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Introduction

Selenia Marabello, *Samuel Ntewusu*

Since 2013, renewed Italian interest in Africa has produced a number of initiatives involving different economic and cultural sectors as well as conferences: examples include the conference on migration and development in 2023 and, most recently, the Italy-Africa political summit in 2024. The new Italian partnership with several different African countries addresses historical, economic and geo-political connections in which Africa, especially the northern part, is treated as an enlarged Mediterranean Sea. Euro-African relations have been focusing on economic issues such as energy, business development and, in particular, migration control. Indeed, as Gaibazzi and Bellagamba (2017) underline, borders between Europe and Africa are being renegotiated as the European Union externalizes border control and "offshores" the management of migration.

In this complex setting – where multiple Italian governments have considered Africa a strategic partner – several initiatives have paved the way for renewed institutional cooperation at the university level. Such cooperation revolves around a plan for sharing knowledge and teaching among European and African universities in relation to global challenges and "science diplomacy".

At the end of 2023, the Italian Ministry of Research launched a specific internationalization programme across Italy and the African continent, in the framework of Italy's National Recovery and Resilience Plan (PNRR). This programme, supported by European Union Next Generation EU funding, was addressed

with various strands to the Global South, including South America.

The University of Parma, in partnership with six other Italian universities[1] and thirty-seven African universities and institutions across sixteen countries[2], submitted the proposal *Academic Collaboration through Higher International Education for a Viable and Equitable Africa with Italy*, acronym ACHIEVE-IT. The project formally began in October 2024 and was completed in May 2026, granting less than two years to organize multiple forms of research mobility and teaching initiatives designed to strengthen long-term academic and scientific cooperation between Italy and African countries. In particular, the project aimed to promote a more equitable and reciprocal partnership model by fostering students and faculty exchanges as well as collaborative research and creating Advanced Skills Programs (ASP), international summer schools, and joint Master's and PhD programs.

Despite the ambitious intentions, project management struggled in pursuing the objectives due to timing issues, increasingly restrictive mobility policies and intense bureaucratization. Nonetheless, by navigating the uncertainty and difficulties of the project, participants were able to consolidate several partnerships and establish others. ACHIEVE -IT has been characterized by interdisciplinarity woven together by some key shared topics such as public health, sustainable agriculture and food security, energy poverty, urban and environmental planning, digital innovation, and social and gender inclusion.

In this plan, the Department of Studies on Language and Culture at the University of Modena and Reggio Emilia established a new partnership with the Institute of African Studies at the University of Ghana, thereby giving both departments the opportunity for short-term stay abroad. Students from both institutions thus had the chance to study in a different academic

[1] University of Modena and Reggio Emilia, University of Ferrara, University of Bologna, University of Salento, Università Cattolica del Sacro Cuore (Piacenza campus), and "Mediterranea" University of Reggio Calabria.

[2] Algeria, Burundi, Cameroon, Cape Verde, Democratic Republic of Congo, Egypt, Ethiopia, Ghana, Kenya, Mozambique, Niger, Rwanda, South Africa, Senegal, Tanzania, and Tunisia.

environment or embark for the first time on fieldwork with the intent of gaining practical experience. In the same manner, researchers and scholars also visited partner universities to evaluate the potential for future joint research.

This book, one of the results[3] of this incipient cooperation among the Unimore group of anthropologists and the Institute of African Studies[4], proposes a collection of essays organized into three sections: the first on the digitalization of land and identity, the second on gender relations and feminist anthropology, and the last on HIV stigma and epidemics. The three sections, based on empirical data collected by the authors through their personal research pathways, raise theoretical and methodological questions in anthropology and the social sciences. While focusing on Ghana, they also engage with larger cultural frameworks such as digitalization as land identification (Narh and Doumbia) and citizenship (Cutolo), gendered knowledge and power (Gribaldo, Atobrah and Pellecchia), and disease management at the micro and macro level (Kwansa, Atobrah, and Pellecchia). By intertwining Ghana and Liberia, Ivory Coast as well as Italy and Myanmar, this ethnographic gaze allows readers to consider cultural, economic and historical processes in specific localities and nations through a multi-level perspective.

Across multiple domains – identity systems, land, epidemics, intimate violence, and cancer care – the chapters show how technocratic or moral narratives (efficiency, inclusion, heroism, family-as-safety-net, voice) can flatten social complexity, mask structural drivers, and shift the burden onto those who are already disempowered. The analyses featured in the volume engage with

[3] Seminars, podcasts, and videos are available on the website of the Laboratory of Ethnology and Anthropology at the University of Modena and Reggio Emilia, the entity in charge of supervising overall project dissemination. For more information: https://www.labetno.unimore.it/achieveit/.

[4] A collaboration between anthropologists in the Master's in Anthropology and History of the Contemporary World at the University of Modena and Reggio Emilia and colleagues at the Institute of African Studies at the University of Ghana. We wish to express our gratitude to Kojo Amanor and Stefano Boni, two colleagues who have been involved in the project and have given us the concrete opportunity to launch it.

and raise larger questions about how people navigate historical legacy of inequality, new practices of social identity, and growing political resentment at the global level.

Employing ethnography[5] as a shared research method, the authors' various triangulations and combinations of data reveal how technocracy, social stigma and disease management impact people's daily lives and the relationship between individuals, state institutions, and access to care. From different perspectives (Atobrah and Gribaldo), the chapters explore how important ethical concern and dilemmas around health are for discerning and understanding the debates on anthropology and feminism. At the same time, they offer an opportunity for further and deeper reflections on methodological choices: to recalibrate proximity, listen to the silences of fieldwork, and prioritize subjects and patients. A powerful echo of ethnographic dilemmas involving the politics of care and the state reverberates across the six studies comprising this volume. Although gender is implicit in the first two chapters, gendered tensions and observations run through all the essays analysing how kinship relations and social identities reproduce gender norms and codes. Furthermore, in the last section, gendered relations and structural power asymmetries are analysed in the light of epidemics by examining socio-political determinants and moral economies of kinship as crucial re/producers of social stigma. In this written dialogue between Kwansa and Pellecchia, stigma – explored through social sciences and medical literature – is shifted from the individual to organization level to show how humanitarian interventions mirror, contain, and cope with social stigma in epidemic breakouts.

Social meanings as well as state and public health objectives and policies are presented in relation to the tactics and practices of HIV and infectious disease patients so as to foreground the

[5] Some of the methodological reflections were informed by the discussions held in the seminars organized as part of the UNIMORE FAR Department project 2025 PI S. Boni. We thank our colleagues, students, and all participants.

«politics of care» (Mol 2008). Atobrah analyses care practices and cultural representations affecting cancer patients, particularly women, by drawing on the Ga social and family scenario of non-communicable disease. As she argues in her chapter, «while family care-giving continues to serve as an essential and foundational support system for cancer patients in Ghana, ethnographic evidence reveals critical imperfections, shortfalls, and ethical ambiguities that challenge the idealized image of the African family as an inherently perfect caregiving institution». Such interventions are usually shaped by multiple factors including inadequate medical facilities, limited medical staff, the practical fact that an individual's illness is often also the concern of the family or kin, and lastly health system governance. Health systems, which should be considered a critical resource for national development, have not received the kind of attention they deserve despite the fact that health and development are intimately linked. This interlinking can be observed in Africa but also several other contexts where economic plans and austerity policies have deeply affected health system and re-organized solidarity nets and the actors of care (Cabot 2016; Douzina-Bakalaki 2021).

Kwansa's article takes kinship, a very classical topic for anthropology in African societies and beyond, and highlights its plasticity (Carsten 2000, 2004) as a way of showing how we might guarantee rights to HIV patients. This ethnography foregrounds relatedness to deconstruct the representation of family as a safety net. In relation to HIV and coping with stigma across borders, there are corresponding interpretations between Kwansa's ethnography and Marabello's work in Italy[6] with the Ghanaian diaspora. Despite being frequently romanticized, family ties are not necessarily a safe place for the patient: migrant women within transnational family networks often keep silent about their pregnancy and delivery until their newborns have been HIV tested to as to obtain a medical certification of healthy status and lack of mother-to-child

[6] One of the authors, Selenia Marabello.

viral transmission, thereby practicing what can be defined a «21-month pregnancy» (Marabello & Parisi 2018, p. 121).

Extending the analysis of the social dimension of the body and groups to different research foci, Cutolo as well as Narh and Doumbia delve more deeply into digitalization as both these essays navigate the notion of citizenship: the individual citizen body and the social citizenship of land administration. Worldwide developments in biometrics and digitalization are not only a lucrative global affair but also a key conceptualization of individuals and property in contemporary neoliberal societies. While Cutolo demonstrates how the relationship between individual body and social identity is remoulded, Narh and Doumbia extend research into the way land digitalization is reconceptualizing social ties and people's link with the land and environment. In as far as land digitalization is considered a critical way of ensuring access, this process entails equally deep-seated challenges in Ghana as well. Apart from the technical difficulties, social and ethnic groups have voiced alarm at this trend and indicated their unpreparedness for digitalization. They are specifically concerned because a similar policy stance adopted in the past served to trigger current conflicts, including several conflicts around land that seem to have been generated in part by earlier forms of documentation in some parts of Ghana.

Chapters ethnographically investigate global issues in Ghana and Ivory Coast to understand how local social contexts and people navigate and react to digital economy initiatives and policies, how they appropriate and define ideas of the self and property, and how new individual identities are moulded by state and supra-national organizations such as the World Bank. Biometrics is considered an effective tool for monitoring and regulating migration flows as well as an efficient way to allocate resources, in both cases related to capital and mobility. While these identification strategies and technologies are currently appearing in digital forms, their roots can be re-traced to a genealogy of institutional surveillance and control beginning in the colonial period. Following this line of reasoning, Banégas and Cutolo

(2025) argue that Africa, today as much as during colonial times, is a sort of experimental laboratory for new personal identification technologies. As such, it represents a good object for thinking about how technological infrastructures impact social relations, social identity, and local areas.

In this sense, contemporary Africa has the power to shed light on other contexts and global processes[7].

It is not a new idea that, except for scholars doing research, travelling and living in Africa, the Western gaze has long orientalized this continent (Said 1978) and invented it (Mudimbe 2007) as the primitive "Other". Reverberations of such orientalization sometimes also be felt in international and interdisciplinary projects such as the one just concluded – they appear almost in the backbones of the project (management constraints and rules on participating universities, etc). This concise volume is the outcome of collaboration. Within the short lifetime of the project, participants sought to gain an understanding of critical issues by more or less "throwing a stone" in the river of knowledge and thereby questioning land, gender, health, and social changes so as to shed light on contemporary neoliberal societies.

Can African history and anthropology generate an innovative perspective on the political frictions emerging in the neoliberal era? How can the Global South's feminism and decolonial understanding of cultural dynamics contribute to the emancipation of imaginaries, politics and knowledge? How and why are knowledge infrastructures, knowledge transmission, and institutions such as universities embroiled in contemporary public debates? These questions serve as a road map for anthropologists and researchers to interrogate current and future political and social plans and their effects on the ground.

[7] This was the main topic of the international conference *Africa as context, Africa as method* held at the University of Modena and Reggio Emilia on 21 May 2026, organized by an international scientific committee. We wish to thank the entire scientific committee and all the speakers for sharing their questions and research data. In alphabetical order: K. Ampofo, J. F. Bayart, A. Cutolo, F. Declich, K. Pallaver, C. Pennacini, P. Schirripa, C. Tornimbeni, and V. Fusari.

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I. Towards a social foundation of land administration digitalisation in Ghana

Peter Narh, *Lamine Doumbia*

1. Introduction

This chapter addresses the question of what relationship and synergies digitalisation of land administration in Ghana creates and fosters between formal institutions and customary landowning communities. Specifically, the chapter identifies ways digitalisation of land administration intersects with communal principles in land ownership, access, and use in Ghana. It suggests that digitalisation in its current neoliberal approach and form disconnects from and weakens control by and benefits to customary landowning communities over their lands. The premise of these authors is that inclusive digitalisation from the community level supports these customary landowning communities to, in partnership with the state, better define, control, and evaluate their lands for their enhanced benefits. Digitalisation as a key reform of land administration in Ghana is underway, with the establishment of land registers holding digitised land transaction records, adoption of digital gadgets and techniques, and streamlining procedures for easier client access to land registration services. Customary landownership norms in Ghana are based on communal usufruct principle of inalienable ownership, access, and use rights. However, this communal principle has existed with and is gradually weakened by liberal regimes of land administration and governance. The digitalisation of land administration is one such liberal reforms that can be defined as procedural and distributional strategies to enhance the efficiency of land access beyond the communal ownership of customary people.

Digitalisation as a strategic approach to land administration transcends digitizing records to include the use of digital gadgets, manuals, and procedures in the design and implementation of all aspects of land transactions and registration processes between land acquirers and the country's Lands Commission. Digitising records is thus a component of the broader process of digitalisation. A core component of Ghana's digitalisation land administration reform is the goal of gradual implementation of the Enterprise Land Information System (ELIS). The ELIS system seeks to authenticate and digitise all land records and administrative procedures at the Lands Commission across the country. Though digitalisation faces key capacity, administrative, and logistic challenges (Owusu Ansah et al. 2024), the process is relatively advanced in the declared land registration districts of Accra, which is the national capital, and in Kumasi the Ashanti regional capital and second largest city in Ghana with its peri-urban areas. While these digitalising resources require high investments, which many communities are unable to afford, an inclusive reform framework should translate digitalisation into benefits for customary landowning communities.

2. Contrasting social control and liberal values in land governance and administration

The relationship between customary and state land administration regimes in West Africa is complex and mostly conflictive. Contested control over land and land administration are key features (Chauveau et al. 2006). Often, formal state land administration reforms are framed within liberal logic, displacing community collective principles and benefits in land. As a result, land governance and administration are frequently associated with conflicts and tensions. The relationship between customary and state regimes of land administration thus lacks synergy and convergence. The concurrent effects of these dual regimes complicate

the relationship between communities and land investors across the region (Ibrahim et al. 2020; Kansanga et al. 2019). State institutions with mandates to manage and register lands exist alongside customary land allocation institutions with little harmony in land allocation and administration (Chauveau et al. 2006).

Across Africa, land administration reforms, which prioritise efficient land acquisition and registration processes have resulted in investors' control over customary land, environmental degradation in agriculture, and contested relationships between investors and community people (Narh 2021; Koch et al. 2019). Despite the negative consequences for landowning communities, these land acquisitions are often legitimised by state legal procedures (Ahmed et al. 2019; Narh 2024). Inequality and social deprivation resulting from land dispossession occur through a combination of state regimes and selfish interpretation of customary norms against communal social principles. These principles though are characterised by challenges guarantee majority of people access to customary land. In this regard, the challenge of land administration and governance has been ways to reconcile and harmonise different legal regimes over land to minimise conflicts, tensions, and power struggles (Delville 2007).

Despite the emphasis on adherence to formal legal procedures to supposedly provide for efficiency in land disposition and acquisition, conflicts and contentions over land acquisition persist within landowning groups, and between these groups and land investors. This is largely due to the failure of legal and distributional approaches in land administration reform to connect with social and cultural values in customary land. For example, Debonne et al. (2021) note economic interests of land investors often exert considerable control over the values and interests of customary landowning communities. The infiltration of customary land management by investors and state regimes through agricultural and agribusiness investments have marginalised landowning people from their lands (Stamm 2009). In essence, land governance and administration reforms in Africa continue to face the

challenge of synergy with communal resource norms of communities. Currently, neoliberal land administration reforms like digitalisation, which encourage land acquisitions and investments in lands disconnect from socioegalitarian principles. DePuy et al. (2022) and Sullivan (2017) caution that land is not merely a resource to be harnessed for economic gain for profit. It can also be developed in a way that minimises disruption to equalitarian ontologies and epistemologies of landowning communities (Ibrahim et al. 2020). Accordingly, to mitigate land alienation from landowning communities, this chapter emphasises the development of frameworks of inclusive regimes for customary landowning communities to be central actors in digitalisation of their lands for their enhanced benefits.

3. Neoliberal digitalisation in Ghana

Digitalisation in Ghana is supported by the Land Act, 2020 (Act 1036). Historically, land is allocated by both the state, which controls approximately 20 percent of all lands, and the customary landowning communities that own about 80 percent. State and customary land administration however are not mutually exclusive. For instance, on the one hand, urbanisation has resulted in extensive allocation of customary land to urban development and managed by the state in core areas. This may reduce the direct control of customary landowners over land in urban areas. On the other hand, recent agitations for lands acquired by the state but remained unused for their original purposes to be returned to their customary owners could reduce the extent of land in effective state control. These dynamics in customary and state land control demonstrate the intersection of customary land administration with that of the state. Yet, land digitalisation at present is not harmonised with customary land administration.

Land allocation is transacted and documented with various informal and formal lease and tenancy documents at various

degrees of formality. The country adopted and practiced the Land Deeds Registration System from the colonial era. Under the Lands Registration Ordinance of 1883 and the Land Registry Ordinance of 1895, all land transaction documents were to be recorded at the national and regional deeds offices. In the post-colonial era, the 1962 Land Registry Act (1962) Act 122 was passed to continue the registration of deeds. However, title registration districts were formed in 1986 through the Land Title Registration Law 1986 (Act 152) and the Land Title Regulation (1986) L.I. 1241. These made it obligatory to register land acquisition for title with the Lands Commission through its regional offices. This has continued to date, sustained further by the Land Act, 2020 (Act 1036) and presently manifesting in the digitalisation with ELIS.

Digitalisation is grounded in the logic of efficiency, denoting minimisation of time, labour, costs, and conflicts in land transactions. This efficiency logic seeks to promote a liberal land market, effective land use management, and supposedly the derivation of more value from land for development (Owusu Ansah et al. 2024; Deyaaso 2025; Amadi-Echendu 2021). The Lands Commission uses technologies including block chain, high resolution scanners, advanced GIS systems and software, mobile phones, and modern internet of things. With these tools, land transactions and registration would be conducted and authenticated electronically, fast, and simultaneously by all parties for instance using block-chains. Digitalisation thus seeks to reduce fraud, conflicts, and complications. This should enhance transparency and efficiency in formalised land service delivery to the public (Abab et al. 2023). The reform is expected to digitise most of the processes involved in land transaction and title registration at the Lands Commission. Theoretically, the entire processes of land transaction and title registration is supposed to be captured in the digitalisation reform. Yet, many of the steps involved face persistent challenges (Owusu Ansah et al. 2024). These challenges include duplications in records, lack of adequate staff capacity

and client awareness to implement the reform, and lack of coordination among divisions of the Commission such as the Client Service Access Unit (CSAU), Public and Vested Land Management Division (PVLMD), Survey and Mapping division (SMD), Land Valuation Division (LVD), and Land Registration Division (LRD), (Owusu Ansah et al. 2024).

Across Africa, digital resources have been employed in many natural resources systems, offering tangible resource management and sustainability benefits. For instance, digitalisation has been a prominent development goal in agriculture (Mazwane 2022), and in wildlife (Fergus et al. 2023). However, the reform has been plagued by contestations, especially with regards to marginalising local people from their lands in favour of external liberal market-oriented interests. That digitalisation offers land administration efficiency benefits is not in doubt. So far, the literature shows that land administration through digitalisation from below can be highly beneficial to landowning communities, the state, and investors.

Heimann et al. (2025) shows for South Africa that locally adapted digital empowerment programs are important and capable of developing the capacities of communities, their voices and expertise towards the stewardship of their lands in partnership with the state to derive maximum benefits. In Rwanda, Mihigo et al. (2025) find that local authorities in Rwanda's land administration digitalisation have been instrumental in supporting state officials of the National Land Authority to identify precise land boundaries and resolve any land disputes before land is digitally recorded. This synergy minimises conflicts between recorded land data and the actual situation on the ground (Mihigo et al. 2025). Luyombya and Obbo (2013) had found that digitisation in Uganda delivered efficiency in land administration, facilitating development. In Ethiopia, digitalisation has been useful for smallholders who use land as collateral for credit, where most people in urban and rural areas hold not more than two hectares of land (Abab et al. 2023; Deyaaso 2025). In that country's

context, potential marginalisation of local people over their lands is minimised through participatory approaches to land administration that support security of land tenure for smallholders (Gebrihet & Pillay 2021). Indeed, Ethiopia's case shows that when local participation is accompanied with power to decide and implement their own land use goals, participation in the process of land use planning and digitalisation enhances the value of land to communities.

Drawing on the East African experiences, land administration reforms in synergy with customary landowning people provide tenure security. Thus, community participation in framing of digitalisation of land administration, as well as remaining integral to the implementation process are necessary conditions for success. In this regard, rural and urban land administration planning that benefits community people can only proceed through a bottom-up approach to capacitate effective participation of social groups including women (Belay 2024). For instance, it is argued that the use of SmartLandMaps enhances the participation by and benefits of digitalisation to communities by supporting the generation of baseline conditions of and rights in land prior to digitising (Lindner 2023). Similarly, (Mazwane 2022) shows that digitalisation of land administration works best when it offers opportunities to local small-scale farmers, rather than to be implemented as big modernist projects.

4. Methodology

Insights in this work is part of broad-based research on land administration reforms that the authors of this chapter completed between 2022 and 2023. In this period, the authors conducted research on the digitalisation process and land administration in general among customary landowners and the regional lands commissions in Accra, Kumasi, and Koforidua. Data was accumulated on key issues that collectively provided insights for

the goal to understand the synergy between customary and state land administration systems, community knowledge of the digitalisation process and access to its benefits, and general investment in customary land. The Greater Accra region, Ashanti region, and Eastern region were chosen because the regional lands commissions in Accra, Kumasi, and Koforidua (regional capitals respectively) were more advanced with digitalisation, ahead of other regions. Interactions with officials of the regional lands commissions and customary land authorities were more generative and grounded, without adherence to predefined strict lines of questions. This approach provided opportunity for unintended but significant insights to emerge.

A methodological objective during field research was categorised into two main themes. First, to investigate the extent to which community leaders like family heads and chiefs who are the first instance of the land allocation process refer to the Lands Commission digitalisation procedures in any way in their land allocation transactions. Second, it was relevant for the authors to also seek to know the extent to which customary landowners and community people were aware of, interested in, and could have access to, the digitised data on land registrations at the Lands Commission. Insights on both themes were pieced together and discussed as outcomes of digitalisation for land control and benefits for community people. These two themes and piecing together into a broader analytical point are in no way exhaustive of the many forms of outcomes of land administration digitalisation for community people. Yet, for this chapter, these constituted the frame with which the authors understood digitalisation synergies between formal and customary land administration systems.

5. Detached in substance and form: some field results

Digitalisation unlocking capital and captives

Contrasting experiences between the Lands Commission and the landowning communities in field interactions were revealed. These include indifference among non-state research participants (customary landowning heads) to align their land allocations with the digitalisation system at the Lands Commission. The field research sought these insights to enable understanding ways customary landowners perceive the digitalisation process as opportunity to strengthen benefits from their lands for the collective landowning community. Customary landowning heads were either not aware of, not educated about, or not consulted on the digitalisation process. They allocate their customary lands often without any reference to digitisation and potential benefits their landowning communities could derive from the reform. For the lands commissions, they held on fast to their mandate of creating an efficient and workable digital environment of land administration. But this mandate begins only after the lands are obtained from their customary owners and brought to their offices. From the opinions on the relevance of the digitalisation process, the lands commissions were more interested in the efficiency of land transactions after the customary processes of allocation are completed.

The commissions were keen on implementing digitalisation, including integrating all land transaction and recordation processes, as Akoto[1] puts it, «...to give practice to the Land Act, 2020 (Act 1036) and the mandate of the commission to deliver efficient land administration». Akoto works in an integrally important department of the commission involved in digitalisation. His sentiment is confirmed in the interaction with Tettey, also at a

[1] Names of all interaction participants are pseudo, created by this research, to confirm to ethical confidentiality in this research.

division of the commission that deals with digitising records. Tettey notes,

> For everyone to see we [Lands Commission] are transparent, we are developing digital records of all the lands you buy in Accra… you know how our people… they can do anything… digitalisation streamlines everything… digitalisation of land administration enhances efficient and updated land records to unlock dead capital in land.

For its reference to "dead capital", these formal articulation of the relevance of land digitalisation construct customary land administration in the hands of chiefs and families as inefficient, conflict-prone, and poorly adheres to national spatial and economic development plans. In a PowerPoint presentation document accessed online[2], the Lands Commission notes it adopts digitalisation of land administration to increase the contribution of land to national development[3]. Various texts on the national Lands Commission's website explains to the reader that the commission with its regional branches also seeks to improve land uses, spatial mapping and data recordation at all levels of land administration, enhance decentralised land administration to the regions and districts across the country, and ensures greater benefits from land for national development.

Related to the formulation of the relevance of digitalisation as unlocking dead capital is the strong trust in external capital (extra regional or national) to foster development. Mohamed, an official of the Lands Commission in one of the regions and centrally involved with land title registration, justifies digitalisation in these terms,

[2] https://lc.gov.gh/landconference/materials/NLC-Fit-for-purpose%20cadastral.pdf.

[3] Ben Arthur, Deputy Executive Secretary, Lands Commission; Presentation titled *Digitalization of land administration in Ghana: Transforming the Lands Commission.* Accessed on 12 January 2026.

> This thing, we are not implementing it here much. We need the materials. But it is a good thing for sure. Everyone needs land, especially investors who bring money, technology, and ideas to develop our lands. Young people, you know the youth as you see… are strolling the streets and doing galamsey [unlicenced small-scale mining]…bad,… destroying our forests and rivers because they do not have jobs. If investors from outside or even the rich guys here can help, why not ensure that they have lands and secure titles, to give them peace of mind.

To Mohamed, investors, usually foreign and Ghanaians with capital, are crucial to deliver development to the country. In this respect, what this means is that the larger society including customary landowning communities, is seen to be better off with capital investments in land secured through digitalisation. The authors of this work do not seek to follow Marxian analysis in this sense because community people sometimes wield considerable power to confront investors and are able to command more benefits from their lands than mere jobs. Yet, Mohamed's views show the neoliberal capitalist underpinnings of digitalisation and land administration in the lands commissions.

The authors of this work listened to a conversation between two young people and a chief's linguist in a community around Kumasi. The youth were expressing their frustration with investors including mining firms, logging firms, and agribusinesses who promise to provide youth with jobs but eventually only a very few people get low-level jobs from these firms. Yet these investors degrade their natural resources beyond repair. The linguist, however, believed such jobs though low level are better than the drudgery of daily menial jobs many youth in their communities engage in, like commercial motor cycling (illegal in Ghana) or leaving for urban areas to sell on the streets. The two young people in the conversation however disagreed with the linguist. They believe investors in their communities are deriving huge benefits from customary lands while community people benefit too little. It is instructive from this conversation to understand

how heterogenous communities are with respect to benefits they expect from investors in their communities. Nonetheless, there is a common meaning in the views of the two young people and those of the linguist. For both sides, investors are not saviours of communities. The linguist's approach expresses only an alternative benefit that is not good enough but serves to ameliorate a worse situation for young people. For the authors of this chapter, while in the experience of the youth investors are extractive actors in their own lands, digitalisation can only secure these lands in the hands of investors and worsen the plight of the communities, further holding them captives in their own lands.

Disconnected from digitalisation

In the study regions, it is easily recognised that customary land administration is tangential to digitalisation. A chief in a peri-urban community near Kumasi contends that the regional lands commission's role in land registration generally was helpful. But then, digital land recording had not reached his chiefdom. Nana (the chief)[4] notes,

> Oh, for me, I feel like… but I am not part of it, so it does not affect how I manage my lands. You are now telling me much about it. For me, my concern is that I am careful to plan my community very well to avoid land litigations, but that is where my power over land ends. Once community people know I am the chief, the one to allocate lands and they know their own usufruct rights and there are no conflicts, this is ok.

The chief's point is that digitalisation is barely known to and disconnected from customary land administration. Thus, the customary authority that allocates land remains detached from digi-

[4] Nana is the customary term for a chief in Ghana. It is endowed with reverence, authority, and sacredness of the position of a chief.

talisation, and this is just the status quo. However, a female youth leader in a neighbouring community to Nana's home emphasised that the regional lands commission has little idea of circumstances in which outsiders acquire land in her neighbourhood. If a family contends a chief was unjustly allocating their customary usufruct land rights to investors, this was not considered to be first resolved in the registration and digitalisation processes at the Lands Commission. The female youth leader laments, explaining she was sharing a general view of the youth in her neighbourhood,

> …the lands people [regional lands commission] do not even know if the lands they are putting on their documents is originally for a widow or not. I hear now they do things on the computer for records [digitised recording], but what should go onto the computer records is that these lands they are putting on records originally may belong to a mother or a widow. How can we eat when someone comes and say he has bought this land for a factory, and his name is in the computer record?

The youth leader further explains that in any case the chiefs are allocating away their lands even prior to digitalisation. But the difference now is, she believes, inaccuracies in how land is allocated if not addressed would now be present across the internet as though they were correct. This she worries about as a disconnection of digitalisation from realities.

This disconnection of customary landowning communities and authorities from digitalisation are also evident from the views of a senior manager at one of the regional lands commissions, who notes,

> …you know because the land is owned by the customary people, we are not really focused on what happens below from here as a commission. We only work to register and digitise what you bring here. For anything else that occurs before you acquire the land, you have to deal with the customary people.

These authors observed at the Customary Land Secretariat (CLS) in Kumasi that indeed, the digitalisation of land records begins only after the customary landowner allocates the land and the acquirer takes their documents to the regional lands commission. The explanation given by an important young official at the Secretariat is instructive,

> For us we only send the land seeker with the site plan to check for themselves about the ownership status of their lands at the Lands [regional lands commission]. When they come back and the land is free, we prepare and sign the indenture and the person takes it away, to wherever they want to.

On the part of some community people, their detachment from the digitalisation process does not, on the surface, constitute anything to worry much about now, as the chief in the above quote expresses. Yet, this is only because they are not aware about digitalisation and the benefits this can offer if they were a central part of the reform. All the community insights presented above explain a situation where the state, by suspending digitalisation above communities, constructs customary land administration as inefficient to justify neoliberal ideals of land administration. In this construction, and subsequent justification of digitalisation that is disconnected from them, customary landowning people become victims of land rights security offered by neoliberalism in land administration.

6. Outcome of disconnected land digitalisation for communiities

Resilience in this context is constructed as the ability of social systems to absorb impactful outcomes of land administration and maintain the communal principles and ownership control over customary land. In this sense, to benefit from their lands whether in their ownership or allocated out of their reach, communities could access and use data generated through land digi-

talisation to support development planning, revenue generation, credit mobilisation and access, land tenure improvements, partnership in land investments, and land administration in general. Piecing together the quotes in the previous sections on the detachment and loss of data especially in the young female leader's sentiments, the resilience of communal norms in customary landowning communities is desired but gravely affected by increasing land allocations.

The authors' field research suggests that communities seek to maintain their lands to sustain their livelihoods and this is where digitalisation could support them with credible documentation and secure rights to access credits, biotechnologies, investment partnerships with others, to sustain their access to lands and livelihoods. Yet, digitalisation currently registers land only as leases; it does not register the usufruct rights in land held by customary landowning people. In this sense, customary landowners are disconnected from the benefits of secure transactions and ownership of land that digitalisation seeks to offer. In circumstances of detachment from, indifference to, or lack of awareness about digitalisation, communities lose out on the benefits digitalisation could provide for their resilience.

Land administration data is exclusively controlled by the lands commissions and foreign software firms that develop the tools. Transactions over customary land is being securely managed between different parties, over and obscured from customary landowners. In this secure digital environment, it is difficult to contest claims to land already digitalised. Thus, communities that face investor misdeeds over lands are constrained from taking control over their previously owned lands, justifiably to seek more benefits (Gyan 2025). Customary institutions for land allocation such as the customary land secretariats lack the capacity to track land transacted and recorded digitally (Kwakye et al. 2024). Rather contrary to the views the regional lands commission official Mohamed expressed in the previous section that investors deliver jobs to the youth, it is well documented over the years

how investors fail to meet the economic, environmental, and social demands and needs of communities in which they work, leading to protracted conflicts (Gyan 2025; Narh 2024; Koch et al. 2019; Amanor 2012).

Monitoring land transactions is important for land administration (Mbogo et al. 2024). For customary landowning communities, it can enable them lay claims over land benefits from investors. Drawing from experiences of land use planning in Tanzania, Huggins (2018) cautions that though application of digital technologies potentially provide community people the opportunity to be involved centrally in and control over land use planning processes, customary landowners are often not in control of how the digitalisation data on their lands are generated, shared, interpreted, adapted, and framed. In Botswana. though the country's Land Administration Procedures Capacity and Systems (LAPCAS) sought to register all lands through digital means, there have been loopholes with data management, delays, resource constraints, and poor coordination of the activities with local people and other stakeholders (Magosi et al. 2014).

Financialisation is one key land use form that has developed and is lucrative for large investors through digitalisation in the absence of stricter regulations. In the Global South generally, Izabela Bludnik identifies that a key failure of digitalisation of land administration is land grabbing. Bludnik (2022) identifies land markets through digitalisation having become means of financialisation of environmental resources, where land acquired is not used for any productive endeavours that benefit communities but to obtain credit, speculated rents, and other financial rewards from global and national financial markets. In Africa, with even the introduction of sophisticated technologies like blockchains and unmanned aerial vehicle (UAV) (Tan et al. 2021) to generate data on land transactions, caution is only proper to identity implications for local people.

The flow of credit from formal financial institutions using land as collateral has become more important through digitalisation

as information on land conditions are more available and accessible. But most of this credit especially in the agricultural sector is being channelled towards large-scale agricultural enterprises that acquire large tracts of land from communities (Abab et al. 2023; Mihigo et al. 2025). Financial institutions prefer to lend to businesses that provide information on security of land tenure where land is used as collateral. This security of tenure is deemed to be preferably obtained through digitalisation. Yet, it is large-scale investors, not smallholders who are the customary landowners, that are digitalising their land rights. In Abab et al. (2023. p. 2) caution is offered that it is often presumed tenure security through land registration and title recordation increases access to credit by enabling small landowners to use the land as collateral. Yet, this is not always the case, noting that evidence of credit effects of land registration and certification programs to smallholders have been rare or are mixed results.

Ben Cousins (2019) found that the loss of control over land through disconnected digitalisation negatively impacts social reproduction for landowning communities. Social reproduction through controlling their lands entails not only economic values but also social obligations. Customary institutions in rural Africa reproduce customary rites and norms including marriage, death ceremonies, kin bonding, chiefly reverence among others. Land provides resources to meet these cultural and social reproductive values. Common property relations in Africa fundamentally are rooted in ontologies and epistemologies where communities see their lands as inalienably communal, including being integrally part of ecologies (Ramutsindela et al. 2025). To this end, resource governance, and in the context of this paper digitalisation of land administration that leads to the breakdown of this communal property relations and personalising land resources in individual investors without benefits to communities ignore and obscure African socioecological reproduction realities (Ramutsindela et al., 2025). Land allocation to investors that drive community people into environmental losses and constrained social reproduction is a

result of the liberal capitalist discourse prevailing dominantly around land.

Youth deprived of livelihood capital are unable to maintain stable and sustainable livelihoods that enable sustainable social reproduction of themselves and their families. Cousins (2019) advises the formation of capital from below to support small landholders. This is where land reform including digitalisation should promote pro-poor investments in land to enable small landholders create better value in their lands. In Gyan (2025), community people lose their lands and their social reproduction capacities to mining firms who circumvent community scrutiny of their land acquisitions, by appealing to formal land administration procedures against the customary norms of land administration. Thus, Gyan (2025) cautions that the transition to digital systems of land administration in Ghana if not carefully managed risks amplifying existing conflicts between communities and investors.

7. Framing digitalisation as a social process

There is strong neoliberal influence on digitalisation in Ghana. This must be done away with to rather promote beneficial outcomes of digitalisation for communities. This chapter aligns with the argument that land reforms and planning in Africa are mostly established as «...liberal rational bureaucratic land tenure systems …and market-based land tenure rooted in neoliberalism that may not reflect local values, social systems, and livelihoods...» (Frewer & Chang 2014, p. 268, cited in Huggins 2018, p. 214). While communities may be involved in digitalisation, care should be taken that they are not cooperating in a process towards liberalisation of their lands. Often, liberal, capitalist, statist, and external models of the utility of land is imposed on local people, marginalising them in the administration of their lands. For Ghana, digitalisation of land administration is heavily supported by external finance and technical resources, making external control over the discourse and practice of land ad-

ministration inevitable. ICT and digitalisation are imperative for progress in all areas including land administration and agriculture. The challenge is how policy frames the implementation of digitalisation to create resources and benefits for community people. Without this framework, digitalisation creates affordances or conditions for the state and its liberal capitalist goal to undermine benefits from land for customary landowners.

Digitalisation disconnected from customary landowners is a liberal economic accumulation of assets, which is part of a systemic approach to maintaining the wealth, power, and hegemony of those who hold power to decide the fate of customary landowning communities. In Rodima-Taylor (2021), digitalisation of land administration in Ghana particularly through the blockchain technology would further alienate and marginalise customary landowning people as wealthy private actors and politicians exploit the process to register lands away from the majority customary landowning people who may lack resources to process digital land registration. Literature barely engages with this neoliberal development and alienation discourse that digitalisation promotes. In this sense, this chapter suggests that digitalisation as is currently implemented is formally presented as though it is the only path to prosperity of society, without much critique of its opposite deprivation effect on communities. Magosi captures the benefit of data from digitsation for communities when they say about Botswana «Good land management allows for efficient management of both land and land information... .to ensure prosperous social and economic development for Botswana's population through transparent, efficient, and effective land management» (Magosi et. al. 2014, p. 1916).

Digitalisation offers new technical approaches to efficient land administration. However, in Ghana, its distribution is shallow, defining land administration as only a technical problem than sociocultural, socioeconomic, and political. In this technical framing of land administration reform, the relationship between customary landowning communities and the state with its agency is one where customary land administration stands accused. Thus, for

being accused, customary land administration is tangential to and disconnected from digitalisation. Yet, a deeper analysis of land administration shows that customary land administration is rather a victim of neoliberalisation of land. It is futile to argue that customary land tenure is incident-free. Indeed, rights-based intra and inter social group conflicts or contestations, irregular allocation, information discrepancies, and inequalities at the land-owning community level are all carried over into the digitalisation system. This affects the credibility and sustainability of land administration.

8. Conclusion

To take a cure from Ben Cousins (2019), to avoid collapse, decay, and the cultural, social, and economic violence that disconnected land reforms like digitalisation pose to customary landowning communities, digitalisation will have to be approached as a complementary between promoting capital formation and social reproduction of communities. This requires a socioeconomic framework designed to implement digitalisation from the communities. In customary land norms in Ghana, customary landowning people hold lands as inalienable usufruct. This is the customary communal principle that holds and bonds communities together and ensures benefits from land to majority. This principle is challenged by various liberal influences on land. Yet, the inaccessibility of digitalisation to customary community people, who are thus disconnected and do not benefit from the reform, weakens this communal principle. The formal state through the Lands Commission with its current neoliberal discourse undermines the resilience of customary landowning people. This is likely to perpetuate poverty and deprivation in Ghana than contribute to solve them.

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II. The "biometric revolution", Ivorian-style. Reflections on the National Registry of Natural Persons

Armando Cutolo

Since the early 2000s, African countries are going through significant processes of digitalization. More than 600 million people on the continent have access to mobile broadband internet, and in 2030 it is estimated that they will be more than a billion. International actors, such as the World Bank, present and promote digitalization as a powerful instrument for growth, creation of jobs, access to education and to financial services. Digitalization is seen also as a crucial instrument for improving access to rights and state services, accelerating the speed and the security of transactions and transforming the relations connecting the citizens with the state.

Nowhere this can be seen more clearly that in the domain of civil registration, where biometrics are transforming the infrastructures of identification. By scanning and codifying the uniqueness of individual bodies – instead of constructing identities by recording statuses and relations as paper-based civil registration does – biometrics are creating a new kind of "legal identity" (Breckenridge 2014; Cutolo 2017; Awenengo Dalberto, Banégas & Cutolo 2021). The World Bank is one of the major players in Africa's "biometric turn". The central argument of the new Washington Consensus is that the legal identification of individuals is a necessary condition for the continent's economic, social, and political development (Gelb & Clark 2013). Biometrics are presented as a technological opportunity to compensate for the endemic weaknesses of civil registration in Africa and achieve the goal of an identification system with universal coverage. The World Bank has made this target part of its "Identification for

Development" initiative (ID4D)[1], which includes regional pilot programmes such as the "West Africa Unique Identification for Regional Integration and Inclusion" (WURI) programme launched initially in Guinea and Côte d'Ivoire in June 2018[2].

Given what is at stake in these processes, driving significant transformations of the relations between African states and societies, social sciences are compelled to take some distance from the optimistic, sometimes utopian, technocratic rhetorics of the promoters of digitalization. Biometrics, and the digitalization of state services in general, need to be seriously scrutinized focusing on the social implications and political consequences produces by the working of their apparatuses.

This kind of stance is found in analysis such as that of Peter Narh and Doumbia in this book, concerning the digitalization of land registers in Ghana explicitly. Narh and Doumbia show that the digital reform of land administration has been conceived of as an instrument to "enhance the efficiency of land access beyond the collective ownership of customary people". Hence, it facilitates investors in obtaining property rights hitherto held by local rural communities, enabling the unlocking of "dead capital in land". Companies operating in the financial sector can now acquire secured rights of land property and use it as a collateral. As a result, the reproduction of rural communities depending on land is put at risk by processes of land-grabbing favoured by digitalization.

Digital reform of land registration is just a field among others in the digitalization of state administration in Ghana. Under a 2006 law, the government made biometric ID mandatory for the entire Ghanaian population. This was propaedeutic to the implementation of the e-Zwich project, the world's first biometric money (Breckenridge 2010), developed by John Kufuor's government in cooperation

[1] https://id4d.worldbank.org/.

[2] https://www.id4africa.com/2018_event/Presentations/InF4/2-4-0_The_World_Bank_Samia_Melhen.pdf; https://documents1.worldbank.org/curated/en/099050225110559061/pdf/P161329-f64eac6f-ea4d-4447-bde2-e38454971325.pdf.

with the Bank of Ghana. Presented as an technology aimed at improving taxation and at asserting control over financial transactions, the e-Zwich was intended, as Keith Breckenridge has observed, «to raise the level of local capitalization by drawing a much larger portion of the issued money supply into bank accounts» (Breckenridge 2010, p. 643), and by including a larger part of Ghanaians into formal economy (Thiel 2020). Developed in connection with a central electronic identity register, managed by the National Identification Authority (NIA), the e-Zwich currency circulates through specific biometric banking cards. Transactions can thus be combined with identification and financial surveillance.

Governmental agencies for identification have proliferated in Africa since the start of the twenty-first century. In Nigeria, an identification infrastructure named National Identity Management Commission (NIMC) has been established in 2007 under the control of the state and the national banking system. Its task was to create and manage a register of natural persons, assigning a unique national identification number to every citizen and issuing a series of «general multi-purpose cards» (GMPCs)[31]. Even though the rollout of these cards has been hindered in the past by the limits of the Nigerian system of civil registration, the idea of an "identification economy" that should work harmonically with digitalization through infrastructures shared by the state and private enterprises, seems by now to be well established among political and financial elites. These kinds of infrastructures will enable banks and investors to «capitalize on the poor» (Breckenridge 2011) by collecting the cash circulating in the informal economy and channelling it into the banking system via biometric cards.

1. Governmentality for the poor

Since 2014, the ID4D working group of the World Bank has promoted and financially supported the implementation of biometric systems of registration and identification in African

countries. In its program of action, the philosophy of the influent Indian philanthropic entrepreneur Nandan Nilekani, creator of the Adhaar biometric identification project in India, is apparent. Since a famous lecture at the World Bank's Center for Global Development in 2013 (CHRGJ 2022, pp. 39-52), Nilekani has publicized the successes of the Aadhaar programme – which has by now equipped more over 1,4 billion persons with a legal identity – becoming the prophet of what has been termed as «the biometric revolution» (Gelb & Clark 2013), and the advocate of a new kind of governmentality.

In 2014, the World Bank's ID4D programme was launched under the auspices of the Bill and Melissa Gate Foundation, providing a major start-up grant, and the support of network of important funders such as the French government, British aid, Norwegian aid, the Omydiar Network, and other actors of the public and private sector who identify with the programme: Mastercard, United Nations Children's Fund (UNICEF), UNHCR, the African Development Bank, and the World Food Programme, to name but a few. The formation of such an international institutional network, with its remarkable economic and political heft, has resulted in the devolution of funds amounting to no less than US$1.5 billion by 2022 for the implementation of biometric ID systems in the Global South (CHRGJ 2022).

A major, radical critique of the ID4D program, has been published in 2022 in a report by the Center for Human Rights and Global Justice at New York University. It denounces the risks of promoting reforms where biometric identification should initially complement, but then gradually replace, existing civil registration and vital statistics systems in the Global South (idem). Following the authors of the report, the concept of individual "uniqueness", being based on what the technicians of the World Bank define as "foundational identity" generated by a biometric template, has at its heart «the construction of autonomous economic actors who will have the capabilities necessary to potentially engage in formal economic markets» (CHRGJ 2022, p. 50).

Beyond the purported goal of allowing individuals to carry out secure transactions with state institutions (as, for instance, requests for administrative documents), and of the implementation of cash transfers intended to «give money to the poor» (Hanlon, Barrientos, & Hulmes 2010), the ID4D project would be designed, following the authors of the report, to provide individuals with a "transactional" or "economic" identity enabled by biometric uniqueness.

As I have tried to highlight in other publications (Cutolo 2017, Banégas, Cutolo 2024), the "foundational identity" developed by World Bank's technicians, depending on the capture of a biometric template, does not more than attesting the existence, in a specific space-time, of an individual body that is distinguishable from others. Doing so, it constitutes a socially muted, bare, identity, generated by the codification of bodily features (fingerprints, iris, face etc.). These features are recognizable only by the machine. In other terms, the concept of "foundational identity' creates a pre-social (and perhaps even pre-legal) identity that can be traced back only to itself — i.e. to the phenotype from which it was generated. It becomes the core of legal identity only following a subsequent process, when it is associated to a name, a date and place of birth, the names of parents etc.

Thus, compared to civil registration, foundational identity works in a an opposite way: civil identity builds the uniqueness of the person by recognizing the individuality of the configuration of its social position and statuses; foundational identity, instead, builds the person and its legal identity by recognizing the uniqueness of a body, to which social position and statuses are attached only after. In brief, the concept of "foundational identity" of WB experts redefines identity basing its uniqueness on the body instead that on the uniqueness of the social person.

A pre- or a-social idea of individuality is then established, referring to a desocialized, depersonalized, de-culturalized body that exists only by its scanning and codification by electronic

machines. It is impossible not to recall, here, the reflections of Giorgio Agamben on biometric identification as a technology that breaks all ties with the recognition of the social person producing an identity with which the subject can't establish a relation (Agamben 2010).

Biometrics, have nothing to do with "bodily" identity, the impressions of fingerprints or the structure of an iris are fortuitous features of the phenotype that have no relationship with an individual's perception of the self. They erase of voluntary dimension of recognizing and being recognized by others, opening the way for coercion.

In an essay published in 1979, Carlo Ginzburg has shown how in 1860 Sir William Herschel, chief administrator of a district of Bengal, borrowed fingerprinting from the Bengali customary signing of contracts, planning to use it as an instrument for identifying and surveilling the colonized: they could not be recognized as "persons" by the colonial administration and could not to be trusted by officials (Ginzburg 1990).

Keith Breckenridge (2014), studying the development of fingerprint identification in the British Empire, has highlighted how fingerprinting was devised as a tool to expropriate colonial subjects from the primary means by which they could assert themselves in the realm of identification and contractualization: writing – and, therefore, speech and testimony. Indeed, biometrics, as a mathematical abstraction (Breckenridge 2021), as a de-linguistic technology, erases the voluntary and mutual aspects of recognition that can be recorded in written documents. Going beyond its imperial past, today biometric de-socialization of identity appears as epistemologically congruent with the ideologically individualistic conceptualizations of the subject.

As a matter of fact, the World Bank has an history in pursuing the intention of creating a new Homo economicus through institutional micro-reforms (Williams 1999). But looking at biometrics from an historical and epistemic perspective, should go beyond the critique made in the CHRGJ report. That

is, we should not limit our perspective to the suspicion that the inclusive and humanitarian part of WB's digital agenda is merely a smokescreen for experimenting with market-oriented technologies. The ID4D campaign for "right to legal identity", along with cash transfer programmes designed to "help the poor", are part of a coherent framework that underscores the emergence of a new form of governmentality making a rupture with the government of "the social" as it has been conceptualized in the twentieth century. This new governamentality and that focuses particularly the societies of the Global South hosting multitudes of unemployed and poor, even when those countries show to have important growth rates.

2. Post-social welfare and the biometric registers of natural persons

As I have recalled above, biometric identification is related to the evolution of international poverty reduction strategies, that increasingly rely on cash transfers (Jacquin 2018; Olivier de Sardan & Piccoli 2018). New development planning policies, supported at great expense by international agencies, have pinned their hopes of tackling poverty on a more streamlined and "reliable" biometric basis for identifying who should receive aid and defining redistributive policies.

By analysing welfare schemes implemented in Namibia and South Africa, based on the periodic distribution of cash to individuals identified through biometric systems, James Ferguson (2012, 2015) has highlighted how their architecture has nothing to do with the "welfare state" of twentieth-century political tradition. They make no reference to specific social categories like the unemployed or inactive worker, nor to the family as the natural unit of social reproduction or childcare. These are not insurance mechanisms linked to employment, such as unemployment benefits or pensions; rather, they are intented to support citizens in countries where regularly contracted wage labour is a

scarce resource and is expected to remain so. Women and men, old and young, adults and minors, unemployed, employed, and inactive individuals all claim, within these schemes, the same right to an identical benefit.

In other words, the recipients of these distribution schemes – like the proposed south African Basic Income Grant – are not socially identified or classified. This has led the anthropologist James Ferguson to speak of a "a-social assistance." The only necessary condition for inclusion in the distribution schemes is having a certified biometric identity. The benefit would be delivered – even for citizens hitherto without a bank account – through a bank card that would allow them to withdraw the same amount each month from a cash machine. This card's electronic chip contains the holder's biometric data, enabling the distribution device itself to recognize him/her through specific equipment. This would prevent theft, unauthorized transfers, and improper access to the grant distribution.

From a theoretical point of view, the coupling of assistance based on unconditional cash distribution with biometric identification appears as congruent. As we have seen, the shift from former civil registration to a "foundational" legal identity implies desocialization. This, in turn, can also be seen as opening the way to new implicit forms of emancipation, if we understand the latter as a liberation of the individual from the ties of authority and dependence embedded in gender, family and community relations. In biometric schemes of distribution, benefits are made disposable to individuals independently from the social categories that they could be assigned to. Elders, husbands, breadwinners, authoritarian state agents and bureaucrats, local big-men or politicians and other possible social actors imposing relations of dependence, lose their role as gatekeepers of the access to the resources provided by the state. The only operation demanded by the system is to reach a cash machine once a month, holding a biometric bank card in order to be recognized as a legitimate recipient.

Post-social assistance can be thought of as theoretically connected to a form of governmentality where the state is enabled to abandon its "will to know" the social. That is, for instance, the will to understand the dynamics that produce the poor. The latter can be simply identified as an individual whose monthly or annual income is found below a certain figure, becoming a target within a scheme of distribution.

The infrastructures enabling these forms of governmentality are generally centered on biometric registers of the population. Among these is the National Register of Natural Persons of Côte d'Ivoire (*Registre National des Personnes Physiques*, RNPP), that I have studied with Richard Banégas (Banégas & Cutolo 2024). As other electronic registers of this kind, it displays a multisided structure, where a database with biometric data is connected to a database containing civil registration data together with a system generating a National Number of Identification for each enregistered person. Following the original project suggested by the World Bank, these functions should have been connected to a "social register" collecting data produced by the National Institute of Statistics (INS), in order to target those who could benefit from new cash transfer programmes (those who earned less than 450 CFA a day; World Bank 2016).

Notwithstanding the "social" name of the register, this system of targeting wasn't axed on a real social categorization or analysis. The sub-set of the population identified as that the poor would have been just as a collection of contiguous, "unique", individuals, defined by foundational identities and co-present in the register. This shaped, a new type of "pastoral power", quite different from the one that Michel Foucault has enquired in his genealogy of modern governmentality (Foucault 2004), where the care of the pastor was concerning "*omnes et singulatim*", the totality of the group and the individual. Cash transfers are conceived, instead, for taking care of a set of individuals never framed as a totality; the knowledge requested is aimed just at enabling the system to target individuals. Consequently,

poverty results just as an attribute of individual identities present in the database.

Introduced by the Ivorian government already in 2014, The National Register of Natural Persons (RNPP) was presented by the government as a panoptic infrastructure facilitating the circulation of identity information through administrative space. It thus fit into the global movement to market biometric identities promoted by the World Bank and a vast network of private actors, and perfectly in the frame of Alassane Ouattara government's post-war reforms aiming at constructing the "emergence" of the country. But in its architecture and intentions, the Ivorian way to biometrization of identities had to chart a different course. In fact, compared to identification agencies such as the Ghanaian NIA and the Nigerian NIMC, and other similar experiences, the Ivorian *Office National de l'Identification* (ONI), that had to manage the Register at that time, was to face a widespread resistance to the idea of axing registration on biometrics instead of the usual civil data and statuses of the person.

While the NIA and the NIMC were charged with implementing biometrics as part of projects for the financialization of the national economy, the ONI has been entrusted with much broader and more political missions since its establishment in 2001, under Laurent Gbagbo's government. These tasks can be understood only in relation to a historical and political trajectory that made citizenship in Côte d'Ivoire a highly sensitive issue, linked to the long-standing presence of a significant quota of migrants from neighbouring countries – an issue around which crystallized a moral panic, aroused by the fear of nationality being "given away" and the suspicion of an unwarranted distribution of national identity cards to foreigners, seen as auxiliary "electoral cattle" of the former single party.

The birth of the ONI under President Gbagbo in 2001 can be regarded as the outcome of a political and institutional history that saw several bodies take turns in the task of identifying – and distinguishing between – citizens and non-citizens. In 2002 the

ONI had replaced the *Centre national d'identification sécuritaire* (CNIS), established in February 2000 with the mandate of issuing nationality certificates and residence permits. The CNIS had, in turn, had replaced the former *Centre d'identification et sécurité* created in 1998, charged with identifying foreigners residing in the country and producing their specific "residence cards" in addition to national identity cards.

All these agencies were created during the period in which the ethno-nationalist ideology of *ivoirité* promoted by the President Henrie Konan Bedié took hold in Ivorian society. Eventually, *ivoirité* was remould in a more anticolonial and radical stance by the nationalist movement supporting the president Laurent Gbagbo (Dozon 2000, 2011; Banégas 2007; Cutolo 2010).

And yet it can also be observed that the creation of the ONI in 2001 exacerbated a trend that had begun ten years earlier when Alassane Ouattara, after establishing the new National Identity Card (Law No. 2 of 2006), had required all foreigners residing in the country for more than three months to carry a residence permit (Law 90-437 1990). If, with the residence permit, Ouattara had divided Ivorian society into holders of "green" (national) and "brown" (residence) cards for security and rationalization purposes, for Gbagbo it was a matter of re-building genuine national political sovereignty by reorganizing civil registration and reforming the electoral register – with the ambition, at the same time, of neutralizing the clientelistic practices that had made "foreigners" the reserve electoral army of the Houphouëtist party.

From the outset in 2001, the ONI was entrusted with three functions: identification, migration management, and the modernization of civil registration. These three tasks were linked by a single underlying concern: finally, to establish "who was who" in terms of citizenship. From this perspective, the modernization and "securing" of civil registration, as a register of information that can establish who has nationality and who does not, and thus produce the citizen, was crucial. «Together, let's modernize

our country! » proclaimed the publicity brochure for the ONI's first campaign, whose title said it all: "Identification of the population, securing civil registration, immigration and emigration". In Côte d'Ivoire, the idea of an inextricable link between identification and modernization preceded the World Bank's ID4D programme by several years.

The ONI did not start down the biometrics path until later, as part of the Ouattara government's "emergence" policy and under the World Bank's influence in the post-crisis period. In fact, it was only in the years after the post-election crisis and the end of the war, under Ouattara's presidency, that the process of civil registration reform resumed, structured by a technocratic rhetoric of modernization in which civil registration and security went hand in hand.

These were the same years when the World Bank became increasingly interested in biometric legal identity, presenting the latter as the key to development. In 2019, the Bank approved US$317.1 million in funding for the International Development Association (IDA) to implement a programme to "facilitate access to services for millions of people [through] foundational identification systems that are inclusive of all persons in the Economic Community of West African States (ECOWAS) territory, irrespective of nationality, citizenship or legal status". This programme, called West Africa Unique Identification for Regional Integration and Inclusion (WURI), started with two pilot projects in Guinea and Côte d'Ivoire financed by special loans (US$122.1 million), aiming to develop "regionally interoperable foundational ID (*f* ID) systems", initially covering thirty-five million people in the two countries.

In 2018, Makhtar Diop, then World Bank vice president for the Africa Region, stated that

> people who lack official proof of identity often face significant barriers to accessing public and private services and becoming full members of

> society. This is especially true for women and the poorest segments of society […] strong identification systems could deliver vital services and other rights to people and give a voice to the voiceless[3].

To a less enthusiastic observer, the WURI appeared as a gigantic biometric panopticon deployed in a geographically crucial region of Africa, whence tens of thousands of migrants depart for Europe[4]. Moreover, one might wonder of what kind of "vital services" were waiting for those who were to be identified, if not those that have been undone and privatized through the structural adjustment plans imposed by the same international institutions that today promote biometric identification. However, it's clear that statements such as those made by Makhtar Diop are referring not so much to African states and societies as they experienced by actual citizens; they refer instead to advent of a future society where foundational ID's will be crucial for cash transfers, digital business transactions, banking inclusion, and the "collateralization" of assets previously unusable for credit. A future where biometric surveillance and commercial transactions will be intertwined, shaping a vast area where the traceability of individuals will transcend national borders, becoming a global laboratory for the new biometric governmentality and anti-poverty policies.

[3] Executive Directors approved an IDA financing envelope of up to SDR 218.1 million (US$317.1 million equivalent) for a "West Africa Unique Identification for Regional Integration and Inclusion" (WURI) Multiphase Programmatic Approach (MPA) program' (World Bank press release, 5 June 2019, https://www.worldbank.org/en/news/press-release/2020/04/28/togo-benin-burkina-faso-and-niger-join-west-africa-regional-identification-program-to-help-millions-of-people-access-services (accessed on 18 May 2022).

[4] "The next phase of WURI will cover Benin, Burkina Faso, and Niger" (World Bank press release, 6 June 2019).

3. The resistance of Ivorian civil registration

The ID4D program was well suited to Ouattara's postcrisis agenda, which aimed at neutralizing the political stakes of identification that had been at the centre in the Ivorian "ID wars" (Banégas, Cutolo 2024). When it came to implementation, however, it encountered a socio-historical context that led, between 2017 and 2019, to the programme being toned down and partially reformulated. The «revenge of the [Ivorian] context» (Olivier de Sardan 2014) put up specific resistance that caused a wrinkle in the World Bank's social engineering.

Indeed, the depoliticization and pacification of the identity issue was only a vain wish in Côte d'Ivoire, where for many years the obtention of the *Carte Nationale d'Identitè* (CNI) had been at the heart of a civil war; where ID cards were often read and "interpreted" by nationalist policemen and civil servants in order to check the ethno-national congruence of names, parents and places of birth; where moral anxieties concerning national ID cards sold-off to "strangers" and the "plundering of Ivorian nationality sovereignty" were shared by many Ivorians. More than a decade after the bloody "Battle of Abidjan" in 2011, citizenship remained a sensitive matter, and the highly controversial notion of "ethnic catch-up" explicitly allowed by Outtara's government – that is, the policy of favouring the formerly (supposedly) disadvantaged people of Mande and Senufo culture and language for key political and administrative positions – meaned that ethnicity was still injecting ID documents with a strong political charge.

It follows that in Côte d'Ivoire, no doubt more than elsewhere, the idea of a "foundational" identification was far from acceptable. Still today the certificate of nationality is one of the most widely used documents for administrative and legal purposes; and of course, nationality – especially in a juridical system where citizenship is heavily based on *jus sanguinis* – has nothing to do with the uniqueness, as it depends on descent – that is, on relations.

In a conversation that me and Richard Banégas had in 2019 with the ONI's director, Diakalidia Konaté, he told us about his discussions with the World Bank experts on the importance of civil registration records. Whereas at beginning of the program the bank was chiefly interested in digital identity and biometrics, the ONECI director succeeded over the course of these discussions in asserting the principle that,

> for us, there is no identity other than the one based on civil registration. Civil registration is what gives individuals their legal existence. […] Identification only confirms the civil registration data that are already there, by taking some information and also by taking the person's biometrics (Diakalidia Konaté, ONI Director, interview, Abidjan, 6 February 2019).

Opposing it to the constitutive function of civil registration, Dialikidia Konaté stressed that biometrics should be kept as a repressive function and must be used to prevent or discover fraud and identity theft. He explicitly questioned whether the World Bank's biometric model, inspired mainly by the Indian experience of Adhaar, was adapted to the Ivorian context. His words are worth to be quoted extensively:

> The [World] Bank was in favour of this approach that facilitates financial inclusion, sets everyone in stone, and ultimately leads to the total dematerialization of people's identity. It's linked to countries' history, to countries' demography, to countries' geography. India is a massive country with millions of people. It's a choice they made! When you go to Peru, civil registration and identification are interlinked. It is linked to the country's history. The two are combined. We went to Namibia, it's the same thing. In Rwanda it's the same thing […] And for us, our history, we are a country of immigration, and the crisis that took place is an identity crisis. And civil registration, in our country, because of the level of development […] today, you cannot wipe out the civil registration data, that is our vision, which represents a heritage. […] It's what makes the difference between the individual's legal identity and official identity […] Indians, they came

> from indirect rule where there were no papers, no identity cards. I received their ambassador here. We live with paper, that's the tradition we have" (Diakalidia Konaté, ONI Director, interview, Abidjan, 6 February 2019).

In 2019, thus, the ONI Director presented civil registers as a kind of collective historical memory; to lose that memory in the name of abstract international standards would jeopardize the very definition of the national community. In the same interview, the director also pointed out that biometrics, itself, does not even necessarily protect against fraud, because people in Côte d'Ivoire often carry someone else's identity card or documents, usually a relative's. This phenomenon, widely known as "René Caillié"– an ironic reference to the nineteenth-century French explorer who travelled across West Africa in disguise (Banégas, Cutolo 2024) – can be avoided only by strengthening civil registration to enable cross-checking, before being combined with biometric identification. That is the only way to avoid cases where an individual's body is registered biometrically under a name that is not their own.

The ONI's discussions with the World Bank began in January 2017 and finally led to a funding envelope of 32 billion CFA francs and the launch of the RNPP, the National Register of Natural Persons, on 14 December 2017. As civil registration and biometric identification were combined, the RNPP was structured into three sections, each managed by a specific server: the biometric registration database, the civil registration database, and the function that, by connecting the two, assign a national identification number (NNI) to each registered individual.

This hybrid outcome can surely be seen as resistance on the part of the Ivorian state apparatuses to the ID4D model. It was followed by other reforms. First, an administrative reform put forward by Interior Minister Hamed Bakayoko, which began with the promulgation of two laws in November 2018: one relating to the modernization of civil registration, the other instituting a special procedure for birth registration and identity res-

toration. The latter was the result of an widely shared awareness that is part of national «cultural intimacy» (Herzfeld 1997): as Diakalidia Konaté has pointed out, many Ivorians live with identity papers obtained illegally from relatives or through multiple illegal registration under fake name, and the government didn't want to take the risk of these illegal identity being associated to an official biometric template. In order to function in real life, biometric identities must be connected to names and civil statuses.

Six months after the promulgation of these laws, in May 2019, the *Office National de l'Identification* (ONI) was transformed into the *Office National de l'État Civil et de l'Identification* (ONECI), enunciating in the public space the resistance (and the momentary victory) of civil registration against the "foundational" ideals promoted by the World Bank.

4. Conclusions

Today, the new biometric *Carte Nationale d'Identité* seems to represent a compromise, standing between biometrics and civil registration. Compared to former ID cards, the names of the parents are no longer visible, having been substituted by the NNI national ID number. In Ivorian public opinion this has raised controversies of moral and political tenor. Rumors concerning the "individualizing" and "descent-blind" aspect of the card recount that this would have been tactically planned to obfuscate the national "origins" of the bearer; hence, to introduce strangers into the national community. At the same time, and quite the opposite of these suspicions, the Ivorian ministries of Justice and of Interiors have organized through the ONECI the presence, in the process of production of the biometric cards, of specific officers in charge of checking and validating the nationality of the applicants.

In an interview made to the managers of the Semlex, the Belgian company manufacturing the card, they have complained

that this kind of validations slow-down considerably their rhythm of production (and so their profit): starting initially with 30, the ONECI is hiring today 200 officers in order to validate cards after having verified nationality certificates. A time-consuming work, keeping the ONECI in a constant delay. Here too, it is apparent that desocializing and depoliticizing effect of biometric identity is kept at distance by the Ivorian national state apparatuses, and the "identity adjustment plan" presented in 2017 by the Ivorian government under the influence of the World Bank has been radically transformed by the Ivorian political context. That is why the Bank nearly retired from the program deciding to invest mostly on WURI, where biometrics is at the forefront.

Even the structure of the National Identity Number (NNI) has been renegotiated. At first, Semlex wanted the NNI to be a purely aleatory unique number, but the ONECI imposed another way of generating it, requiring that its initial elements would have to be connected to the person (representing sex, decade of birth etc.), only then followed by aleatory numbers. Semlex had to accept the request, even though generating unique ID number should ideally imply their abstract, non-semantic value. The Ivorian authorities showed the same attitude when they refused the possibility of using the NNI in administrative procedure instead of names.

As Ago Christian Kodia, the new director of ONECI, observed, even though the production of national ID number is at core of RNPP, the primal elements of civil registration – registration of names, places of dates of birth etc., remains the real, social and juridical "foundation" of the Ivorian system of identification. And, just as the former director said, biometrics remains only as a means to secure identities and defend uniqueness. In the end, in the Ivorian context we can observe the dialectics having connected and confronted two different apparatuses. One based on language and writing, connected to the social realm and to documentary governmentality; the other based on the mathematical abstraction of bodily uniqueness, and congruent

with post-social forms of governmentality. Although each one of them tends to affirm its own regime of veridiction, their mutual hybridization in Côte d'Ivoire is just another example of the heteronomy of ends that often disrupt the teleology of neo-liberal social engineering.

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III. Ethical concerns in cultures of family caregiving: evidence form a feminist ethnographic study of cancer in Ghana

Deborah Atobrah

1. Introduction

Globally, the family is noted as the best non-medical care provider for various forms of dependencies, including disability, aging, and debilitation (Proot et al. 2003). Women are acclaimed as primary caregivers for their dependent family members (Folbre 2001; Waerness 1984; Atobrah 2009). In many African societies, family unpaid caregiving, particularly within the non-medical domain is most critical for the wellbeing and welfare of patients with chronic diseases including cancer (Atobrah 2013). Over time, major socio-cultural changes such as rapid globalization, urbanization and modernization, and their concomitant effect on social systems, have gravely affected care delivery within families. Changing gender dynamics, with women's increased participation in rigid formal work and the increased nuclearization of families have affected care delivery within households. Against the backdrop of rising incidence of cancers, the above factors culminate in the need for an inquiry into how care has changed, and the extent to which African family care suites its characterization as *safety net* for patients. The limitations of family care have seldom been interrogated, as dominant bioethical considerations in Africa have mainly focused on institutional and facility-based care provisioning for patients (Laar 2022). Care provided at home by families for patients is usually seen as sacrosanct, and hardly interrogated. The key questions engaged in this chapter are: to what extent could the traditions of family care for Ga cancer patients be inimical to the wellbeing and welfare of patients? Yet, how does

the feminist anthropologist respond to the limitations of family responses to cancer patients within Ga families?

The following reflection draws on ten-month ethnographic field research on eight Ga persons in Accra diagnosed with cancer, their family and affiliates, and key informants knowledgeable in Ga traditions of care.

2. Background and Context of the Study

The background of this chapter is established on a brief description of cancer in Africa, its care demands, ethnography on family care for the chronically sick, and the tensions between ethnography and feminist research principles.

The rising prevalence of cancer and other non-communicable diseases (NCDs) has become a formidable global health challenge, with low- and middle-income countries (LMICs), including sub-Saharan Africa, bearing an increasingly disproportionate share of this burden (Bray et al. 2024). In Ghana, this escalating crisis is evidenced by an increase in cancer cases, from approximately 24,009 in 2020 to over 27, 385 in 2022 (Bray et al. 2024). This surge is driven by a complex interplay of epidemiological transitions, aging populations, and the rapid urbanization of African societies. As lifestyles shift toward more "Westernized" patterns, characterized by nutritional transitions, physical inactivity, environmental pollution, increased tobacco and alcohol consumption, the incidence of malignancies such as breast, prostate, and liver cancer continue to climb (Adjaye-Gbewonyo et al. 2025). These demographic, environmental and behavioural shifts have created a "double burden" of disease, where fragile health systems must simultaneously grapple with persistent infectious diseases and the rising tide of chronic, long-term diseases including cancer (Ogola & Gachemba 2025).

There is so far very scanty evidence of traditional knowledge on cancer. Although de Graft Aikins (2002) notes in her study

the existence of cancer in Ghana as far back as the nineteenth century, there is very little evidence of it in anthropological and historical accounts. Chemotherapy did not commence at the Korle Bu Teaching Hospital[1] until the 1970s and was initially restricted to lymphodemas (Ankrah-Badu 1988). Because cancer or its descriptions neither have local names nor existed in Ga oral traditions, it could be conjectured that there was low incidence of cancerous conditions, diagnosis or effective treatment in traditional times. Diseases such as yaws, leprosy, epilepsy, and tuberculosis that were common have been registered in Ga traditions of illness and health, yet there are no established traditional beliefs about cancers. It is possible that the few patients who acquired it in the past may have died within a very short time for lack of treatment, hence its absence in the local cultural profile. Any similitude of cancer may also have been attributed to spiritual causation, and not viewed as natural disease. Many disease conditions described as such were broadly categorized as *suu hela* (curse disease).

Various cancers have very peculiar care needs. Generally, the diagnosis of cancer of whatever type evokes so much fear and apprehension. Patients thus need emotional care aimed at addressing and alleviating such fears and worries, and all other forms of support and personal assistance that help a patient live a comfortable life. Such care involves some unique challenges. Caregivers need to provide not only practical assistance but also intense emotional support, particularly to reassure patients that their diagnosis is not an immediate death sentence.

Ethnography on sub-Sahara African family systems demonstrate the central role that kinship plays in sustaining dependent people, showing a strong linkage between the existence of the corporate descent group and sibling unity, solidarity, filial piety, and responsibility (Fortes 1978; Goody 1982; Oppong 1974). Like

[1] Ghana's largest hospital established 1923 during the colonial era. It gained teaching hospital status in 1962.

other responses to chronic illness, care is not perfunctory. Norms and values around caring for the chronically ill are deliberately constructed, and determined by several socio-cultural factors such as notions on disease causation, contagion and recovery prospects (Awedoba 2001). Hence, the assumption of a high-quality family care for every patients could be a fallacy. Limitations in family care for the seriously sick emanate from the gender cultures of the Ga people, typified by men's low participation in house work, overwork of female patients, low emotional care for patients and the high care burden placed on family members.

As a feminist ethnographer studying a vulnerable population, a reflection on the critique on the compatibility between feminist principles and ethnography is expedient. In ethnography, the long, persistent and somewhat intimate contact with the research participants could predispose them to exploitation by the researcher as it turns the ethnographer into a critical and powerful instrument in the research process and outcome (Guba & Lincoln 1981; Goode & Hatt 1952). As such, there have been mixed connotations to how the principles of ethnography resonate with female attributes and feminist principles of egalitarianism, reciprocity, friendship, empathy, connection and fairness, to the connections between ethnography, the female researcher, and feminism (Oakley 1981; Du Bois 1983; Mies 1983; Reinharz 1983). Furthermore, the condition of a chronic illness could deepen respondents' vulnerability and intensify power dynamics between them and the researcher.

Stacey (1988), found some contradictions between ethnography and feminism, thereby calling for inquiry into how their intersection might maximise the attainment of feminist principles. Stacey observes that both the ethnographic process and its product breach feminist standards «precisely because ethnographic research depends upon human relationship, engagement, and attachment, it places research subjects at grave risk of manipulation and betrayal by the ethnographe» (1988, pp. 22-23). For Stacey, the ethnographic process gives huge powers to the ethnographer to

exploit and exert undue power over her research participants, features that oppose feminism. She therefore proposes that ethnography is inimical to feminism, and a fully feminist ethnography is not possible. In a rejoinder, Wheatley (1994) challenges Stacey's standpoint, arguing that whatever exploitative tendencies characterise ethnography ought to be addressed as epistemic flaws, and to be tackled irrespective of whether it is employed by feminists or not (Wheatley 1994).

Compelling as it may be, the debates on ethnography for women and by women are dominated by perspectives of feminists from the global north, with assumptions of feminist research principles across time and space. There has been no consideration of the realities and experiences of the female researchers in Africa. The vulnerability of cancer patients in Africa, which is likely to intensify the power dynamic between the researcher and patient research participants, coupled with long-term interactions of ethnographic field research calls for a serious uptake of ethical and patient-centred approaches to safeguard research participants and meet ethnographic and feminist research ethics. In essence, the care of both the family and the researcher for cancer patients are intertwined in responding to both ethnographic and feminist ethics of placing the needs of the researched at the centre of the research process.

The central argument of this chapter is that while family caregiving continues to serve as an essential and foundational support system for cancer patients in Ghana, ethnographic evidence reveals critical imperfections, shortfalls, and ethical ambiguities that challenge the idealized image of the African family as an inherently perfect caregiving institution. By examining the lived experiences of families in Accra, this analysis uncovers a complex reality where the "safety net" is often fragile and under immense strain. The contradictions between cultural ideals and the daily practices of care reveal that home-based environments are not always safe or patient-centred, but are instead spaces of shifting responsibilities, emotional tensions, and negotiated ethics. The

second goal of this chapter is to demonstrate the tensions of a feminist ethnographer in observing family care and its limitations among cancer patients.

3. The Ga People of Accra

The Ga are the indigenous people of Accra, and they form about 8 percent of the Ghanaian population[2]. Traditionally, a Ga person belongs to his *weku* (kin group) and is expected to be an active participant in the lineage events and ceremonies (Kilson 1974). Robertson (1984) notes that traditionally, «men's and women's economic functions were separate but complementary» and the corporate kin mode of production, segmented by sex, was a common characteristic of the Ga (Robertson 1984, p. 13). The women wielded a high level of productive autonomy, accumulated much capital, and acquired property and wealth mainly through their trading activities. Ga women were astute and prosperous traders, and many of them flourished in trading at the Makola market and financially supported their relatives (Nypan 1960). Men, on the other hand, enjoyed western education (Robertson 1984), whilst few Ga girls attended school[3]. Many girls dropped out of school, despite the Education Ordinance of 1852, which sought to encourage the education of girls. Claire Robertson (1984) attributes this to the failure of the poll tax, inadequate public schools, the fear of girls becoming "uncultured," and the fact that «girls were needed at home for domestic duties and trading» (ibidem, p. 139). Generally, household children were available for errands and support in performing household chores, thereby easing the chore and care burden of adults.

[2] Ghana Statistical Service 2022.
[3] Annual Colonial Reports 1890-1938, cited in Robertson 1984.

Even though the Korle Bu Teaching Hospital[4] was opened in Accra in 1923, biomedicine experienced low usage and acceptability within this period. The hospital facility was shunned by many Ga people and they adhered to their usage of herbs *shikpon tsofa* "ground medicine" (Senah 2003; Twumasi 1975). Generally, persons with chronic diseases were likely to die earlier and so would not require prolonged periods of care. The socio-economic and socio-cultural context of the era has been noted to have greatly influenced care norms and practices. The onset of a chronic illness evoked varied reactions to the provision of care, some of which are discussed below.

4. Ga Traditional Conceptualization of Illness

The traditional responses of the Ga to chronic illness are generally based on the interpretations and meanings ascribed to concepts such as personhood, illness, disease causality, and wellness, much of which is documented by Margaret Field (1961). Field noted that every Ga person is composed of three elements: *susuma*, *kla*, and *gbomotso*. The *susuma* is the soul of the person and the *kla* maintains his breath and life. The *kla* is invisible and is perceived to have organs which correspond to the organs of the physical body such as head, legs, and eyes. Thus, when an organ of the *kla* is affected, it manifests in the physical body as a disease, deformity, or defect. The *gbomotso* is the physically visible constituent (the body), believed to carry or house the *susuma* and the *kla*. Often, when the *susuma* and the *kla* are affected by an activity, there is a manifestation of various forms of weakness in the *gbomotso*, which usually implies illness or death.

[4] Ghana's biggest teaching hospital, established in the colonial era.

The Ga prioritize disease prevention over treatment. Thus, they promote certain traditional measures to ward off illness. The commonest and most applied illness prevention strategy is to abstain from mentioning the name of an illness and rather to use metaphors, since «names are always powerful to attract their namesakes» (Field 1961, p. 120). Another form of illness prevention was to know what one's *kla* abhors so as to avoid it. This could be norms and taboos on food as well as refraining from particular activities. It was also believed that moral uprightness shielded one from diseases caused by angry *kla*, curses, and *sisai* -ghosts. Special forms of protection were also acquired from medicine men (*tsofatse*) to help ward off the negative influences of malevolent forces, the powers of witches, and to provide protection against specific illnesses and other afflictions. If traditional means of disease prevention failed and a person was afflicted by a serious illness, families responded with a variety of possible traditional care options. These include the use of home remedies such as herbs, tree barks and roots, also commonly used by other ethnic groups (Field, 1961, Twumasi 1975, Senah 2003). Generally, medicine is referred to in Ga as *tsofa* (tree root), which depicts the acceptance and wide use of herbs. Field, for instance, indicates that most adults, particularly women, had ample knowledge of medicinal herbs and products to treat minor ailments. This is one of the reasons why the moment a person feels that he is ill, he should first tell an adult member of the household. The patient is only accorded the "sick role" and sent to a traditional healer when the condition is deemed serious (Twumasi 2004, p. 38).

5. Ga Historical Traditions of Care for the Seriously Sick

As cancer does not exist in the historical research profile of the Ga people, this section examines plausible historical Ga tradition for people with serious illnesses, a category within which cancer

fits. Like many other societies, family care among the Ga was largely feminized although there are clear division of roles between males and females. Robertson (1984) points out how daughters and women bore the highest burden of care for the old and seriously infirmed. Caring activities for the chronically ill were also communal, involving relatives, friends, neighbours, and friends of the patient's relatives. When a patient became moribund, an initial family meeting was held among the patient's siblings, his parents' siblings, and his own children to discuss how to provide adequate care.

Care was further facilitated by the high fertility levels of the Ga people in the past[5]. An individual was likely to have had several siblings, children, nieces, and nephews to support and help when the need arose. In a few instances of wealthy families, paid maids, slaves, and pawns were involved in care. Traditionally, the chronically sick person was never allowed to be hungry and was thus adequately fed. It was also considered very important for kinsmen, friends, neighbours and well-wishers to visit the sick except for mental illness and other conditions which attracted stigma, chronic illnesses were rarely kept secret (Mullings 1984). It was thus necessary that people got to know about the patient's condition and visited him. Having many visitors was an indication of a patient's social standing. Gift giving during prolonged chronic illness as also an important culture. Gifts of all kinds were given to the seriously sick as a sign of concern, and it did not matter whether the gift had direct bearing on the illness. Men mostly gave money. The period of ill health was thus a suitable time for friends and relatives to reciprocate all the good the patient had done for them. Gifts were given «freely and unresentfully» (Robertson 1984, p. 222). Ga traditions also had built-in provision for emotional care to enhance the mental wellbeing of a patient. Respondents expressed this form of care as *tsui*

[5] In the 1970s, on average men bore 14.1 children and women 6. 8 cfr. Robertson 1984, p. 209.

hamor (giving of heart). Ga people believe that when one is worried, one's heart is "wearing off" or "eating away", commonly put as *etsui miiye* (his heart is eating away or eroding). Family and friends of sick people usually lavished *tsui hamor* (giving of heart), *mishedzemor* (comfort), empathy, concern, affection, and love on the sick person.

In the personal domain, the seriously ill patient usually had to be bathed, cleaned, and his surroundings tidied to avoid embarrassments when being visited. Self-contained houses were rare in Ga traditional households. There were strict rules guiding the performance of intimate activities for a patient. For instance, a patient's own children were not allowed to bathe him or her, irrespective of the children's age. It was considered embarrassing for children to see their parents' nakedness, as made explicit in the popular Ga saying "*bi enaa enyer yayaimli*" (a child does not see its mother's nakedness). Thus, the patient's female sibling, mother, or elderly female kin were traditionally designated to attend to the intimate needs of the patient. The patient ought to be shown due respect by having personal care needs attended to by older females in the kin group.

Caregiving was also extended to caregivers. Friends and affiliates of the caregiver would visit the caregiver to express their sympathy. In fact, a significant proportion of the gifts presented to the patient was meant for consumption and use by the caregivers to appreciate their caregiving efforts. Such appreciation was called *ayekoo hamor* (congratulations giving).

Whereas the discussion so far depicts a glamourous picture of family care within Ga traditional societies for the seriously sick, this chapter, elucidates the care limitations and deficits in the care of cancer patients in Accra. I question some of the care practices and how they inure to the wellbeing and welfare of patience.

6. The Study

The data were derived from a larger ethnographic study of twenty-four Ghanaians diagnosed with serious diseases – including cancer, stroke, chronic diabetes, and chronic renal disease – members of their families, and networks of caregivers (Atobrah 2009). Here the focus is on eight cases of persons diagnosed with cancer – one with nasopharynx cancer, one with ovarian cancer, two with breast cancer, one with cancer of the endometrium, two with prostate cancer and one with both breast and ovarian cancer. Patience-centered methodologies were used to collect data through in-depth conversation-style interviews, and participant and non-participant observations with the eight patients, their spouses, and other relatives (Wright & Flemmons 2002). The participants were recruited for the study from the Center for Radiotherapy at the Korle Bu Teaching Hospital in Accra with the help of medical personnel at the facility. Ethical clearance was obtained from the Institutional Review Board of the Noguchi Memorial Institute for Medical Research of the University of Ghana.

All the interviews and observations were carried out by the author, a feminist ethnographer. In each case at least ten conversations were carried out focused on the family's participation in caring for their sick members. Relevantly, critical reflexivity called for an appraisal and reckoning of the various strands of the researcher's identity and how those strands possibly influence the research. This reinforced by positionality, which guides the ethnographer to mitigate and reduce the effects of her persona and biases on the research process and outcome (Berger 2015; Ahmed et al. 2011). While the researcher may bear several intersecting identities, being a feminist and a female researcher within the cultural operatives of Africa, and how the researcher's femaleness marks the ethnographic research process and outcome are critical.

Ghanaian society remains deeply communal, and it would have been considered culturally unacceptable for anyone, even

the ethnographer-observer, to visit a chronically ill person and not show care by helping in some way. As cancer is imbued with supernatural beliefs and is almost considered a taboo subject, a deep level of comfort, trust, and even friendship needed to be established before patients and their families would discuss the subject (see Atobrah 2009; Antwi & Atobrah 2009). Questions were open-ended and value-free to avoid luring respondents into giving particular responses.

7. Caring for Cancer Patients

In this study, family caregivers have been categorized into three main categories; primary caregivers, financial caregivers and supportive caregivers, as operationalized below. These categories are not mutually exclusive, in that there are instances where a primary caregiver could also be the financial caregiver. Also, a patient would usually have more than one person performing functions in these categories. Distinctions in the performance of care duties by different persons as categorized as primary caregivers, financial caregivers and secondary caregivers.

The primary caregiver is a member of the kin group, mostly within the nuclear family of the cancer patient, who emerges or takes up the role of being responsible for the patient's care. Primary caregivers in this study were mostly wives, daughters and sisters of patients. The wellbeing of the patient in terms of disease treatment and care satisfaction greatly depends on the effectiveness of the primary caregiver. A cancer patient who does not have a primary caregiver(s) is likely encounter profound crises in care. The primary caregiver is the interface between the patient's family on one hand, and health workers, patient's former work colleagues, friends and neighbors on the other hand. The primary caregiver coordinates all other caregivers and their caring activities for the patient, and is responsible for disseminating information on the latter to the appropriate persons. Moreover the

resilience of mothers in supporting and caring for their children even under extremely difficult situations was well exhibited in the study and acknowledged by all.

In most cases a financial caregiving is needed: treating cancer in Ghana is usually accompanied by a high financial burden because there are no welfare provisions, and patients have to pay-out-of-pocket expensive treatments such as chemotherapy and radiotherapy. Typically, the cancer also bears other costs on, pain and symptom relief drugs, x-rays and the several laboratory analyses to be done. Furthermore, patients have to bear other incidental costs such as hiring taxis to and from the health center, extra expenses on dietary restrictions and requirements, cleaning materials and detergents, and diapers, as may be needed. The few patients whose children were in some sort of employment were very happy with the part played by the latter in assisting with the purchase of drugs, and other supplies required for their upkeep. Two of the patients studied were receiving regular remittances from relatives living abroad.

The local context of chronic illness renders the patients highly dependent on the benevolence of several other people, in particular supportive caregivers. Two Ga proverbs are highly significant to this discussion, thus: *ake wao kome mɔɔ mgoo*, literally meaning, you do not catch a louse with one finger, and *ke tso kome kpee koryoor*, *ekuor*, that literally means: when a single tree is met by a strong wind, it breaks. These two proverbs imply that certain tasks are too heavy to be carried by an individual, and require the diverse support and assistance of kin members, community members and friends to ensure their execution.

The living arrangements in most Ghanaian homes render even healthy adults highly dependent on others, worse so for cancer patients with very low performance status will be much more dependent on others to live meaningful lives. The supportive caregivers are the ones who do the daily domestic routine activities for the patient and perform a great deal of routine activities including running errands, cleaning up vomit, fetching

water for bathing and collecting bath water after bathing, sleeping in hospital with the patient, buying drugs, and just being around the patient. This category of caregivers usually acts upon the instructions and directives of the primary caregiver.

The condition of chronic illness evokes intense emotions particularly among the close relatives of the patient. Participants worried intensely for having to endure pain, physiological changes including loss of breasts and other body parts through mastectomy, hysterectomy and hair loss, bodily swellings and general body wilting. Patients also worry about issues of general livelihood, such as the loss of income amidst high hospital bills, and interruption in personal ambitions for family and career development. Most of these also pose much embarrassment to patients and their families. Patients also suffered much emotional stress worrying over what various people would think or say about them because of their illness and the resultant physiological changes. They also worried about lifestyle changes and restrictions, particularly those pertaining to diet and mobility. Many become depressed, moody, frustrated and sometimes felt guilty for having brought the disease upon themselves. Many of the patients also felt lonely. They saw themselves as belonging to a new group of people with a new identity as "cancer patients". They were then no longer able to relate well with their family and friends, because of shifts in the former's interests, aspirations, experiences and concerns.

While patients expected great levels of *tsui hamɔ*, (giving of heart) *miŋshɛdzemɔ* (giving of happiness), empathy, concern, affection and love from caregivers, expressed in caring activities and various forms of communication, the effect of the actual disease and side effects of various forms of treatment and therapies on patients does not predispose them to receive emotional care. Many patients become overly suspicious, offensive, paranoid, bitter, resentful, unappreciative, nag a lot, become self-centred, and are seen as difficult. I am reporting the words of Kailey, 31, a university graduate who is highly knowledgeable about her

condition of cancer of the breast and the ovaries, and has had mastectomy and hysterectomy recounts about herself thus:

> I talk a lot... I talk about anything, I just talk and I am free, anything that worries me I have to say it and be free. My husband says I nag too much. I think it is because of the hysterectomy (she used the same word) I had, I am undergoing some kind of menopause at the moment.

Spiritual care by family members, comprising of care in the religious domain, and other forms of care which have to do with activities on spirituality in relation to the illness, its treatment, cure or even with the death of the patient is widespread. Spiritual care also has to do with beliefs in ancestors or ghosts (*sisai),* witchcraft (*ayɛ kpɛmɔ*), curse (*loomɔ*), abomination (*musu bɔɔ*) and issues connected to other entities of the patient's own personhood; such as soul (*kla*) and spirit (*susuma*). This aspect of care is based on Ga traditional beliefs about disease causality, treatment and cure. In some cases, female relatives conferred with *wɔŋtsɛmɛi* (traditional priests) to ascertain the spiritual cause of illness.

Spiritual churches, prophetesses and prophets were others that patients and their families resorted to for spiritual solutions to their illness. Importantly, spiritual activities such as praying with patients, accompanying them to special church programs such as crusades, and healing services were important ways caregivers showed emotional care to patients (this overlaps with spiritual care). While some spent just a few hours in these facilities for prayers and spiritual fortification, others spent months camping in churches and places of prayer for spiritual healing and cleansing. In some of the churches (spiritual and independent) certain spiritual rituals were performed with the use of specific symbolic materials on patients. Most patients were given "anointing oil" (olive oil which has been prayed over by a church leader) to smear on specific parts of their bodies (typically on the affected organ), and at particular times. Some patients were also asked by prophets and prophetesses to put drops of "anointing oil" in their food

before eating, and patients also drunk it raw. It was also sprinkled on the bed before lying on it to sleep. Patients also received water that has been prayed over by spiritual leader, popularly called "holy water". One patient who lived in a prayer camp for six continuous months was taken to the beach once every week for spiritual bathing in the sea by the leader of the prayer camp. Patients were also asked to wake up at specific times in the night (when wicked forces and witches are believed to have become most active) to pray. All these require constant moral and physical support from family caregivers who were also involved, and participated actively in most of these spiritual rituals. For instance, a patient's wife had to live in the prayer camp for six continuous months so that she could assist him in bathing, feeding, sleep with him in the room and cook for him. Revelations on disease causality are also sometimes made at these spiritual churches. While the consultation is usually made in the interest of the patient, it has led to some family conflicts in certain cases.

Consultations at a prophet's, made on behalf of a 41-year-old cancer patient by his mother and sister revealed that someone in the family had given him a gift which contained the charm that caused the illness. The prophet did not give them any further description of the culprit, the particular period the gift was given, and even the content of the gift. The ambiguity of the revelation created so much tension, suspicion and conflict in this particular family. The patient's wife, who was his primary caregiver, was the first to be suspected but when she threatened to leave the patient, the suspicion was made on another person. It was interesting to note that families which had consulted the *wɔŋtsɛ* for disclosure on disease causality shifted to Christian religion and particularly independent churches, charismatic churches and prophets for further treatment of their disease. Many family members accompanied patients to prayer camps and prayer meeting. Others showed solidarity in spiritual ways through having morning devotions and family prayer sessions together. Family member's provision of care for spiritual relief of disease

was very important to them, particularly based on the popular belief that it is not every disease that you cure in the hospital-*dzee hela fɛɛ atsaa yɛ hospital*.

8. Secrecy and Confidentiality

Keeping the health status (diagnosis) confidential was very important for cancer patients, fearing that cancer diagnosis signifies death, tragedy, pain and misfortune, and if people got to know, they would only instill fear into them. While patients were not concerned about stigma, or at least it did not reflect in their conversations and conduct, they were troubled that if people got to know they would be stared at, gossiped about, pointed to, and they would become the talk of town. Most patients who could articulate the impact of people's reaction to their disease condition pointed out that they did not like sympathy, but liked to be empathised with, adding that sympathy made them feel miserable and unfortunate, especially when they were trying to come to terms with their disease. It always drew their mind to the very issues in their lives that they would want to forget. Several patients indicated however that, the reaction of most people to their disease was that of sympathy and not empathy, so they would rather that people did not get to know because what they desired was empathy. They therefore tried as much as they could to look and appear normal.

When Ann had a mastectomy while still in the university, her parents arranged for her to relocate to a private hostel, where she had a single room to herself. According to her, it was very important to keep her condition secret because:

> People talk too much about things that do not concern them. When people get to know they would talk and I will never be able to complete my tertiary education. I had to try very hard to look normal even if it was inconvenient.

Trying to be normal is a difficult state to maintain, and means many sacrifices of privileges and rights for patients. I report a woman's experience. Okailey was in formal employment when she was diagnosed with cancer of the cervix. Although she could have claimed her expenses on medical treatment including her surgery, she chose to bear all the costs with a loan she took from her banker at an interest rate of 28% per annum. Although she could have asked for a refund of her medical bills from her employers, she rejected that option. She did this because she did not want anyone in her office to know about her condition. Also, instead of taking sick leave, she used her annual leave for the surgery so that people in her office would not know she was sick. She would also not ask for excuse duty when she needed time off to rest and recuperate, and tried to work hard so that no one would suspect she was ill. She rarely missed work even when she was ill or depressed. The result was that she soon broke down, earlier than normal.

Also, the extent and the importance of keeping a diagnosis secret is closely related to the visibility of its pathophysiological signs and symptoms, and the extent to which these can be concealed. One patient who has had a mastectomy had been successful in concealing this from their own adult children, (19, 16, and 12 years old) with whom she shared an apartment. This meant that she and her husband, who is the only household member aware of her status, do not discuss her condition at home. Bottling up and not talking about one's disease condition with significant persons could also have some negative psychological effects on a patient. Such levels of confidentiality and secrecy would not have been necessary or possible for a diabetic who has been amputated or a stroke patient with all the visible signs of paralysis.

Managing the spread of information disclosure of chronic illness was so important to some patients that they had to relocate to the residence of their mothers, aunts or sisters, so that the people in their original neighbourhood would not see them in their ill health and physical deterioration.

9. Care limitation/Care Deficits

It was observed that emotional care, through showing empathy, and affection were only frequent at the onset of disease or at its discovery. Caregivers got very tired and their emotional support to patients waned. They misconstrue patients' emotional difficulties as their deliberate attempt to frustrate them, or to gain attention and undue service from them. Many of them therefore spoke harshly to patients and recount thus:

> I have given her heart (encouraged her) all these past two years but she is always eating her heart (worried); I don't know what else to tell her. It is not easy for all of us. We are all tiring.

> These days she has become very difficult, she complains too much, she doesn't appreciate any of these things we do for her. When visitors come she sells us (complains about us) to them and we are very hurt.

> But he must know that I am already doing a lot for him, I tell him that he will be alright, but he still worries. Sometimes I will spend time to cook for him but he will not eat because he is thinking. I have told him that we should all look up to God for his healing.

Despite the important role of touch in emotional care provision (Chang 2001) particularly by family members in the home, I did not observe hugging, gentle and re-assuring touches, or caresses, or stroking by any caregiver. These were considered untraditional and foreign. Physical contact between caregivers and patients was restricted to assisting patient to sit up or get up from bed.

Cancer treatment is very expensive for the average Ghanaian family[6]. The National Health Insurance Scheme (NHIS), launched in 2003, covers the cost of consultation and surgery at the Korle Bu Teaching Hospital. However, the government is slow to reimburse providers, and in reality many patients end up paying out

of pocket because providers are reluctant to accept or treat patients who are dependent on the national insurance. Further, patients have to bear incidental costs such as hiring taxis to and from the hospital, following special dietary requirements, and purchasing cleaning materials and personal hygiene products. Generally, care in the domestic domain is complicated by the lack or scarcity of basic biomedical gadgets, household gadgets and disposables that facilitate sick care in the home. For many patients the financial burden of cancer, especially when it also involves the loss of the woman's income, is almost as enormous as that of the disease itself.

While most women cancer patients were grateful for their husbands' material contribution to their care, it was critical that none of the husbands contributed significantly to the physical care of their wives, not even at the end stages of the disease when the patients became critically dependent on others for basic daily care. There were no observations of, or reports of, men helping with the feeding, bathing, cleaning, or toilet needs of their wives. Until they became critically ill, the wives had been responsible for household work, and even during the illness none of the men cooked or did the laundry, even their own. Husbands also seldom accompanied their wives on routine hospital visits, and when their wives were admitted to the hospital it was a daughter or other female relative who became the primary caregiver.

Abigail had had four surgeries for breast and ovarian cancers and several cycles of chemotherapy. On each occasion she moved to her parents' home so her mother and sisters could care for her because she didn't want to burden her husband with the side effects of the treatment. He cannot do the things that my mother and sisters can do for me. Once she felt somewhat better

[6] Household incomes are generally low, with an average annual gross household income of about GH₵ 6,645.00 (GSS 2014), while patients have to pay near "international" rates for chemotherapy and radiotherapy treatment.

she would return to her marital home so that, as her mother puts it, «she could go and look after her husband and home».

Generally, wives were aware that they were perceived as burdens to their families and endeavored not to worsen the dispositions of their caregivers by nagging and complaining about so-called mundane issues. In compensating, some wives continue to do so much housework despite the stress and strain of their cancer diagnoses. Clara, for example, who had had a mastectomy about two years earlier, was exhausted by the demands of housework in addition to her work as a secretary. She had not told her children about her cancer diagnosis, not even her eighteen-year-old daughter who was in the university. She had to act "normal" and keep doing most of the housework. On weekends, she did the laundry, by hand, for the entire family—her husband, the two younger children, and herself. Her husband remained fussy about his meals and seldom ate food prepared outside the home, and so she to prepare all the household meals early in the morning before going to work, sometimes with some help from her children. If she was too ill to cook, she had to arrange for help from her sister, who was not always available.

The wives in the study often expressed disappointment that their husbands were inconsiderate, and they did not show enough affection or comfort them during the most challenging periods of their illness, particularly when they were depressed or in physical pain.

Some husbands even suggested that the cancer might be the wife's fault. A participant who was diagnosed with end-stage endometrial cancer was accused by her husband of having contracted the disease through an extramarital affair. He ignored and neglected her.

Unlike their wives, none of the husbands overtly expressed fear, distress, anxiety, or worry. Instead they seemed withdrawn, especially during the wives' final days, and eventually moved out of the marital bedroom. But throughout they never missed work, in some cases setting off early in the morning and returning when every member of household was asleep.

Reflections on past relations and pre-existing family tensions with various members, particularly those within the immediate family, came up naturally in conversations with patients and their caregivers. These gave the basis to explore the extent to which the situation of chronic illness has resulted in family solidarity or family conflicts. Within the conjugal unit of some patients, there was evidence of the condition of illness creating family solidarity than family conflict. The illness became a family challenge, which each member of the conjugal unit must at least show some concern towards, in every way possible. Families commenced and continued some new activities together, and the commonest of these is the prayer sessions families held together each morning, to pray on issues that affect the family and chiefly for the patient's recovery. Many called this "morning devotion". Within the nuclear family however this kind of solidarity did not cut across for all husbands and wives. While wives who were caring for sick husbands became more resolute, and marital commitment and love were enhanced after the onset of illness, it was not the same for husbands. Wives, who recounted past marital conflicts and ill treatments from husbands, easily forgot about the past and were observed to lavish their sick husbands with care. This was the opposite when husbands had to care for their sick wives.

A wife recounts that her husband had extra-marital sexual relationships for some years prior to his illness, and this resulted in much marital conflict and abuse by the man. Unfortunately for the wife, her mother-in-law and sister-in-law supported her husband in his pursuit to the extent of persuading him to divorce his wife and marry one of these other women. The relationship between the wife on one hand and her husband and his relatives on the other became so bad that when the husband became chronically ill with cancer, with poor prospects of recovery, his wife was accused of having caused it through a curse because of the prior maltreatment from her husband. She was however cleared when consultations made by her mother-in-

law and sister-in-law at the *wɔŋtsɛ* clear her of the allegation. This woman has «put the past behind her», as she states, and has been resolute in caring for her husband with very scanty resources and under extremely difficult circumstances.

I also observed a woman, who had divorced a patient several years prior to the onset of his chronic illness and was re-married, perform so much caring activities for her former husband. This is a mark of solidarity and care in undeserving conditions.

The condition of chronic illness did not create much solidarity between the conjugal family and the kin members of the patient. Much mistrust existed between the nuclear family and the extended family, and some patients would specifically ask that particular people in their extended family must not be told about their illness. Expressing one's emotions of anger and bitterness in response to offences committed by a patient is constrained by feelings of sympathy, empathy and care, being the socially approved feelings towards a chronically ill person. Significantly, conflicts that ensued among members of the conjugal unit, notably among siblings and children of the patient, were in relation to their grumbling over the performance of care duties for the patient.

The practice of talking to patients and caregivers separately during the field research revealed the enormity of communication blockage between patients and their caregivers. This commences right from the time of disease diagnosis. In many cases, patients kept their diagnosis from intimate persons such as husbands, children and wives, who ended up being responsible for their care at home. It was possible for patients to do so in the initial stages when their clinical manifestations were not very severe. Other patients also lied about their diagnosis and mentioned milder ailments as responsible for their signs and symptoms. Eventually, by the time the patient declares the diagnosis to his family, she/he might have somewhat overcome the initial intense effects of diagnosis. Alternatively, caregivers then commenced their own cycle of grieving over a gloomy diagnosis at a time when patients may

have come to terms with their condition and are beginning to cope with it. This affects patient-caregiver relationship in many ways. For instance, caregivers are quiet when patients want to talk, or caregivers may be crying out of shock, when patients have stopped crying from the shock of diagnosis.

Communication lapses were also observed during the whole period of treatment and nursing of patient. Patients, for reasons I could not clearly discover, kept other vital information from their caregivers. A cancer patient for instance, who later became diabetic, never told her caregivers (adult children and husband) about her diabetic status. She would just refuse meals she thought were inappropriate for her diabetic status without giving reasons, but she felt free to update me on changes in her blood sugar level. This posed a dicey situation for me when her daughter complained that she had become choosy with her meals and keep rejecting food she had not requested. I could not tell them she had developed diabetes because it was not up to me to make that disclosure. In another case, there was never the mention of the word "cancer" between a patient with her caregiver. The latter once said: «although I know the doctors have told her it is cancer, she has not told me and she doesn't know that I know it is cancer». Such lack of communication flow hindered care satisfaction and bred mistrust among patients and their caregivers.

As patients became weary of their conditions, and feelings of helplessness and hopelessness sets in, they became extremely frustrated and depressed. Manifestations of such feelings showed in their communications and general interactions with people, particularly with their caregivers, the very people who spend so much resources to support and assist them. Several patients become paranoid and unbearable, and exhibited characteristics that made it very difficult for caregivers to support them. Some patients became unappreciative and snobbish in their utterances. Patients, who had been powerful and held high status before the onset of illness, (male patients, bread winners, or household heads), try to remain resolute and assertive. Traditionally, it is ex-

pected that a patient be meek, subservient, and just follows the instructions of the caregiver, even if he/she thinks and believes otherwise, in order to merit or warrant affection, empathy and encouragement from caregivers. Alternatively, when a patient shows any contrary attributes such as being willful, assertive and resolute, it is commonly said that he does not behave like a sick person; *efeee eniŋ tamɔ helatsɛ*. Patients "difficult" behaviour demotivates effective caregiving. Also, as patients become moribund, they sometimes lose their mental capabilities and may behave like children; messing up, spilling drinks, dropping plates and cups, thereby irritating caregivers, who often view such behaviour as deliberate actions of patients to give them more work. Again, patient's urinary and faecal incontinence is sometimes seen as laziness on the part of patients.

Elderly caregivers were more experienced and reacted better to such attitudes by ignoring the difficult traits and being resolute in caring. Younger caregivers, with no experience felt very discouraged and overwhelmed by such attitudes. The lack of knowledge by caregivers on attitudinal changes in patients colours their interpretation of such behaviours. It is a fact, for instance, that patients who undergo hysterectomy experience premature menopause and could exhibit menopausal symptoms even at age thirty-one. The lack of knowledge on this may cause their being viewed as difficult. Also, most therapies for cancers of reproductive organs- breast, ovaries, and endometrium are hormone based and these affect the emotional and mental state of the patient, causing her to behave in somewhat unacceptable ways. General therapy for cancer are executed with highly potent drugs which have all kinds of side effects, but it is very difficult for caregivers to bear patients' difficult behaviours. Caregivers would usually say about patients who assertively comment about the negligence of caregivers thus: «*helastɛ enaa ehe mɔbɔ*- this sick person does not have pity on himself», and they lose heart in their caregiving activities.

The erosion of cultural support systems without the provision of alternative social welfare systems has created an immense

care deficit. These are manifested in the general weakening of communal relations and care, and concern for each other, in favour of deepened individuation, secrecy and confidentiality, unwillingness to solicit assistance and care, and stronger feelings of embarrassment at the condition of chronic illness.

Family members are generally resilient in caring for their chronically sick relatives. Care activities are mainly borne by female members of the nuclear family. Other members of the kin group, such as aunts and cousins, are not involved in caring, as existed in the past. With the absence of visible institutional programs and support to mitigate the burden of chronic illnesses on both patients and caregivers, family members endeavored to provide care under intense stress and strain. Family care remains the preserve of females of all ages, and crises situations were posed when there were no female relatives disposed to caring for the sick. While marriage did not make much difference in the care of sick wives, it greatly enhanced the care status of sick husbands. Generally, husbands provided very minimal care to their sick wives while wives lavished as much care on their sick husbands as possible.

10. Feminist Paradoxes, Ethnographer's Conflicts and Tensions

As a woman and a feminist, the realities of research respondents hit with one of the most agonising and dreaded diseases, evoked my gender sensibilities and created tensions within me. Seeing female cancer patients, whether at mid-stage or end-stage, being saddled with so much responsibility for housework was extremely depressing for me. It was troubling that husbands did not take up any housework, even in these gloomy situations. Husbands did not consider housework as their duty, it had to be performed by their wives or some other woman. It was equally worrying for me that I could not help to bring relief to my "sisters" in any structural way. Raising the issues would sensitize the women on the matter and

they could be affected psychologically. I also did not want their husbands to feel I was instigating their wives. After all, dealing with cancer was stressful enough for each of the households. Again, I found husbands' failure to give affection and emotional support to their sick wives inconceivable. Expectedly, I empathized with the women a great deal, most of whom felt deeply rejected and neglected by the men they love so much. This upset me intensely, but I could not express my sentiments even to the wives who were the victims. I pretended to "understanding", just to conform to normative Ghanaian femininity behaviours, but was internally conflicted and continuously worried that I could not address the issue with their husbands. Another fact that created further tensions in me was patients' femininity compliance to the hurtful effects of their husbands' attitudes of neglect and their enactments of masculinity. I was indeed troubled by the compliance of wives and their seeming understanding and accommodating of their husbands' behaviours. Several of them made excuses, at least at first, for their husbands' inability to do the housework or involve themselves in practical care. Furthermore, the process of performing gender and employing patient-centred method was physically and emotionally draining for me as patients got very attached to me. I got emotionally involved in the pain, fears, deterioration and helplessness. I must have been too empathetic and immersed in the issues of respondents and their comfort albeit at my own expense. I myself got hypochondriac.

To some extent, the ethnographic process in Africa does conflict the ideals of feminism but not in totality, only partially agreeing with Stacey's assertion of ethnography contradicting feminism (Stacey 1988). When ethnography pays attention to culture and contextual issues, and for that matter the differential gender relations in African societies, there would be little room for conflict. The female ethnographer acts in accordance with cultural tenets, and condones with same. She does not undermine the gender arrangement by superimposing feminist standards on her respondents.

Within the Ghanaian context, leveraging female capabilities, which often resonate with femininity ideations, places the female researcher advantageously for ethnography. Shifting between identities and negotiating positions become essential for the success of the study. After all, the researcher is not an activist on the field. An important submission of this chapter is that ethical tenets of patient-centred methods, which put the interest of patients above the interests of the research, is likely to dismantle hierarchies in the research relationship and prevent the exploitation of patients in the ethnographic process. Patient-centred methods utilizes feminine resources and are helpful in studying female cancer patients, particularly those in Africa, by supporting them and relieving them of their physical and emotional burdens. It promotes reciprocity, care, empathy and mutuality between the researcher and the researched.

While family caregiving continues to serve as an essential and foundational support system for cancer patients in Ghana, ethnographic evidence reveals critical imperfections, shortfalls, and ethical ambiguities that challenge the idealized image of the African family as an inherently perfect caregiving institution. By examining the lived experiences of families in Accra, this analysis uncovers a complex reality where the "safety net" is often fragile and under immense strain. The contradictions between cultural ideals and the daily practices of care reveal that home-based environments are not always safe or patient-centred, but are instead spaces of shifting responsibilities, emotional tensions, and negotiated ethics.

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IV. "Goodbye. And I hope not to see you again". Research relations to be forgotten

Alessandra Gribaldo

For a social science's researcher going into the field means many things. Not least among these is the fact that the field provides experiences that endure over time, the forging of long-lasting bonds, and in some cases, friendships. In anthropology in particular, fieldwork – beyond mere rhetoric – has often the power to shape the researcher as an individual who puts themselves on the line, highlighting what is a fundamental aspect of ethnographic research: the relational dimension. Typically, over the years, anthropologists continue to maintain contact with the people they met in the field, with whom relationships are deployed on various levels – of familiarity, trust, and mutual interest – starting from (and despite of) the unequal power relations that often underpin the very possibility of research.

Anthropology, as is well known, is the discipline that, among all the social sciences, has most extensively addressed the ethical and relational dimensions: throughout the discipline's history, the people contacted and encountered have evolved from figures to be recounted and remembered (beginning with Casagrande 1960) into indispensable individuals, called upon in various ways as co-authors – both individual (the informant) and collective (the community). It is impossible here to trace the various forms of co-authorship found in ethnographic research, from classic texts such as Shostack's *Nisa* (1980) and Crapanzano's *Tuhami* (1980) to Gay y Blasco and Hernández (2020), via Kopenawa and Albert (2013): however, it is worth noting that the process of reflecting on the meaning of the fieldwork has never come to an end and is an integral part of anthropological ethnographic research.

A comparison with Deborah Atobrah's work (in this book) on an ethnography of noncommunicable diseases allows me to revisit methodological issues in anthropology and the ethics of feminist methodology. It is particularly through its interplay with feminist theory and practice that ethnography has been able to highlight the importance for the researcher of recognizing her own position within the society from which she comes. This positioning, in fact, shapes the experience of research and ethnographic inquiry as well as the very definition of the object of study, requiring the ability to actively recognize power relations. As Haraway (2016) argues, research also entails active participation, achieved by formulating questions that one's interlocutors find genuinely interesting, the need to constantly recalibrate one's ability to perceive and respond, and to do all this with tact and kindness: thus, producing knowledge and positioning oneself means show responsibility to act at one's best. What this implies is an issue of ongoing debate within the field of anthropology.

The history of the debate on the ethics of ethnography and feminism is well known. Between the late 1980s and early 1990s, two essays with the same title, *Can There Be a Feminist Ethnography?*, were published, written respectively by Judith Stacey, a sociologist, and Lila Abu-Lughod, an anthropologist. Based on her research, Stacey questions whether we can take for granted that research relationships in feminist ethnography are inherently more egalitarian and respectful; on the contrary, paradoxically, the risk is that it exposes the subjects involved to greater danger and exploitation compared to other research methods. Drawing on Strathern's (1987) reflections, the sociologist argues that the asymmetrical relationship inherent in ethnographic work cannot be entirely avoided and that, therefore, a "completely feminist" ethnography cannot exist: there can be "partially" feminist ethnographies. This means the researcher's awareness of the partiality of her own ethnographic vision and the need to question the ethical dimensions of the research with a specifically feminist sensibility regarding power imbalances, while accepting the risks inherent in the ethnographic method.

While one cannot disagree with her conclusions, however, as Atobrah notes, Stacey relies on a conception of the relationship between ethnography and feminism that fails to account for negotiations, flexibility in research design, and above all the communal dimension of research; she treats the subjects of research as isolated figures, thereby substantially underestimating the agency and objectives of the individuals involved and, more broadly, the powerful force of culture and community. Following Atobrah's argument, we could also cite two other examples: Dána-Ain Davis (2013) revisited the issues raised by Stacey based on her research experience among abused Black women in the United States. In a context marked by neoliberal policies, Davis notes how it became important for these women that their personal stories be collected and heard by people in positions of greater power in the pursuit of justice. A different experience concerns Ribeiro Corossacz's (2019) research among Brazilian domestic workers' union members. In this study, the opportunity to share their biographical and political trajectories was seen as a way to strengthen the collective struggle for the recognition of paid domestic work and the subjectivity of Black women within a shared framework where researcher and workers are united around common political goals.

Recently, Tauber and Zinn (2021, p. 13) posed the following question, based on the observation that gender issues are no longer central to new publications and do not receive particular attention: "Have the insights of past critiques and experiments been absorbed to the point where discussion is no longer needed?". If we view the ethnographic narrative through the lens of the struggles, failures, and arguments produced by feminism, inevitably, as anthropologists, we are confronted with a Droste effect, or "tunnel of mirrors," which occurs when two mirrors (reflecting the identical image of the universal human being and the particular gender that constitutes it) are placed opposite one another. The image is repeated infinitely, creating a series of specular refractions that multiply endlessly, progressively

shrinking. The theme of gender, though present, is ultimately often sublimated; it fragments, becoming something else, as if it were no longer a central theme but rather a signal of a possibility to conceive the field in an alternative way, becoming a sort of "ghost theory" that has lost its object (Holbraad and Pedersen 2017; Heywood 2018). From this perspective, it is interesting to note that more than a decade ago, Graeber (2012), in his discussion of violence and the power of bureaucracy, found himself at a certain point (re)discovering feminist theory: at the end of his article, he refers to an early draft that was completely oblivious to the fact that he was proposing an argument that had already been developed historically and to which he could easily have referred. The nature of socio-sexual hierarchies and the ways in which they constitute institutions and relationality itself are no longer at stake in anthropological theory, as if they had exhausted their momentum: where is the *institution of gender*? (Mayblin 2019).

One might wonder why it is always necessary to periodically rediscover feminist politics and theory, when it has never ceased to generate critical thought – both within and outside anthropology – making a decisive contribution, starting with the crisis of representation highlighted by Abu-Lughod (1990), who rightly noted the contradiction inherent in the erasure of the female and feminist contribution to anthropological writing in the postmodern era. For Abu-Lughod, conducting feminist ethnography means creating a tension between ethnographic practice and writing, while also striving to write in a non-dominant manner, with care and engagement. It is rather paradoxical that the editors of a text that has had such an exceptional impact as *Writing Cultures* (Clifford & Marcus 1986) did not include feminist anthropologists among the authors, as their work was not deemed relevant or incapable of expressing experimental and unconventional forms of writing. The paradox lies in the fact that the feminist approach was the first to raise the issue of the partiality of the ethnographic gaze, power dynamics, and the necessity of positioning; despite

this, the statement «"truths are partial" is one that is habitually attributed to "postmodern" anthropology rather than to feminist anthropology» (Ribeiro Corossacz 2013 p. 95, *my translation*). Conversely, the accusation of partiality is the criticism constantly leveled at feminists, who are portrayed as those concerned with women rather than with general issues.

Perhaps it is not merely the tendency of most male anthropologists to avoid reading gender and feminist literature – to evade, skip over, or forget feminism in anthropology appears to be a position that deals with temporality; gender is systematically out of step with the times. Gender issues point to a temporal dimension and at the same time of emancipation making difficult to integrate them into a line of reasoning that easily connects to the history of scholarship. Gender cuts across research obliquely and often in tortuous ways, creating an ever-shifting morphing. The themes concerning feminist ethnography are undoubtedly stubbornly awkward within the discipline; they insist on issues that counterbalance any universalist tension, become entangled in personal histories, and point to different sensibilities. On these issues, Atobrah rightly points to the impossibility of generalization, the need to focus on and dwell upon individual encounters, and the importance of the relationship that is created – with care and commitment on the part of the researcher – leading to familial bonds and closeness over time, even after death. In this sense, Atobrah's position aligns with Trinh Minh-ha's 1989 proposal of the concept of "speaking nearby" – speaking while being close – which entails:

> a woman's voice, or a woman's hand, which goes to meet things in the dark and pass them on without deafening, without extinguishing in the process. Intense but gentle, it holds words out in the direction of things or lays them down nearby things so as to call them and breathe new life into them. Not to capture, to chain them up, nor to mean. Not to instruct nor to discipline. But to kindle that zeal which hibernates within each one of us (Trinh Minh-ha, 1989, p. 132).

In relation to Atobrah's work, I will attempt here to draw parallels with my own experience, which –though starting from a similar approach – yields different results, likely because I was dealing with a topic – domestic violence – that has its own unique characteristics.

In my ethnography on intimate partner violence, I sought to situate it within a broader debate on gendered subjectivity, power, and agency. What interests me here is the type of relationship that emerges when working on a topic involving testimony and pain, navigating the interplay of possibility, necessity, and duty. Elsewhere, I have discussed the intimate contradictions that mark the field of domestic violence, the possibility of testifying, the duty to do so, and the pathologizing of the desire not to speak, on the part of women abused by an intimate partner (Gribaldo 2021). As recently argued: «anthropological writing has itself long been implicitly shaped by concerns with freedom of expression, including commitments to speaking truth to power, calling out epistemic injustice, or, in an older idiom, giving anthropological subjects voice» (Candea et al. 2025, p. 50). In this context, communication in the field and research ethics fall within the scope of an analysis of the «discursive engineering of the public contexts in which speech occurs and the ways in which communication is variously shaped, hindered, encouraged, and wrestled over by actors in different ways» (id, p.58). While, on the one hand, there is now a widespread discourse that emphasizes the need to speak out against gender-based violence – and thus the importance of diverse voices coming together to form a single, unified chorus that reflects a collective demand – on the other hand, the risks involved are less obvious, as demonstrated by the outcome of the "Me Too" movement's demands (Gribaldo 2019). At stake is a discourse of the therapeutic power of narrating, which can also be found in anthropological works on violence (Jean-Klein & Riles 2005, p. 178-179), that primarily identifies women as subjects who must speak out and tell their story. Declaring an experience of violence means claiming rights

and invoking change through reference to one's personal history. At the same time women who experience violence first-hand know that testifying in front of the institutions entails the risk of being marginalized, judged excessive, seen as playing victim, and thought of as manipulative: women do not speak, speak too little or too much, their testimonies are paradoxical in their very constitution. The act of "speaking violence" (Gribaldo 2021, p. 4) is a complex and partially contradictory endeavour. Women are flouting the law and, at the same time, ignoring feminists' calls to come forward. And, in various ways, they withdraw not so much from ethnographic research (even though many women refused to meet me for an interview, and only those women who were "following a programme" at the women's centre agreed to participate), but also from what I referred to at the outset as the specific dimension of ethnographic relationality that is intended to generate anthropological knowledge. That is, the dimension of collaboration, mutual interest and potential friendship over time. Being an insider, being part of the community, as we know, is not in itself a guarantee of a politically correct ethnography, just as identifying as a woman does not automatically mean one understands other women's positions better, nor does it result in a feminist ethnography. In the case of my research, I encountered difficulties similar to those faced by Deborah Atobrah during her research, precisely because I was so close to the subjects under investigation.

One afternoon, in the early days of research, upon entering the women's shelter in Bologna and going to the wrong floor, I found myself face to face with two staff members who insisted there had been a mix-up, that our appointment was at a different time; it was only after several minutes of trying to find a solution that would allow us to meet that I realized it was a case of mistaken identity. The person the staff were expecting following a phone call had not turned up (as, they told me, often happens in cases of women abused by their partners) and they had mistaken me for her, thinking it was an oversight or a delay. In

my appearance and manner, I was absolutely indistinguishable from an abused woman seeking an urgent consultation. On another occasion, the woman I was interviewing and I laughed because we were wearing the same shoes and a very similar jumper. On one occasion, in the midst of a torrent of words about the violence she had suffered and her partner's perverse methods of control, a woman I was interviewing – who, as she spoke, seemed to be studying my reactions – stopped and said to me: «What effect does it have on you?».

Once I had the chance to write about the research, I decided not to use the interviews and the conversations I had with abused women and focus mainly on the ethnography of court hearings, not only because I wanted to respect the anonymity of the women who agreed to speak. I had difficulties in addressing the imponderable diversity of women victims. Why one woman decided to press charges and invited me to go with her to a TV program to speak out, whereas another told me her story in a whisper, wondering what might ever lead a woman to press charges, was not straightforwardly correlated to class, origin, condition, level of violence, or family history. Moreover, the peculiarities of these events could only lead to generalizations that I had no intention of encouraging, given that these are precisely the kinds of narratives that easily become part of a shared, sensationalist and quickly forgotten collective imagination, which evidently concerns the "madness" or "perversion" of the partner in question. But, in addition to my wish to address structural issues that prevent women from expressing themselves in court and being believed, there was also my desire to engage with feminism and with the possibility of speaking nearby, of remaining silent, of reclaiming silence. If feminism poses a collective question of being there and making an impact on society, who should ask the questions and to whom?

As Atobrah points out, our conversations with women who face discrimination within their families because of their husbands should certainly not be treated as a topic for family discussion, a

political issue to be championed, or a subordinate position to be overcome. In the call to report abuse or, more simply, to speak out, women are placed in a position they have not necessarily chosen, and which fails to consider the consequences for those who speak out, particularly women in situations of contextual and structural vulnerability. The desire to protect oneself and one's children is recognized in feminist practice as legitimate and paramount by lawyers and staff at women's shelters, who provide all the necessary support to alleviate the guilt of those who do not wish to report the abuse, finding ways to ensure safety and a life free from violence. Who can afford to expose themselves and suffer for the cause of gender-based violence? Who can recount things that will often not be believed in court? Expressions such as «Do you understand what I am saying?» reflect the victims' own perception of the difficulty in being believed and the awareness of the possibility of a shared experience.

And yet my role as a researcher required, by definition, speech, testimony, memory, and the recounting of a toxic relationship that people wanted to forget – for a thousand reasons, not least to put the failure of their relationship behind them, to have the chance to reimagine themselves as different, free, and to start a new life. Listening to their testimonies led me to find a necessary nearby space, a sort of active listening in the face of different modes of expression, ranging from a torrent of words and demands, to broken sentences, suggestive silences, and tears. This understanding, listening and connection, which was obviously based in part on sharing a position of gender and "closeness", nevertheless just as inevitably evaporated immediately after the meeting. Even three-hour-long interviews, which likely represented an outpouring and a release, ended with a sigh of relief when I switched off the recorder. What was certainly missing in my relationship with the women I came into contact with was the continuity of the relationship, as is typically expected in the ethnographic tradition of anthropology. On the contrary, the women I met expressed a desire never to speak of these issues

again, either to me or to anyone else, and that the interview marked a point of closure. When saying goodbye, the farewell was often tinged with irony: we would smile and exchange awkward phrases such as "all the best for the future", "hang in there" or "good luck"; one young woman told me quite openly that she hoped never to see me again. There is no circumstance in which I would have looked forward to a new meeting, a relationship, or even a recognition: on more than one occasion, I have happened to bump into a woman I had interviewed on the street and, together with her, pretended we had never met, ignoring one another.

As Atobrah suggests it is not productive to assume a homogenous ethnographic process, which suggests a unitary research ethic. In this sense, feminist ethnography does not claim to have a single set of ethical principles, a consistent approach, or purity of intent. The field involves negotiation: second thoughts, adopting stances different from those taken in everyday life, the discomfort of appearing and being different or of producing something that does not immediately correspond to our ideal, settling for an incomplete relationship. As a researcher I felt both too involved and at the same time not involved enough, not only because of privilege, but also simply because in health and not in a toxic relationship. Research intents twist confronting reality, contexts, the people we meet. To return to Trinh Minh's ha reflections: «language is at the same time a site for empowerment and a site for enslavement […] the space of language and meaning is constantly interrupted or effaced by the gaps of non-senses, absences, and silences» (Minh ha in Chen 1992, p. 86). The relation with ethics and language is for a woman always more complex than expected as «to be a woman is to be in a situation» (Butler 2016, p. 298). When Atobrah writes about love and respect for the people she meets in the field, she explores a theme that remains crucial to the discipline regarding the entangled and uncomfortable merging of the personal and professional.

As is well known, Ruth Behar has passionately explored this topic suggesting that «anthropology has always been vexed about the question of vulnerability» (Behar 1996, p. 5). New questions arise regarding the possibility of conceiving involvement and pain as a space of knowledge, and research as a possibility «to risk proximity, to write from *within* it rather than *about* it» (Dantzer 2026). Can the power dynamics between those who conduct research as a profession and the research subjects be managed, addressed, re-enacted and re-examined on a day-to-day basis? To what extent does the field itself allow us to rethink the researcher's role and their own political stance? What and how much can we do in the field to accommodate our research participants, and when, in some cases, must we simply disappear from their lives? When is it not even appropriate to begin a research project?

Almost forty years ago (1987), Marilyn Strathern suggested that the difficult relationship between feminism and anthropology was the paradoxical result of a close connection, in that both disciplines concern the notion of difference: of gender in one case, of culture in the other. But whilst feminism combats its "other" in the form of patriarchy, anthropology has a different relationship with cultural difference, supporting, investigating and understanding its meaning. Anthropology and feminism produce a sort of mutual mockery in which anthropology criticises feminism's claims to address a single subject (women) and feminism criticises anthropology's relativist claims and its inability to see the power asymmetries in the ethnographic encounter. This tension has not dissipated over time: various anthropologists adopt postcolonial, Black, transnational, Indigenous and feminist perspectives to critique and intersect cultural differences with power, struggles, practices and change. Feminist movements continue to challenge the discipline of anthropology, just as anthropological approaches constantly engage with and challenge feminist, queer and trans movements and practices. It is precisely this "uneasy" relationship that creates a vibrant space for reflection. The feminist approach in anthropology has also

proved fruitful through works that do not necessarily focus on gender per se, but use the theories and practices of feminist reflection to engage with different areas of anthropological knowledge. There are few instances in which this is readily recognised. Feminist anthropology is therefore not something that can be strictly identified, even though one can, of course, be both an anthropologist and a feminist, as the author is. It is therefore necessary to conceive of the encounter between anthropology and feminism as a dynamic: "feminist anthropology" is one of the most productive paradoxes, and the ethnographic dimension is undoubtedly its field of experimentation.

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V. Kinship, stigma and pursuit of safety experience of people livinh with HIV in Ghana within the contecxt of New Treatment Guidelines and UNAIDS 90-90-90 targets

Benjamin K. Kwansa

1. Introduction

I first met Maame Amponsah seventeen years ago, at the beginning of my ethnographic fieldwork on the everyday lives of people living with HIV (PLHIV) in Ghana. Over the course of this long-term engagement, her life has reflected many of the social, relational, and moral complexities that characterise the HIV experience in the country. Since our initial meeting, she has lost her first husband (who was also on antiretroviral therapy (ART) and later a second partner, to whom she never disclosed her status because her viral load had long remained undetectable. She has since remarried, and these successive marriages have been some of the ways she has sought to normalise her life, combat persistent stigma, and reclaim a sense of social legitimacy.

The death of her first husband, Daniel, triggered widespread rumours about her own HIV status, especially as his illness advanced and he showed symptoms commonly linked to AIDS in local discussions. Although she eventually gained strong support from clinic staff, peers (notably leaders of the now-defunct PLHIV associations), and members of her church, her birth family largely distanced themselves from her during this period. This falling-out has never fully been resolved. Even now, she still faces subtle but noticeable forms of exclusion when she returns home for family gatherings, such as funerals or other communal occasions.

Despite these tensions, she has remained dedicated to her treatment. She continues to travel a significant distance to access ART at a facility far from her community, a habit driven by both routine and the need to keep her treatment confidential. Although she now visits the clinic only twice a year to collect her medications, this journey remains part of her broader strategy to prevent unwanted disclosure. At fifty-four, she has outlived many of the peers she started therapy with, yet she has also become a quiet pillar of support for newer clients at her current facility.

Over the past twenty years, the global HIV landscape has experienced a significant transformation, primarily driven by the introduction of the UNAIDS 90-90-90 targets in 2014. These targets aimed, by 2020, for 90% of all people living with HIV (PLHIV) to know their status, 90% of those diagnosed to be on sustained antiretroviral therapy (ART), and 90% of those on treatment to achieve viral suppression (UNAIDS 2014). The overall goal is to eliminate AIDS globally by 2030, known as Agenda 2030. Supported by the World Health Organisation's "Treat All" (or Test and Treat) policy, which recommends immediate ART initiation for all PLHIV regardless of CD4 count or clinical stage (WHO 2016), these initiatives laid the normative and operational groundwork for restructuring national HIV programmes worldwide.

Ghana aligned itself with this global momentum through the Ghana AIDS Commission (GAC), the Ghana Health Service (GHS), and the National AIDS/STI Control Programme (NACP). The National HIV & AIDS Strategic Plan (2016-2020) incorporated the 90-90-90 framework, setting ambitious targets for early diagnosis, universal treatment initiation, and expanded viral load suppression (Ghana AIDS Commission 2016). In 2017, the President reaffirmed the national commitment to achieving these goals, signalling renewed political will and garnering substantial support from global partners, including WHO, UNAIDS, PEPFAR, and the Global Fund. Between 2016 and 2017, Ghana adopted the "Treat All" policy, enabling every individual diagnosed with

HIV to begin ART immediately (Ghana Health Service 2017). This paradigm shift was institutionalised in the updated Ghana Guidelines for Antiretroviral Therapy and later in the Consolidated Guidelines for HIV Care, which emphasised differentiated service delivery, task shifting, and the integration of HIV services across multiple tiers of the health system (Ghana Health Service 2019; NACP 2022). These reforms reoriented HIV care towards greater accessibility, efficiency, and clinical standardisation.

Yet, the country's progress towards the 90-90-90 targets was uneven. By the end of the 2020 UNAIDS benchmark, 63% of all people living with HIV in Ghana knew their status, 95% were on sustained antiretroviral therapy, and 73% of those on treatment had achieved viral suppression (GAC 2022), thus only meeting the second target. Persistent structural limitations, including gaps in viral load testing capacity, shortages of human resources, commodity security issues, and broader health system constraints, continue to hinder implementation (Ayisi Addo et al. 2018). At the same time, deep-seated social and cultural barriers, such as stigma, discrimination, and the weakening of family-based care systems, undermine disclosure, impair adherence, and contribute to attrition from treatment (Ouner et al. 2025; Addo et al. 2022).

As Maame Amponsah's story illustrates, the promise of universal treatment, viral suppression, and long-term survival often coexists with persistent stigma and fragile kinship relations. This paper explores how PLHIV reconstruct protective forms of "practical kinship" through peer networks, healthcare workers, and other relational resources to secure safety, emotional support, and continuity of care. More significantly, this paper shows that while policy shifts have improved biomedical outcomes, they have neither erased stigma nor resolved the moral ambivalence surrounding HIV. Instead, they have reconfigured the social terrain within which PLHIV negotiate identity, care, and belonging. Attending to these dynamics is crucial for understanding how global targets are lived, negotiated, and made meaningful in the lives of those they are designed to benefit.

2. Literature Review

Anthropological scholarship over the years has demonstrated that kinship is not merely a biological fact but a culturally patterned system of moral obligations, reciprocity, and care. Foundational work, including Radcliffe-Brown and Forde's (1950) analyses of African kinship systems, Fortes's (1969) emphasis on kinship as the foundation of social order, and Goody's (1973) comparative studies, highlights the centrality of kinship in shaping rights, responsibilities, and caregiving in African societies. Barnes's (1973) distinction between *genetrix* and *genitor* similarly underscores that kinship relations are socially constructed, while Bloch (1973) shows how short-term economic pressures can undermine long-term moral obligations embedded in kinship systems. In contemporary contexts, urbanisation and economic precarity have been found to reshape extended family roles in Ghana (Clark 1999; Read & van der Geest 2019; Oppong 2021), reaffirming that kinship remains dynamic and context-dependent.

These insights correspond with HIV scholarship in sub-Saharan Africa, which demonstrates that the epidemic is rooted in broader social and moral contexts rather than functioning solely as a biomedical issue. Kinship networks influence illness experiences, treatment-seeking behaviour, and disclosure decisions (Livingston 2012; Kwansa 2013; Niehaus 2018). In line with Carsten's (2000; 2004) idea of "relatedness," family in African settings is a practical and moral construct formed through shared care, co-residence, and reciprocity. However, HIV-related stigma often disrupts these networks. Studies across the region suggest that fear of blame, gossip, and social exclusion can fracture kin ties and hinder disclosure (Dako-Gyeke 2016; Kwansa 2013; Mbonu et al. 2009). In Ghana, stigma intersects with gendered expectations and kinship norms, making the household a vulnerable space for many PLHIV (Addo et al. 2022; Kwansa 2013; Dako-Gyeke & Dako-Gyeke 2013; van der Geest et al. 2019).

Such disruptions lead PLHIV to reconfigure their social worlds by cultivating what has been called practical kinship:

adaptable, purposeful relationships that serve as kin without necessarily being based on biological ties (Carsten 2000; Levine 2008). In HIV contexts, these ties reshape expectations of responsibility, trust, endurance, and moral accountability around the experience of illness. They usually develop through peer networks, friendships with fellow PLHIV, and trust-based relationships with healthcare workers (Russell et al. 2016; Whyte 2014; Kwansa 2013; Dapaah 2012). Such networks provide not only material support, including help with accessing care (e.g. transportation), but also emotional solidarity, adherence support, and a sense of belonging. These relational formations constitute what Nguyen (2010) describes as HIV sociality – affective communities built through shared experiences of stigma and survival.

Care for PLHIV is influenced by social power, institutional norms, and personal agency; what Mol (2008) describes as «the politics of care». This concept helps clarify how PLHIV navigate tensions between biomedical expectations, such as adherence and viral suppression, and social realities, including secrecy, stigma, and changing kin support (Parker & Aggleton 2003; Kwansa, 2013). Healthcare workers often become central figures in PLHIV's practical kinship networks, extending care beyond clinical treatment to encompass emotional support, protection, and discretion (Dapaah 2012; Van der Geest et al. 2019). Although Ghana's "Treat All" policy and progress towards Agenda 2030 represent significant biomedical advances, persistent stigma and unstable kin support continue to influence engagement with care (Ouner et al. 2025; Addo et al. 2022). As Clark (1999) demonstrates in her study of Asante kinship, caregiving duties are grounded in economic precarity and moral negotiations. PLHIV's reliance on alternative networks, such as peer groups, NGOs, and supportive clinicians, therefore reflects both HIV-related stigma and broader shifts in how kinship and care are organised in contemporary Ghana.

Table 1 below highlights the main changes between earlier (pre-"Treat All") HIV treatment guidance and the more recent consolidated guidelines used in Ghana (in line with WHO/UNAIDS policy shifts).

Table 1. Summary of HIV treatment guidelines in Ghana.

Component	Older guidelines (pre-"Treat All" / pre-2016)	Newer guidelines ("Treat All" / consolidated 2017–2019 & updates)
Treatment eligibility	• ART initiation based on CD4 thresholds and/or WHO clinical staging. • Patients often had to reach a CD4 cut-off	• Immediate ART for all diagnosed PLHIV regardless of CD4 or stage ("Treat All"). • Ghana adopted "Treat All" (2016–2017) and codified this in the national ART guidance
Primary monitoring metric	• Reliance on CD4 counts and clinical assessment • Viral load is limited or used sparingly where available.	• Viral-load testing as the primary tool for monitoring ART effectiveness • CD4 is used mainly for advanced disease assessment. • Ghana guidelines emphasise routine viral load monitoring where available.
Definition of a stable client	• Terms and criteria varied; "stable" was often loosely defined (time on ART + adherence), leading to inconsistent practices.	• More precise criteria for "established on ART": e.g., ≥6 months on ART, evidence of adherence, no current illness, and viral suppression (or surrogate markers where VL unavailable). • Supports differentiated care.
Visit frequency and dispensing	• Frequent clinic visits and monthly dispensing are common for many clients.	• Differentiated Service Delivery (DSD) – Multi-month dispensing (3–6 months for stable clients) – Less frequent clinic visits – Community pick-up options • Reduces patient burden and clinic load
First-line ARV regimens	• Regimens often based on NNRTI backbones (e.g., efavirenz) and older NRTI combinations • Rollout of new drugs is gradual.	• Updated regimens incorporate newer drugs (e.g., dolutegravir (DTG) roll-out plans from 2018–2019) • Improved pediatric formulations and WHO-recommended first-line combinations. • Ghana planned DTG roll-out in 2019
Advanced disease management	• Less standardised approaches in resource-limited settings – Opportunistic infection guidance is uneven.	• Stronger guidance on management of advanced HIV disease and co-infections (TB, cryptococcus), with standardised prophylaxis and referral algorithms

[1] Key sources: Ghana consolidated guidelines (2017/2019), WHO 2016 ARV guidelines, UNAIDS 90-90-90 materials (UNAIDS 2014; 2019).

Service integration	• Testing, PMTCT, and ART are often in separate program silos • Integration varied by facility.	• Consolidated guidelines integrate HTS (testing), linkage, ART, PMTCT, and differentiated models into one framework to strengthen the continuum of care.
Task-sharing and workforce	• More clinician-led care • Limited task-sharing policy in some settings.	• Explicit support for task-sharing (nurses, lay cadres, peer navigators) to expand service capacity and decentralize care.
Data and targets orientation	• Less emphasis on cascade metrics, before the 90-90-90 global push.	• Oriented to 90-90-90 (and later 95-95-95) cascade metrics: testing, treatment coverage, viral suppression – with routine monitoring and reporting emphasis. • Ghana incorporated the 90-90-90 targets into its national strategic planning.
Patient privacy and differentiated access	• Clinic-level variability; stigma concerns often led patients to travel far for care.	• DSD and decentralisation seek to reduce stigma-related barriers • Confidentiality and data protection remain critical implementation concerns • Clinics increasingly offer community-based options (self-testing guidance is also standardised).

3. Conceptual Framework

This study sits at the crossroads of kinship studies, stigma theory, and the anthropology of care, leveraging sociological and anthropological insights to explore how PLHIVs in Ghana manage social and institutional relationships in their pursuit of safety and wellbeing. The framework views HIV care not merely as a biomedical activity but as a relational practice influenced by moral expectations, emotional bonds, and institutional structures.

Practical Kinship and the Reconfiguration of Relatedness

Building on Carsten's (2000; 2004) reconceptualisation of kinship as an ongoing process of "relatedness," this study adopts the

concept of practical kinship to explore how PLHIV construct alternative networks of care when biological kinship becomes unreliable or unsafe. While classical kinship studies emphasise the moral and organisational structures of kin in African societies, contemporary ethnographies in Ghana show that HIV-related stigma can significantly reshape these obligations. Kwansa's (2010; 2013; 2014) work documents how PLHIV navigate fractured family relations, spiritual expectations, and secrecy to secure care outside the home, often finding greater reliability in religious communities, therapeutic networks, or friendships formed through shared illness (see also Whyte 2014).

Similarly, Dapaah (2012) and Dapaah and Spronk (2016) demonstrate that Ghanaian treatment centres often function as surrogate households; spaces where nurses, counsellors, and other PLHIVs provide emotional and moral support that biological families might withhold. Van der Geest et al. (2019) describe these hospital-based relationships as «diverted intimacies», a redirection of affection, trust, and dependence from kin networks to institutional spaces. These ethnographies reveal that practical kinship is a lived, relational strategy through which PLHIV reconfigure belonging, maintain confidentiality, and rebuild identity within stigma. In this context, practical kinship is regarded as a form of social ingenuity and resilience; an adaptive method to create kin-like bonds that offer safety, trust, and daily moral recognition in the absence of reliable familial care.

Stigma, Politics of Care, and the Pursuit of Safety

HIV stigma is understood here through Goffman's (1963) concept of spoiled identity and Parker and Aggleton's (2003) view of stigma as a structural, relational, and moral issue. In Ghana, stigma manifests through gossip, moral judgment, and social sanctions that make disclosure and seeking care socially risky (Kwansa 2013; Dako-Gyeke 2016; Addo et al. 2022). PLHIV often weigh the risk of exposure against the need for support,

leading to selective disclosure, concealment, and careful navigation of household relationships.

Ghanaian literature emphasises that the pursuit of safety extends beyond medical survival to include managing social risks. Kwansa's (2013) ethnographic research demonstrates how PLHIV balance secrecy and trust within family environments, where HIV is linked to sexual impropriety or religious transgression. Dapaah (2012) shows how patients fear ridicule, blame, or distancing from relatives, leading them to seek refuge in treatment centres where stigma is less severe, and confidentiality is better protected. Therefore, the framework conceptualises stigma as a force that influences daily decisions and relational strategies through which PLHIV attain emotional, material, and therapeutic safety.

The study also explores the idea of HIV sociality; forms of emotional attachment that stem from shared experiences of illness, vulnerability, and survival (see Nguyen 2010; Whyte 2014). In Ghana, these socialities often form within ART clinics, peer support groups, and networks of long-term clients who mentor newer patients (Dapaah & Spronk 2016). Such spaces act as centres of social repair, where PLHIV exchange advice, encouragement, and practical support while collectively facing stigma.

The politics of care (Mol 2008) offers an additional analytical perspective for understanding how care is distributed, limited, and (re)negotiated within these institutional settings. Care is shaped not only by health system priorities but also by the moral labour of healthcare workers, who often extend their roles to include counselling, protection, and fostering trust and confidentiality (Dapaah 2012; Kwansa 2013; van der Geest et al. 2019). These relationships blur the boundaries between formal and informal care, illustrating a therapeutic landscape in which emotional support and relational security are as vital as biomedical effectiveness.

Global and National Policy Drivers: The 90–90–90 Agenda and Ghana's "Treat All" Approach

Ghana's adoption of the "Treat All" guidelines and alignment with the UNAIDS 90–90–90 targets underpin the policy context of this study. These global commitments seek to normalise HIV treatment, promote universal testing, enable immediate ART initiation, and achieve sustained viral suppression (See Table 1). However, the framework highlights that such biomedical scaling-up relies on levels of social support, disclosure safety, and kinship stability that do not always align with local realities. As the literature on PLHIV in Ghana indicates, the success of the national HIV guidelines depends not only on ART access but also on the relational infrastructures, including networks of trust, practical kinship, and HIV sociality, which enable PLHIV to stay engaged in treatment.

The framework, therefore, places HIV care in Ghana within a broader context of relational and moral negotiations where kinship, stigma, and institutional care intersect; it shows that the success of the 90-90-90 agenda depends as much on social infrastructures of trust and care as on biomedical access. It highlights how people living with HIV mobilise practical kinship and institutional social networks to navigate stigma, both at hospitals and in the community, and to secure the safety needed for long-term treatment in light of the new guidelines.

4. Methodology

The study employs a comparative longitudinal ethnographic approach to explore how PLHIV in Ghana redefine kinship, secrecy, and care amid changing policy and therapeutic landscapes. Two cohorts form the foundation of the research. The Ashanti cohort consists of individuals first engaged between 2007 and 2010 during earlier fieldwork in Offinso and Kumasi (Kwansa

2010; 2013; 2014). Eleven remain in contact, along with four socially connected participants recruited after 2013. The Greater Accra cohort, recruited in 2025 at the Abokobi Polyclinic, includes seven PLHIV whose experiences reflect Ghana's current "Treat All" environment. In both cohorts, the study also examines close associates: individuals trusted with participants' HIV status and involved in their daily care.

Sampling is purposive, aiming to capture heterogeneity in treatment trajectories, gender, age, socioeconomic status, and relational circumstances. Recruitment is facilitated through treatment facilities, support groups, and community networks, with snowball sampling used to reach not only other PLHIV but also significant others, close associates, and socially connected PLHIV. Associates are contacted only after the participant grants permission, and each provides independent consent, thereby preserving the participant's control over disclosure.

The data collection includes life histories, semi-structured interviews, participant observation, and social network mapping. Life histories track long-term illness journeys for the Ashanti cohort and offer baseline and follow-up narratives for the Greater Accra cases. Interviews are conducted flexibly during field visits, after major life or treatment events, or by phone. Close associates provide corroborating viewpoints on care, secrecy, and relational tensions. Participant observation occurs across clinics, homes, churches, workplaces, and community gatherings, capturing everyday negotiations of stigma and care. Fieldnotes contain descriptive accounts and reflexive memos. Social network maps display changing patterns of emotional, material, and informational support. Interviews are audio-recorded with consent, transcribed, translated from Twi, verified for accuracy, and coded in NVivo.

Considering the sensitivity of HIV issues in Ghana, confidentiality protocols are strict. Ethical approval was secured from the Ghana Health Service Ethics Review Committee. Participants give informed consent, interviews are held in private

settings, and pseudonyms are used to protect identities. Provision for referrals to psychosocial support is in place if needed, though none have been required since 2015, and modest reimbursements cover transport or phone expenses.

The analysis combines inductive and deductive coding to identify patterns across themes, such as kinship practices, stigma management, and care. Longitudinal narrative analysis traces shifting stories of illness, belonging, and disclosure over time. Triangulation across interviews, observations, and associate accounts enhances credibility, while reflexive memos provide an audit of analytic decisions. Limitations include recall bias, attrition, and social desirability, mitigated through prolonged engagement, triangulation, and the inclusion of multiple interlocutors, where possible.

5. Findings and Discussion

Maame Amponsah's vignette in the introduction to this paper – her careful management of treatment, the burden of secrecy, and her improvised networks of support – encapsulates the central dynamics shaping life with HIV in contemporary Ghana. Her experience mirrors the broader patterns observed across the study: fractured kin relations, calculated decisions about disclosure, and the strategic use of religious and therapeutic spaces to create safety and belonging. These findings demonstrate that HIV reshapes the social and moral worlds in which personhood and care are negotiated. Living with HIV emerges not only as a biomedical task but as a relational, moral, and spiritual endeavour carried out amid persistent stigma, uneven kin obligations, and policy-driven expectations of responsibility. Participants across the study sites continually rebuilt their social lives through pragmatic and affective practices focused on survival, dignity, and a sense of moral worth.

Reconfiguring Kinship Under HIV: From Biological Ties to "Practical Kinship"

Across both cohorts, HIV compelled participants to renegotiate the boundaries of kinship as biological ties were strained by stigma, fear, and moral blame. Many participants, particularly in the Ashanti cohort, reported that disclosure remained dangerous within the household. Esther, one of the women from the Ashanti cohort, insisted that "the day I tell my husband will be the end of me," echoing the persistent risk of marital dissolution, blame, or violence that disclosure could trigger. These findings align with earlier Ghanaian ethnographies documenting how HIV unsettles the moral foundations of family life, rendering some PLHIV "unsafe" within their own households (Dapaah & Spronk 2016; Kwansa 2013; van der Geest et al. 2019). Family members often continued to associate HIV with moral or spiritual failure, leading participants to manage illness privately and depend on non-biological networks. A hospital worker in Accra explained that many families only sought confirmation of a relative's HIV status after their death, a phenomenon that underscores the lingering fear and moral ambivalence surrounding HIV in Ghana. Such dynamics mirror van der Geest et al.'s (2019) observation that "avoidance" within families is often balanced by the emergence of new, clinic-based intimacies.

Indeed, as biological kinship weakened, participants increasingly fostered practical kinship (Carsten 2000) – relationships built through shared suffering, reciprocity, and emotional support. HIV clinics, support groups, and peer networks became spaces where PLHIV met others who "understand what I am going through," as Massa, a long-term participant, explained. He repeatedly described meeting fellow PLHIV as *m'ahyia me nua* ("I've met my kind"), emphasising how shared diagnosis fostered new moral solidarities. Similarly, Mr Nkansah stated that only when he met people who knew his status could he "smile without faking it."

These findings correspond with Dapaah's (2012) and Dapaah and Spronk's (2016) descriptions of Ghanaian clinics as surrogate homes – spaces of continuity, reliability, and affection. They also support Kwansa's (2010; 2013) argument that HIV sociality fosters alternative moral communities through which PLHIV navigate stigma and re-establish a sense of belonging.

Stigma, Secrecy, and the Politics of Disclosure

Although Ghana's HIV programme has expanded significantly under the 90-90-90 and "Treat All" policies, stigma, both social and biomedical, remains deeply rooted (Nyblade et al. 2019). Throughout both cohorts, participants continued to conceal their status from spouses, parents, (adult) children, and other family and community members. Secrecy remained a carefully managed survival tactic, influencing daily decisions about where to seek care, how to store medications, and whom to trust (see also Kwansa 2013).

Under the differentiated service delivery (DSD) models, long dispensing intervals (e.g., 6-month refills) allowed many to keep their HIV status private. Hasiya's story illustrates this well. Despite discovering her HIV infection during PMTCT while her husband had been on ART for three years, she explains how long refills and meeting her nurse discreetly at her church helped her maintain privacy. After her husband's death and her conversion to Christianity, she became more consistent with her treatment, leading to viral suppression in 2019. These forms of quiet support highlight the way biomedical and religious spaces intersect in the pursuit of moral and social safety (Kwansa 2014; Prince 2012).

It was observed in both the Ashanti and Accra cohorts that stigma had developed into more subtle, internalised forms; what some scholars refer to as responsibilised stigma (Bernays et al. 2017), where biomedical expectations (such as viral suppression and perfect adherence) create pressure to be a "good patient." They argue that clinics can become places where PLHIV

experience stigmatisation for non-adherence or less-than-perfect adherence to treatment, because this behaviour is viewed as a deviation from the expected perfect compliance of a "responsibilised" citizen. Participants described anxiety and guilt when ill, missing check-ups, losing pills, or experiencing viral rebound, with fears of moral judgment rather than contagion from hospital staff. Asiamah, a forty-year-old man in the Accra cohort who has been on treatment since 2022, explained that:

> I can tell from the way the nurse talks to me that she is not pleased with my progress and that I missed my appointment two weeks ago. She keeps comparing me to other patients she says came here in worse conditions yet are now doing very well. Coming for my medical checks and collecting my medicines has become a daunting task. If I had my way, I would go somewhere else, where I wouldn't be compared to others. She doesn't understand how I manage to take my medicines and come here as often as I do. I have nowhere else to go, so I just gather the courage and come.

Thus, stigma persists not only through public shaming but also through internalised moral surveillance.

Significantly, and related to the above, the comparison across cohorts highlights important temporal shifts. Between 2007 and 2015, PLHIV faced limited treatment options, intense stigma, and fragmented social support. By 2025, Ghana's full adoption of "Treat All" and alignment with the UNAIDS 90-90-90 goals significantly increased ART access and normalised treatment. Six-month refills, decentralised care, and counsellor engagement have markedly transformed the therapeutic landscape. However, as Nguyen's (2010) concept of therapeutic citizenship suggests, expanded access also brought new expectations: to adhere to treatment, suppress viral load, and take on biomedical responsibility. These expectations have created new hierarchies – between those who "perform" responsible patienthood and those who struggle (as in Asiamah's case above) – which results in stigmatising behaviours from health workers who expect more from the

latter. Therefore, while policy shifts have improved biomedical outcomes, they have not eradicated stigma or resolved the moral ambivalence surrounding HIV. Instead, they have reshaped the social environment within which PLHIV negotiate identity, care, and belonging.

6. Moral Worlds, Therapeutic Dimensions and the Pursuit of Safety

Religion remained a crucial source of meaning-making, moral guidance, and spiritual safety. Many participants viewed their illness as divine punishment or a test, using religiosity as a resource to restore moral integrity. Irene, a 29-year-old woman from the Accra group, exemplifies this. She regularly attends prayer meetings because they make her feel "at peace with God and man." However, her intense fasting sometimes led to missed doses, highlighting the tension between spiritual discipline and medical adherence. These findings echo earlier studies that emphasise the importance of prayer, deliverance, and moral healing in Ghanaian HIV experiences (Adogame 2013; Kwansa 2010; 2014). Religious communities also provided emotional and material support, often functioning as quasi-family networks (e.g., brothers and sisters in Christ), offering care that biological families sometimes withheld. This supports the idea that in Ghana, spiritual belonging can serve as an alternative kinship resource in the face of stigma (Dube 2007; Heaton et al. 2020).

Safety (social, moral, and therapeutic) emerged as a dominant organising principle throughout participants' narratives. Many made relational decisions based on whether a relationship protected or exposed their status. Serwaa in Ashanti and Yaw Kumah in Accra described withdrawing from romantic partnerships that felt risky and nurturing those that ensured confidentiality. In Yaw Kumah's case, for example, although his girlfriend had been "by His side throughout his ailment" that

led to him discovering his HIV-positive status, he explains that the relationship became less safe for him because of her family.

> My girlfriend is not nosy, but she is not strong enough [emotionally to handle the HIV-positive verdict]. She trusts me so much that she believes I am being truthful with her. I was fortunate to have been diagnosed with TB [tuberculosis], which she knows about. What I did not tell her was that I was also diagnosed with HIV, and I have been living with the infection since [2023]. We ended the relationship because she kept telling me how her family suspects that I may be HIV positive and that she should advise me to go and check my status. When I was not cooperating, she said they had asked her to go and take the test as well. I knew that continuing the relationship would eventually lead them to find out my status, so I broke up with her.

For Serwaa, she changed the facility where she accessed therapy because it continually proved unsafe.

> I completely stopped going to the [usual] treatment centre after I ran into the guy I was romantically involved with on my way to the clinic [a distant one from where I live and work]. At the time, the relationship was still developing, and I had not disclosed my status. Seeing him there unsettled me. I was certain that if he became suspicious or began asking questions, it could expose my situation and damage both my reputation and the relationship. I knew that once such doubts were planted, it would be difficult to contain them.
>
> […] After nearly eight months of staying away from the centre and from him, my sister [a female member of the PLHIV association whom I consider like a sister] encouraged me to transfer to another facility [also farther from my residence and work]. That is how I ended up in this new place. What I appreciate here is that I have met new people who are very supportive, while still maintaining some friendships from the previous centre.

In this moral calculus, safety often took precedence over public welfare concerns: participants would rather maintain secrecy than disclose information to prevent onward transmission or to encourage their partners to seek help, as in Yaw Kumah's case (see also Kwansa 2013).

Historically, safety has involved both invisibility (especially to avoid stigma in communities) and therapeutic predictability (such as continuity of care, secure access to ART, and trust in health workers). Over time, however, safety has come to be defined almost entirely by therapeutic predictability, as clinics have become trusted moral spaces, while families have remained sites of moral ambivalence. This highlights a broader anthropological understanding that therapeutic landscapes in Africa are inherently moral as well as medical (Whyte 2014; Livingston 2012).

7. Reimagining Kinship and Care in Ghana's Contemporary HIV Landscape

This longitudinal ethnography contributes to anthropological debates on kinship, citizenship, and moral economies by illustrating how HIV alters the relational and ethical foundations of social life in Ghana. Three intersecting insights emerge:

First, the findings expand scholarship on "practical" and "emergent kinship" (Carsten 2000; Sahlins 2013) by demonstrating how PLHIVs actively reconfigure relatedness in contexts of stigma and biomedical monitoring. In both the Ashanti and Greater Accra groups, kinship functions as a moral project rather than an inherited structure – one that is continuously remade through care, reciprocity, trust, and discretion. Consistent with earlier Ghanaian ethnographies (Kwansa 2010; 2013; van der Geest et al. 2019; Dapaah & Spronk 2016), biological kin often withdraw in the face of HIV, prompting participants to create alternative networks with peers, health workers, church members, or counsellors. These relationships gain the depth and obligations typically linked with

kin, embodying what Sahlins (2013) refers to as a "mutuality of being." Such solidarities also exemplify what Comaroff and Comaroff (2001) describe as the capacity to generate a sense of belonging and protection when normative kinship breaks down.

Second, the study engages debates on therapeutic citizenship (Nguyen 2010; Biehl 2007; Robins 2006) by demonstrating how Ghana's adoption of the UNAIDS 90-90-90 targets and the "Treat All" policy reshapes HIV subjectivity. Adherence to testing, lifelong treatment, and viral suppression becomes a form of moral responsibility, positioning biomedical compliance as a key aspect of responsible citizenship. Participants' accounts – expressions of worry about missed doses, pride in being "undetectable," or guilt when ill – illustrate the internalisation of biomedical norms as moral virtues. Yet, this form of citizenship remains deeply ambivalent. As global health scholars have observed (Fassin 2007; Livingston 2012), therapeutic regimes can both empower and discipline. In Ghana, these expectations intersect with local moral worlds shaped by secrecy, spirituality, gendered hierarchies, and the precariousness of care. Thus, therapeutic citizenship emerges as a negotiated, morally charged identity rather than merely a technocratic outcome of global health policy.

Third, the study adds to the literature on the moral economies of care (Fassin 2007; Livingston 2012; Moyer 2015; Ticktin 2011) by showing how PLHIV navigate overlapping regimes of obligation across households, churches, clinics, and informal peer networks. Safety – social, moral, and biomedical – is a key organising principle. Participants constantly evaluate what to disclose, whom to trust, and how to secure care without facing stigma or surveillance. Care, in this context, is not only therapeutic but also deeply moral: it involves negotiating boundaries between compassion and control, dependence and autonomy, inclusion and exclusion. These negotiations emphasise the ethical labour involved in living with HIV and the effort to craft what Mattingly

(2014) describes as a "good life" amid structural constraints and social judgment.

These insights demonstrate that Ghana's changing HIV landscape cannot be fully understood through biomedical metrics alone. While the goals of the 90-90-90 framework have increased access to treatment, they also intersect with deep-seated moral values, kinship norms, and spiritual practices that continue to influence how PLHIV experience care, inclusion, and personhood. The findings show that kinship under HIV is increasingly hybrid – part biological (where support persists), part institutional, and part spiritual. As ART becomes routine, PLHIV rely on these mixed networks – health workers, fellow patients, and church communities – to maintain dignity and safety, selectively engaging relationships that meet their needs. In this context, biomedical care has not displaced kinship but expanded the relational avenues through which individuals create meaningful and supportive social worlds. This challenges linear narratives of biomedical progress by emphasising that social belonging remains as vital to wellbeing as access to treatment. A relational and moral anthropology of health is therefore crucial – one that explores the ethical and social spheres where therapeutic interventions are lived, negotiated, and reshaped. For Ghana's HIV response to reach its full potential, it must engage these moral and relational worlds, fostering environments where kinship, in its various forms, becomes a resource for life rather than a source of stigma.

8. Conclusion and Policy Implications

This study has explored how PLHIV in Ghana manage stigma, kinship, and safety within a rapidly changing landscape of HIV policy and clinical practice. Using nearly twenty years of longitudinal ethnography in the Ashanti Region and more recent work in Greater Accra, the findings reveal that Ghana's biomedical achievements – universal ART eligibility, viral suppression targets, and

the expansion of the "Treat All" model – have not removed the social and moral complexities of living with HIV. Instead, they have reshaped them. As ART becomes routine and viral suppression is celebrated as a sign of responsible citizenship, PLHIV face new demands, pressures, and vulnerabilities regarding what it means to live "well," "carefully," and "morally" with HIV.

The persistence of stigma, though increasingly subtle, exposes the limits of biomedical normalisation. While explicit discrimination has decreased, moral judgments related to purity, discipline, and respectability persist within families, churches, and intimate partnerships. These moral undercurrents influence disclosure practices, household negotiations, and the very sense of belonging. Simultaneously, the ethnography illustrates that safety is not a state granted by policy but rather a fragile and relational achievement. Through selective disclosure, reciprocal care, and careful cultivation of trust, PLHIV build overlapping networks of support with peers, counsellors, and sympathetic health workers. These networks often prove more dependable for accessing care and support for their condition than biological kin, and they become vital to both emotional resilience and therapeutic continuity.

Conceptually, the study enhances understanding of practical kinship, therapeutic citizenship, and moral economies of care. PLHIV mobilise new forms of relatedness that transcend kinship norms and institutional boundaries, creating hybrid moral communities that serve as intermediaries between household intimacy and the impersonal nature of the healthcare system. At the same time, the institutionalisation of HIV care has led to new forms of biomedical moral citizenship where adherence, disclosure, and viral suppression are given ethical importance. These types of citizenship empower some individuals while disciplining others, exposing the complex relationship between global health governance and local moral worlds.

Ghana's HIV response must, therefore, go beyond a narrow focus on biomedical indicators to address the relational and psychosocial factors that support long-term engagement in care.

Achieving the 95-95-95 targets will require incorporating mental health support, stigma-reduction strategies, and community-based interventions into routine services, while formally recognising the vital role of practical kinship networks – peer groups, adherence clubs, and clinic-based relationships – as essential parts of care through funding, training, and institutional backing. At the same time, policy and communication strategies should avoid moralising adherence and disclosure, instead adopting supportive approaches that acknowledge structural barriers, emotional realities, and gendered inequalities. Strengthening confidentiality systems across all levels of service delivery – in digital records, pharmacy dispensing, community refills, and differentiated service delivery – is vital for building trust and ensuring patient retention. Finally, tackling stigma should involve engaging families, faith communities, and local leaders in reshaping the moral narratives surrounding HIV. Ultimately, sustaining Ghana's progress depends not only on providing treatment but also on recognising HIV care as a social and moral process rooted in trust, relational support, and the everyday work through which PLHIV secure safety, dignity, and a sense of belonging.

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VI. Healing from stigma, explanatory narratives and stigma reduction pratices in the medical humanitarian activities of Médecines Sans Frontières

Umberto Pellecchia

Just after he left the small clinic in the rural southern part of the Thyolo district in Malawi, James[1] greets with a smile the other patients waiting inside before jumping on his bicycle. As every Tuesday, the clinic's waiting room is more crowded than usual, since in addition to the regular patients, there are also those who, on that day, must collect the antiretroviral medicines treatment (ART) for HIV for their Community Groups in the district. And there are a lot of medicines to carry! Indeed, each member of a Group takes a turn: once a month, one person goes to the clinic to pick up the medications for all the others. Each Group has an average of ten to fifteen members. As a result, whoever is on duty that day carries quite a load of antiretroviral boxes, which will later be redistributed to the rest of the group during a monthly meeting.

ART Community Groups (CAGs), developed by Médecins Sans Frontières (MSF) in Malawi and Mozambique, were designed as a community-based model of HIV care aimed at stabilizing long-term antiretroviral therapy (Decroo et al. 2017). Their primary functions include decentralizing treatment delivery, reducing the burden of frequent clinic visits, and supporting ad-

[1] The name is fictional. In 2014, I conducted a four-month ethnographic study in southern Malawi (Thyolo District) commissioned by Médecins Sans Frontières to describe the functioning of the decentralized model of care Community Antiretroviral Groups (CAGs). The research involved participant observation and in-depth interviews. Data collection was carried with the help of two (male and female) local collaborators.

herence through peer-based organization. By rotating drug collection among group members, CAGs reconfigure access to care while attempting to embed treatment within everyday social relations. At the same time, they function as moral and narrative spaces, where responsibility on ART is collectively produced and monitored. Within MSF programs, CAGs thus operate not only as logistical solutions to overstretched health systems, but also as sites where patient behaviour is explained, shaped, and evaluated, often through the language of stigma and its reduction (Pellecchia et al. 2017).

That day, James is carrying two plastic bags full of blue-and-white boxes – one hanging from each side of the bicycle's handlebars – and sets off toward his village, about twelve kilometres away. The uneven road and the bicycle's surely non-all-terrain wheels, jolt him on the saddle, while the bags dangling from the handlebars shake at every bump, clattering the pills inside the boxes and producing a loud *rattle, rattle*. When he was sick, it would have been unthinkable for him to ride his bicycle twelve kilometres under the hot sun. The virus had weakened him to the point that he had lost dozens of kilos, and the little muscle he had left was barely enough to lift his arm to take a bite of food. At some point, the virus had taken away his strength, and along with it, his work, his income, and his dignity. He, as other people living with HIV, was subjected of marginalization and suspect from most of the community members. The fear was not really about the fact that he potentially could spread the disease, rather on the reasons why he took it at the first place. James was a farmer, living barely above the subsistence. People associated his disease with a lack of strength at work, misfortune and immoral behaviours. Then, thanks to ongoing treatment, peer support, and the structured organization of the CAGs, the man gradually regained his strength, and his welcoming smile once again found its place on his face. That day, at the end of the long journey from the clinic, when James turns off the main road and onto the dirt path that runs through the village, past

the scattered houses, he gets off his bike and proceeds very slowly, gripping the handlebars to keep them steady. He knows too well that if his neighbours were to hear that *rattle, rattle* coming from the bags full of medicines, they would immediately identify him again as an HIV-positive.

1. Exploring stigma in Médecins Sans Frontières

James's story, with its complex interplay of recovery, strategic use of silence, and the constant negotiation of visibility, is emblematic of how stigma permeates everyday life even within well-designed models of care (Goffman 1963; Kleinman 1988; Das 2007; Singer 1994; 2009; Marabello 2017; Brazy-Nancy 2025). His careful effort to quiet the rattle of the pill boxes captures not only the persistence of social judgement despite all efforts of normalizing the experience of HIV, but also the tension between public health narratives and lived realities (Kwansa in this book). The attempt to design a decentralized care model that meaningfully integrates social dynamics – such as in the CAG approach – is both innovative and deeply significant, signalling the effort of investment in holistic forms of care. At the same time, the "real" reality of people's lives persistently spills beyond the contours of these models, challenging their assumptions, stretching their adaptability, and reminding of the need to ground health interventions in the full complexity of patients' lived worlds.

Stigma is widely recognized as affecting health access and outcomes and constitutes a subject very well scrutinized in public health and social sciences (Stuber et al. 2008). Public health scholarship has increasingly approached stigma as a multi-level, structurally embedded process, drawing on anthropology and sociology to move beyond individual behavioural framings. Contemporary reviews in *The Lancet Public Health* highlight how «structural stigma – societal-level norms, conditions and policies – shapes health inequities across populations», a trend further

confirmed by scoping work showing that more than half of all structural-stigma studies in health were published after 2021 and frequently build on social-science foundations such as the *Social Science & Medicine* special issue on structural stigma (Stuber et al. 2008). Additional frameworks emerging from global health and mental-health research propose ways to measure and reduce structural stigma, including Delphi-based tools for health-system assessment and educational approaches grounded in structural competency that guide actionable interventions within clinical and organizational environments (Hatzenbuehler et al. 2024; Eschliman et al. 2024; Gurung et al. 2025; Sukhera et al. 2022).

This paper adopts a critical, practice-oriented approach, analysing both explanatory narratives about stigma and the concrete reduction strategies used in MSF (Quaranta 2014). Its key objective lies in bringing together reflections on stigma, socio-political determinants of health, and humanitarian action. In fact, stigma operates along multiple, intersecting trajectories that shape both health experiences and institutional responses. First, certain public narratives stigmatize specific populations – such as migrants subjected to racializing discourses or LGBTQ+ communities – thereby excluding them from equitable access to healthcare and aggravating both their physical and mental health conditions. These forms of stigmatization act socially and structurally, reinforcing marginalization and limiting engagement with health systems. A second direction involves the ways in which affected populations internalize or reproduce stigmatizing narratives about particular diseases, which in turn influences how they respond to illness and health interventions. Conditions such as Ebola virus disease, Lassa fever, and HIV have long been surrounded by fear, moral judgement, and misinformation. These disease-cantered stigmas shape local perceptions of risk, affect care-seeking behaviours, and shape community reactions to biomedical interventions. A third trajectory emerges within institutional and organizational settings. Health actors, including humanitarian agencies, sometimes construct explanatory frameworks grounded

in culturalist assumptions or oversimplified understandings of social dynamics. These framings can inadvertently generate or reinforce ideologies of stigma, influencing operational strategies, the design of health programmes, and the interpretation of community behaviours. In such cases, stigma becomes embedded not only in public discourse but also in institutional logics and decision-making (Parker et al. 2003; Link, Phelan 2014).

In this paper, I aim to capture this multifaceted ecosystem of stigma by examining how it is conceptualized, produced, and managed within MSF. Through analysing both organizational narratives and field-level practices, the goal is to understand how MSF actors navigate stigma as a social, cultural, and operational phenomenon and how their responses shape humanitarian action more broadly. To undertake this analysis, I rely on a combination of ethnographic and observational data. Most of the ethnographic cases discussed originate from my long-term fieldwork conducted over the past decades as an anthropologist and research coordinator with MSF in a variety of humanitarian settings. Within MSF, research is typically initiated at the request of either the Operations Department which is responsible for overseeing humanitarian programmes or the teams directly engaged in emergency responses at both coordination and project levels.

The scenarios examined in this paper are predominantly epidemic or outbreak settings alongside selected examples from other humanitarian environments. Fieldwork in these contexts relied on classical ethnographic methods, including interviews, group discussions, participant observation, and, when appropriate, participatory approaches. Beyond direct ethnography, the analysis also incorporates both direct and indirect observation of organizational discussions on stigma occurring across different levels and forums within MSF. Indeed, as a Research Advisor, my role encompasses scientific coordination and strategic oversight. This includes participation in thematic debates, conducting briefings and debriefings with field anthropologists, contributing to internal reflections on the integration of social sciences into humanitarian

responses, and engaging in multidisciplinary technical discussions. This position provides a vantage point from which to observe how the notion of stigma is conceptualized and mobilized within the organization, extending beyond the boundaries of any single case study. To complement the observational material, I also reviewed MSF's scientific literature alongside relevant public guidelines and organizational reports.

2. Stigma as a barrier

Within the organisational discourse of MSF, the word stigma is frequently invoked as a barrier to care, an undefined entity that creates a chilling effect on people's access to facilities or adherence to treatment or understanding of the biomedical nature of the illness. The concept often moves between culturalist explanations where communities' alleged beliefs and traditions are presented as central to stigmatization and a sort of de-historicized interpretations that locate stigma in patients' attitudes or behaviours. In the first aspect, stigma appears linked to local cultural frameworks that need to be debunked; in the second, it becomes something addressed through personal counselling or behaviour-change interventions. These tendencies persist with a certain level of tenacity even though social sciences, and anthropology in particular, have significantly influenced MSF's approaches to medical practice and contextual analysis (Véran et al. 2020). As in the case of stigma, certain broad concepts continue to circulate as standard organisational categories for interpreting complex social realities. Terms such as behaviour and perception, for instance, are still commonly mobilised when MSF reflects on community dynamics: the former to describe actions that require explanation, the latter to capture beliefs, attitudes, or cultural patterns. Another recurrent notion, especially when examining access to care, is indeed that of the barrier. Often used in a prescriptive sense, the term can imply, based on epidemiological in-

dicators or contextual assumptions, that communities face a relatively uniform set of obstacles limiting access to services, adherence to treatment, or the attainment of an acceptable quality of life.

Of course, many of the populations with which MSF works do face substantial constraints (conflict, epidemic emergencies, displacement, and chronic impoverishment) and conditions that undeniably shape the challenges encountered in seeking or maintaining care. At the same time, framing these challenges primarily through the notion of barriers may inadvertently simplify the diversity of experiences and responses observed across different contexts. Such framing can make more difficult to recognise the forms of agency, resilience, and adaptive strategies that communities mobilise, even in acute or protracted crises. It may also obscure the multiplicity of factors that influence access to care, of which stigma is only one dimension, and often not the cause. While MSF does at times explicitly acknowledge the social production of stigma, for example in HIV programmes focused on key populations, its use of the concept tends to be undefined and all-encompassing.

A useful illustration of these uses emerges from MSF's recent Hepatitis C Test-and-Treat campaign in the Rohingya camps of Cox's Bazar, Bangladesh, in 2025, that was analysed by an anthropological assessment conducted by a field anthropologist[2]. The 2025 Hepatitis C Test & Treat campaign in the Rohingya camps of Cox's Bazar was launched by MSF with the objective of expanding access to diagnosis and treatment in a context of high HCV prevalence and historically limited care. The campaign aimed to initiate treatment for up to 10,000 patients across several camps and was organised around two complementary screening strategies: a door-to-door approach, in which outreach

[2] The anthropological assessment *Hepatitis C Campaign in Rohingya Refugee Camps, Bangladesh*, 2025, is an unpublished internal report based on a three-month ethnographic mission conducted by a field anthropologist part of the MSF-Brussels pool.

teams visited households to test all adults aged 18 and above, and a sentinel-site model, where screening took place in designated community locations such as mosques or community halls. In both methods, individuals first underwent rapid diagnostic testing (RDT); those testing positive were referred for PCR confirmation and linked to MSF's Hepatitis C clinics for treatment initiation if eligible. The campaign relied on outreach teams composed of nurses and community-based team members, integrated follow-up mechanisms for absent individuals, and coordinated closely with community leaders to support mobilisation and ensure broad participation. To accompany the rollout of the campaign, an anthropological assessment was carried out to identify potential barriers in access and activities to reduce stigma. The formulation of the assessment's objectives emerged from reports suggesting possible resistance among different groups living in the camps, raising concerns about a potentially low acceptance of the campaign. In parallel, MSF identified the need to evaluate the two screening strategies to better integrate community perspectives into its operational approach. As such, the rationale behind the assessment rested on two complementary logics: on the one hand, a more prescriptive orientation shaped by the assumption that stigma could hinder participation; on the other, a more inclusive orientation aimed at ensuring community engagement and capturing local experiences throughout the rollout of the campaign. While designed to work together, the two logics also conveyed distinct representations of the communities themselves. The first tended to reproduce a more stereotypical portrait, assuming stigma as the principal impediment to participation; the second adopted a more inclusive stance, foregrounding engagement and recognising the community's capacity to shape the intervention

And in fact, despite years of constrained access to Hepatitis C care, the assessment found communities to be highly receptive to testing and treatment. Far from showing reluctance or stigma related to supposed cultural beliefs, most Rohingya families

reported an eagerness to engage with the campaign, interpreting the arrival of treatment as an opportunity after decades of exclusion from formal healthcare, both in Myanmar and in Bangladesh. This enthusiasm was rooted not in biomedical understanding alone, but in lived histories of illness, in the moral economies of care, and in the significance attributed to rare forms of accessible treatment in a humanitarian setting. Yet, strong receptivity coexisted with persistent structural impediments. Many of these constraints did not originate from stigma, but from the material, social, and political conditions shaping daily life in the camps. Mobility restrictions limited access to care for those who required permission or support to leave the household; financial pressures and the reliance on informal providers continued to shape health-seeking pathways; and the physical landscape of the camps (steep hills, monsoon conditions, dispersed shelters) complicated systematic follow-up. These factors collectively demonstrate how obstacles to care cannot be reduced to attitudes or perceptions but must be understood as embedded within broader configurations of displacement, precarity, and limited autonomy.

Gender norms emerged as particularly significant in shaping both access to testing and experiences of illness. Women's mobility was tightly regulated, often requiring accompaniment or explicit permission from male relatives. This limited their ability to attend sentinel sites and constrained access to information, particularly in the absence of female staff. As the assessment highlights, women frequently remained in the background during household visits, receiving second-hand explanations mediated by husbands, brothers, or mothers-in-law. Moreover, the vulnerabilities connected to gender extended beyond mobility: exposure to sexual violence, the inability to negotiate condom use, and the health risks associated with partners' extramarital relations placed women at disproportionate risk of Hepatitis C exposure and rendered them more dependent on male decision-makers for seeking care. Once again, in this context, what might be superficially interpreted as stigma is better understood as the product of

gendered power relations, where women's experience of illness is rooted in logics of gender inequality rather than in cultural beliefs about the disease itself.

These insights are critical when reflecting on why an anthropological assessment was initially planned for this context. Early assumptions (including within MSF) suggested that poor uptake or hesitancy might be linked to «stigma around Hepatitis C» attributed to undefined cultural beliefs or to resistance from local informal doctors allegedly in competition with the formal health structures. However, the findings complicate this assumption. If forms of stigma exist, they are not generalised across the community, nor rooted in disease-specific cultural taboos; rather, they reflect the structural and relational dimensions of gender and structural violence. In this sense, what appears as stigma is not an isolated cultural obstacle, but the manifestation of broader dynamics of inequality situated within the broader political and historical conditions that have shaped Rohingya lives: decades of state-led discrimination in Myanmar, restrictions on movement, and limited access to education and formal healthcare have produced a long-term landscape of vulnerability and exclusion. This structural violence has not only shaped health-seeking behaviours and trust in institutions, but also the social positions from which individuals navigate illness, risk, and visibility.

The Bangladesh case shows a conceptual shift about how stigma is mobilised within humanitarian and public health discourses of MSF. Much of those discourses identify stigma as a barrier to testing, counselling, adherence, or access to care; but as Paul Farmer reminds us, such explanations risk becoming «immodest claims of causality» simplifying complex social processes into psycho-social categories while leaving the harder, more structural questions unexplored (Farmer 2001, chap. 9). If certainly stigmatization operates as a chilling device, at the same time its notion – stigma – is often employed without qualification, functioning as a convenient explanatory category that can obscure the deeper social inequalities shaping people's lives.

3. The individual stigma

After highlighting the explanatory use of stigma as an all-encompassing category to account for barriers to care, a further analytical step about how MSF's uses and works around stigma, concerns the risk of individualisation, both in explanation and in intervention. Within MSF's clinical practice and responses in humanitarian context, stigma is specifically understood through the lens of internalisation, that means with a focus on the mental health consequences of exclusion, discrimination, and devaluation[3]. Those aspects eminently social, are clinically identified in the individual psychological symptoms, shaping self-perception, emotions, and conduct, often to the extent of becoming self-stigmatization. The impact of such internalisation is indeed quite significant: it can self-limit the patient in, for example, adhere to treatment or, in general, to seek for care and trust the health providers. The psychological approach to stigma and its therapeutic practices tackle the perceptions, the attitudes and the emotional aspects of the individual, attempting to restore self-confidence. This takes place in MSF's programs through individual therapy or group work, specifically through counselling and psychoeducation[4].

The psychological perspective is very important in showing how stigma is a lived experience and how the embodiment of social dynamics influence deeper level of the self. As Campbell and Deacon (2006) explain, stigma can be operatively broke-down in individual, macro-social and multi-level dimensions. Psychology can work on reinforcing the active role of the patients in building their resistance to the different levels of discrimination supporting them in their rehabilitation and possibly in re-gaining a role in the society. At the same time, this analytical

[3] See for example: https://doctorswithoutborders-apac.org/en/stories/from-stigma-to-strength-an-hiv-survivors-story.

[4] See: https://www.doctorswithoutborders.org/latest/it-isnt-written-our-foreheads-we-have-hiv.

angle is not exempted by implications. By privileging the psychological uptake of stigma, attention can shift from the relational and structural processes through which stigma is produced to its symptomatic manifestations at the level of the individual. Stigma risks being approached phenomenologically as an inner state to be mitigated through coping mechanisms or cognitive re-framing rather than structurally, as a dynamic embedded in history and asymmetries of power (Singer 2009).

This tension between individual and structural becomes visible when examining MSF's own scientific production on stigma across different medical and social contexts. A 2021's cohort study conducted in rural Uganda shows how internalised HIV stigma is associated with depressive symptoms, measured using the Hopkins Symptom Checklist. The analysis highlights that these symptoms decreased during antiretroviral therapy. Counselling and ART adherence support are described as central mechanisms through which patients re-frame their self-perception and regain a sense of normality and confidence. It is interesting that as the Authors describe the mental health implications of stigma, gradually the emphasis shifts towards therapeutic mitigation mechanisms rather than examining the social and structural roots of the stigma itself (Bebell et al. 2021).

A similar focus on the emotional and psychological dimensions of stigma emerges in qualitative research (Sumbi et al. 2021) on HIV disclosure among children and caregivers in Kinshasa, DRC. Here, stigma is primarily articulated through fear, anxiety, and emotional burden, particularly in relation to disclosure decisions. Caregivers describe counselling sessions as spaces able to prepare both adults and children emotionally for disclosure, helping them anticipate reactions, manage distress, and develop coping strategies. Stigma is thus addressed through progressive psychological readiness, with mental health support positioned as a key tool to mitigate anticipated discrimination. Likewise, another qualitative study adopting the Photovoice participatory methodology with MDR-TB patients and women living with

drug-resistant tuberculosis in Mumbai, India, describe stigma through feelings of shame, fear of disclosure, and isolation, with counselling framed as essential to sustaining motivation, adherence, and emotional resilience. The everyday experiences of stigmatization solicited via the pictures taken by the participants is, ultimately, described through their individual impact and the level of socialization is framed into the peer-support and counselling (Mahbub et al. 2024).

This body of work shows that MSF's engagement with stigma is certainly not based in psychological reductionism, and neither is confined only to biomedical frameworks. The daily environment of the patient, the social relations, family configurations, and community norms are regularly taken into account, and mental health interventions respond to concrete forms of suffering that accompany illness and exclusion. Yet, despite this, stigma is often rendered operationally visible through responses that centre on individuals such as counselling, peer support, and efforts to strengthen coping capacities. This reflects a pragmatic commitment to improving care experiences and outcomes (Redfield 2006). From an anthropological perspective, this organizational orientation opens up further reflections: rather than positioning MSF's psychologically approach to stigma as something to be challenged outright, an attention to the broader structural conditions that produce stigma may in fact complement and reinforce therapeutic interventions. In fact, by situating individual experiences within their wider social and relational contexts it can be highlighted how stigma is continuously shaped and reproduced. In this direction, addressing its manifestations without engaging these underlying dynamics may limit the actual longer-term effectiveness of care, as the conditions that give rise to stigma can persist and re-emerge in patients' everyday life.

4. The stigma rebound

A paradoxical feature of stigma is that it does not operate solely through negative mechanisms, such as derogatory attributions; in some contexts, even the attainment of good clinical status or adherence to public health measures can themselves become sources of stigmatization. This is quite true in epidemics and outbreaks, where the differentiated responses of the society to public health measures can develop categorizations and characterizations that eventually trigger mechanisms of stigmatization (Kelly et al. 2019; Fassin 2007; Pellecchia et al. 2015). In fact, epidemics tend to enter the collective memory not only as biomedical events but as shared social dramas. As Charles E. Rosenberg observed, epidemics unfold like *stories* with a dramaturgic form: they begin at a moment in time, proceed on a stage limited in space and duration, follow a plot of increasing tension, move toward a crisis of individual and collective character, and eventually drift toward closure (Rosenberg 1989). And like all dramaturgies, epidemics are populated by characters: victims, perpetrators, experts, outsiders, and, of course, heroes.

The COVID-19 pandemic made this narrative structure globally visible. Across vastly different contexts, populations were sorted into moral categories: those who complied with public health measures were framed as responsible citizens, while those who hesitated, resisted, or were unable to comply were portrayed as threats to the collective. This dichotomy often ignored structural constraints such as precarious labour, mobility requirements, unequal access to healthcare and yet it proved powerful in shaping public discourse. Epidemics, in this sense, produce not only illness but also moral economies, assigning value, blame, and legitimacy to different social actors.

A similar narrative happened in the 2014–2015 Ebola outbreak in West Africa, even if within a far more unequal global extension. MSF responded to the largest Ebola epidemic in history, which primarily affected Liberia, Sierra Leone, and Guinea and resulted

in the deaths of almost 11,000 people. The outbreak broke within a political and institutional landscape profoundly shaped by decades of civil conflict, structural adjustment, and chronic underinvestment in public health systems. As documented in the book *The Politics of Fear* (Hofman, Au 2017), national governments did not have the capacity to diagnose, isolate, and treat cases at scale, while international agencies were slow to mobilise, blocked by bureaucratic hesitation and uncertainty about declaring the outbreak as an international emergency. The result was a fragmented response in which responsibilities were unclear, and institutional coordination delayed the epidemic's response. Within this context, MSF emerged as one of the few actors capable of intervening decisively and early. By establishing Ebola Treatment Centres, conducting surveillance and contact tracing, developing safe burial protocols, and advocating publicly about the severity of the outbreak, MSF filled critical gaps left by both national governments and global institutions, especially at the onset. Importantly, its response was never purely biomedical. Clinical care was inseparable from public health measures, community engagement, and political advocacy, positioning Ebola as a social and institutional crisis as much as a viral one.

Despite this complexity, the social realities surrounding Ebola were often interpreted through relatively simplified explanatory frames. At the community level, expressions of fear, mistrust, and resistance were frequently grouped under the broad label of stigma intended again as a barrier to care, and commonly linked to cultural beliefs, misinformation, or limited understanding. International media coverage often echoed this perspective, drawing attention to spiritual interpretations of illness, burial practices, or perceived gaps in knowledge among local populations. While these accounts tried to make sense of community responses, they at times reproduced neo-colonial imaginaries that depicted communities as culturally fixed or reluctant to engage with biomedical interventions. As a result, broader political histories, conditions of economic insecurity, and experiences of institutional

neglect that significantly shaped responses to the epidemic were less visible.

Within this moral discourse, Ebola survivors became particularly visible as key characters of the Ebola's story. During the outbreak, they were rapidly elevated to the status of heroes: living proof that recovery was possible, symbols of hope in a landscape dominated by death. Survivorship was mobilised as evidence of biomedical success and as a resource for public health messaging. At the same time, anthropological research consistently documented how survivors faced severe stigma upon returning to their communities, ranging from social avoidance and exclusion to fear of contagion and, in some cases, violence. Survivors occupied an ambivalent social position: celebrated publicly yet often marginalised privately; visible as symbols, but invisible as social and economic actors (Pellecchia 2020).

Alexander[5], whom I met in Monrovia in early 2015, exemplifies this contradiction. When I first encountered him, he was sitting on a plastic chair outside a large MSF warehouse near ELWA 3's Ebola Treatment Centre. Behind him stood a tall panel covered with colourful handprints left by recovered patients: an artefact of hope, success, celebrating life. Alexander himself had survived Ebola only a few months earlier, after a prolonged and critical stay in the treatment centre. Physically, however, he was far from recovered. He suffered from persistent headaches, impaired vision in one eye, and chronic fatigue. «Physically, I'm alive» he told me, «but psychologically, I'm dead like the others».

Alexander's illness trajectory had been marked by uncertainty from the start. When symptoms appeared, his family initially isolated him within the family compound, bringing food and water while trying to protect themselves. After days without improvement, they sought external help, and in mid-October 2014

[5] The name is fictional. I took part to the MSF Ebola response in late 2014 and early 2015 as anthropologists, conducting research and assessments mainly in Monrovia city and north-west Liberia.

he was admitted to MSF's ELWA 3 Centre. His condition deteriorated to the point that clinical staff concluded his case was hopeless. Yet he remained stable longer than expected and eventually recovered, becoming one of the early Ebola survivors. At discharge, Alexander participated in a ritual developed by MSF's health promotion team. Survivors were welcomed at the edge of the red zone with applause and singing and invited to leave their handprints on the panel marking the transition from inside to outside. These gestures materialised hope and celebrated survival, but they also marked a liminal passage. Once beyond the treatment centre, survivors like Alexander entered a social world shaped by fear, suspicion, and economic collapse.

Alexander initially believed that survival would allow him to return to normal life. Before Ebola, he had worked as an electrician and assisted a pastor in a neighbourhood church and after discharge, he imagined resuming both roles. This hope quickly proved to be an illusion. Former clients stayed away, uncertain whether he was truly cured or still dangerous. His physical impairments reinforced doubts, leaving room for rumours and moral suspicion. Even within his family, questions emerged: why had he survived when others had not? Was he truly healed, or somehow different? As the epidemic continued to devastate Liberia's already fragile economy, Alexander found himself without work, resources, or autonomy. At 35, he became dependent on his family, a position he felt as deeply humiliating. Like many survivors, he faced not only fear of contagion but also economic exclusion and social immobility. In this context, Alexander engaged closely with MSF and other survivors. He joined awareness-raising activities, volunteering to promote clinical services and educate communities about Ebola. He was encouraged to share his story as a living testimony to counter fear and stigma. «They told me I was a hero because I had survived» he explained «they said my story would help people believe and fight stigma». For a time, he embraced this role with enthusiasm, although the pressure of being always "to the top" was deeply felt. And in

fact, gradually, its limits became apparent. Volunteering provided symbolic recognition but at the cost of impersonating constantly the role of the «good patient» which clashed with the reality of being isolated form his social fabric and, especially, with no income (James et al. 2020). Indeed, survivors were visible as messengers but remained excluded as workers and citizens. Together with other survivors, Alexander began to reflect on their shared condition. They identified unemployment and lack of economic opportunity as the primary obstacles to reintegration. In response, they organised themselves into an association of Ebola survivors, aiming to create collective visibility and advocate for livelihoods, training, and institutional recognition. The association sought support from state authorities and international organisations, hoping that their symbolic status would translate into concrete assistance. These efforts were largely unsuccessful, as survivors were recognised rhetorically but not structurally, in a context shaped by a collapsed economic system that severely constrained the possibility of material support.

This trajectory reveals a shift from Ebola survivors being celebrated as moral exemplars or «imaginary heroes» to becoming politically constrained actors that navigate precarious post-epidemic realities. Alexander's experience underscores that stigma cannot be reduced to fear of contagion or cultural misunderstandings alone. Instead, it is sustained through structural exclusion, economic marginalisation, and the pitfalls of institutional failures to convert humanitarian recognition into lasting forms of social inclusion. The public elevation of survivors as heroes as a motivational device rests on a moral narrative that valorises survival while obscuring the conditions that shape life after survival.

Reading through the lens of Nguyen's therapeutic citizenship (2010), this form of humanitarian recognition as *good patient* build definitely an identity among survivors and an engagement that helped MSF's medical activities in spreading hope among the community affected. However, it also produced ambiguous claims to belonging, where survivors are acknowledged as worthy

subjects of care and moral praise but yet remain excluded from the material and political resources necessary to secure stable livelihoods. The build-up of heroism thus emerges as a fragile and ambivalent category, paradoxically re-bounding new forms of stigma. Rather than resolving, it risks displacing it, substituting symbolic visibility for structural support and masking renewed forms of stigmatization under narratives of resilience.

5. Conclusions: healing from stigma

The WHO's and IFRC's *Social Stigma associated with Covid-19: Guide to preventing and addressing social stigma* is a very straightforward and clear checklist intending to support Governments, media and local organisations on how to address this impactful social phenomenon. The 5-pages document explains how «evidence clearly show that stigma and fear around communicable diseases hamper the response [and] what works is building trust in a reliable health service and advice, showing empathy with those affected» (p. 2). Interestingly, the whole part on «building trust with services», apart from this first statement, completely disappear from the rest of the guidelines that instead focus on communication's tips (don't call Covid-19 the «Chinese virus») and access to information («facts, not fear will stop the spread», p. 5). Despite the structural dimensions of stigma are recognized as actual drivers of health, most of the times the solutions to *heal* from them remain phenomenological. Moreover, the intersectionality of these structural dimensions is little recognized, so createing a further challenge for health organizations: the interlink between gender, privilege, class, and race is among stigmatized communities so intimate that interventions on a single aspect risk to produce a silo approach ultimately ineffective.

Would these considerations bring to the conclusion that stigma is an unavoidable variable of any public health intervention? To a certain extent, stigma being an element of structural violence will perdure as long as the violence does (Farmer 2004; Farmer et al.

2006). As the latter can be fought only with an acknowledgment of the historical inequalities and political dimensions of health, at the same time stigma should be addressed – exactly because of its intersectional nature – in an inter-sectorial approach (Link, Phelan 2001; Briggs 2003; Fassin 2007). In a context like the one of MSF that means that rather than juxtaposing psychological intervention and social analysis, the two approaches should aim at collaborating by creating a syntony in action between individual intervention, construction of health messages, and social action (Hatzenbuehler et al. 2013; 2024). A coordinated work between multilayered and interconnected actions would respond to the intersectionality inner in stigma and the compounded elements (marginalization, poverty, sexism, racism, classism) leading to sever health outcomes. Acting solely at individual level risks to alleviate cognitive symptoms but would leave exposed, with the risk or re-bound, the person once she/he gets back in society. As the stories narrated in this work show, coping mechanisms don't work in a vacuum and self-resilience: personal strength acquired through counselling can work if the social conditions ideally change. Possible ways for organizations such as MSF interested in people-centred care might entail to invest programs with participatory methodologies aimed at involving patients as agents of change in civil society. For example, networking with community-based realities, migrants' groups, or associations. On parallel, the science supporting humanitarian actions at medical and context analysis can meaningfully integrate social knowledge and political analysis with epidemiological understandings, for instance during epidemics and outbreaks. Trust building, in that sense, becomes intimately related to health outcomes and strategies, therefore relying less on generic access to information and more on engagement. Following this vision, stigma and stigmatization turn to be from sentinels of suffering – explanatory approach – to entry doors for a decolonizing approach to global and public health, therefore interlinking the microlevel of interventions withing the macro-dimensions of inequalities.

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