

The dark side of privacy: Stigma, secrecy, and HIV/AIDS in Ghana

Le côté sombre de l'intimité: La stigmatisation, le secret et le VIH/SIDA au Ghana

Abstract:

This article explores contradictions in the experience and practice of privacy. It describes how extreme privacy is managed in Ghanaian communities where physical privacy is nearly impossible in everyday life and analyses the dilemmas that people living with HIV/AIDS face concerning their privacy. On the one hand, because of the possible repercussions of disclosure, they prefer to conceal their HIV/AIDS status. On the other hand, over-concern about privacy leads to suffering and death and the perpetuation of disastrous stigma. When a disease is heavily stigmatised, as is the case for HIV/AIDS in Ghana (and many other countries), privacy may not only protect but also endanger a person's life. The article is based on participant observation (including informal conversation) in two hospitals and two communities in Ghana.

Keywords: *privacy, stigma, secrecy, HIV/AIDS, hospital, community, Ghana*

Resumé

Cet article étudie les contradictions qui caractérisent l'expérience et la pratique de l'intimité. Il décrit comment la vie privée à outrance est gérée dans les communautés ghanéennes où l'intimité physique est presque impossible dans la vie courante. Il analyse aussi le dilemme auquel font face les personnes vivant avec le VIH/SIDA en ce qui concerne leur intimité. D'une part, compte tenu des effets négatifs possibles que comporte la révélation de leur état par rapport au VIH/SIDA, ils préfèrent ne pas déclarer qu'ils sont séropositifs. D'autre part, une trop grande préoccupation concernant le respect de leur vie privée conduit à la souffrance et à la mort, et pérennise leur stigmatisation. Lorsqu'une maladie est fortement stigmatisée, comme c'est le cas du VIH/SIDA au Ghana (et dans beaucoup d'autres pays), le désir de conserver son intimité pourrait pousser une personne soit à s'isoler soit à se tuer. L'étude se base sur une observation participante dans deux hôpitaux et deux communautés au Ghana.

Mots clés: *intimité, vie privée, stigmatisation, secret, VIH/ SIDA, hôpital, communauté, Ghana*

1. Introduction

The concept of privacy – like several other concepts – defies a precise definition because it refers to experiences that are too close to 'see' it properly. 'Privacy' may be hard to define, but nearly everyone seems to be convinced that it is an indispensable part of human life. Scholars largely agree that privacy is a precondition for the development of personal identity. Smith (2004: 11250), quoting the philosopher Bok, defines privacy as protection from "unwanted access by others". This protection, he continues, provides freedom and creates room for self-control, self-reflection, and self-expression (see also Magi, 2011). The Stanford

Encyclopedia of Philosophy (DeCew, 2013) lists a number of attempts to capture the meaning of privacy: ‘control over information about oneself’, ‘required for human dignity’, ‘crucial for intimacy’, ‘necessary for the development of varied and meaningful interpersonal relationships’, ‘the value that accords us the ability to control the access others have to us’ or ‘some combination of these’. For the purpose of this article we will use the concept of privacy as a condition of life in which a person feels comfortable, safe and secure within his/her social environment, in its narrow *and* wider sense.

Both historians and anthropologists have pointed out that the social and physical conditions considered necessary for privacy in the present day Western situation have not been constant throughout history or across different contexts. Aries (quoted in Smith, 2004) has argued that until the 17th century, very few people in Europe spent time alone, while anthropologists who base their views on direct observation have described in detail people across the world who hardly have anywhere that could be considered private. House construction (including sanitary facilities) and crowded living conditions often do not allow for any physical privacy. This does not mean, however, that there is no desire for privacy among people living under such conditions, or that they do not have access to privacy at all.

In the absence of physical boundaries and hiding places, one particular kind of privacy is well described by Patterson and Chiswick (1981) with regard to Sarawak Dayak communal longhouses in Kalimantan, Indonesia, which offer practically no physical opportunity for individuals to be alone. This ‘problem’ is compensated for by social mechanisms that guarantee a sense of privacy. For example, when a quarrel erupts, others may leave the scene (p. 137). Central to this article is the search for ultimate privacy in a society where physical solitude is hard to sustain.

As mentioned, we should not conclude that the absence of physical privacy implies the acceptance of a lack of privacy. The social strategies mentioned above prove the opposite. Moreover, it is not unlikely that the longing for privacy rather grows with the absence of the physical conditions that make it possible; after all, scarcity fans desire. Conversely, an abundance of (physical) privacy, one could argue, is a luxury that may be underestimated by those who enjoy it and may lead to boredom and loneliness. The paradox of the Western sanctification of privacy on the one hand and the almost exhibitionistic revelations of personal experience and thought via social media on the other can be understood from this perspective.

In this paper, which tells stories of the desire for privacy in an African context, and the potential negative repercussions of such privacy, we have two underlying intentions. First, we want to present another culture of privacy at a junction in time when discussions about privacy are focused entirely on industrialised, digitalised, and technically advanced societies. The experiences of people in Ghana show another picture of privacy as a basic human need and right. The second objective is to place some question marks above what we have just called the ‘sanctification of privacy’. Privacy is an inherently ambiguous concept; it is indispensable for human existence, yet it can also disable and destroy this very existence. In this article we will present a more nuanced and critical insight into the concept of privacy.

Privacy implies secrecy, another concept that needs to be introduced here. Secrecy is derived from the Latin verb *secernere* (to sever, cut off) and refers to keeping people out of one’s personal domain. But a secret may also have an opposite effect as is suggested by the the German term *Geheimnis*). *Geheimnis* is derived from ‘*heim*’ or ‘home’. It points at the

intimacy that thrives in the secure place of one's home. Sharing a secret with someone is a way to establish intimacy with another person. A secret, therefore, can have an excluding as well as an including effect. People with HIV/AIDS in Ghana – and in many other societies – are however uncertain as to what the safest choice is. Who can be trusted? Disclosure is once and forever and cannot be undone. As long as one is not certain about the trustworthiness of the other person, it is prudent to keep certain things secret, which may include lying. A secret can always be revealed when it is safe to do so and a lie can always be withdrawn. Secrecy, in short, is an indispensable 'tool' to protect one's privacy in threatening circumstances.

The reason for strict secrecy and great anxiety about privacy is the risk of stigmatization when information spreads about someone's HIV status. 'Stigmatization' will be used in the meaning that Goffman (1963) gave to it: 'spoiled identity'. The social consequences of stigmatization for affected individuals or groups can be devastating, in particular with regard to people with HIV/AIDS as has been shown in countless studies (e.g. Gielen et al., 1979; Parker & Aggleton, 2002; Lugalla et al., 2014; Judgeo & Moalusi, 2014; Rispel et al., 2015). Stigma is attached to the social identity of people when they are found to possess attributes that mark them as deviant, and as a result are treated as different persons. Who you *are* is overshadowed by what you *have* (cf. Kwansa, 2013:10). The fact that people may feel or internalise stigma even when overt stigmatisation does not take place, makes matters extra complex (Scambler, 2004; Weiss, 2008; Herek et al., 2009).

We first provide some ethnographic background to privacy in Ghanaian society and briefly describe the research that provided the data for this paper. Next, we present and discuss the effects of severe privacy on the lives of people living with HIV/AIDS in Ghana, both in the community and in the hospital. General reflections on privacy, secrecy and stigma will conclude the article.

2. Privacy in Ghana: Conditions and concerns

In Ghana, housing and other living conditions for the majority of the population¹ do not provide the degree of physical privacy that people in higher income societies are used to. In Amsterdam, the Netherlands, for example, more than one half of the city's households is occupied by just one person, and most multi-person family households occupy spacious accommodation where all members – including children – have their own (bed)room. In Ghana, data from the population and housing census (2010) shows that only about 18 percent of households are one-person households; they are, furthermore, most common in middle and high income urban settings and relatively rare in rural and low income contexts. Most people in the latter category live in shared structures, commonly referred to as 'compound houses', which comprise more than one half of dwelling units in Ghana. The one-person households in rural areas that do exist are mostly rooms within a larger family house that are rented to tenants. Most of the activities of tenants who live alone, however, are visible to – and are talked about by – the other occupants of the house.

¹ This does not apply to households in the middle-highest wealth quintile, which usually occupy single family apartments.

Much of life in compound houses, such as socialising, cooking, eating, and doing laundry, takes place outside, particularly in rural communities.² With some exaggeration, one could say that when people go to their room, it is likely to be for sleeping, sex, or for a private conversation.³ Furthermore, 'indoor activities' are only private to a limited extent, because the other occupants of the house know that a person is in the room and therefore probably doing something 'private'. Physical privacy is particularly scarce within families, as couples often sleep with several children in one room, if not one bed. Private possessions of the family members are also difficult to hide or keep in safe places due to limitations of private space.

Many, if not most, people in rural areas – at least in Southern Ghana – only have access to public toilets. Not having a private toilet in the house has for a long time been a Ghanaian tradition, though this is slowly changing. Recently, with improved access to piped water for the more well-to-do, the building of private water closets is gradually increasing, also in rural areas.

Taking into account the fact that our depiction of limited access to private physical space for Ghanaians is more true for lower income groups and rural households, one could say that little happens in these households that remains hidden from others in the house. Quarrels or secret love affairs quickly become known to co-inhabitants and neighbours. The walls have ears indeed, as a Ghanaian proverb says. When a research assistant staying with one of us in a rented room quarrelled with his wife, the head of the house called the two in and told them to live together in peace.⁴

Of course, one should not limit privacy to physical space and overlook 'relational' space. It is possible to be in a (physically) crowded space and yet keep a distance and respect others' privacy. Indeed, Ghanaians do not necessarily think that their social setting poses a significant problem. It is considered problematic, however, to conceal significant secrets from close relatives or friends such as a parent, partner, sibling, or a more extended relation (neighbour or friend), as will be discussed further below. An efficient strategy for granting or keeping some kind of privacy is to pretend that one has not heard or seen something. Even children learn at an early age to keep secrets and shut up. The ability to keep silent and not to gossip about others is generally regarded as an important virtue, something that one masters as one grows older. An elder, a proverb goes, does not gossip. This does not mean that gossip does not take place. On the contrary, gossip is practised on a wide scale, but the 'advantage' of gossip is that it is in itself a private act: information exchanged in confidence. The paradoxical result is that a secret may be widely known and yet remain a secret because the medium of spreading the news is a secretive one.

² Census figures from 2010 show that one fifth of Ghanaians cook in the open. This is also true for washing and other daily household chores. People are, however, increasingly using their 'own' spaces for such activities, and many look for rooms that can afford them a degree of privacy. 'Self-contained' rooms are therefore more and more preferred.

³ Today, however, many Ghanaians, even the relatively poor, have access to TVs, DVDs, etc., partly due to the influx of second hand 'dumped' goods from the West, so they may have more reasons to spend time indoors.

⁴ An example of the audibility and visibility of 'private' life in an African community is presented in Van Hekken's (1986) (Dutch) ethnography of a Tanzanian village. Quarrels in the family can be heard by neighbours, who start to gossip about it, which may eventually lead to sickness in the family. The lack of privacy enables strict social control, and is underpinned by illness aetiology; the translated name of the sickness is 'neighbours' breath'.

The night plays an interesting role in the production of this pretended privacy. Disapproved of and shameful activities that take place under the cover of darkness are not really shameful, because the actor has taken the trouble to hide them. Even when others have seen what the person has done (and this increasingly happens with the presence of electric lighting in streets and houses), they conclude that he/she has at least shown respect by acting in the night. Doing improper things in broad daylight is truly shameful; the night – dark or not – provides privacy and safeguards one's public position (Van der Geest, 2008).

This social construction of privacy is, however, put to the test when it comes to one of the most stigmatised health conditions of today, HIV/AIDS. Figures from the Ghana AIDS Commission website⁵ show that the prevalence rate of HIV/AIDS in 2013 was 1.3 percent. Antiretroviral therapy (ART) was introduced in 2001, and has since then become available at a growing number of health facilities through nationwide scale-up efforts. In 2011, there were 140 operational ART (antiretroviral therapy) centres, and the intention is to have at least one ART centre in each of the country's 170 districts.

The relatively low prevalence of HIV/AIDS in the country (compared to East and Southern Africa) has a downside: having the infection is rarely publicly discussed. People with an HIV positive status or with the disease AIDS are severely stigmatised, and only very few dare to reveal their condition to others, including close relatives and friends. Fear of stigmatisation is the main obstacle in the fight against HIV/AIDS. It is against this background of fear and shame that the research for this paper was conducted.

3. Fieldwork

Most of the data on which this paper is based was collected in a multi-sited and multi-level research project that studied how actors at different societal levels experience and manage the problems of HIV/AIDS. The objective of the project was to explore obstacles in the fight against HIV/AIDS in order to improve the efficacy of national and local policies in dealing with the disease.

All researchers were anthropologists. Two Ghanaians carried out participant observation: one in two communities (one rural, one urban) in the Ashanti Region of Ghana, the other in two hospitals (one rural, one urban) in the same region. The third (Dutch) researcher focused on policy makers, researchers, academics, and journalists involved in the study of and policy in relation to HIV/AIDS. Kodjo A. Senah (from Ghana) and Sjaak van der Geest (Dutch) were the overall supervisors of the project. The ethnographic data for this paper comes from the two Ghanaian researchers.

Participant observation, in their case, implies that they familiarised themselves with and spent time in the company of the people whom they studied. For the community perspective, these were mainly people with HIV/AIDS and their relatives and/or friends. Kwansa met them and held informal conversations with them in their home situations or at other locations chosen for privacy reasons. Among other things, he also worked with the respondents on their farms and other places of work, such as quarries and selling points, and

⁵ http://ghanaims.gov.gh/gac1/aids_info.php

attended communal gatherings (such as funerals and church services). In most cases, though the people with HIV/AIDS knew of the research topic and objectives, the relatives and neighbours did not know that he was conducting research on HIV/AIDS. His visits looked like the visits of a friend, which in fact they often were (Kwansa, 2013: 33, 35). The second researcher, Dapaah, adopted a largely similar research approach in the two hospitals, where he observed patients with HIV/AIDS, peer educators, nurses, and doctors. 'Participation' in his case included sitting and conversing with patients in the waiting room and during meetings, and helping nurses and peer educators with odd jobs (Dapaah, 2012; Dapaah & Moyer, 2013). Ethical clearance for this aspect of the research was provided by both hospitals.

Both researchers established excellent rapport with their informants and won their trust. Not only did they listen to their stories, but they also actively tried to help them where possible, for example by providing emotional and material support and mediating contacts with relevant others. Throughout their studies, they have protected the anonymity of their informants.

4. Privacy, stigma, and HIV/AIDS in the community

Because of the strong stigma surrounding HIV/AIDS, many people do not want to know that they have this 'dreaded disease'. Few voluntarily and/or knowingly go for an HIV test, for instance if they suspect that they may be infected or just want to be sure that they are not, or when a test is mandatory (as in the case of a foreign embassy to acquire a visa or by a church to get married). A significant majority of the people in our research who had the disease had been tested for HIV without their knowledge as part of a routine diagnostic examination. Some of those who *were* aware of the fact that they had been tested for HIV decided not to go back for the results. Not knowing their condition, they reasoned, was better than hearing their death warrant and facing social exclusion. As a consequence of the reluctance to know about their HIV status, many of the HIV positive respondents often only found out at the end stage of their illness trajectory. They were brought to hospital in a very serious condition, where they were tested and their status determined. Most respondents explained that, at this stage, they were compelled to inform their caregivers, at least those who were with them when the test results were given.

Almost all of the HIV positive persons whom the researcher in the community met said that their first reaction after getting the result was to 'end it'. After considering the possible reactions of their family, friends, and the general public, they thought that death would be 'worthier' and thus a better option. Those who chose to live but still keep their status private were mainly those who were diagnosed when they were relatively healthy. The initial shock and confusion notwithstanding, they were in a better position to choose from the options available to them. The majority decided to follow the ART regimen and/or any other option, including the use of spiritual therapy (Kwansa, 2010; 2014), that might help them to manage the situation and thereby conceal their status. Due to the absence of overt symptoms or progression of the disease, little change occurred in their everyday lives after testing positive. They were therefore not compelled to reveal their status to those in their environment.

Those who were married or in a sexual relationship, especially the women, often did not reveal their status, even to their partners. They knew what the consequences could be if their partner were to find out: breakdown of the relationship and divorce, loss of financial support, and disclosure to unwanted others. More than eighty percent of the HIV positive people followed in the community, and a slightly higher percentage (85 percent) of clients in the two hospitals, had not disclosed their status to their family or friends. For those whose status was disclosed to relatives, two consequences were possible: exclusion or collective concealment by the family, to prevent what Goffman (1963) has called ‘courtesy stigma’: stigmatisation by association. An example of severe exclusion *and* collective concealment was the case of a very sick woman whose relatives refused to spend an extra penny on her when they found out that she had tested HIV positive. “She was going to die anyway and the money would go waste”, a nurse explained. About three weeks after the researcher met her, he saw her obituary notice all around the community. A grand funeral was held for her. The family rejected and gave up on their relative at the end of her life, but still celebrated her in death to conceal and avoid the shame of AIDS. In a clear act of collective impression management, the funeral was the family’s strategy to keep the real cause of her death ‘private’, even though many in the community were probably aware of the fact that she had died of AIDS.

In some households, families who learned from the hospital that their family member had been diagnosed as HIV positive would mistreat him/her. In one case, the family of an HIV positive woman kept her in a room and barred her from speaking to anyone. No one could visit her, not even her own children or the staff from the hospital. One day, the researcher and a nurse demanded access to her room to check on her. When the relatives steadfastly refused, the nurse decided to make a scene by shouting and accusing them of preventing them from seeing their sick family member. Only after this were they allowed to enter the room. The woman was lying on a mat in a virtually empty room, with only a few cloths for cover, two eating plates, a cup, a tablespoon, and a chamber pot. She explained that she had seen them every time they had come by the house and been refused entry on previous occasions, and had not been travelling as her relatives had always claimed. She had been denied any visitors, and only saw the world through the doorway to her room. She sobbed:

They open the door in the morning when my sister comes in with my food and to empty the chamber pot. They don’t talk to me; they don’t even ask me about my health. I have run out of medicines and when I told her she says what good is the medicine if I am going to die anyway. They don’t care whether I take my medicines or not. They are waiting for me to die, but even death does not come and visit me (Kwansa, 2013: 86).

Considering the possible consequences for HIV positive persons of revealing their sickness, it is hardly surprising that few willingly do disclose their HIV status to others.

Though the people living with HIV in the study were more likely to trust people in their own household than others with their private affairs, it was found that they were

nevertheless not inclined to inform them when they began receiving treatment for the illness.⁶ Many kept all of their medical records – hospital cards, prescription forms, and even their medicines – in their possession and away from prying eyes. One woman explained that she hid her medicines in her suitcase, under a number lock; one man hid his pills under the family sofa. After a hospital visit, some patients disposed of the ARV packages and leaflets even before they had left the hospital. Another strategy was to scratch off the writing on the containers or put the medicines into a different box altogether. One woman explained:

...they [her family] know that I take medicines every day, but what exactly I take no one knows. My little sister is the reason why I hide the medicines. She is the only one who is more highly educated. She is inquisitive. I know she will read everything about my medicines if she gets them... (Kwansa, 2013: 96).

In some cases, the family did not want to know their relative's diagnosis, in an attempt to protect both the patient and themselves. The sister of one infected man believed strongly that his disease was spiritual. She helped her brother with fasting and prayers and took him every Wednesday to a prophet, since "no one knew what was wrong with him, and only God can help out". By not disclosing the source of his sickness, this man gained the support of his sister. In the past, he had been very supportive of his family, so after he became sick he had moved back to his hometown in order to receive proper treatment as well as the support of his family. Though comments from some people in the community suggested that they suspected that he had 'that disease', the family thought (or wanted to think) otherwise. Once his niece told the researcher that she had heard people saying that her uncle had AIDS, but, she said, "they don't know what they are talking about. Can't they see that he is getting better every day? We do everything with him, and then we should be infected too by now" (Kwansa, 2013: 83).

A middle aged man explained to the third author that he was worried about his reputation if his status would be revealed, and feared that his own children and other relatives and people in his environment would turn their backs on him and he would lose his job as a teacher:

If they get to know about it, they will no longer respect me. When I call on them, they will not acknowledge me. They may not want to come near me. Because of the disease they will call me names and tease [harass] me... But if I don't tell people that I am sick, I am [still] respected and [well] regarded... If I disclose it to people, they may even stop giving me some assistance, because they will assume that I will die very soon (Van der Geest, 2015: 259).

5. Privacy, stigma, and HIV/AIDS in the hospital

⁶ Fidelia Ohemeng (2013) reports from her research among 25 AIDS patients in a Ghanaian hospital that they were most inclined to reveal their disease to someone whom they thought they could trust completely and who would be willing and able to care for them. Such a person was most likely to be a close female relative.

The obsession with privacy that people with HIV have, both at home and in their community, follows them when they visit the hospital, as the research by Dapaah (2012) shows. The hospital is not only a place where HIV is treated and its progression possibly halted; it is also an unsafe place where the truth about a person's HIV status can be revealed and leaked to others. The fact that both hospitals in our research had specific, separate HIV departments did not always guarantee the privacy that HIV patients desired.

Fear of the hospital as a place of unwanted disclosure is one reason why many people refuse to get tested or to accept hospital treatment, as discussed in the previous section. For those who do – eventually – accept hospital treatment, there are three main risks involved: staff members may 'talk'; patients themselves may be spotted by others at the hospital; and treatment always requires an 'adherence monitor', someone to whom the patient must reveal his/her status. Although they assure confidentiality, doctors, nurses, or counsellors may be careless and unintentionally reveal the fact that a person is HIV positive to others. Such a piece of information may spread through the gossip network and reach relatives, neighbours, and others in the community. An example of how easily an unintended breach of confidentiality may happen was provided by a female research participant, who explained that after she had tested HIV positive and been referred to the ART clinic for treatment, she could not find her way there. She asked a nurse to help them locate the facility. While the nurse was leading her to the clinic, another nurse met them and asked her colleague where she was going. The nurse responded that the woman had been referred to the AIDS clinic but could not find her way, and so she was leading her there. At the moment that the nurse made this statement, other patients waiting for treatment suddenly turned to look at them. To the woman's distress, this nurse had inadvertently disclosed her HIV positive status to these other patients (Dapaah, 2012: 65).

Hospital staff may also reveal a patient's status on purpose; for 'good reasons', as they believe. One nurse explained that health workers sometimes disclose the status of clients to others in the interest of the clients or their spouses or children. She said that in some cases, they cannot just look away and allow infected female clients to breastfeed their babies, since the children could become infected through the breast milk. She also said that nurses had received complaints from husbands asking why health workers instructed their wives not to breastfeed their newborn babies. The health workers also thought that it is important to involve spouses or close relatives in the counselling of HIV positive mothers on how to prevent passing the infection on to their babies. The nurse commented:

The truth of the matter is that as health workers, sometimes we are compelled by circumstances to disclose a client's status to others in order to save lives... although we know this is against the code of ethics of our profession. Clients should understand that we do not intentionally do this to expose them as positive persons or embarrass them in front of their husbands or family members... (Dapaah, 2012: 68).

Whether such an action is well intention or not, the result may be the same: divorce and rejection by the family, as Dapaah (2012: 66-69) reported in a number of cases.

A second risk of the hospital is that a person may be seen by someone at or near the ART clinic, and the observer will then conclude that the person is an HIV/AIDS patient. But even if a patient is spotted elsewhere in the hospital, the observer may start to wonder or ask questions. Some people with HIV therefore prefer to visit a hospital far away from their home and thus avoid meeting acquaintances. Others emphasise that the location of the HIV clinic should be better concealed to prevent other patients and food vendors from passing by and being able to observe people going in and out. Furthermore, many believed that the name of the clinic should not reveal the fact that people with HIV/AIDS are treated there. One client remarked:

... I think that the doctors must move the clinic away from this place because the present location is not hidden. It is also close to the main gate of the hospital. Besides, the women selling at the gate can see every client entering or coming out of the clinic. So they have been making some bad remarks about those whom they know in this town. Personally, whenever I am entering the clinic or coming out, I always look around and make sure that nobody I know will see me... Otherwise the news would get to my community that I have the disease and I will face the rejection of my relatives... (Dapaah, 2012: 70).

Despite these concerns and possible efforts to make the location where people with HIV are treated within a hospital more discrete, it is nevertheless unlikely that such concealment will be achievable. As HIV/AIDS is highly stigmatised, it attracts a lot of attention. There will always be visitors who will find out where the clinic is and will spread the news.

The last risk factor of hospital treatment is that staff not only put pressure on HIV clients to inform relatives, in particular partners, about their status, but they also oblige clients to find a 'buddy' or 'adherence monitor', whose task is to help the client to follow strictly the medication regimen and other treatment rules. The involvement of such a person is required for adherence counselling, but the 'monitor' may tell others about the client's status even before the counselling has begun. One client was refused treatment for several weeks because she did not present an adherence monitor. When the researcher asked her in a conversation why she was reluctant to bring a monitor for adherence counselling, she said that when it comes to HIV/AIDS, it is better not to talk about it with relatives:

The moment you tell one relative and bring him to the clinic, other relatives will hear that you have it [HIV/AIDS]. And they will start avoiding you for bringing shame (*animguaseε*) to the family... Now the problem I am facing is how to get a trusted person outside of my family to accompany me to the clinic for treatment. This is what is delaying the start of my treatment, but the nurses will not understand and help me get the treatment without such a person (Dapaah, 2012: 74).

Health workers told the researcher in the hospital that some clients go so far as to approach a person on the street whom they do not know, and they ask them to be their adherence monitor, in order to avoid the risk of their relatives hearing about their status. One client explained:

I cannot trust any of my relatives to come with me for counselling. I do not want to bring my wife either because she does not know that I have this disease. My fear is that if I bring a relative and he gets to know that I have this disease, my wife and other family members will hear of it. My wife would divorce me and I would lose the respect I have in the family as an immoral person. So I felt that I should bring a stranger who does not know my wife or any of my relatives... (Dapaah, 2012: 75).

6. Discussion and conclusion

The purpose of this article is to present a more nuanced picture of privacy by studying its dynamics in a context of extreme anxiety and shame about personal conditions of disease and approaching death. Our study has shown that many people living with HIV keep their status secret, even when the disease progresses and the symptoms become obvious. Indeed, many HIV positive persons only disclose their status when they are convinced that it will not jeopardise their safety. They weigh the benefits against the costs of disclosure. Most, however, fear that the reactions to disclosure will be negative – including stigmatisation and social exclusion – and thus they do not disclose at all, not even to their spouses. Eileen Moyer (2012), studying young HIV positive adults in Zanzibar, confirmed that individual and family honour and the possibility of living a ‘normal’ life holds people back from disclosing their HIV status, even though they know that disclosure is necessary in order to find treatment and fight stigma. Disclosing or not disclosing is tied to shame and respect, both for the individual as well as the entire family. In an attempt to keep up family honour, some relatives go to the extent of hiding an HIV positive family member. The data from our research suggests that the majority of those who reveal their sickness become isolated, lose their social status, and live in fear, while the majority of those who receive help from relatives and friends are those who have not disclosed their HIV positive status.

The public image of HIV/AIDS is loaded with fear, blame and social disgrace. The stigma surrounding the disease probably derives less from moral condemnation of sexual promiscuity than from its association with death, as Niehaus (2007) has argued for South Africa. Fear of people who are ‘already dead’ and inaccurate ideas about the risk of infection lead to the ostracism and social death of HIV positive persons. It is therefore no surprise that people with HIV/AIDS do all they can to conceal their condition. Their search for ultimate privacy in a society where, as we have seen, privacy is hard to sustain also leads them to forego available treatment options. At the same time, we should nevertheless add that these people do not simply succumb helplessly to the fear of social exclusion. At every stage and in every difficult situation in which they find themselves, they devise (new) strategies in order to cope.

The ‘paradox of disclosure’ (according to Paxton 2002) is that revealing one’s status appears a deadly risk but once it has been done, it may rather relieve the stress and open the way to effective treatment and increased well-being. Several studies point this out (Parker & Aggleton, 2002; Paxton, 2002; Parsons et al., 2004; Steuer, 2012; Hardon & Poser, 2014;

Mfecane, 2014). In a – perhaps over-optimistic⁷ – conclusion to a study of 75 HIV speakers from twenty different African countries, Paxton (2002: 559) observed that:

Virtually all speakers ...had no regrets and saw only the benefits of public disclosure. The paradox of coming out openly as an HIV-positive person is that by facing AIDS-related stigma, one finds psychological release – liberation from the burden of secrecy and shame. Disclosure is beneficial to all concerned. It enriches the speakers' lives and it helps the community.

Hardon and Posel (2014: S1) are more cautious and sketch the contrasting stands of medical professionals and people with the disease. The former emphasise that secrecy is... undesirable, psychologically, if not socially, harmful, never wholly benign and something to be overcome. ‘Speaking is healing’...” But for patients the decision is more complex. They calculate “what they can gain and risk losing when they disclose their condition. Who speaks, what is said, how it is said, where it is said and what is withheld is embedded in a wider matrix of generational hierarchies and cultural norms” (p. S9). The authors call upon advocates of disclosure and sexual rights need “to think more contextually and tactically in promoting truth-telling” (p. S1).

This dilemma shows the ‘dark side of privacy’: the privacy they seek robs them of the support and professional medical help that they need in order to overcome their problem. Their fear of exclusion may not always be based on reality – relatives and friends may in fact show compassion and support – but they do not want to run the risk of the opposite occurring. Anticipated or perceived stigma may be stronger than actual experienced stigma (Scambler, 2004; Weiss et al., 2006; Antwi & Atobrah, 2009: 123-127; Kwansa, 2013). In this case, privacy thus becomes a self-imposed imprisonment and an obstacle to the personal development and well-being that it is supposed to engender (cf. Smith, 2004).

Another, equally grave, consequence of such persistent concealment of the disease is the risk that infected people pose to healthy spouses and other sexual partners. Removing the stigma surrounding HIV/AIDS is a precondition for relaxing the desperate concerns of HIV positive persons about privacy and keeping the disease hidden, but stigma proves to be the most unruly element of the HIV/AIDS epidemic, leading to a tragic vicious circle. Statistics do not tell us how many HIV positive people in Ghana die without having been diagnosed, let alone being seen by a doctor, but the devastation of stigma makes it likely that they are many. Stigma is widely recognised as the most stubborn factor obstructing an effective fight against HIV/AIDS and the scale-up of ART in Ghana.⁸

One of the objectives of the national scale-up exercise was to make the services more easily available, the theory being that access to treatment saves lives and restores health, combating the image of AIDS as an instant death sentence and thereby reducing the persistent stigma associated with it (cf. Maman et al., 2009; Winskell et al., 2011). A reduction of the

⁷ ‘Over-optimistic’ because public speakers are by definition the successful and celebrated HIV/AIDS disclosers. Little is known however of those who did regret their disclosure.

⁸ Similar observations have been made in other African and non-African countries: Winskell et al. (2011), Moyer (2012), French et al. (2014), Judgeo & Moalusi (2014), Rispel et al. (2015), and many others.

stigma associated with the disease would make HIV positive persons less concerned with maintaining privacy. Our study has shown, however, that privacy (secrecy) and stigma still dominate patients' lives, in spite of the increase in the number of ART sites. The unfortunate implication is that the scale-up exercise has not achieved one of its major objectives, at least at the time at which our study was carried out.

The prisoner's dilemma in which people with HIV in Ghana find themselves draws attention to the harmful 'side effects' of an 'overdose' of privacy. Good living presupposes a balanced mix of privacy and sociality. People must sacrifice some of their privacy to live well, safely, and healthily. When privacy becomes an obsession and a matter – literally – of life and death, people cut themselves off from the companionship and support of relatives and friends. Overcoming stigma remains the major challenge in Ghana's – otherwise successful – fight against HIV/AIDS.

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