency response actions highlighted on the utilization of CICPs through informal networks to bolster local response to a serious health problem in informal settlements namely the Kibera slums in Kenya (25). Specifically, the CICPs have played an immense role in promoting sanitation, contact tracing, and initiating isolation measures for suspected cases. Additional examples of the application of CICPs in emergency response includes the Ebola virus epidemics in West Africa and the DRC where they mobilized community adherence to

basic infection prevention measures including sanitation precautions (26). A distinct advantage is the use of CICPs in populations suffering from the ravages of war or natural disasters such as the Democratic Republic of Congo and Somalia. Notably, CICPs have been used successfully to undertake screening for cardiovascular disease in war tone countries like Syria and Yemen (27); this has potential application in warring African states. This versatility proves that CICPs have a great utility in supporting health systems that are under pressure. In such circumstances, CICPs have the potential to make an enormous difference as first-line responders and coordinating with external responders through rapid exchange of actionable data (28). This reduces the cost of emergency response since the CICPs are already within the emergency situation and may take prompt actions when provided with relevant support. Another successful example of the enormous potential of the CICPs in emergency response applicable to African settings is the Vietnamese village health collaborators who extend the reach of services beyond the formal health system (29). Established in 1999 through a ministerial directive, this informal workforce has sustainably contributed to the betterment of key health indicators in addition to accelerating UHC. During the prevailing COVID-19 crisis, Vietnam remains one of the countries with the lowest number of cases (268 cumulative cases, 216 recoveries, and no deaths as at Jun 2020). Although Vietnam has a limited capacity for massive testing, the CICPs (village health workers) have been instrumental in surveillance, detection of cases at the grassroots, and effecting quarantine measures. The mountainous nature of Vietnam renders most of the country inaccessible, hence, the vital role of the informal health workforce that resides within the community and has a better contextual understanding. In addition to providing a readily available workforce deployable in emergency situations, CICPs also provide health education, hygiene and sanitation, food safety, disease prevention, maternal and child health, first aid, family planning, and implementing health programs. As such, the work undertaken by the CICPs has an immense impact on UHC and could be potentially augmented through additional capacity building and support. CICPs within the informal networks also have the potential to support the health of the elderly population that continues to grow rapidly in sub-Saharan Africa from approximately 46 million to 165 million by 2050 according to WHO estimates (30). Family members and friends constitute part of the informal social networks with the potential for improving health outcomes for the elderly particularly when empowered and accorded the relevant support from the formal health sector. CICPs have also shown much promise in the provision of rehabilitative services including traumatic brain injury (31). This potentially takes the caring burden off the formal healthcare workers as family and informal networks step in to support the rehabilitation of their loved ones. A Nigerian based study also shows how CICPs have been relied upon to provide rehabilitative services to children with cerebral palsy (32). Though not widely acknowledged, the formal healthcare system equally utilizes CICPs in meeting the care needs of hospitalised patients. More than often, family and friends provide additional care including nutrition, promoting patient hygiene, and providing ongoing psychosocial support to the hospitalized patients. For instance, a recent publication shows how CICPs provided informal care to stroke patients admitted in an acute Nigerian hospital (33). Despite the availability of organised health services, utilisation

may be influenced by the complexities of socio-cultural context. The intersectionality of gender dynamics, belief systems and perceptions of health care and of health professionals are notable factors (34). Uptake of existing healthcare services is fundamental in achieving the UHC agenda, hence, the need for considerations to overcome any potential barriers. However, the formal healthcare system is already overburdened and has limited capacity to navigate all the socio-cultural barriers limiting service utilization. CICPs provide a unique workforce residing within the same social environment. In the context of marginalized communities, CICPs are capable of providing socio-culturally acceptable and accessible healthcare services thus promoting good health and well-being. CICPs have been successfully utilized in bridging health disparities as observed in a study where CICPs provided parent-child interaction therapy (PCIT) to treat development conduct disorders amongst Latino families (35). With relevant support and training, the CICPs were able to overcome social-cultural barriers by virtue of their unique positioning and effectively delivered the PCIT to families that required it (36). There is a marked difference between the type of care provided by the formal healthcare workers and CICP's. CICPs provide a more personal level of care due to their closeness to the individuals under their care. Care is directed appropriately since CICP's have an intimate knowledge of the patient's circumstances (37). The utility of CICPs is equally evident in improving access to health promotion interventions that rely on informal networks in promoting health behaviour change. This is exemplified in the "Health works for women" intervention where work-based natural helpers influenced women to adopt positive health behaviours namely smoking cessation, healthy eating, physical activity, and cervical screening (38). Notable is the relevant training and information materials given to the natural helpers involved in this intervention. Informal networks provide a suitable environment for individuals to continuously discuss their health concerns with CICPs freely and obtain relevant advice. Unlike in the formal healthcare system, people tend to trust their friends and peers more than a healthcare worker they have met for the first time. Studies of sexual and reproductive health amongst adolescents in Uganda, found that young people approached CICPs about contraception and sexually transmitted diseases (STDs) since they had a longer relationship with them that was built on trust and confidentiality (39). Evidence has shown that gender differences may pose a challenge to accessing healthcare services thus undermining the ultimate goal of UHC. A recent study on social support and informal health networks reported a tendency for inclination towards one's gender when seeking social support (40). Mental health services also utilize CICPs for continuity of services outside the formal healthcare systems. Despite facing many challenges, CICPs have provided care to persons with severe mental disease in Ghana (41), a country with limited capacity for mental health services. Another study on alternative mental health services described the vital role played by churches in promoting the mental well-being of their members (42). Persons in need of mental health support tend to easily trust service providers from their socio-ethnic context. As such, it is much easier to establish a therapeutic relationship and this could significantly impact on the treatment outcomes as chronicled in "the role of the black church in the south" study (42). This is also supported by another study which demonstrated how natural helpers bridged health disparities amongst minority African American men

(43). Informal care providers could also provide psychological support following traumatic events. This was the case following the September 11 terrorist attack where a significant number of people shared their traumatic

experiences with hairdressers, librarians, and bartenders (44). CICPs are also critical in the management and prevention of NTDs through a series of activities including mass drug administration, health education and providing feedback on the side effects experienced by the community members (45). Even in civil unrest, CICPs continue to deliver care and worthy of note is the malaria testing and treatment programme during 6 years of war in the Central African Republic (46). In integrated community case management of childhood illnesses, CICPs have provided essential treatment for diarrhoea, pneumonia and malaria in remote areas of Uganda (47)and the cost evaluation of such interventions by CHWs in South Africa showed that they can be funded from domestic health budgets (48) thereby reducing the risk of economic hardship resulting from large out-of-pocket expenditures. CICPs are also very instrumental in the early diagnosis of cervical cancer (49) a growing health challenge in Africa (2).

Criticisms and counterarguments

Discussions on whether or not to integrate CICPs as part of the formal healthcare delivery system remain inconclusive with protagonists highlighting some perceived challenges. Several cases have been highlighted in mainstream media whereby CICPs masquerade as trained healthcare professionals providing substandard services and often soliciting payments for poor quality services. This may also be compounded by the weak law enforcement mechanisms in sub-Saharan Africa and endemic corruption that endangers the health of the unsuspecting public. It's also been argued that CICPs lack the capacity to self-regulate as professionals and often align themselves with multiple programmes provided, they earn a stipend, and this potentially compromises their effetivness as well as the set standards in care delivery. In addition, the dynamics in urban populations may make it impossible for CICPs to fulfil their primary objectives. However, these challenges can be overcome through the establishment of the necessary regulatory structures to govern the capacity building of CICPs, integration into the formal healthcare services, their practice, and other professional bottlenecks. CICPs may occasionally feel overburdened and distressed to meet the high demands on their constantly changing roles. In addition, their lack of training prior to assuming their roles further complicates their functioning and may undermine the quality of care they provide. However, it is possible to provide the CICPs with additional support and training either remotely or through organised formal learning activities. The CICPs also gain knowledge and experiences through caring which are transferrable as they continue to support other members of their social networks with similar health needs undoubtedly relieving pressure from the formal health systems. Involving CICPs in providing mental health support services has also been criticised due to the risk of suffering compassion fatigue specifically following prolonged exposure to traumatic accounts (50) in addition to the stresses that come with this role (51). However, this can be overcome by creating the relevant psychosocial support systems for CICPs to cater for their mental health needs. Additionally, providing appropriate links to the formal healthcare system could make the CICPs more effective especially when required to

escalate the care of patients requiring specialized treatments. It is important to note that informal care givers quickly transition into their roles often requiring huge adjustments that may include discontinuing school, and changing or giving up formal employment. The mental pressure associated with these sudden adjustments may overwhelm some caregivers and render them helpless (23,30,52–54). Consequently, providing vital support including training of the CICPs helps minimize any potential distress and make them more effective in their inevitable roles (55). Although family caregiving has some therapeutic effects on the caregiver (56), looking after deteriorating patients may increase their stress levels (52) which in turn disrupts the harmonious functioning of the CICP's family (57). Informal caregivers also bear huge economic burdens due to the lack of compensation, additional expenses they incur to look after loved ones, and the opportunity costs for getting formal employment or running a business (53,58–60). Another criticism for utilizing CICPs is linked to the challenges associated with the recruitment and retention of this critical workforce into the formal healthcare services. A high attrition rate of the CICPs has always characterized programs utilizing this approach. In some instances, resentment and lack of trust have led to the alienation of CICPs. However, it is possible to overcome these challenges by carefully tailoring the CICPs recruitment and deployment. As suggested by evidence from a Ugandan based study (61), applying the natural helper model can potentially bolster the community's trust and cooperation with informal care providers. The burdens faced by CICPs may also be overcome by adapting gender identities and enhancing generational social exchange as highlighted by a review on the care working dynamics within the complexities of widespread HIV infections and fragmented families in the east and south African regions (62).

Conclusion

Healthcare systems in sub-Saharan Africa face enormous challenges that could potentially slow the attainment of UHC. The constantly changing needs for sub-Saharan Africa's population specifically the ballooning elderly population, acute healthcare worker shortages, widespread epidemics, and poorly equipped healthcare systems increases the need to further strengthen and expand her health workforce. Notably, the acute shortage of healthcare workers significantly limits access to essential healthcare services. This calls for an urgent need to innovatively diversify and extend the reach of healthcare workers. CICPs offer potential promise and can improve access to existing healthcare services by complementing the formal healthcare system. This is based on evidence of their application across different services, for example, HIV management, mental health, emergency response, rehabilitative services, chronic diseases, malaria and end of life care. Undoubtedly, the demands on CICPs have continued to rise with increasing life expectancy making their utility ineffective (63). Despite the highlighted shortcomings, remote assistance including psychological support for CICPs can potentially improve the community's health competence, which proves invaluable in varied circumstances beyond the reach of formal health services and accelerate UHC. Having considered the different points of view regarding this subject, our position on integrating and capacitating CICPs as part of the formal healthcare to accelerate UHC remains the best option!

References

1. World Health Organization. The work of the World Health Organization in the African region. 2019
2. United Nations Department of Economic and Social Affairs Population Division. World Mortality Report 2015. 2017.
3. Gouda HN, Charlson F, Sorsdahl K, Ahmadzada S, Ferrari AJ, Erskine H, et al. Burden of non-communicable diseases in sub-Saharan Africa, 1990–2017: results from the Global Burden of Disease Study 2017. Lancet Glob Heal. 2019 Oct;7(10):e1375–87.
4. Piatti-Fünfkirchen M, Lindelow M, Yoo K. What Are Governments Spending on Health in East and Southern Africa? Heal Syst Reform. 2018 Oct;4(4):284–99.
5. World Health Organisation. Global Spending on Health: A World in Transition. 2019.
6. Acharya S, Lin V, Dhingra N. The role of health in achieving the sustainable development goals. Vol. 96, Bulletin of the World Health Organization. World Health Organization; 2018.
7. Oleribe OE, Momoh J, Uzochukwu BS, Mbofana F, Adebiyi A, Barbera T, et al. Identifying Key Challenges Facing Healthcare Systems In Africa And Potential Solutions. Int J Gen Med. 2019 Nov;Volume 12:395–403.
8. World Health Organisation. Thirteenth General Programme of Work (GPW13) Methods for Impact Measurement. 2020.
9. World Health Organization. Tokyo declaration on universal health coverage: All together to accelerate progress towards UHC. Universal Health Coverage Forum 2017. 2017.
10. WHO; UNICEF. Declaration of Astana. Glob Conf Prim Heal Care. 2018;2893–4.
11. Tulenko K, Møgedal S, Afzal MM, Frymus D, Oshin A, Pate M, et al. Community health workers for universal health-care coverage: from fragmentation to synergy. Bull World Health Organ. 2013;91(11):847–52.
12. Cometto G, Ford N, Pfaffman-Zambruni J, Akl EA, Lehmann U, McPake B, et al. Health policy and system support to optimise community health worker programmes: an abridged WHO guideline. Lancet Glob Heal [Internet]. 2018 Dec;6(12):e1397–404. Available from: https://linkinghub.elsevier.com/retrieve/pii/S2214109X18304820
13. Lehmann U, Sanders D. Community health workers: What do we know about them? 2007.
14. Koon AD, Goudge J, Norris SA. A review of generalist and specialist community health workers for delivering adolescent health services in sub-Saharan Africa. Vol. 11, Human Resources for Health. BioMed Central; 2013. p. 54.
15. Olaniran A, Smith H, Unkels R, Bar-Zeev S, van den Broek N. Who is a community health worker? - A systematic review of definitions [Internet]. Vol. 10, Global Health Action. Co-Action Publishing; 2017 [cited 2021 Feb 11]. p. 1272223. Available from: https://www.tandfonline.com/doi/full

/10.1080/16549716.2017.1272223
16. DiClemente RJ, Crosby RA, Kegler MC. Emerging theories in health promotion practice and research : strategies for improving public health. First Edit. San Francisco: Jossey-Bass; 2002. 414 p.
17. Sudhinaraset M, Ingram M, Lofthouse HK, Montagu D. What Is the Role of Informal Healthcare Providers in Developing Countries? A Systematic Review. PLoS One. 2013 Feb;8(2):54978.
18. Chan EYY, Gobat N, Kim JH, Newnham EA, Huang Z, Hung H, et al. Informal home care providers: the forgotten health-care workers during the COVID-19 pandemic. Vol. 395, The Lancet. Lancet Publishing Group; 2020. p. 1957.
19. Ballard M, Bancroft E, Nesbit J, Johnson A, Holeman I, Foth J, et al. Prioritising the role of community health workers in the COVID-19 response. BMJ Glob Heal. 2020;5(6):1–7.
20. Maher D. 'Leaving no-one behind': how community health workers can contribute to achieving the Sustainable Development Goals. Public Heal Action. 2017 Jul;7(1):5–5.
21. Community Action Network. Community caregivers: the backborne for accessible care and support. 2013.
22. Osafo J, Knizek BL, Mugisha J, Kinyanda E. The experiences of caregivers of children living with HIV and AIDS in Uganda: A qualitative study. Global Health. 2017 Sep 12;13(1).
23. O'Neil DS, Prigerson HG, Mmoledi K, Sobekwa M, Ratshikana-moloko M, Tsitsi JM, et al. Informal Caregiver Challenges for Advanced Cancer Patients during End-of-Life Care in Johannesburg, South Africa and Distinctions Based on Place of Death. J Pain Symptom Manag. 2019;56(1):98–106.
24. Kusi G, Mensah ABB, Mensah KB, Dzomeku VM, Apiribu F, Duodu PA. Caregiving motivations and experiences among family caregivers of patients living with advanced breast cancer in Ghana. PLoS One. 2020;15(3).
25. Wilkinson A, Ali H, Bedford J, Boonyabancha S, Connolly C, Conteh A, et al. Local response in health emergencies: key considerations for addressing the COVID-19 pandemic in informal urban settlements. Environ Urban [Internet]. 2020 [cited 2020 Aug 1]; Available from: www.sagepublications.com
26. Marais F, Minkler M, Gibson N, Mwau B, Mehtar S, Ogunsola F, et al. A community-engaged infection prevention and control approach to Ebola. In: Health Promotion International [Internet]. 2016 [cited 2020 Aug 9]. p. 440–9. Available from: https://academic.oup.com/heapro/article/31/2/440/1750493
27. Honein-Abouhaidar G, Noubani A, El Arnaout N, Ismail S, Nimer H, Menassa M, et al. Informal healthcare provision in Lebanon: An adaptive mechanism among displaced Syrian health professionals in a protracted crisis. Confl Health. 2019 Aug 28;13(1).
28. Wistow J, Dominelli L, Oven K, Dunn C, Curtis S. The role of formal

and informal networks in supporting older people's care during extreme weather events. Policy Polit [Internet]. 2015 [cited 2020 Aug 2];43(1):119–35. Available from: https://www.ingentaconnect.com/content/tpp/pap/2015/00000043/00000001/art00007

29. Tran BX, Phan HT, Thi Nguyen TP, Hoang MT, Vu GT, Le HT, et al. Reaching further by village health collaborators: The informal health taskforce of Vietnam for COVID-19 responses [Internet]. Vol. 10, Journal of Global Health. 2020 [cited 2020 Aug 1]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7242882/
30. Aboderin I, Geneva JE-J-WHO, Switzerland U, 2017 U. Towards long-term care systems in sub-Saharan Africa. 2017;
31. McIntyre M, Ehrlich C, Kendall E. Informal care management after traumatic brain injury: perspectives on informal carer workload and capacity. Disabil Rehabil. 2020 Mar 12;42(6):754–62.
32. Olagunju TJ, Fatudimu MB, Hamzat TK. Clinical-Demographic Variables and Compliance with Home Programme among Nigerian Informal Caregivers of Children with Cerebral Palsy. Med J Zambia [Internet]. 2017 [cited 2020 Aug 9];44(3):157-165–165. Available from: https://www.ajol.info/index.php/mjz/article/view/168181
33. Akosile CO, Banjo TO, Okoye EC, Ibikunle PO, Odole AC. Informal caregiving burden and perceived social support in an acute stroke care facility. Health Qual Life Outcomes. 2018 Apr 5;16(1).
34. Mathivet B, Kutzin J. Free health care policies: opportunities and risks for moving towards UHC. Geneva World Heal Organ [Internet]. 2017 [cited 2020 Aug 2];(2). Available from: https://apps.who.int/iris/rest/bitstreams/1085211/retrieve
35. Barnett ML, Davis EM, Callejas LM, White J V., Acevedo-Polakovich ID, Niec LN, et al. The development and evaluation of a natural helpers' training program to increase the engagement of urban, Latina/o families in parent-child interaction therapy. Child Youth Serv Rev [Internet]. 2016 [cited 2020 Aug 2];65:17–25. Available from: https://www.sciencedirect.com/science/article/pii/S0190740916300871?casa_token=EoEP6RzpNf0AAAAA:mrY1D-LZQlKofLnmDVvQgL8NQND0Jg__AUk2SmG0k8A8T13LsGTdzq6MY4_UIq3E1PITkAi1q94
36. Acevedo-Polakovich ID, Niec LN, Barnett ML, Bell KM, Aguilar G, Vilca J, et al. Exploring the role of natural helpers in efforts to address disparities for children with conduct problems. Child Youth Serv Rev [Internet]. 2014 [cited 2020 Aug 2];40:1–5. Available from: https://www.sciencedirect.com/science/article/pii/S0190740914000474?casa_token=MhgB9xwQsAQAAAA:Bv0H4sHKHSpREnXytNKaJJDv_eKN3w4mctmJSqZ12GFJeomY5h29YOmVvLQB7KU_JiYkkZVpZO8
37. Riedel M, Kraus M. Informal Care Provision in Europe: Regulation and Profile of Providers. ENEPRI Research Report No. 96, November

2011 [Internet]. 2011 [cited 2020 Aug 10]. Available from: www.ceps.eu
38. Tessaro IA, Taylor S, Belton L, Campbell MK, Benedict S, Kelsey K, et al. Adapting a natural (lay) helpers model of change for worksite health promotion for women. Health Educ Res [Internet]. 2000 Oct [cited 2019 Jul 7];15(5):603–14. Available from: https://academic.oup.com/her/article-abstract/15/5/603/639482
39. Stark L, Landis D, Thomson B, Potts A. Navigating support, resilience, and care: Exploring the impact of informal social networks on the rehabilitation and care of young female survivors of sexual violence in Northern Uganda. Peace Confl [Internet]. 2016 [cited 2020 Aug 10];22(3):217–25. Available from: https://psycnet.apa.org/record/2016-38187-004
40. Rodríguez-Madrid MN, Del Río-Lozano M, Fernandez-Peña R, Jiménez-Pernett J, García-Mochón L, Lupiañez-Castillo A, et al. Gender differences in social support received by informal caregivers: A personal network analysis approach. Int J Environ Res Public Health [Internet]. 2019 [cited 2020 Aug 2];16(1). Available from: www.mdpi.com/journal/ijerph
41. Ae-Ngibise KA, Doku VCK, Asante KP, Owusu-Agyei S. The experience of caregivers of people living with serious mental disorders: A study from rural Ghana. Glob Health Action [Internet]. 2015 [cited 2020 Aug 9];8(1). Available from: http://dx.doi.org/10.3402/gha.v8.26957
42. Blank MB, Mahmood M, Fox JC, Guterbock T. Alternative mental health services: The role of the Black church in the South. Am J Public Health. 2002 Oct 1;92(10):1668–72.
43. Scott TN. Utilization of the Natural Helper Model in Health Promotion Targeting African American Men. J Holist Nurs [Internet]. 2009 [cited 2020 Aug 2];27(4):282–92. Available from: http://jhn.sagepub.com
44. Lieberman D, II JM, Wissow L, Powers R. Natural Helpers After The Terrorist Attacks Of September 11. 2010 [cited 2020 Aug 2]; Available from: http://www.webmedcentral.co.uk/article_view/1181
45. Omedo MO, Matey EJ, Awiti A, Ogutu M, Alaii J, Karanja DMS, et al. Community health workers' experiences and perspectives on mass drug administration for schistosomiasis control in Western Kenya: The SCORE project. Am J Trop Med Hyg [Internet]. 2012;87(6):1065–72. Available from: https://www.ajtmh.org/downloadpdf/journals/tpmd/87/6/article-p1065.xml
46. Ruckstuhl L, Lengeler C, Moyen JM, Garro H, Allan R. Malaria case management by community health workers in the Central African Republic from 2009-2014: Overcoming challenges of access and instability due to conflict. Malar J. 2017;16(1):1–10.
47. Brenner JL, Barigye C, Maling S, Kabakyenga J, Nettel-Aguirre A, Buchner D, et al. Where there is no doctor: Can volunteer community

health workers in rural Uganda provide integrated community case management? Afr Health Sci [Internet]. 2017;17(1):237–46. Available from: https://www.ajol.info/index.php/ahs/article/view/156383/145995

48. Nkonki LL, Chola LL, Tugendhaft AA, Hofman KK. Modelling the cost of community interventions to reduce child mortality in South Africa using the Lives Saved Tool (LiST). BMJ Open. 2017 Aug;7(8):e011425.
49. Awolude OA, Oyerinde SO, Akinyerni JO. Screen and Triage by Community Extension Workers to Facilitate Screen and Treat: Task-Sharing Strategy to Achieve Universal Coverage for Cervical Cancer Screening in Nigeria. J Glob Oncol. 2018 Jul;4.
50. Coetzee SK, Klopper HC. Compassion fatigue within nursing practice: A concept analysis. Nurs Heal Sci. 2010 Jun;12(2):235–43.
51. Dechman MK. Peer helpers' struggles to care for "others" who inject drugs. Int J Drug Policy [Internet]. 2015 [cited 2020 Aug 2];26(5):492–500. Available from: https://www.sciencedirect.com/science/article/pii/S095539591500002X
52. Oyegbile YO, Brysiewicz P. Exploring caregiver burden experienced by family caregivers of patients with End-Stage Renal Disease in Nigeria. Int J Africa Nurs Sci. 2017;7(June 2016):136–43.
53. Kipp W, Tindyebwa D, Rubaale T, Karamagi E, Bajenja E. Family Caregivers in Rural Uganda : The Hidden Reality. Health Care Women Int. 2007 Nov;28(10):856–71.
54. Moore AR, Vosvick M, Amey FK. Stress, social support and depression in informal caregivers to people with HIV/AIDS in Lomé, Togo. Int J Sociol Soc Policy. 2006 Jan 1;26(1–2):63–73.
55. Mason N, Hodgkin S. Preparedness for caregiving: A phenomenological study of the experiences of rural Australian family palliative carers. Health Soc Care Community. 2019 Jul;27(4):926–35.
56. Mthembu TG, Brown Z, Cupido A, Razack G, Wassung D. Family caregivers ' perceptions and experiences regarding caring for older adults with chronic diseases. South African J Occup Ther. 2016;46(1):83–8.
57. Iseselo MK, Kajula L, Yahya-Malima KI. The psychosocial problems of families caring for relatives with mental illnesses and their coping strategies: A qualitative urban based study in Dar es Salaam, Tanzania. BMC Psychiatry. 2016 Dec;16(1):146.
58. Nortey ST, Aryeetey GC, Aikins M, Amendah D, Nonvignon J. Economic burden of family caregiving for elderly population in southern Ghana : the case of a peri-urban district. Int J Equity Health. 2017;1–9.
59. Addo R, Agyemang SA, Tozan Y, Nonvignon J. Economic burden of caregiving for persons with severe mental illness in sub-Saharan Africa: A systematic review. PLoS One. 2018 Aug 1;13(8).
60. Moore AR, Henry D. Experiences of older informal caregivers to people with HIV/ AIDS in LOME, TOGO. Ageing Int. 2005;30(2):147–66.

61. Turinawe EB, Rwemisisi JT, Musinguzi LK, de Groot M, Muhangi D, de Vries DH, et al. Selection and performance of village health teams (VHTs) in Uganda: Lessons from the natural helper model of health promotion. Hum Resour Health [Internet]. 2015 Dec 7 [cited 2019 Jul 7];13(1):73. Available from: http://human-resources-health.biomedcentral.com/articles/10.1186/s12960-015-0074-7
62. Schatz E, Seeley J. Gender, ageing and carework in East and Southern Africa: A review. Glob Public Health. 2015 Nov 26;10(10):1185–200.
63. Keating N, Otfinowski P, Wenger C, Fast J, Derksen L. Understanding the caring capacity of informal networks of frail seniors: A case for care networks. Ageing Soc [Internet]. 2003 [cited 2020 Aug 2];23(1):115–27. Available from: https://www.researchgate.net/publication/231948157