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For the impact they had on many of the ideas I present here, I would like to express my gratitude to the “Making/Unmaking” reading group (2021)—in particular, to Yanina Gori and Angelantonio Grossi who proposed to us to collectively read Audra Simpson’s article, “On Ethnographic Refusal” (2007)—to Katie Kilroy-Marac, and to Francesco S. Longo. I would also like to thank Laura Faranda and the MaDAf team and associated members for their insightful comments on preliminary presentations of this paper. Finally, I am very grateful to the two anonymous reviewers and the editorial team for their engaging reading of the article and their extremely stimulating suggestions and critiques.

1 **Data related to this article:**

Photographs, field notes and messages (2021–2022) from which extracts are reproduced in this article.

Introduction

- 2 This article revolves around a paradox. It constitutes a contribution to a journal—and a special issue—specifically aimed at addressing the materiality of sources, but it actually focuses on the absence of a source, on its denied materiality. Drawing on fifteen months of anthropological research on experiences of madness and practices of mental

health care in rural southwestern Ghana (Nzemaland, Western Region, 2013–2022), in the next few pages I propose to reflect on a particular ethnographic source (an interview) I could not have access to—to use a widespread yet somewhat alienating terminology often used when talking about fieldwork.

- 3 In the call for papers that stimulated the writing of this piece (Aït Mehdi et al. 2022), ethnography is evoked as a research tool capable of grasping “invisible” dimensions of madness that can easily end up being concealed in written sources. As suggested by the authors, this is true especially in relation to the multiple perceptions and representations of experiences that may be labelled as “madness” and/or “mental disorders” as well as in terms of “something else,” as it is the case in the story I will present in this article. To a large extent this is due to the fact that the main sources in ethnographic research are people, or, to be more accurate, relationships with people. People with whom researchers spend time as they juggle the intricacies of everyday life, navigating different healing options and epistemologies as well as material constraints, affective relationships, and social expectations—just to name a few of the key factors informing the lives and therapeutic itineraries of patients and caregivers I met in Nzemaland. On the other hand, this people-centred and relational quality of ethnography carries substantial ethical dilemmas with it: why should researchers be allowed into the intimacy of people’s everyday lives, especially when pain and suffering play a huge role in them? And then, given the frequent, often multilayered, power and privilege imbalances that inform the relations between researchers and their interlocutors,¹ to what extent can we really talk about “consent” in ethnographic settings? What do we as ethnographers “leave behind”—to use the evocative expression recently proposed by Jennie Gamlin and Rochelle Burgess (2023; see also Fassin 2017)—in the lives of the people involved, when the research is finished? Such questions are of course even more cogent in the field of mental health research, where the potential “vulnerability” of the subjects involved is a constant preoccupation. In the last few years, the ethics of research has increasingly become an academic concern, though often in the bureaucratised form of ethical clearance applications, ethics review committee protocols, and informed consent forms. As anthropologists have repeatedly highlighted, not only are such practices borrowed from the hard sciences and thus often not easily translatable into the field of ethnography (see among others, Bell 2014; Wynn 2018; Bell and Wynn 2021), but they also seem de facto more effective in protecting researchers rather than the research participants (Fassin 2006; 2008; Anonymous 2022; Constable 2022; Shannon 2022; see also Bourgois 1990). As a matter of fact, the role of these practices within the social sciences is highly contradictory and problematic. They are boring, insidious, occasionally frustrating procedures researchers often complain about in the corridors of their institutions, but they also compel more recent generations of scholars to reflect on aspects that were long ignored and disregarded in disciplines such as history or anthropology.² At the same time, however, they may also end up lifting the weight of moral dilemmas and political discomfort off researchers’ shoulders thanks to the soothing power of rules and bureaucracy (Graeber 2015; Wynn and Israel 2018). Within the domain of anthropology, it is undeniable that ethical decisions and dilemmas are at the core of ethnographic research: they are, for instance, at the core of the kind of relationships we as anthropologists choose to establish (or not) with our interlocutors, at the core of what we choose to do (or not) in “the field,”³ at the core of what we choose to disseminate (or not) afterwards. Through the analysis of an ethnographic episode of refused consent, in

this paper I would like to suggest that such issues require a constant ethical and political questioning that goes well beyond the filling up of “consent forms” and “checklists.” In this perspective, following Audra Simpson’s powerful theorisation (2007; 2014; 2016), focusing on refusal, rather than on consent, could prove useful to emancipate ourselves from the jargon of review boards and to acknowledge—rather than perhaps too quickly dismiss—the many doubts and dilemmas that ethnography poses in order to further develop a collective, ongoing reflection on the ethics and politics of doing research on madness and mental health with people. At the same time, refusal could also prove to be a generative practice (Simpson 2007; McGranahan 2016), capable of pointing our attention towards those “invisible” dimensions of madness that are too often concealed—together with the power dynamics that inform their “invisibility”—underneath biomedical and psychiatric discourses and labels.

Setting the scene: an ethnography of mental health care in Ghana in times of Global Mental Health

- 4 In the last decade, especially after the approval of a new law aimed at “scaling up” and decentralising psychiatric services in the country in 2012 (Republic of Ghana 2012), Ghana has increasingly acquired a “vanguard” role in the Global Mental Health (GMH) discourse (Quarshie 2022, 239).⁴ When I started carrying out research on mental health care in Ghana in 2013, my initial aim was to explore how the GMH policies introduced within the framework of the new legislation played out in Nzemaland—a rural border area geographically located at the margins of the state, relatively far from centralised psychiatric institutions,⁵ unprovided with mental health NGOs (unlike other areas in the country), and generally overlooked in the ever-growing scholarship on mental health in Ghana. Throughout the last decade, while community-based psychiatric services increasingly became more present on the ground,⁶ my research interest progressively concentrated on their interaction with other healing practices. In a context marked by a manifest therapeutic plurality like Ghana, non-biomedical practitioners such as traditional healers, Christian prophets, and mallams⁷ are a crucial resource for people affected by mental health issues and their families. Recognising their indisputable relevance in the Ghanaian mental health arena, in line with GMH orientations, the new Mental Health Act proposed to establish collaborative relationships between psychiatric institutions and so-called “unorthodox” practitioners⁸ with the final aim of improving the provision of mental healthcare services in the country. Thus, my ethnographic research focused on everyday “collaboration experiments” (Draicchio 2020) and looked at what people (psychiatric nurses, charismatic pastors, traditional healers, patients, and family members) actually did across different therapeutic traditions and at the intersections of different ideas of mental suffering and care. It is precisely at one of these intersections that the ethnographic encounter I will write about in the next few pages took place.
- 5 The research this paper draws upon was carried out between 2013 and 2022⁹ and took place in different sites: namely, the psychiatric unit of a district hospital, a health centre provided with a psychiatric nurse (since 2020), multiple prayer camps,¹⁰ churches and traditional shrines, and private households where people affected by mental suffering and/or their relatives lived. Though the reflections I present here are deeply rooted in my long-term engagement with “the field” and in my ethnographic

experience as a whole, this article specifically draws on fieldnotes, conversations, and ethnographic observations pertaining to the last phase of my doctoral fieldwork (November 2021–January 2022).

Antecedents, or refusal number 1

Fadhila,¹¹ girl (15 years old), “psychosis:” came with her brother. He apologises because they were supposed to come on the 25th but they are showing up only today. In her [clinical] history there was written that she had previously been to [toponym omitted—district town where another psychiatric unit is located] and then visited a mallam, because they were convinced that a spirit/spirits were possessing her. She sees “spiritual cats.”

They [the family] want her to stop taking medicines, she [seems] very shy, but says that she doesn't want to. Francis and Henry are very upset, especially the second. But she is underage and the legal dimension is important (Francis), she cannot decide for herself. Friction. Brother says she has stopped taking drugs because “she is not mad!”

(Personal field notes, District hospital psychiatric unit, 29 November 2021)

- 6 These are the notes I quickly took on my phone while I was going back home from the psychiatric unit where I first met Fadhila and her “brother” Dave: the main protagonists of the ethnographic episode I will explore in this article. Later, I elaborated those notes in a vignette that I included in my PhD dissertation:

Mondays are usually busy at the psychiatric unit, especially when compared to the slowness—sometimes even boredom—that often characterises normal working days during the rest of the week. “Clients” and caregivers come and go. People wait. Patient files are created or updated. Questions are asked. Drugs are prescribed. There is kind of a rhythm that usually defines Monday mornings at the unit, with the nurses rapidly moving from one patient to the next. If the possibility of tensions, arguments, and complaints is always there and somehow punctuates the unit's Monday rhythm (i.e. people complaining for the waiting, for the lack of the required psychopharmaceuticals, for their excessive price, or for their unwanted effects), it is not common for this rhythm to be interrupted. Sometimes, however, particular occasions of unexpected friction may arise and force psychiatric nurses to stop for a while, somehow interfering with the way they are used to imagine and perform their daily activities. These occasions are rare, but powerful. So, it was a November Monday morning in 2021 [...] when the fifteen-year old Fadhila and her twenty-year old family friend Dave visited the unit for the second time, as they were asked to do by the nurses during their previous meeting a couple of weeks earlier. Fadhila was first brought to the hospital by Dave, who introduced himself, as it often happens, as her “brother.” Her record said that she was diagnosed with psychosis, as she claimed to see and hear the voices of multiple spirits, some of whom looked like cats and pushed her to attack people. “Everything is fine now”—maintained Dave, holding tight a tiny plastic sachet full of antipsychotic tablets. Francis and Henry, two of the unit nurses, asked Fadhila to come closer to their desk. They asked her how she was feeling and whether she could still see and hear the spirits. Speaking softly, almost murmuring, she said, “Only sometimes,” but she was now ok, she was feeling a lot better than when she first came. Her eyes were looking down, but her gaze was lively and bold. The nurses agreed, she looked healthier: the drugs were working—they commented. Dave, however, was shaking his head: she didn't need them, her family didn't want her to take them anymore. Francis and Henry looked at each other, then turned to Fadhila: “What do you think? Do you want to take these tablets or not?” She nodded timidly, but didn't look—at least to me—too convinced either. They repeated the question a couple of times, obtaining the same, feeble answer. “She is not mad!”—insisted Dave—when

the nurses started to educate him (to use the unit jargon) about mental illness, the drugs, and the need to keep taking them even when the sickness seems to be gone, because “you never know when it is going to come back.” Dave kept shaking his head, raised his voice, and put the tablet sachet on the nurses’ desk: what had happened to Fadhila was “something else,” she didn’t need any pharmaceuticals, this was her family’s decision. After a long moment of silence during which the two nurses kept looking at each other, and then at me, disheartened, Francis, the unit’s “in-charge,” said there was nothing they could do, the girl was a minor and from a juridical point of view it was up to her family to decide for her.¹² [...]

After they took off, Henry picked up the drugs Dave had previously bought from the unit and turned the sachet over in his hand. He looked outraged: what the family was implying was that Fadhila’s condition “was spiritual” and they knew, from their previous consultation with them, that she had already visited the shrine of a traditional healer before going to the hospital. But how could they refuse treatment when it was evident that the girl’s condition had improved? How could they not understand that? How could they not agree on that?

(Draicchio 2023, 172–74)

- 7 My encounter with Fadhila, thus, was marked by a refusal—the refusal of psychopharmaceutical treatment voiced by Dave on behalf of the family—that had nothing to do with me, at least not directly. As I will try to show in the next few paragraphs, however, I think that a connection could be established between this refusal (Refusal number 1) and another one (Refusal number 2), which involved myself and my ethnographic practice a lot more explicitly. But let me get to that gradually.
- 8 Though many facets of the moment of friction I had just witnessed were still unclear to me,¹³ I immediately felt it was a very meaningful event and something quite relevant to reflect upon in light of my research focus on the articulations of psychiatric and spiritual approaches to madness and mental suffering. So, before Dave and Fadhila left the hospital, I asked them if I could get in touch with them in the coming days in order to visit them in their hometown.
- 9 I visited them a few days later. When I arrived, I was invited to sit in the house compound with Fadhila, her parents, Dave, and other family members: I explained what my research was about, stressing multiple times—as I usually did in similar occasions—that, even though I had first met Fadhila and Dave at the hospital, I was not a health worker and that they should not in any way feel compelled to talk to me if they did not want to. They told me that they were happy to share their experience with me, and with the same determination, Dave and Fadhila’s uncle repeatedly emphasised that indeed the people at the hospital were wrong, that they did not understand, that they wanted to explain to me how mistaken the nurses were. At a certain point, while we were still talking, one of the spirits came to Fadhila. We quickly moved inside the house as her body started shaking. While the spirit was within the girl, demanding in a slurred voice for objects (e.g. talcum powder, cigarettes) and money, smoking, writing words spelled backwards on the floor, and giving advice to some of the bystanders—including myself: “The people you stay with, don’t trust them,” I was told. Dave urged me to watch and to take pictures. His insistence made me feel uncomfortable, and even more so because during the meeting, Dave had complained about the fact that Fadhila had deleted from his phone all the photos and videos he had taken of her: if she erased them, perhaps she did not want those pictures to be taken in the first place. There was no way I could ask Fadhila’s permission at such a moment—and I did not want the spirit’s consent, I wanted her own! So I told Dave that I preferred not to. When the spirit left, however, looking relatively shocked, but also somehow delighted about what

she quickly realised had just happened, Fadhila insisted that I snap a picture of her and that we take one together, with her body still covered in talcum and the ritual objects the spirit had used still scattered around the room.

Photo 1. After the spirit left (1)



Fadhila's house, 2 December 2021.

Photo by the author.

Photo 2. After the spirit left (2)



Fadhila's house, 2 December 2021.

Photo by Dave.

- 10 During that visit, I somehow received a visual and experiential explanation of what it was that the nurses “did not understand” according to Fadhila’s family. This was evident to the point that I could not help but wonder to what extent in that occasion the girl was freeing herself from a label projected onto her (i.e. mental illness, psychosis) and reclaiming the relationship with a spiritual world that is part and parcel of everyday life in the context she grew up in, and to what extent, instead, she was responding to her family’s expectations and, in that particular case, to their willingness of letting me really understand what was really going on.
- 11 In any case, it was clear to me that her story was more intricate and layered than it appeared at first sight during Fadhila and Dave’s meeting with the mental health unit

staff. Put simply, what Fadhila was going through was not an “illness” to be healed from, but a complex experience that would have hopefully resulted in her becoming a healer capable of mastering her relationship with “her spirits,” or “her people” as she had started calling them. It was, as I was told in subsequent conversations with Fadhila’s family and other people involved, a relationship that ran in the family: her grandfather was a healer too.

“It can’t be possible,” or refusal number 2

Good afternoon Madam Cecilia, how are you doing? I hope by the grace of God you are in a healthy condition as I am now. Please, we called the man [...] about what you wanted to do, the man we said we would call, yes, we called him, but he said it can’t be possible. So, we should let you know because it can’t be possible. He said if we try, what will happen, we won’t like that, so he warned us and he warned—the man we told you that we’d call and let you know: so, he said it can’t be possible.

(Dave, Whatsapp voice message, 15 January 2022)

- 12 A couple of days before receiving this message, I had visited Fadhila and her family and asked them whether I could record an interview with them, stressing—as I usually did—that they should not feel compelled in any way to necessarily say “yes.” Interviews have never been the core of my ethnographic work. It took me a long time to start feeling comfortable pulling out my recorder or my phone in front of a person who was about to discuss often very personal, sometimes painful experiences. Even when I was able to overcome that feeling of discomfort, I often had the impression that formal interviews represented just one layer of reality, one side of the story, so to speak, while meeting people repeatedly, conversing informally, spending time together, sharing experiences, worries and needs, and to a great extent just living everyday life with others, could prove more enlightening (see among others Hsu 2007). Nevertheless, with time I also started conceiving of interviews as useful tools capable of leading not only my interlocutors to reflect retrospectively on “aspects of life which may not surface elsewhere” (Hockey 2002, 214; see also Smith, Staple, and Rapport 2015), but I also reconsidered previous interpretations, notes, and memories, subsequently allowing me to just listen, again and without mediation, to stories told in the first person. Furthermore, when you are immersed in it, the practice of ethnography can sometimes feel volatile and there is something arguably comforting about the materiality of a recording that you can “bring back home:” those were my final weeks of fieldwork and I perhaps needed that kind of reassurance, especially because I had the constant impression of not being able to grasp all the layers implied in Fadhila’s story—a story that was still in the making of course.
- 13 It was—and this could be the subject of another whole article—the first time someone explicitly answered “no” to my request of recording. When I first asked, Fadhila’s parents and her “therapy management group” more broadly (Janzen 1987) did not deny their consent immediately, but they were not sure about what to do: during the previous weeks, Fadhila—accompanied by Dave and her mother—had visited a shrine in the Eastern Region of Ghana, where a healer—the person Dave referred to as “the man” in his voice message—had given Fadhila and her family members a set of strict rules to follow. Among his instructions, there was also the prohibition to use or come close to electronic devices. Thus, they were afraid it was not safe for her to record an interview at their house and they wanted to consult with “the man” before doing anything.

- 14 When I received Dave's message, I was puzzled: what was their refusal really about? It seemed to concern many things at the same time: it had to do with Fadhila's "vulnerable" status of "patient"—a person subject to therapy—as much as it had to do with her not being "mad" or "mentally ill" in her and her family's perspective. It had to do with spiritual entities, whose presence Fadhila was learning not to eradicate, but to manage. From this angle, refusal number 2—the interview refusal—appeared to me very much tied to refusal number 1—the psychopharmaceutical drug refusal. On the other hand, however, I had not specifically asked to record the interview with Fadhila or in her presence, so—I thought—the refusal might also have been a polite, indirect way to partially "withdraw consent"—to go back to the jargon of ethics review committees and forms. Though Fadhila and her family kept inviting me to their place, welcomed me warmly on subsequent occasions, and continued conversing with me about many things including the girl's "condition," that possibility could not be completely ruled out. Was I intruding excessively? Thanks to Fadhila's family's reaction to my request and to Dave's subsequent message, I was suddenly reminded that "consent" is not a given: it needs to be constantly re-established and continually questioned.
- 15 As suggested by bioethicist Carey DeMichelis (2020) with regards to her fieldwork on childhood biomedical refusal (i.e. situations in which young people or families attempt to resist or refuse forms of biomedical treatment) in North American hospitals, often when confronted with refusal the most common reaction is to simply ask: why? In the specific case of her research focus, she observes:
- When considering biomedical refusal, it is tempting to jump straight to the question: "Why is this family refusing treatment x?" This question is important, but it is perhaps not the first one that needs answering. A prior, but less frequently asked question is: "What precisely is this family refusing?" To get traction on this question, I propose backing up still further to ask: "What is it that parents are consenting to, when they say 'yes' to treatment?"
(DeMichelis 2020, emphasis in the original)
- 16 The same kind of reasoning, I suggest, could be applied to the two episodes I have called here refusal number 1 and refusal number 2: what precisely was being refused? What precisely was consent about? And furthermore, who were the subjects of consent and refusal?

Questioning consent, or the generative power of refusal

- 17 In the last few years, after the publication of Audra Simpson's seminal work (2007; 2014), refusal has increasingly become a subject of theoretical and methodological discussions in anthropology.¹⁴ In Simpson's research and in the growing scholarship informed by her theoretical proposal, refusal is something that pertains to both the ethnographer and her interlocutors. In her work on the Mohawk of Kahnawake's rejection of the authority and sovereignty of both U.S. and Canadian states, Simpson explores her interlocutors' political refusal—the everyday practices and experiences of people "that simply refuse to stop being themselves" (Simpson 2014, 2)—as well as the ways in which they sometimes decided to hold back information from her within the ethnographic setting. At the same time, in the framework of a broader refusal to

uncritically embed her research within the lineage of a discipline (anthropology) that has been deeply involved in the colonial project of indigenous elimination, she also introduces the concept of “ethnographic refusal” to theorise her own choices to withhold, in her writing, information, stories, and details that could be detrimental to the Mohawk community, whose political aims, preoccupations, and struggles she shares as a citizen of the Kahnawake Mohawk Nation herself.

- 18 Simpson’s work on the “generative” power of refusal is also, on a very essential level, a call to reconsider theory and/as ethics in ethnography (McGranahan 2022, 295). It reminds us how relevant it is to critically engage with the political and historical situatedness of people “as sources,” which basically means conceiving of them as a lot more than just that, and to reflect on the non-neutrality of ethnographic research and writing, as practices rooted in constant processes of decision-making that concern what to account for or not to account for in scholarly production. To a certain extent, this also means reflecting on what we as ethnographers ask our interlocutors to “consent to” when we involve them in our research.
- 19 With regards to the episode I have presented here, I argue that Fadhila’s family’s refusal to record the interview could be framed as a denial of consent to the objectification of that story into a source, and more specifically into the form of a “mental illness” case. Paraphrasing the words used by Savannah Shange in her insightful analysis of the “epistemic and ethnographic refusal” of one of her young interlocutors in the San Francisco high school where she carried out fieldwork (Shange 2019, 16), Fadhila’s family’s refusal could be read as a choice “not [to] concede to the terms by which we seek to know her” and her story. In this perspective, that refusal was generative because it was a reaffirmation of the need to take spirits seriously in Fadhila’s story and to put the girl’s health first in a connotation that went beyond its solely biomedical or psychiatric definition. Without the risks of sharing details of spiritual knowledge and family history—the missing layers I was hoping to grasp and “record”—in such delicate circumstances, the refusal worked in the direction of letting me “really understand” what was going on in contrast with the scene I had first witnessed at the unit.¹⁵ Furthermore, it is important to point out that, as it was also stressed at the unit when Francis stated that Fadhila “could not decide for herself,” in both episodes the subjects of refusal and consent were multiple: they formed a collective entity that tied together “the patient,” family members, caretakers, healers, and spirits.¹⁶ This kind of multiplicity is not well reflected in the bureaucracy of research ethics, where consent is generally conceived of as an individual process. In contexts like the one I described here, where illness, mental distress, and/or spirit possession are dealt with collectively by “therapy management groups,” however, it is evident that the request of individual consent looks like nothing more than a fictive practice. To a certain extent, the limits of an individual-centred approach to consent were actually reflected in the ethical clearance process my project was subject to in 2020 and 2021: since my research was aimed at involving subjects identified as “vulnerable,” in the protocol approved by the Ghana Health Service Ethics Review Committee, the presence of a relative/caretaker was posed as a necessary condition for obtaining “informed consent” from “mental health patients,” in order to ensure that “the basic conditions to conduct the research were respected.” This condition, however, was more related to the issue of “consent” in the specific field of mental health,¹⁷ and more particularly to the key role of “substituted decision-makers”

(Combrinck and Chilemba 2021) attributed to family members and caregivers as “guardians”¹⁸ and “personal representatives”¹⁹ of patients in current Ghanaian mental health legislation. Moreover, Fadhila was a minor, so when I first visited their house, in line with the protocol, my initial intention was to speak to Fadhila’s parents, to explain what my project was about, and ask their consent for involving them and their daughter in my research. However, as soon as I was invited to sit in the house compound, it became evident to me that consent had to be sought from Fadhila’s parents as well as from the other family members and friends who were taking care of her. And what about Fadhila herself? Trying to explain to her what my research was about and why I was interested in her story was one of the most important steps for me, and I did it repeatedly to the best of my capacity. From a formal point of view, however, this was paradoxically a marginal aspect. In other words, in a case like this one, where there is no evident friction between the ethical clearance protocol and the actual process of consent seeking in the ethnographic setting, the way formal consent is conceived of fails nevertheless to account for the collective, stratified nature of decision making (and refusal). Similarly, and perhaps more importantly, it fails to account for the complex network of power relations in which Fadhila was embedded across the human and the spiritual realms. And it is precisely at the crossroads of these two realms that Fadhila is “vulnerable,” and subject to her family, her healer’s, and “her spirits” decisions, but at the same time also potentially (and hopefully) “powerful,” thanks to a relationship with the non-human that she is learning to manage.

- 20 There are, obviously, many other possible interpretations and answers to the question: what was Fadhila’s family’s refusal precisely about? (Ng 2020, ix–xii). And, as I said, since the very beginning I have never ruled out the hypothesis of a deeper intention of the family to interrupt our ethnographic relationship and/or not wanting to share any more details of Fadhila’s story: it is mainly for this reason that I did not insist any further, in any way, by saying for example that I could have recorded the interview in another location, far from Fadhila, or that I could have carried out a formal interview without recording it. Indeed, though it might appear as a simple and straightforward process in protocols and forms, the possibility of “withdrawal” requires a particular kind of care and attention in the context of ethnographic research, where relationships between the anthropologist and her interlocutors are never just “research relationships.” Indeed, whereas in biomedical disciplines as well as in other social sciences that use ethnographic methods (e.g. sociology), “relationality beyond the strict confines of the researcher/participant role is treated as a problem to be solved,” “undesigned relationality”—and the possibility to establish intimate and friendly relationships with research interlocutors beyond the “extractive” aim of “data collection”—are a key feature of anthropological fieldwork (Bell 2019, 10). Being a methodology rooted in the experience of “living together” with other people, observing and participating, with the ultimate aim of “co-producing knowledge (...) within an interactive Self/Other dialogue” (Tedlock 1991, 82), in ethnography the boundaries between life and research can easily appear blurred, for both the researcher and her interlocutors. Thus, after the interview refusal, aware of the social obligations of hospitality that surely informed our relationship, I tried to pay particular attention to the ways in which Fadhila and her family members and friends interacted with me. Even though they definitely did not have to, they apologised repeatedly for not having

been able to satisfy my interview request and I never had the impression that they did not want to talk to me anymore or found my presence intrusive.

- 21 Thus, though my doubts were not completely dispelled, I decided to write about Fadhila's story in my dissertation, somehow reassured by the feeling of still being "welcome" in Fadhila's home. My choice, however, was also motivated by the conviction that hers was a story that was important to include within the framework of my research on collaborative practices of mental health care involving psychiatric nurses and spiritual/religious healers. In particular, the ways in which refusal number 1—the drug refusal—was framed as an unreasonable "lack of knowledge" and a "lack of understanding" by the nurses at the unit was to me an evident expression not only of the obvious power imbalance between practitioners and patients in the therapeutic setting, but also of the underlying hierarchy of epistemologies that dominates the health workers' practice—a hierarchy that might be quite easy to reproduce as researchers when we take the psychiatric unit/hospital as our main location. Indeed, the attempt to educate Dave and Fadhila as a reaction to their refusal reflects the power relationship that informs the encounter between doctors/nurses and patients and caregivers, as well as, more broadly and at the same time more specifically, the power dynamics that inform the articulation of Western psychiatry and local epistemologies.
- 22 These power dynamics are a key feature of the Global Mental Health discourse that informed the promotion of the practice of "collaboration" between psychiatric and non-biomedical practitioners in Ghana (as well as in many other countries in the Global South). Indeed, together with the "treatment gap,"²⁰ the idea of a "gap of knowledge," often described in terms of "lack of mental health literacy," is one of the key axes of GMH. In the recently issued World Mental Health Report, for instance, it is stated that: "Low demand for mental health care can also be driven by *low levels of health literacy* about mental health, including a *lack of knowledge and understanding of mental health* as well as prevailing beliefs and attitudes that undermine the value placed on mental health and effective mental health care" (World Health Organization 2022, 65–6, emphasis added). Partially tied with refusal number 2 (the interview refusal), the refusal of Fadhila's psychiatrisation challenges this dominant discourse on collaboration and on what mental health care is (or should be), forcing us to complexify these notions and practices "from below."
- 23 Finally, as this article demonstrates, I still stand by this interpretation and the decision to write about Fadhila, but in a special issue that aims to reflect on the methodological and ethical implications of carrying out research on madness/mental illness, I think it is important not to conceal the possibility that my ethnographic choice could be/have been wrong. In other circumstances, where for instance people were in a condition of suffering and vulnerability that seemed to me too extreme and I felt that my ethnographic presence was indeed intrusive, I took a different decision—even if I could have probably obtained "formal consent" from their family members. And here the question remains open: to what extent can the choice to exclude people from research on these grounds further marginalise their experiences and worldviews?

Conclusion

- 24 In this article, drawing on the generative concept and practice of refusal, I have tried to carry out a reflection on the methods and ethics of doing research on madness and mental health from an ethnographic perspective. Rather than giving fixed answers, I have tried to suggest the importance of exploring questions worth asking, beyond their normative crystallisation in bureaucratic conceptualisations of consent. Far from reproducing a mere self-centred narrative that may end up obscuring the presence and views of others—a risk that is always there in anthropology—focusing on the things that puzzle us as researchers, on the things we do or do not write about, could also be an epistemological tool to employ in order to critically reflect in ethical terms on the mechanisms of knowledge production.
- 25 More broadly, in line with the aims of this special issue, by telling a piece of Fadhila's story, I have also tried to highlight the value of carrying out research on madness/mental illness outside and beyond the physical and epistemological spaces of psychiatry, as well as the importance of working with the “non-recorded” and “the non-recordable” and with the “bits and pieces” ethnography is made of (McGranahan 2022, 292).

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NOTES

1. Think for example of my own positionality as a white European PhD student, based at a Global North institution granting me access to financial and training resources that appear incommensurable when compared to the possibilities of most of my interlocutors, and allowed to travel frequently and with ease to an African country like Ghana—while the right to mobility of people living there continues to be constantly and violently denied by EU migration policies.
2. As for anthropology in particular, the attempt to critically deal with its colonial roots and to "reinvent" its practice (Hymes 1971), both in ethical and political terms, has been made in different phases of the history of the discipline since the 1960s (Caplan 2003; see, among others, Asad 1973, Abu-Lughod 1990, Bourgois 1990, Escobar 1993, Scheper-Hughes 1995, Tuhiwai Smith 1999). In the last two decades, in parallel with the development of "audit cultures" in academia (Strathern 2000), attention has been increasingly paid to the tensions between the bureaucracy of institutional ethical assessments and the deeper ethical conundrums that characterise ethnographic practice. In addition to the works cited above, see also among others Dilger, Husche, and Mattes (2015).
3. Here, I put the term in quotation marks as I think that, used uncritically, it may sometimes contribute to create an artificial, neat separation from other life experiences, somehow denying the interconnectedness of the time of life and the time of ethnography and reifying a rhetoric imaginary of "the field" as an inherently "exotic," even "mystical," experience. Put in other words, we could say that to a large

extent “the field” is—also—just life. On the relationship between fieldwork and life, McLean and Leibing 2007. On the limits of “the field” as a metaphor for ethnographic research, see also Hsu 2007.

4. First introduced in the public debate in 2001 by US Surgeon General David Satcher (Satcher 2001), the expression Global Mental Health emerged as a strong paradigm in public health policies in the second half of the decade, after the publication of the influential article, “No Health Without Mental Health” (Prince et al. 2007) and a series of related papers in the *Lancet* in 2007, and the subsequent foundation of *The Movement for Global Mental Health* in 2008. The main aim of the movement was to enhance mental health care services in low and middle income countries and to reduce the so-called “treatment gap,” that is the “the gap between the numbers of people assumed to be suffering from mental illness and the numbers receiving treatment” (White et al. 2017, 12), where treatment is largely understood as pharmaceutical. For a more detailed contextualisation of the Ghanaian mental health reform within the broader history of the politics and policies of health care in the country, see Draicchio 2020.

5. The Accra Psychiatric Hospital and the Pantang Psychiatric Hospital in the capital city and the Ankaful Psychiatric Hospital in Cape Coast (Central Region).

6. While, despite a considerable increase, trained psychiatrists in the country are still extremely exiguous in numbers and mostly concentrated in psychiatric hospitals and big urban centres, since 2012 there has been a major increase in the number of trained community-based mental health nurses: from 200 to now over 2,000 in the whole country. This change was reflected in the Nzema area, where the number of community psychiatric nurses assigned to the district where I carried out my research went from four in 2013 to ten in 2022.

7. Muslim healers whose therapeutic practice draws on the Quran.

8. The term “unorthodox” is used to identify non-biomedical practitioners in the text of the 2012 law (Republic of Ghana 2012, 7, 16), revealing quite explicitly the crucially asymmetric way in which “collaboration” is envisioned in Ghanaian mental health policy and the Global Mental Health discourse more broadly.

9. The research was conducted in six different fieldwork periods: October–November 2013, July–November 2014, June–July 2017, November–December 2018, January–March 2020, August 2021–January 2022 (with two short visits carried out also in July 2019 and July 2022).

10. Prayer camps are religious healing sites usually embedded within (neo)Pentecostal/ (neo)Charismatic churches where people deemed “mad” or “mentally ill,” as well as people facing other kinds of health and life problems, seek spiritual therapy, through practices like prayer, fasting, and deliverance, with the mediation of prophets, prophetesses, and pastors (see, among others, Fancello 2008, Larbi 2001, van Dijk 1997).

11. Though I am now aware of the ongoing thought-provoking discussions on the uses of anonymity and pseudonyms in ethnography (Weiss and McGranahan 2021), I had not critically reflected on this practice at the time I submitted my ethics review application to the Ghana Health Service Ethics Review Committee in 2020 and 2021. In compliance with what I declared in those applications, in this article as in the rest of my work so far, all the names of the people mentioned are pseudonyms and details of their stories were either changed or omitted in order to preserve anonymity. For the same reason,

in order to avoid identifiable details, I do not indicate precisely the name of the district and the clinical facilities where I conducted my investigation.

12. Though it might be argued (see below) that the nurses were (reluctantly) accepting Fadhila's family decision because, from a sociocultural point of view, they recognised it as a legitimate prerogative of her "therapy management group" (Janzen 1987), here Francis was referring to the Mental Health Act, which states that, "Parents or guardians of children under the age of eighteen years receiving psychiatric treatment shall represent them in matters concerning the mental well being of the children including consent to treatment." (Republic of Ghana 2012, 27).

13. For instance, I didn't immediately understand why Fadhila and Dave had undertaken such a long trip to the hospital—their hometown was indeed quite far from it—just to let the unit nurses know that Fadhila would have stopped taking the medications they had prescribed her. As the nurses first—and Dave and other people I met in their hometown later—explained to me, they were sent to the unit first and foremost to collect a certificate requested by the local police station where the girl was reported to for "violent" behaviours (i.e. threatening to attack a woman she believed was a witch with a knife, aggressively accusing someone else of hiding "bad stuff" in their shop).

14. See, for instance, the whole *Cultural Anthropology* "Openings" section edited by Carole McGranahan 2016; McGranahan 2022; Ng 2020, ix–xii; Shange 2019; see also the *Journal of the Royal Anthropological Association* special issue "On Irreconciliation" edited by Nayanika Mookherjee (2022).

15. On a side note, it is interesting to note how a different kind of "source," perhaps even "more material" than a recorded interview, that is the photographs Dave and Fadhila urged me to take at a time when electronic devices were not yet interdicted, acted in a similar way in our ethnographic relationship.

16. Indeed, it was the spirits who told Fadhila not to take the hospital tablets in the first place.

17. At a global level, consent is currently a key issue in the field of mental health both in terms of research (see for instance Loue 2021; Ruiz-Casares 2014) and practice (World Health Organization 2022, 85–8). With regards to the latter, discussions of consent are crucially tied to critical concerns such as restraint, coercion, and involuntary treatment. For instance, in his analysis of the ways in which US community psychiatric nurses ethically navigate a therapeutic environment in which "constraint becomes both a component of care and its ethical limit" (Brodwin and Velpry 2014, 525), anthropologist Paul Brodwin has highlighted how the practice of informed consent paradoxically becomes a practice of constraint that ends up limiting the autonomy of the patient (Brodwin 2013).

18. "A person with mental disorder who is unable to manage that person's personal affairs because of the mental disorder shall be protected in matters such as finances, business, occupation, marriage, the right to found a family, the right to treatment of choice, testamentary capacity and other legal issues for the benefit of that person" (Republic of Ghana 2012, 28).

19. " 'Personal representative' means a person who represents the interest of a person with a mental disorder who may be a family relation or friend, whether appointed by the court or not" (Republic of Ghana 2012, 40–41). According to Act 846, people

identified as “personal representatives” are required to give their consent (e.g. to treatment and other medical procedures) on behalf of the patients they represent when the latter are “unable” or “incapable” of doing so.

20. See note 4.

ABSTRACTS

Drawing on fifteen months of ethnographic fieldwork conducted between 2013 and 2022 on experiences of madness and practices of mental health care in rural southwestern Ghana, in this paper I propose to take as a point of departure, a specific episode in which the relatives of Fadhila—a girl I had first met at the psychiatric unit, where she was diagnosed as “psychotic”—refused to give consent to record an interview with me. The refusal was motivated by the strict instructions that Fadhila and her family were given by the traditional healer who was taking care of her: among many other things, the girl was not allowed to come close to any electronic device and her family felt it was unsafe to record an interview at their house. The refusal had to do with Fadhila being a “patient” as much as it had to do with another refusal: that of drugs and psychiatrisation. Indeed, the refusal had to do with spirits, the spirits that occasionally possessed Fadhila and were trying to make her a healer, according to her, her family members, and the traditional specialists they had visited. The refusal, however, may also have been a polite, indirect way to “withdraw consent”—to use the jargon of informed consent forms and ethics review committees. Though Fadhila and her family kept inviting me to their place, welcomed me warmly in subsequent occasions, and conversed with me about many things including the girl’s “condition,” that episode pushed me to reconsider the limits of formal consent and the need to constantly question it and re-establish it—a complex dynamic that sometimes the bureaucracy of “ethical clearance” processes in academia may contribute, paradoxically, to erase.

Analysing this ethnographic episode in light of the powerful concept of ethnographic refusal introduced by Audra Simpson, I propose a reflection on the ethical and methodological implications of considering people as “sources” in ethnographies of madness and mental health.

Cet article se fonde sur quinze mois de recherches ethnographiques menées entre 2013 et 2022 sur le terrain, dans la région rurale du sud-ouest du Ghana, sur les expériences de la folie et les pratiques de soins en santé mentale. Je propose de partir d’un épisode spécifique, au cours duquel la famille de Fadhila, une jeune fille que j’avais rencontrée au service psychiatrique où on l’avait déclarée « psychotique », a refusé de consentir à l’enregistrement d’un entretien entre elle et moi. Ce refus était dû aux consignes strictes que le guérisseur traditionnel qui s’occupait de Fadhila avait communiquées à la jeune fille et à sa famille : parmi les nombreuses interdictions qui lui étaient faites, Fadhila n’avait le droit de s’approcher d’aucun appareil électronique et sa famille estimait qu’il était risqué d’enregistrer un entretien à leur domicile. Le refus était autant lié au fait que Fadhila soit une « patiente » qu’à un autre refus : celui des médicaments et de la psychiatrisation. En effet, le refus était lié aux esprits qui prenaient parfois possession de la jeune fille et tentaient de faire d’elle une guérisseuse, selon Fadhila, les membres de sa famille et les spécialistes traditionnels qu’ils avaient consultés. Toutefois, ce refus a pu tout aussi bien être pour eux une façon polie et indirecte de « retirer leur consentement », pour employer le jargon utilisé dans les formulaires de consentement éclairé et les comités d’évaluation éthique. Bien que

Fadhila et sa famille aient continué à m'inviter chez eux, qu'ils m'aient reçue chaleureusement plusieurs fois par la suite et qu'ils m'aient parlé de nombreuses choses, y compris de l'« état » de la jeune fille, cet épisode m'a amenée à m'interroger sur les limites du consentement formel et sur la nécessité de constamment le questionner et le ré-instaurer ; une dynamique complexe que, paradoxalement, les processus administratifs d'« approbation » par les comités d'éthique dans le monde universitaire ont parfois tendance à éliminer.

En analysant cet épisode ethnographique à la lumière du puissant concept de *refus ethnographique* forgé par Audra Simpson, je propose de réfléchir aux implications éthiques et méthodologiques liées au fait de considérer les personnes comme des « sources » dans les ethnographies de la folie et de la santé mentale.

Este trabalho foi inspirado por quinze meses de trabalho de campo etnográfico, realizado entre 2013 e 2022, sobre experiências de loucura e práticas de cuidados de saúde mental em meio rural, no oeste do Gana.

Neste artigo, proponho tomar como ponto de partida um episódio específico em que os familiares de Fadhila - uma menina que encontrei pela primeira vez na unidade psiquiátrica, onde foi diagnosticada como “psicótica” - se recusaram a consentir em gravar uma entrevista comigo. A recusa foi motivada pelas instruções estritas que Fadhila e a sua família receberam do curandeiro tradicional que a estava a tratar: entre muitas outras coisas, a menina não foi autorizada a aproximar-se de qualquer dispositivo eletrónico e a família sentiu que não era seguro gravar uma entrevista em sua casa. A recusa tinha a ver com Fadhila ser uma “paciente” mas também com uma outra recusa : a dos remédios e da psiquiatrização. Na verdade, a recusa tinha a ver com espíritos, os espíritos que ocasionalmente possuíam Fadhila e estavam tentando fazer dela uma curandeira, segundo ela, seus familiares e os especialistas tradicionais que tinham consultado. A recusa, no entanto, também pode ter sido uma maneira educada e indirecta de “retirar consentimento” - para usar o jargão dos formulários de consentimento informado e dos comités de revisão ética. Embora Fadhila e sua família tenham continuado a convidar-me, me tenham acolhido calorosamente em ocasiões subsequentes, e conversado comigo sobre muitas coisas, incluindo a 'condição' da menina, esse episódio levou-me a reconsiderar os limites do consentimento formal e a necessidade de questioná-lo constantemente e de o restabelecer - uma dinâmica complexa que às vezes a burocracia dos processos de “apuramento ético” na academia pode contribuir, paradoxalmente, para apagar.

Analisando este episódio etnográfico à luz do poderoso conceito de recusa etnográfica introduzido por Audra Simpson, proponho uma reflexão sobre as implicações éticas e metodológicas de considerar as pessoas como “fontes” nas etnografias da loucura e da saúde mental.

INDEX

Mots-clés: ethnographie, consentement, éthique, refus ethnographique, folie, psychiatrie, guérison traditionnelle, Ghana

Geographical index: Ghana

Keywords: ethnography, consent, ethics, ethnographic refusal, madness, psychiatry, traditional healing, Ghana

Palavras-chave: etnografia, consentimento, ética, recusa etnográfica, loucura, psiquiatria, cura tradicional, Gana

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