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Health, Illness and Cancer in Mayotte: Multicultural Experiences in a Medically Underserved French Territory

Authors: Hagège M¹, Ali-Hamadi A², Klass M², Oddou S², Serhal R², Equipe Isocarma¹, Khettab M^{3,4}

¹ Univ Paris Est Créteil, INSERM, IMRB, F-94010 Créteil, France

² Service de Gynécologie et d'Obstétrique, Centre hospitalier de Mayotte, 97600, Mamoudzou, France.

³ Service d'Hématologie-Oncologie, CHU de La Réunion, 97410, Saint Pierre, France, & Université de La Réunion, Saint Denis, France.

⁴ Centre d'Investigation Clinique, CHU de La Réunion, 97410, Saint Pierre, France.

Résumé en français (250 mots)

Mayotte fait partie du territoire français et des régions ultrapériphériques de l'Union européenne, mais le problème de santé publique posé par les cancers est méconnu et peu documenté. Cet article passe en revue la littérature sur la santé, les maladies et les cancers à Mayotte, du point de vue des sciences sociales et de l'épidémiologie. Il commence par mettre en lumière les spécificités de la démographie et de la société mahoraise, et montre que les infrastructures de soins sont insuffisantes pour répondre aux besoins de la population. Il passe ensuite en revue les études en sciences sociales sur la santé et la maladie à Mayotte et montre que la question politique de la migration imprègne la gestion et les expériences de la santé sur l'île. Il propose enfin une focale sur l'épidémiologie du cancer du col de l'utérus et un examen des données disponibles sur le dépistage, la prise en charge, le traitement et la prévention. L'article se conclut par un rapide tour d'horizon des recherches en cours et lance un appel urgent à la production de données et de recherches sur la santé et les maladies à Mayotte.

Résumé en anglais (250 mots)

The island of Mayotte is part of the French territory and one of the European Union's Outermost Regions but there is a significant lack of data and research on health and cancers in Mayotte. This article reviews the literature on health, disease and cancer in Mayotte, from the perspectives of social science and epidemiology. It starts by shedding light on the specificities of Mahoran demography and society, and shows the healthcare infrastructure is insufficient to meet the population's needs. It then reviews social science studies on health and illness in Mayotte and shows that the political issue of migration permeates the management and the experiences of health on the island. It ends with a focus on the epidemiology of cervical cancer and a review of the available data on screening, treatment and prevention. The article concludes with a quick review of ongoing research and urgently calls for more data and research on this critical public health issue.

3-6 mots clés : Mayotte, cancer du col, inégalités, expériences du cancer

3-6key words: Mayotte, cervical cancer, inequalities, experiences of cancer

Mayotte has emerged from a long history as part of the Comoros Islands then French colony, and waves of migration from the Indian Ocean and Africa. Since the second half of the twentieth century, traditional regional mobility has been turned into a politically charged issue of immigration. The Republic of Comoros gained its independence from France in 1975. Three referenda were held in 1976 to assert Mayotte's status as a French island, but it remains disputed to this day (1,2). The flow of

people, goods and social ties within the archipelago have continued, though France has been hardening its border policies since the 1990s (3). Despite United Nations' sanctions, the island became a French *département-région* in 2011. This has had a significant impact on cancer care, as it has divided the population into two groups: those with documentation and national health insurance, and those without. This is one of the many profound political, social and economic changes that have shaped Mayotte in the last 50 years, creating a society permeated by social inequalities. Health management has emerged through a particular set of mechanisms, based on Mahoran society and culture and the French metropolitan models that have been plated onto them since the 1990s (4). Today's health, care and cancer in Franco-Mahoran society should be understood as a product and a reflection of the historical mechanisms that constructed its society and its territory.

This article offers a review of the limited literature and ongoing research on health, care and cancer in Mayotte; it ends with a focus on cervical cancer based on the few available publications and supported by available healthcare activity data.

1. An Ethnically Rich, Polarized and Underserved Population

Mayotte's ethnic and cultural diversity can be gleaned from its languages: Shimaore is the most frequent native language and is spoken by Mahorans and Comorians (71%); followed by Kibushi (or Shibushi) as the native language of people of Malagasy origin (23%); French is the native language of only 2% of the population but about 60% of people in Mayotte can understand and speak it (5). The 2019 census reported 270 372 persons living in Mayotte, but this underestimation does not account for the sub-population circulating within the Comoros Archipelago and the Indian Ocean. Census data estimated undocumented immigrants account for 30–40% of the population (or 50 000–60 000 individuals), although this percentage does not distinguish between individuals who are eligible to French nationality or a resident permit but have not done the paperwork, and those who are ineligible (6).

French law has been implemented since 2011 (with some local adaptations, or *dérogations* (7)), but there remains an influence of local Mahoran law, which includes elements of Islamic and “common law” (*Droit dit “coutumier”*) (8,9). The population's makeup paints a grim picture of access to health and services in a welfare state.

Inequalities are significant but the population is overall quite poor, with 84% poverty and a GDP per capita as low as a third of that of hexagonal France (10). For example, only a third of the population benefits from welfare (11).

There are two significant axes of polarization of Mahoran society today, age and administrative status. Mayotte features a rapidly growing and young population, almost two thirds of which are under the age of 25 years old (60%) (6). Half of the 270 372 residents are foreigners (48%) mainly from the neighboring Union of Comoros but one third of them are born in Mayotte (6). Very few foreigners have a temporary or permanent residence permit (*étranger en situation régulière*), which entitles them to national health insurance; latest data published indicates 9 800 permits delivered in 2007, most of which were renewals (12).

These two halves of the population living in Mayotte, split across the line of administrative status, documented or undocumented (*situation régulière* or *irrégulière*), have access to different institutional resources, infrastructure, and formal work. Unlike in other French *départements*, undocumented foreigners are not eligible to state-sponsored healthcare (*Aide médicale d'Etat*), leaving them without health insurance.

In terms of health coverage, this line between documented and undocumented is not as clearcut as it seems, as residents and nationals (*en situation régulière*) may not benefit from national health

insurance if their paperwork has not been completed. In other words, “insured” and “uninsured” do not coincide with “documented” and “undocumented,” as some documented individuals may be uninsured but eligible to health insurance.

Mayotte’s healthcare infrastructure is mainly public and limited to a main hospital in Mamoudzou, five health centers and fourteen dispensaries (12). With the exception of the obstetrics department of the main hospital, all are severely understaffed (13). The island only has 87 physicians/100 000 people, including 34 specialists (Hexagonal France has 339 physicians/100 000 people, including 186 specialists (14).) As for cancer care, there are one oncologist and one hematologist in the central hospital, for all cancer patients in Mayotte (but breast, ovarian, uterine, cervical, and endometrial cancers are admitted by the gynecology department). Finally, as in other French outermost regions, there is very low access to clinical trials (15). This

The healthcare infrastructure of Mayotte has been affected by the Covid-19 pandemic, although the exact mechanisms and effects are difficult to estimate at this stage. Moreover, very little data and analysis have been published on the pandemic itself, let alone effects on cancer experience and care - although some personal accounts have shed light on the effects on the island’s structural inequalities (16). The population has not been hit as hard as other French overseas territories or neighboring countries, with a total death toll of 175 and a total number of 19 994 cases from March 2020 to September 2021; the incidence has mostly stayed below the threshold of 50 cases for 100 000 residents, except for two minor peaks below 150 cases for 100 000 residents in April to May, and November, and a peak at 850 cases for 100 000 residents in January 2021 (17). However, the lockdown period of February to March 2021 has hit poorer individuals very hard, as it prevented many from informal work and means of making ends meet, thus endangering food security (numbers of affected individuals are unknown (18).)

Many Mahorans are more exposed and do not have access to prophylactic measures, including social distancing, due to poor access to healthcare and poor living conditions; the pandemic may lead to increased vulnerability to social inequalities in cancer screening and care and perhaps to more significant inequalities in access to screening and care. Mobile cervical cancer screening services (Rédéca) report decreased activity during the pandemic and the lockdown, which could lead to increased late-stage diagnoses. Effects of the pandemic also include a delay in the publication of 2020 and 2021 medico-administrative data on diseases, including cancers.

2. Experiences of Health and Illness in Mayotte

There is little to no social science data on the experiences of health and illness in Mayotte but the Mayotte’s anthropology points to some foundational trends (19,20) – although these could benefit from being revisited, as recent migrations and political changes have significantly altered Mahoran population and society. M. Lambek points to a specificity in Mahoran knowledge schemes (and other societies that make up “peripheral Islam”), related to alternative sources, namely, sorcery and possession by spirits. Forms and tools of knowledge come from several origins: Madagascar, South-East Asia, Islam, Swahili and Bantu societies, and western cultures. This cultural diversity is the result of complex historical processes shaped by colonialism.

This analysis has not been applied to considerations of the body, health or illness to the best of our knowledge, with the exception of a short page in S. Blanchy’s dissertation (8,19). However, the notion of health literacy, as in the capacity to nurture and develop patients’ access to information, their understanding of what is at stake and their decision-making, has been explored recently from a sociological perspective (21). As for perceived health, it is split along age lines, with over 7 out of 10 people reporting their health as good or very good, and adults over age 45 reporting chronic illness (1

in 3) or a limitation due to a health problem (1 in 4) (22). Women over age 45 are in worse health than men, and in worse health than women in hexagonal France (22).

Today, there is a great divide in Mayotte, between those who have access to social and health insurance and those who do not. This permeates both experiences of the disease and individual and collective relationships to the State. Healthcare is subsidized only for those who are insured, although refunds of healthcare medications costs are irregular, and healthcare professionals have also been reported to be unwelcoming and socially distant with insured patients (36). However, for most uninsured, social and living situations are reported as precarious, and related to poorer perceived health and more difficult access to biomedical health services (23). For undocumented residents, intensive repatriation policies result in frequent police raids, the fear of which reduces mobility in public spaces, and thus recourse to healthcare (24,25). These two different experiences of healthcare converge through the lens of the political issue of immigration and the discourse around the figure of the undeserving foreigner: in the case of maternal health, political anti-immigration policies, such as underfunding of maternal health clinics seen as catering to underserving foreigners, feed a politically constructed but performative xenophobic discourse (26). This leads to discrimination against those perceived as undocumented Comorians nationals (27).

3. Cervical Cancer in Mayotte

There are only a few epidemiological studies on cancer in Mayotte, namely pediatric cancers (28) and cervical cancer (29). There is very little prevalence data, as there is no local cancer registry or national healthcare database, and using health insurance data does not paint an accurate picture of the cancer burden, as over a fourth of residents are not included (11).

Cancer-related activity data seems to point to an increasing cancer burden in Mayotte. However, some records do not accurately reflect activity: cancer-related care activity progressed by 17% in 2008, in a context where chronic diseases are the most frequent motive of recourse to biomedical care (Florence et al. 2008, 27). Medical evacuations of patients with tumors increased by 16% in 2020 (31). In 2018, there were 677 hospital stays for cancer care, compared to 818 in 2017 and 735 in 2016 – these vastly underestimate actual numbers of stays as they do not account for patients without health insurance (32). Mortality related to cancer accounts for 16% of causes of death in Mayotte in 2013–2015– although causes of death are poorly documented (24% are undefined) (33).

This last section offers a focus on cervical cancer, because its rates are high in the region (50-52 per 100 000 (34)) and recent screening programs have made some data available. As a preventable disease, it is the focus of recent Cancer policy plans such as the European Union's Cancer mission (35). The human papilloma virus (HPV) often causes cervical cancer, and its associated risks can be reduced by safer sex practices, HPV immunization and regular screening through Pap/HPV tests.

Hospital reports and screening data from local cervical cancer screening campaigns reveal an increasing cervical cancer burden. Cases of cervical cancer diagnosed at the central hospital have increased since 2018 (36) (though the number of cases for 2019 and 2020 are yet unpublished). The number of applications by the gynecology department of the central hospital for medical evacuations for cervical cancer care rose from 22 in 2019 to 35 in 2020 (37).

Cervical cancer screenings are free and carried out by the Rédéca network (*Réseau de dépistage des cancers*, 63%), and by midwives in private practice (37%) (38). Screening data indicates the coverage rate is low, around 30% in 2016–2018 (vs. 59% in hexagonal France) (38). However, little is known about the total population targeted for organized screening, i.e., women living in Mayotte between the ages of 18 and 49 years old, with no history of gynecological cancer. 39% of the 5547 women screened by the network in 2018 were uninsured, compared to 46% in 2016 (38). This could

indicate that uninsured women are getting fewer screenings, as most women screened in private practice are insured.

The percentage of abnormal smears (6%) is higher than in hexagonal France (4%) (38). The difference in the distribution of cytological abnormalities is also striking, with a high-grade abnormality rate of 19% in Mayotte (versus 15% in hexagonal France) (38).

As of 2019, cases of gynecological cancer are brought to weekly discussion by cancer specialists (*Réunion de concertation pluridisciplinaire*) for the course of treatment decision, following national protocol (39); they convene online and bring together staff from the Mayotte central hospital and Reunion Island Sainte-Clotilde clinic and University Hospital (36). In terms of treatment, the central hospital offers conization and chemotherapy. For other treatments such as radiotherapy and curietherapy, patients are transferred to the Sainte-Clotilde clinic in Reunion Island; in 2020, 54 patients were medically evacuated for cervical cancer treatment in Reunion Island (36).

There is little to no data on the human papilloma virus vaccination coverage and no immunization campaign (36). Local health insurance data suggests over 21 000 women between the ages of 11 and 19 are eligible for immunization (this underestimation does not include uninsured women, because they are ineligible or eligible but have not completed the paperwork) and 41% qualify for free immunization due to low income (*ExoTM*) (40).

Conclusion

There are a growing number of studies conducted in Mayotte, that promise to shed further light on illness, disease and its context. Doctoral dissertations in anthropology are underway on the topics of mental issues and rites of possession (41) and youths in Mayotte (42). The experience of one particularly vulnerable group, poor women and men living with cancer, and the discrimination they face in seeking and receiving care in Reunion Island and Mayotte hospitals in 2018–2019 are the subject of the CORSAC3 study, on a group of 25 patients with various cancers (results are unpublished, for protocol see (43)). The ongoing ISOCARMA study seeks to qualify and quantify social inequalities in cancer experiences and care trajectories (2021–2025), using qualitative data on breast and cervical cancer in Mayotte. It will describe how experiences of health, disease, and healthcare are embedded in a context of production and reproduction of inequalities and how they vary with gender, age, class, and origin and span across Mayotte, Reunion Island and mainland France (44).

This literature review calls for further investigation by social sciences and public health to generate current and accurate data on experiences of cancer in Mayotte and its context, and its welfare and healthcare system in particular.

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