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Therapeutic mobility and breast cancer in France: experiences of African women

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Abstract

While breast cancer is the most common cancer globally, not all women have access to quality care. Long considered a disease of high-income countries, low- and middle-income countries are now facing a major public health issue regarding cancer. This is the case in sub-Saharan Africa, where access to quality breast cancer treatment is often lacking. This context leads some women to travel abroad, particularly to France, hoping to save their lives. This article aims to examine the experiences, the social cost and the perceptions associated with therapeutic mobility for breast cancer in France. To this end, this study uses a qualitative method based on nineteen biographical interviews with women from sub-Saharan Africa with breast cancer who have migrated to France seeking for treatment. It shows that these women often face significant difficulties throughout their care and life paths in France. Main issues lay in accessing care, housing insecurity, loneliness, and administrative instability. This reflects how the double biographical disruption, caused by cancer and migration, impact entire disease trajectories, from entry to care to post-breast cancer period. With this research, we suggest extending the concept of social death to the issue of women who have undergone therapeutic mobility for their breast cancer in France. Highlighting the experiences of women who remain almost invisible in the public arena, this article analyses poorly heard realities and shows how social inequalities in health can be found even in reconstructing oneself after breast cancer.

Keywords

Breast cancer, social inequalities, access to care, therapeutic mobility, biographical disruption, migration, France, sub-Saharan Africa.

Introduction

Breast cancer, a global health concern leading to therapeutic mobilities

While breast cancer is the most common cancer globally and the leading cause of cancer death among women worldwide, not all women have access to quality care (1). Disparities between low- and middle-income countries and high-income countries are considerable, whether in incidence, mortality, or 5-year survival (2). While the incidence rate in high-income countries has stabilized since the 2000s and the mortality rate has fallen by 40% between 1980 and 2020, both these rates have steadily increased in low- and middle-income countries since the 1990s. They are now higher than in many high-income countries (3). Regarding the survival rate, a prospective cohort study conducted in sub-Saharan Africa (SSA) between 2014 and 2017 showed that the 3-year survival rate was 50%, whereas the survival rate in high-income countries is between 85% and 90%, all stages combined (4) (in 2018 5-year survival rate was 87% in France (5)). Long considered a disease of high-income countries, the poorest countries now face a major public health issue with cancer.

In this study, SSA refers to all countries on the African continent except Western Sahara, Morocco, Algeria, Tunisia, Libya, and Egypt. In SSA, breast cancer is the most common cancer and the second leading cause of cancer mortality behind cervical cancer (3). Several facts characterize breast cancers in SSA: 70% of women with breast cancer are fifty years old or younger, roughly ten years younger than women in high-income countries (6). The disease is usually discovered at a late stage: in SSA, 65% of women are diagnosed with locally-advanced or advanced breast cancer (7). In comparison in France, 60% of cancers are detected at an early stage (5). Half of the women who die of breast cancer in SSA are under the age of fifty (1), while the median age at death is seventy-four in France (5). The provision of breast cancer care faces a significant shortage of infrastructure, materials, technical, financial, and human resources (8). In some SSA countries, the technical platform does not allow for a

comprehensive treatment of breast cancer. For instance, Benin does not have radiotherapy equipment, while in Mali only one radiotherapy accelerator is available, however frequently unavailable due to repeated breakdowns (9). These difficulties also affect access to chemotherapy and immunotherapy: many countries in SSA do not have access to trastuzumab, a targeted therapy frequently used in the treatment of a subtype of breast cancer, even though it is registered on WHO essential medicines list (10). In addition, the cost of theoretically available drugs remains too high for many women in the absence of universal health coverage (3,11,12). Although some governments have instituted free and widespread chemotherapy policies, their implementation is still insufficient (13).

These various shortcomings result in fragmented care pathways and therapeutic wanderings, jeopardizing the quality of care and women's lives. In this context, some women leave their country to treat their breast cancer abroad. These migratory movements, which are still poorly described and quantified in breast cancer, constitute therapeutic mobilities. Therapeutic mobilities correspond to the circulation of knowledge, health professionals and individuals seeking care (14). When studying therapeutic mobilities, it is common to distinguish between therapeutic immigration and medical tourism. Therapeutic immigration would concern poor populations, while medical tourism would involve the elite; medical tourism would underlie a time limitation in the mobility, while therapeutic immigration would imply staying in the arrival country (15).

Both therapeutic migration and medical tourism have been studied concerning cancer, highlighting their effects on patient care experience and access to care. In the context of medical tourism, motivation for seeking cancer care abroad has been found to be multifactorial. It has been associated with requesting second opinions (16,17), accessing specialized care unavailable in the country of origin (16–18) and with the cost-effectiveness of care, the latter

being cited in most literature as a critical factor for medical tourism (18). In the arrival country, patients face issues throughout the cancer care process.

In 2019, a study identified the issues associated with medical tourism for each cancer care step in Japan (16). Major issues in the pre-treatment phase include the lack of patient clinical information and the problems associated with timeliness of treatment and travel; in the treatment phase, inaccurate self-evaluation of the disease status and request for inadequate therapies; in the post treatment, they include the need of a continuous treatment following return home and problems with payment.

In the French context, in 2015 a study has offered a gendered approach to medical tourism and therapeutic immigration, allowing for a detailed understanding of foreign women's experiences when seeking cancer care in France (15). It documented the conditions of arrival in France and the disease diagnoses, when women arrived in France primarily for health reasons or other reasons. It also provided an understanding of cancer care experience in a migratory context, identifying three configurations in women's logics of presence: breaking apart, scattering, and disconnection. Finally, it brought out how the decision to stay in France after cancer care is influenced by life conditions and opportunities in the arrival and in the origin country, which tend to evolve throughout the migration and care processes. The importance of this study is also found in its discussion on the relevance of opposition between medical tourism and therapeutic immigration. Such categories poorly reflect reality's complexity, "marked by the blurring of temporal, spatial, and social categories"(19).

To better reflect women's experiences, we chose to study these population movements using the concept of "therapeutic mobility" to overcome the socio-economic and temporal assumptions underlying these two categories (19).

Therapeutic mobilities reveal global health inequalities, while also reproducing and increasing them (20,21). Indeed, once they arrive in France, they become “sick foreigners” (22), a particular status vector of social inequalities in health.

Access to healthcare for “sick foreigners” in France

Access to care and access to rights for foreigners in France

Access to care is a fundamental and universal human right, inscribed as such in numerous international texts (WHO Constitution Preamble (1946), United Nations Universal Declaration of Human Rights (1948)) and in French Law (French Constitution (1946), Law of March 4th, 2002) (23). It can be defined as “the timely adjustment between the need for care expressed by an individual and the ability of the healthcare system to respond to it” (23). Laurent Chambaud associates the fundamental notion of access to rights, which can be understood as the gap between theoretical rights and effective rights (24).

In France, several dispositions allow foreigners to benefit from financial coverage of care, including the Aide Médicale de l’Etat (AME - State Medical Aid) and the residence permit for health reason. AME allows foreigners in an irregular situation to access healthcare.

While it gives the right to complete medical and hospital care coverage, AME can only be allocated after the person has resided in France illegally and uninterruptedly for more than three months (25). In practice, this means that they must remain in an irregular situation for at least three months after their visa expires. Moreover, the legal deadline for processing an AME file is two months, extending the time between arrival and access to care (26). Since AME cannot be obtained immediately after arrival on French territory, it can be problematic from an urgent care perspective.

Foreigners may also be entitled to health insurance when regularized through a residence permit for health reasons. It can be granted if the health status requires medical care, the lack

of which could have “exceptionally serious consequences”; and if, given the availability of care and the characteristics of the health system in the country of origin, the person would not be able to receive appropriate treatment there (27). This residence permit allows access to care via the Protection Universelle Maladie (PUMa, formerly Couverture Maladie Universelle CMU - Universal Health Protection). Application to a residence permit for health reasons is evaluated by doctors of the Office Français de l’Immigration et de l’Intégration (OFII - French Office for Immigration and Integration) and granted by the prefect. In 2020, 3694 residence permits for health reasons were issued, all pathologies combined (number of first residence permits for health reasons granted to adult foreigners in metropolitan France) (28). However, no information is available on the share of residence permits granted for cancers (or breast cancers), as neither OFII’s activity reports nor OFII’s reports to Parliament provide data on this topic (28–31). Therefore, we provide information on favorable opinions issued by the OFII for cancers. In 2017, the rate of favorable opinions issued by the OFII for cancers was 70.3%, making it the fourth pathology with the highest rate of favorable opinions (29). It was impossible to obtain this rate for the following years, as it did not appear in OFII’s reports to Parliament nor in OFII’s activity reports since 2017 (28–31). Since cancers account for approximately 12.4% of applications for residence permits for health reasons, it is possible to estimate the number of favorable opinions given for cancers in 2021 at 2,415 favorable opinions (32). However, granting of residence permits for health reasons is the competence of the prefect, who can decide not to follow opinions issued by OFII’s doctors. As a result, this number of favorable opinions issued for cancers cannot be equated with the number of residence permits actually allocated for cancers. More importantly, while both OFII’s 2017 and 2018 reports to Parliament mention the “significant share” (29,30) breast cancers occupy in applications for residence permits related to cancer care, it was impossible to obtain

information on how significant this share exactly is. Therefore, there is no available data on how many women undertake a therapeutic mobility to France for their breast cancer.

Administrative complexity and consequences on cancer disease trajectories

Although these different dispositions theoretically allow foreigners to benefit from healthcare coverage, their access is complex, due to continuous evolving of criteria and procedures. Legislation has progressively become stricter over the years and is now closely linked to administrative situation and urgency of care regarding health status (33). This complexity has a direct impact on effective access to rights and access to care (34). By influencing both representations and practices of health and social workers, it can lead to differential treatments, extending to discriminatory refusals of care (35). Although discriminatory refusals of care are prohibited by law, these practices specifically affect patients benefiting from CMU and AME (36,37). Changes in public policies concerning access to healthcare for foreigners are therefore likely to impact on the illness trajectories of foreigners, including in the field of cancer (33). Precarious administrative situations of newly arrived immigrant women with cancer (diagnosed in their country of origin or in France) complicate their care and life paths in France (38).

In France, breast cancer is the most common cancer (58,500 new cases in 2018) and the first leading cause of cancer mortality for women (5). Breast cancer care pathway is standardized and complex: each phase requires numerous examinations and consultations with multiple professionals. The treatments implemented (surgery, drug therapy, radiotherapy) are heavy, both physically (pain, side effects) and psychologically. Being a long-term condition (treatments last several years), breast cancer can have repercussions on women's personal, emotional, social, and professional lives (39–41). Such repercussions are likely to have specific effects for women seeking care abroad.

Therapeutic mobility for breast cancer: a double biographical disruption?

Cancer constitutes a biographical disruption in bodies and in life paths (42). Numerous studies explored how cancer, a chronic disease according to the WHO definition, constitutes a biographical disruption “marking a 'before' and an 'after'” (43). The experience of migration leads to geographical, physical, social, emotional, and therefore biographical disruptions (44). It profoundly and definitively disrupts life paths. If cancer and migration in themselves can cause biographical disruptions, therapeutic mobilities can generate specific difficulties due to the “double experience of danger” – danger that the disease poses to oneself and danger of migration to an unknown place (45). If previous studies have identified particular effects on patients and access to care associated with therapeutic mobilities for cancer (15–18), to date in France no study has allowed for an understanding of the specificity of women’s experiences after therapeutic mobility for breast cancer. In many societies, breasts are considered the emblem of femininity (46). Because it can involve surgical ablation of the breast (mastectomy), breast cancer underlies a specific biographical disruption, which calls for a specific reconstruction, “not limited to surgical practice, but [including] the acceptance of a different body and also of a different life, modified by the experience of the disease” (47). The dual experience of migration and breast cancer is thus likely to affect women in a specific way.

The present study aimed to examine how the specific “double biographical disruption”, caused simultaneously by breast cancer and migration, affects women’s experiences of the disease. At the intersection of the sociology of migration and the sociology of health, and based on the narratives of women from SSA, we studied the experiences, the social cost, and the perceptions associated with therapeutic mobility for breast cancer in France. We retraced their care and life paths using a qualitative approach based on nineteen biographical semi-directive interviews with SSA women who had experienced therapeutic mobilities to France for their breast cancer.

Materials and Methods

Biographical interview is a particular semi-structured interview technique that has proven to be successful in exploring life paths in the areas of cancer and migration (33,42,48).

Interviews used open questions addressing life events from before and after migration. Questions explored women's life in their country of origin before breast cancer (for instance, information on place of birth, marital status, children, education, employment) and their experience with the disease before migration (chronology of events related to breast-cancer discovery/suspicion, including treatments followed, if any). They established a description of the migratory journey, focusing on the dual experience of breast cancer and migration (for instance, reasons for departure and expectations associated with migration). Questions also addressed administrative events related to accessing healthcare in France, as well as difficulties encountered and potential resources mobilized in the process. They explored the experience of care for breast cancer and its impacts on life pathways in France, to understand women's personal, social, and professional life situation, and identify obstacles and resources.

Questions were developed based on exploratory fieldwork conducted in France in 2020. The interview grid is available in the Appendix. It is important to note that this study was not intended to generalize about women's lives and experiences. It aimed to highlight the experiences of women who usually remain invisible, and to provide an analysis of their still-too-little-known-and-heard realities.

Study population

We chose to lead this project in the Ile-de-France region, because it is France's region with the largest number of migrants (49), and the largest number of breast cancers (50). We interviewed women treated for breast cancer in the department of Senology of Saint-Louis Hospital in Paris, and the Oncology Unit of Delafontaine Hospital in Saint-Denis (treating annually 800-1000

breast cancers and around 70 breast cancers respectively). The choice of these two hospitals was also motivated by pre-existing links with the care teams based on exploratory research work carried out previously, and which facilitated study implementation.

We included women aged 18 years or older, from a SSA country, who had experienced therapeutic mobility to France for their breast cancer (i.e., whose breast cancer had been diagnosed prior to migration), who were currently being treated for their breast cancer in one of the above-mentioned hospitals, who were still living in France at the time of the interview, and who understood and spoke French fluently. Breast cancer had to be the main reason for migration: the diagnosis had to have been medically established in the country of origin or had to be highly suspected. Treatment could have been initiated or not in the country of origin. Women had to have received care in France, whether the treatment was still active or not.

Data collection

Researchers and health practitioners recruited women during consultations in the two hospitals participating in the study. The interviews took place between May and July 2022, and women were interviewed up to three times. Throughout the entire study, we were careful to respect the usual ethics norms: respect of anonymity (use of pseudonyms), request for consent, request for authorization before recording, deletion of all identifying elements (for instance, date and place of birth) in the transcripts.

Results

Nineteen interviews were conducted with eleven women, with a median length of seventy minutes. Women came from Cameroon (3), Côte d'Ivoire (3), Mali (2), the Republic of Congo (1) and Senegal (2) (Table 1). Countries of origin of participants reflect the composition of the foreign population treated for breast cancer at Saint-Louis and Delafontaine hospitals (51).

Ages went from thirty to fifty-nine years old, with a median age of forty-six years old (in comparison, median age at diagnostic is sixty-three years in France (5)). Eight out of eleven women were married and ten out of eleven had children. Socioeconomic profiles of participants in their country of origin were diverse: several women came from wealthy backgrounds (two were health professionals – a doctor and a pharmacist – and one was the owner of a fancy restaurant), while others were from more modest backgrounds (a seamstress, two secretaries, a hairdresser, a street vendor; professions of other respondents is not known).

For the participants, first symptoms and/or diagnosis in the country of origin occurred between 2008 and 2022. They arrived in France between 2009 and 2022. For almost all participants, breast cancer diagnosis occurred at a young age and at a locally advanced stage.

Interviews were fully transcribed, then analyzed manually and a posteriori, following three stages (52) : first, a micro-analysis of the corpus using open coding to identify categories and their properties; then, an axial coding to allow category articulation; finally, a selective coding in order to retain themes that documented our research question.

Participants' administrative and healthcare pathways were long and complex, involving many professionals. Although these women were recruited at Hôpital Saint-Louis (Paris) and Hôpital Delafontaine (Saint-Denis), the structures and people (particularly the healthcare professionals and social workers) mentioned in this article are not necessarily related to these two hospitals. Results are presented chronologically, following three distinct stages in women's life with the disease: accessing healthcare, living throughout cancer care, and life post-breast cancer. For an explanatory model of women's experiences when undertaking a therapeutic mobility for breast cancer in France, see Figure 1.

1. Accessing healthcare for breast cancer in France

Women we interviewed left their country under precarious conditions to access healthcare in France: how does this determine and complicate access to care upon arrival in France?

Migrating to save oneself

It is necessary to examine what breast cancer represents for these women in order to understand the reasons that led them to undertake a therapeutic mobility. For eight out of eleven women, breast cancer is an explicit synonymous of death, and according to them this association corresponds to a widespread social representation in their country. This has a strong impact on their experience of the disease, and it conditions their hopes in recovery: in their country, they view themselves as *"already condemned"*. This social representation is reinforced by personal experience: six out of eleven women mentioned that they knew at least one person who had died of breast cancer (mother, sister, friend, acquaintance). Therefore, many attribute this representation to their decision to leave their country. *"You know, cancer, when we talk about cancer in Africa, what we see is death. That's what even pushed me to get into this. Because all the women that I have seen and that I have known who have had cancer, they are dead."* (Rokya).

Women undertake to leave their country to seek care abroad on the advice of their family, friends, or doctor. Their expectations vary according to the situation: some migrate in search of a reliable and definitive diagnosis (two out of eleven women), because the one made before migration often varies widely according to doctors and hospitals. For others (six out of eleven women), going to France promises a more accessible and effective treatment, even for those who had initiated chemotherapy in their country (six out of eleven women). The treatments available in France are perceived as being of higher quality and more effective than those available in their country. Although expectations associated with migration vary, women report never having considered migration before being forced to do so. Therapeutic mobility thus

seems to be a matter of survival instinct: for these women, migrating is not a choice but an obligation, which they only decide to do as a "*last resort*". For them, it is the last stronghold before death: "*I wouldn't encourage someone in an adventure like that, but when you're in the situation I was... For me, it was this or death. Try what is offered because you're going to find healing or stay there. And you're going to die.*" (Marie).

Departure organization requires a strong financial, administrative, and social mobilization, involving the women and their entourage. Large amounts of money are involved, whether to get a visa, finance the trip, daily life, and health care upon arrival in France. Ten out of eleven women report difficulties in raising this money, describing the sale of goods, businesses, plots of land, or property, and situations that sometimes lead to indebtedness. Difficulties are also found on the administrative level. Out of the seven women who applied for a visa, five encountered obstacles in obtaining it, reporting delays ranging from weeks to several months, and visa refusal. Knowing these obstacles, five out of eleven women left without a visa, either using a migrant smuggler or traveling under a false identity.

Delay between decision and actual departure is generally long, up to a whole year. As breast cancer is a rapidly evolving disease, most women arrive in France in poor health condition.

These situations of extreme distress at departure induce very high expectations upon arrival in France. Because for these women remaining in their country means an almost-certain death, migration represents their only chance of survival and the possibility of a "*second chance*".

From shock to resignation

Once in France, the duration between arrival and first medical consultation varies from a few days to several months. Different modes of entry into care were identified: through Médecins du Monde - a French medical non-governmental organization (four out of eleven women), a

hospital emergency room (three out of eleven women), or a scheduled consultation (four out of eleven women).

Urgency is confirmed with cancer diagnosis. The women interviewed recounted the shock that occurs with the diagnosis, either because it confirms their intuitions, or because they had not realized the seriousness of their health condition before migration. This shocking state intensifies when they realize they must stay in France longer than they had anticipated. One fear proved to be particularly prevalent, that of dying in a country that is not theirs. Despite this distress, they have resigned to staying in France and undertaking care there. Sonia expresses the distress she faced, first when being diagnosed with breast cancer, then when discovering the complexity of the treatment ahead of her: *“The doctor consulted me and said it was cancer. I was devastated. But how do I do? I’m in a country far from home, how do I do? And then I accepted it. I said to myself: “I must be strong. I don’t want to die in someone else’s country”. (...)* *What was in my head: if we removed the breast, the cancer is over. But then there is still something else to do, and you must do it! I didn’t know that there was chemo and radiotherapy. When she finished the operation, I said to myself “It’s over!”.* *But after the operation, there is still a lot left to do. (Sobbing) It’s hard! I thought it was over, but the fight goes on.”* (Sonia)

Confusion and administrative complexity

The women’ situations of vital emergency require them to benefit from social rights as quickly as possible to access health care. For them, accessing medical coverage is a complex process. Firstly, because when they arrive in France, they are not aware of the mandatory steps to obtain a medical coverage. Most of them are not even aware of a medical coverage: none of the women said they had come to France because they knew their treatment could be financially taken care of. Their reasons for coming to France appear to be more related to the deadlock they had reached in their country, the reputation of the French health system, and the presence of

potential acquaintances in France. They express a great confusion about the administrative steps needed to access medical coverage and healthcare.

Several ways of accessing healthcare were identified. When the women came without a visa (five out of eleven women) or when the visa have expired when they enter the healthcare system (three out of eleven women), one of the ways of accessing healthcare begins in a Permanence d'Accès aux Soins de Santé (PASS - Health Care Access Permanence), followed by an application for the AME usually done by hospital social workers. PASS are structures "adapted to people in precarious situations, aiming to facilitate their access to the health system and to accompany them in the steps necessary for the recognition of their rights" (53). In this scenario, the women incur no costs for their care. Another scenario begins with the Soins Urgents (Urgent and Vital Care Program), followed by an application for the AME made at the hospital. The Urgent and Vital Care Program is made for foreigners in an irregular situation who do not meet the conditions for obtaining the AME. It allows them to receive punctual care, only in hospital (54). Unlike the first one, this scenario generates bills ranging from 10,000€ to 15,000€ for the two women who accessed healthcare that way. These amounts correspond to care provided during the waiting period before obtaining the AME. One of these two women had this bill reduced partly, in contrast the other was banned from French banking. Another woman, whose visa had not yet expired when she entered healthcare, had to pay several thousand euros in care fees before being taken in charge in a PASS. She explains that she paid in the hope that it would speed up the start of her treatment. Financial consequences are therefore major for some of the women.

The complexity of accessing social rights can also have deleterious consequences on the ability to receive care. Three out of eleven women have had their treatment delayed, sometimes by several months, because they were not yet covered by the AME.

Differential treatments in access to care

Faced with these obstacles, the attitude of the medical and social personnel appears to be a fundamental dimension of access to care for these women. They face differential treatments in access to care, which can positively or negatively impact their care pathways.

Deleterious effects of these differential treatments are due to negative behavior of some healthcare providers and social workers. These attitudes are strongly linked to the figure of the “foreign patient who is costly to the healthcare system” (33). This representation is present among some caregivers and administrative staff, particularly in cancerology, where the treatments used are expensive (33). For the women we met in this research, some mention the suspicion they are subjected to when accessing care through PASS. Others indicate that they have been victims of discriminatory care practices. For some, this discrimination can go as far as refusal of care. This is what happened to Dora: in this interview, she talks about the refusal of care she was confronted with because of her origins, but also about the consequences of this discriminatory practice on her disease’s experience and on her mental health, which was already significantly weakened due to migration. *“The doctor said: “Why didn't you treat yourself at home? You come here and take the stuff from the French. You had to continue the treatment at home, why did you prefer to come here?”. When they say things like that, they don't know that do things that will lead us to commit something irreparable. When the doctor told me, “You have to go and treat yourself at home”, my solution was to commit suicide”.*

As these attitudes of suspicion and discrimination are not shared by all health and social workers, differential treatments can also have positive consequences on access to care for these women. In this case, the situations reported result from derogatory practices put in place by doctors and social workers. The emergency in which some women find themselves can thus lead medical and social personnel to adopt practices that run counter to administrative procedures and organization of care in the hospital. These “positive” differential treatments, set

up by medical and social personnel while waiting for social rights to be opened, serve as a bulwark so that women do not remain without care: *"How did Doctor [name] do the treatments, the injections and all that? I would come in secretly, and she would give them to me secretly, without me going through the administration or the reception service. Until we got a situation."* (Ketline). These practices echo the *"politics of compassion"* (55): in this context, these women are not treated because of a right - right to health - but because of the vital urgency they face, that is, *"in the name of suffering and misfortune"* (55). For these women, it is not the law that guarantees them access to care but the compassion of the people they face in their journey. Here, it is *"a matter of humanity that is at stake"* (Ketline).

Arrival in France thus seems to be marked by a harsh confrontation between expectations and reality. Since migration to France is seen as the only chance of survival, as opposed to staying in the home country, which symbolizes certain death, expectations linked to therapeutic mobility are very high. If all the women interviewed eventually end up being treated for their breast cancer in France, this entry into care occurs in precarious conditions, which foreshadow their life course with the disease in France.

2. Living in France throughout breast cancer care: a pervasive precariousness

This research highlights the specific difficulties women encounter after they have entered care, when living with the disease in France. These pathways are marked by three main forms of precariousness: housing, affective, and administrative precariousness. How does this multidimensional precariousness lead to these situations of significant vulnerability?

A multidimensional precariousness

- **Housing insecurity and mistreatment**

Having stable, decent, and appropriate housing is essential throughout breast cancer treatment. The women interviewed have major difficulty in this regard. Once in France, most of them (nine out of eleven) are hosted, at least initially, by a family member or an acquaintance. Refusal of accommodation, unsuitable environment, mistreatment, eviction: all the stories are similar, and the instability of housing situation characterizes them. For some women (five out of nine), this instability begins when the person who is supposed to host them refuses to receive them: faced with the reality of a sick person in need, friends and acquaintances quickly turn their backs on them. Other women find accommodation for a while, but this is done in difficult conditions, the environments being unsuitable for seriously ill people. Thus, rest and tranquility, essential during cancer treatment, are made very difficult. Despite these difficulties, women are forced to comply with the living conditions imposed by their hosts for fear of being evicted.

Four women spontaneously reported verbal and psychological violence from their hosts. This is linked to the fear that the cancerous disease inspires. This fear concerns the disease itself (fear of being contaminated), the physical appearance linked to the treatment's side effects (loss of hair), and the fear that the situation - therefore the obligation to host - will continue indefinitely. This rejection leads to expulsion of some women (three out of nine), aggravating their precarious situation. Ketline recounts her eviction by her host, which forced her to resort to emergency accommodation: *"The person I was staying with couldn't take it anymore, because she realized that there was no way out for me. My hair was falling out and her daughter said that she was afraid of me because I was sick. She was traumatized, at school she couldn't take it anymore, because there was someone at home who was sick, who had cancer. She couldn't stand to see me and all that. And so, one morning I arrive, her door is closed, I am in the corridor. She left for the weekend without warning. So, I stayed in the corridor for two days. With the fatigue of the cancer, with the chemo and all that".*

Many women find themselves on the street and must resort to emergency accommodation, sometimes during the acute phases of their treatment. These emergencies often last several months, going through a succession of different accommodation and thus worsening the housing instability. The most suitable accommodation type, Therapeutic Coordination Apartments, is often only obtained after months or even years of waiting. Precariousness of accommodation is thus a key issue, as it has a tremendous impact on living conditions during the cancer treatment. Not having someplace to call “home” makes living with the disease even more complex for these women with little or no support network in France.

- **Loneliness and emotional insecurity**

Loneliness and isolation characterize the women’s pathways with the disease. For them, the issue is not only about suffering because of cancer treatments (side effects of chemotherapy, difficult acceptance of mastectomy), but also about facing this suffering alone. Having migrated without their family, they often can only little benefit from the support of their relatives and friends in their home country. This is especially true for women who have not informed their family and friends of their illness. They make this choice because they do not want to worry their family and friends, especially when their children are young. On the contrary, other women who have communicated their illness to their family and friends, do not always find real support, especially from their husbands. Six out of eight married women report having been progressively abandoned by their husbands. This abandonment often begins before migration when symptoms appear or when the cancer is announced. For these women, migration to France, associated with the social image cancer holds in their home country, complete these marital and sometimes family disruptions.

This estrangement leads to a feeling of guilt, that of having left their children, in most cases of young age, to be treated abroad. Many women mention the difficulties encountered by their

children remaining in their home country (failure in school, early alcohol consumption), attributing them to their departure and holding themselves responsible. While some women maintain regular contact with their families through telephone and video calls, they emphasize the difficulty of obtaining real support from their relatives back home. For the latter, the distance prevents them from fully understanding the complexity of situations encountered by the women in France. Calls are not very conducive to expression of suffering, and so relatives abroad are not always able to help. Sonia evokes this difficulty in communicating her suffering to her sister through phone calls: *"They cut off [my breast], I told my little sister I would show her, but she said no, she didn't want to see. So what am I going to tell her? So when we call each other, I tell her, 'It's okay, there's no problem. I don't want to worry them'".*

When asked about psychological support provided by their hosts, most women said they had not received any, either because their hosts were unavailable or because the women censored themselves from expressing their suffering for fear of adding to the burden they felt they represented for their hosts. Forced to face their difficulties alone, these women can only rely on themselves. Without an attentive ear to listen, free and soothe them, this solitude in adversity leads to an accumulation of suffering, which results in situations of great distress, and even of despair. To cope, some women go into denial about their illness and their situation. Marie evokes the extreme distress she feels living throughout cancer care in France, leading to suicidal thoughts: *"At one point, if I didn't have my daughter, I think I would have killed myself".*

- **Administrative insecurity**

To a severe material and emotional insecurity is added an administrative insecurity. Since breast cancer treatment takes place over several years, these women are forced to stay in France for a long time and, to do so, they must get a residence permit for health reasons. These residence permits are obtained after several months of waiting, due to the numerous supporting

documents needed, and because of the complexity of the procedure for granting them. These permits are only valid for one year, and the renewal process must be initiated shortly after receiving the first residence permit. This long and tedious process generates instability in administrative situations.

This complexity in administrative pathways is inherent to the procedures, but also linked to the fact that they must be carried out together with cancer treatment, even when women find themselves in a very poor state of health: *"I remember that I was in pain, I was slumped over, but I went to the prefecture. I had to! I would come with a folding chair, and then I would put it down to sit. Because at the prefecture they don't care if you're sick or healthy."* (Ketline)

This administrative circuit appears to be particularly inappropriate, both to these women's health conditions and to their housing situation. As the application for a residence permit for health reasons requires a stable address, some women have their address registered in third party structures (social hotels, associations). But it happens that these structures do not transmit the mail in time, with sometimes catastrophic consequences on the outcome of the administrative procedures. As the procedures for obtaining a permit are not flexible, these situations can lead to administrative wandering. Many women report a feeling of weariness about this endless loop of administrative procedures, and the distress it plunges them into.

This distress is also due to the anguish generated by the instability of their situation regarding the right of residence in France. Several women explicitly mention the terror they feel about being arrested by the police during the treatment period (when their visa expires, before they apply for a residence permit, or if problems occur with the application). Some women report moments of their treatment period when they would stay locked up at home all day for fear of being arrested, even fearing to go to their medical appointments. These situations of administrative insecurity generate stress and appear to be very burdensome for these women. Many of them express trouble in reconciling this stress with the anxiety associated with the

disease and the suffering linked to the treatments. Some even wonder how they could manage to heal in such conditions: *"That's often what I used to say to myself, 'You're worried, how are you going to get well? You are stuck with this question of the residence documents...'. I often wondered, after my treatment, how I was going to get out. Are they going to come and get me with handcuffs or...? That's all that was in my head. Because I told myself that I was in violation. I broke the visa, so how am I going to get out? The police, often, there were days when I was asleep, I woke up with nightmares, I saw police officers..."* (Rokya).

Administrative insecurity reinforces the isolation previously mentioned, because obtaining a residence permit is needed to be able to travel. Many women explain that they have been unable to see their families, specifically mentioning their children, sometimes for several years because of the instability of their residency situation. Administrative insecurity thus appears to be an aggravating factor of emotional insecurity and isolation, as social ties are subordinated to obtaining a residence permit.

None of the women interviewed have been refused a residence permit for treatment. Therefore, it seems that in the context of therapeutic mobility for breast cancer, the issue lies more in the conditions for obtaining a residence permit than in its criteria (cancer is one of the pathologies with the highest rate of favorable opinions issued by OFII's medical board (29)). This administrative pathway appears poorly adapted to the health and social realities of women who have migrated to treat their breast cancer. Along with accommodation and support, it strongly conditions their experience of the disease in France. Importance of these three aspects is summarized here by Ketline: *"I was already on chemo, my hair was already falling out, I was already unrecognizable. I was given a hard time! In fact, I didn't have any respite between the administrative documents, the chemo, the abuse... I haven't been given any break!"*.

Support networks: the central role of caregivers and social workers

This context makes the existence of a support network during care essential. The interviews highlight the central role of hospital caregivers and social workers in creating this network. The women emphasize their role in their experience of the disease in France. They reported that the psychological support provided by caregivers and social workers is decisive in the key stages of the care process, particularly at the time of diagnosis and for treatment acceptance (particularly mastectomy): *"It's not an easy thing when you are told you have cancer. You are demoralized. If there are people who show you that, yes, you are important, then you have the courage to live. The social worker at [the hospital] gave me motivation, it's like someone who gave me another life. The way she talks to me, it gave me hope!"* (Dora).

In this context, many women emphasize the importance of creating a trusting relationship with their doctor. Involvement and humanity of medical and social staff appear even more essential for these vulnerable women: *"I don't know if I'll be able to forget Doctor [name]. Because apart from the fact that he is a doctor... The way he behaved in my situation, for him it was compassion. He was very supportive, just because I was going to the hospital! And when I had difficulties, in my head I said to myself, 'Anyway, Doctor [name] will know how to handle it.' And that's what gave me a lot of comfort."* (Iris). The expression *"he/she fought for me"* came up many times in the interviews, testifying of the hospital caregivers' and social worker's strong involvement in these erratic paths.

Although the medical and social personnel are mostly supportive, many women reported that they do not always dare to ask them for help. This failure to seek help can be explained by the shame felt by some women about their precarious situation and/or by the fear of *"abusing"* – a wording noted in several interviews – the help they received in France. Kept silent, untold difficulties aggravate already precarious situations.

The support network formed by healthcare providers and social workers in the hospital seems to strongly condition the experience of care and the experience of the disease for these women.

Although their role is sometimes ambiguous in terms of access to rights at the time of entry into care, most of these professionals appear to be supportive during care. However, situations of no recourse to help clearly highlight the need to strengthen and diversify this support network.

3. Reconstructing oneself: how to think post-breast cancer period in a context of therapeutic mobility

For women who have had breast cancer and have undergone therapeutic mobility, thinking about post-breast cancer cannot be done without thinking about "after-migration". Thus, thinking about the future requires recovering from one's illness, but also healing from one's history. How does these women's vulnerability impact on the process of rebuilding their lives?

How to build the future? – Between children and professional prospects, administrative requirements

We have already shown that the therapeutic mobility undertaken by the women interviewed in this research is not a matter of chosen immigration. Once treatment is over, some women express the desire to return to their home country. However, fearing that they would have to face a recurrence of their cancer there, and anticipating shortcomings in treatment, they decide to stay in France. These decisions are taken reluctantly and generate suffering. Marie evokes the difficulty of making this default choice, which again is a matter of survival instinct: “*Some days I say, 'I really want to go back', and other days I say to myself 'If it happens again, what will I do?' It's not an easy thing to do. It's not easy, it's a disease that disrupts your whole life.*”

While most of the women had no plans to settle in France before migration, some of them do end up considering a future there. Thinking about the future in France then depends on the possibility of bringing their children, professional prospects, and stabilization of their

administrative situation. Bringing their children to France implies proceeding to a family reunification. This procedure is complex, subject to legal residence, resources, and housing criteria. One of the women interviewed succeeded in bringing her daughter to France this way, while another made numerous requests, without ever succeeding. This is the case of Kadidiatou and whose breast cancer is linked to a hereditary genetic anomaly. For fear that her daughter is also a carrier of this anomaly, and with the wish that, if necessary, her daughter could be taken care of in France, she has been desperately applying for a family reunification for seven years - without success so far.

Professional prospects also condition future plans in France. Four of eleven women got a job during their post-treatment life, and two accessed professional training. All of them testify to the beneficial impact working again had on their self-esteem after cancer: *"It helped me a lot, because the very fact of getting out of all those worries... It helped me a lot. You're going to spend time thinking about something other than the disease, the family... It's not just money, it's also psychological. At least I can know that I am active."* (Rokya). But finding a stable job requires a residence permit. Several women report difficulties in finding a job because of the precariousness of their administrative situation. These obstacles do not only impact job search, but also working conditions of some women, as the instability of their residency status exposes them to precarious jobs.

Thus, even after treatment, life paths remain subordinated to the administrative situation. It determines their professional and family projects, and even impacts their reconstruction process.

How to rebuild oneself? – Physical and identity reconstruction after breast cancer and migration

Access to reconstruction – both physical and identity-related (56) – appears to be intrinsically linked to plans. For these women, losing one or both breasts impacts the desire to return to their home country. Having only one breast (or none) left can prevent the wish to return to one's home country. This is due to the fear of stigmatization of *"one-breasted women"* in their country, to the fear of inability to perform specific household tasks upon their return, or to the fear of no longer being able to have a love and sexual life. Impossibility to fathom a personal life in their home country after a mastectomy makes this return unthinkable for some women. This is even more true for the women interviewed shortly after their mastectomy. Sonia, who was interviewed a few weeks after her mastectomy, evokes this impossibility to fathom a return to her home country, despite her wish to return home: *"I want to go back, but what can I do there, with only one breast? To do what? Resume the activities there? With this thing, will I be able to carry heavy loads? With one side, will I be able to load? And then you'll see, everyone will talk about it."*

There also seems to be a link between one's return project and one's breast reconstruction project. The latter is often only considered in the event of long-term settlement in France, and not in the event of return to the home country. Rokya had a mastectomy in 2020. Not knowing if she would be able to stay in France, she chose not to undergo reconstruction surgery, fearing that she would encounter problems with her prosthesis and would not then be able to benefit from appropriate care when she would be back in her home country.

Issues raised in this research – self-image, intimate life, plans to return home or to settle down in a foreign country – demonstrate the need to specifically accompany women who have undergone therapeutic mobility for breast cancer in their access to reconstruction processes, both physically and in terms of identity. As these women were particularly isolated, they shared a great need to express their suffering in the post-breast cancer period. Marie here talks about her need to be accompanied by a professional to regain her self-confidence and to resume her

life after her breast cancer: *“I am always sad. I have lost my confidence. I hope that with time it will come back. A young woman like me, normally, there, I am cured! I just need to rebuild, but now I don't even let anyone into my life. I even said to myself that maybe I need to see a psychologist. I am healed but... I feel like I am not the same person anymore. After cancer, it's hard to have a normal life. It's very difficult.”*

Conclusion: Therapeutic mobility for breast cancer, a context at risk of social death?

For these women, social representation of breast cancer and conditions of care in their home country force them to undertake therapeutic mobility. This is a last resort care, as France is seen as the only chance of survival. Although all the women we met during this research end up receiving effective treatment for their cancer once they arrive in France, their care and life paths are particularly complex. Therapeutic mobility appears to be a context holding a high vulnerability risk for these women. At the time of entry into care, they are exposed to discrimination and treatment delay; during care, they are exposed to precarious accommodation, isolation, administrative wandering, and severe psychological distress. Persistence of vulnerability among women who arrived in France several years ago shows that therapeutic mobility can also impact the post-breast cancer period. Therapeutic mobility seems to induce specific biographical disruptions, the repercussions of which are found throughout treatment process, and even in reconstruction processes. In the case of therapeutic mobilities, the biographical disruptions caused both by breast cancer and by migration have a synergistic effect on life trajectories.

For these women, lasting estrangement caused by migration, combined with the difficulty of recreating social ties in France and the administrative uncertainty, generates a loss of connectedness; poor access to reconstruction processes hinders their identity and body reconstruction. These situations are consistent with Králová's underlying characteristics of a

social death (57). Although migration is seen as the only way to escape a biological death, we suggest the concept of social death (57–59) can be extended to the issue of women who have undergone therapeutic mobility for their breast cancer in France.

It has been shown that post-breast cancer period is still poorly thought out in SSA (60). With this research, it appears that the post-breast cancer period is not, in fact, thought out for all women in France. Which is perhaps the most glaring social inequality in health: that of unequal access to self-reconstruction, and therefore unequal access to life. In the case of these women, social inequalities in health do not only appear at the international level (between their home country and the arrival country), but they also exist at the French level, embodied in the differences observed throughout the entire journey with the disease, from entry into care to access to support care. This finding is consistent with work showing that therapeutic mobilities reveal and reproduce social inequalities in health (20,21). For these women, therapeutic mobility thus requires reconciling the process of self-reconstruction after breast cancer with that of projection into the future, marked by a split - between two countries, two lives, two identities.

Recommendations

As presented in this study, women encountered difficulties that have less to do with the possibility of receiving care than with the conditions in which this care is experienced. The role of support networks appears both essential and insufficient: although women testify of the support provided by most hospital care providers and social workers, solutions implemented are more a matter of "muddling through" than organized procedures. Situations of no recourse to assistance demonstrate the need to strengthen and diversify these support networks, so that women experiencing care in France for their breast cancer in a therapeutic mobility context can be better cared for.

- Strengthening support networks:

Vulnerability situations women face in the context of therapeutic mobility call for adapted breast cancer care, approaching treatment of disease together with material, administrative, social, and psychological issues. Therapeutic mobility thus exacerbates the need for a holistic patient approach (61) in breast cancer care. Awareness needs to be raised among medical, paramedical, and social hospital staff on issues related to the experience of care for breast cancer in a therapeutic mobility context. We hope that this article will contribute to the visibilization of these issues.

- Diversifying support networks:

It is necessary to associate with other actors to help hospital staff provide such targeted care. Patient associations can be decisive in facing breast cancer care, from the diagnostic to the post-breast cancer phase (41,46). Associative networks have also proven their usefulness, and sometimes their imperativeness in the field of migrant health (62,63). There is no association specializing in helping foreign women with breast cancer in the Ile-de-France region (64). An association specifically dedicated to accompanying women experiencing therapeutic mobility for their breast cancer, i.e., an association that would link the issue of breast cancer to that of migration, would strengthen existing support networks. Such a structure could provide centralized assistance on key issues (access to rights and care, housing, administrative procedures, and psychological support). Built on a peer support model (65,66) to ensure relevance, it would also have an adapted support care mission, to specifically accompany women in their post-breast cancer reconstruction process. Support could be thought out in partnership with hospital services, both in terms of reporting and redirecting women to the association, and of awareness-raising actions targeting hospital staff.

Study limitations

Study's temporal constraints, associated with the difficulty of accessing its studied population, only allowed us to conduct nineteen interviews with eleven women. Hospital oncology being a sensitive environment, approaching women was a slow process but necessary to ensure an ethical posture and to build reciprocal trust. Although these points made it difficult to access potential participants, data saturation on principal research questions was obtained.

Temporal constraints also restricted our inclusion criteria to French-speaking women only. For practical matters, analyzing data in other languages would have been difficult. Although this criterion could have influenced women's countries of origin, results showed they were still representative of the foreign population treated for breast cancer at Saint-Louis and Delafontaine hospitals. However, inclusion of non-French speaking women would be enriching for future studies, using an interpreter if necessary.

Finally, this study was conducted in Ile-de-France, a region with a high density of cancer care facilities and a large share of the migrant population in France. Conducting this study in another geographical context could bring out other professional practices and solidarity networks and highlight new difficulties and resources.

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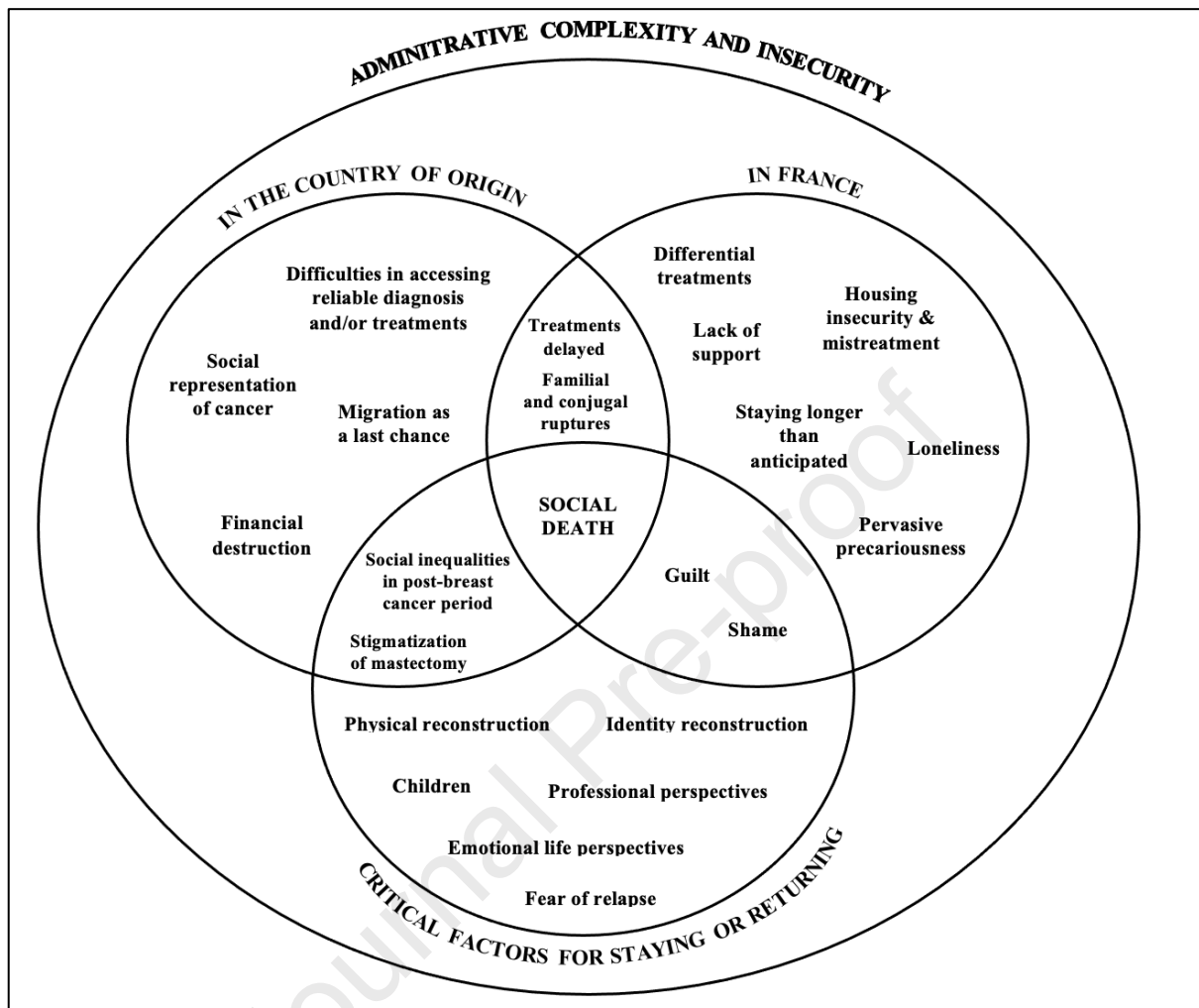
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Table 1: Participant summary

Pseudonym	Age	Country of origin	Number of interviews	Year of arrival in France
Iris	38	Cameroon	2	2013
Sarah	30	Côte d'Ivoire	1	2022
Marie	34	Cameroon	3	2019
Kadidiatou	48	Mali	2	2009
Ketline	47	Côte d'Ivoire	2	2016
Diana	59	Cameroon	1	2018
Dora	46	The Republic of Congo	2	2016
Rokya	44	Mali	3	2019
Sonia	46	Côte d'Ivoire	1	2022
Khadija	32	Senegal	1	2019
Astou	49	Senegal	1	2017

Figure 1: Explanatory model of experiences of women undertaking therapeutic mobility for breast cancer in France



Highlights

- Women migrate to save themselves and see therapeutic mobility as their last chance
- Once in France, housing is a major difficulty and a source of suffering
- Administrative difficulties impact women at all stages of their experience
- Therapeutic mobility holds the risk of a social death in France
- Post-breast cancer period is not sufficiently thought-out in France for these women

Conflicts of interest

We declare no conflict of interest.

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Authors contributions

Louise Ludet: data curation, formal analysis, writing – original draft. Clémence Schantz: conceptualization, data curation, formal analysis, funding acquisition, methodology, project administration, supervision, validation, writing – review and editing. Luis Teixeira: supervision, validation, writing – review and editing. Gaëtan Des Guetz: supervision, validation, writing – review and editing.

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