



Lived experience of State-sponsored intra-national overseas therapeutic mobility for stem cell transplantation

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ABSTRACT

This article focuses on the lived experience of patients with haematological cancer who were transferred from La Réunion (a French overseas Department) to mainland France to undergo allogeneic haematopoietic stem cell transplantation (allo-HSCT). Based on a qualitative study conducted between February 2020 and January 2021 with allo-HSCT recipients, their family caregivers and healthcare professionals, we examined the social, economic and cultural factors shaping the patients' complex experience. We have called this kind of State-sponsored intra-national medical transfer "overseas therapeutic mobility". The patients' experience of this therapeutic journey beyond their geographical and cultural frontiers has some similarities with transnational therapeutic mobility. Overseas therapeutic mobility to undergo highly technical treatment requires considerable logistic efforts and mobility skills. The remoteness of their families and their affective and cultural environment give mobile patients a feeling of disorientation and causes them much social suffering. The two-fold condition of being a sick person with a possibly lethal disease and being treated overseas can be regarded as a double ordeal. In addition, the unfunded costs place a heavy burden on the patients and those whose families have limited resources. This study points to the cleavages which occur between post-colonial overseas regions and mainland France, and the territorial inequalities existing in patients' access to specialized treatment due to French policies of healthcare centralization.

1. Introduction

This article focuses on a type of therapeutic mobility to which little attention has been paid so far in the literature: that involving patients from French overseas regions who have to leave their homelands to undergo highly technical treatment. More specifically, we propose to document the "lived experience" (Kleinman, 1988:4) of patients with haematological cancer inhabiting the French overseas Department of La Réunion, who have to be transferred to mainland France, several thousands of kilometers away, in order to undergo allogeneic haematopoietic stem cell transplantation (allo-HSCT). The case of this bone marrow transplant for patients inhabiting La Réunion is particularly relevant for studying therapeutic mobility because it brings to light some differences and similarities between this medical transfer and transnational cancer care (Kangas, 2011; Kaspar, 2019). It thus helps to

understand many of the issues raised by intra-national and transnational therapeutic mobility, and to document the geographical disparities which exist in the availability of specialized therapies. These medical innovations have created new therapeutic needs, especially in the field of cancer care, which oblige patients to travel far from home to undergo high quality care (Kaspar, 2019).

Allo-HSCT is a well-established effective therapy for haematological cancer with an unfavourable prognosis, for which it is often the only life-saving curative approach available. However, the risk of dying in mainland France during the treatment cannot be ruled out because of the graft complications and the severity of the patients' condition. This treatment, which is currently performed only at highly specialized centres of excellence (37 in France), was not available in La Réunion at the time of this study. The first allo-HSCT performed in La Réunion took place in December 2021. Some transplants are planned for 2022, but

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many patients will still be referred to mainland France. Allo-HSCT recipients inhabiting La Réunion must spend at least three months in mainland France for the graft and the post graft period.

The cost of the patients' medical transfer and that of the transplantation procedure are entirely covered by the French government. Haematologists recommend that a family caregiver should accompany each patient to mainland France. The carer's travel and accommodation expenses are generally paid for in the case of an allo-HSCT transfer, whereas this possibility is not systematically granted to patients with other diseases requiring a medical transfer.

Although the transfer to undergo an allo-HSCT is a State-sponsored therapeutic journey, access to highly technical treatment and tertiary care is still subject to social inequalities in France (Lombrail and Pascal, 2005), and especially to geographical inequalities between mainland France and the various French overseas regions such as La Réunion (Hagège et al., 2022). It has been suggested that these inequalities caused by disparities in the supply of care may have been increased by French policies designed to centralise complex cancer care programmes (Huguet, 2020).

In addition to the physical and psychosocial effects endured during the allo-HSCT procedure and the post graft period, the geographical and cultural distance between mainland France and La Réunion have social and financial effects on patients and their families. This socio-medical practice is currently evolving, and therapeutic mobility for bone marrow transplantation has its own specificities. However, the lived experience of transplanted patients and their relatives can help to understand the various social and financial issues underlying the medical transfer for innovative or highly technical treatment of many patients living in French overseas regions, as well as in remote areas worldwide, such as rural residents in Canada (Mathews and Ryan, 2017) and Australia (McGrath, 2006).

Based on a qualitative study conducted with allo-HSCT recipients, their family caregivers and healthcare professionals, the aim of this article was to document how patients experienced their therapeutic transfer and the events involved. The respondents' narratives brought to light many of the socio-economic and cultural factors responsible for shaping this complex personal experience and document the ways in which territorial health inequalities occur.

1.1. Overseas therapeutic mobility

During the last few decades, much interest has been focusing on the topic of patients having to travel abroad for therapeutic purposes (Bell et al., 2015; Kaspar et al., 2019; Musso et al., 2012; Naraindas and Bastos, 2011; Ormond and Lunt, 2020; Roberts and Schepers-Hughes, 2011; Sakoyan et al., 2011). These transnational journeys have sometimes been referred to as "medical tourism", an expression to which several authors have objected. The word "tourism" masks some aspects of patients' actual experience because it does not reflect the financial efforts they have to make or their physical and emotional sufferings (Connell, 2015; Inhorn and Patrizio, 2009; Kaspar, 2019; Ormond and Lunt, 2020; Song, 2010). Various more suitable terms were therefore proposed, such as "medical exile" (Inhorn and Patrizio, 2009), "cross-border mobility" (Bochaton, 2015), "medical nomadism" (Lunt, 2020), "biotech pilgrimages" (Song, 2010), and "medical migration" (Roberts and Schepers-Hughes, 2011) in order to reflect the variability of the context. These politically-charged terms place the accent on the structural factors involved, such as the resources required, the barriers to patients' access to healthcare services, the cross-border transfers, and the "increasing commoditisation of health care" (Ormond and Lunt, 2020:4181). Just as the term "tourism" was rejected because it suggested leisure activities, short holiday periods and wealthy travellers, the term "migration" has also sometimes been criticized because it conjures up a picture of migration, poverty, and the idea that migrants intend their destination to be permanent (Ormond and Lunt, 2020; Sakoyan et al., 2011). In order to avoid these economic and political

issues and the corresponding connotations (Kangas, 2010; Sakoyan et al., 2011), we have decided here, in line with previous authors (Kaspar et al., 2019; Sakoyan, 2012), to adopt the term "therapeutic mobility", which covers all the many kinds of health-related movement (Kaspar et al., 2019). Here we have dealt specifically with patients' mobility by documenting their experience (Kangas, 2010) and the conditions under which people have recourse to distant healthcare structures (Sakoyan, 2012). By looking at the social, cultural and political settings involved in these therapeutic transfers, which determine patients' experience of the care and the quality of life in the host country or region (Sakoyan et al., 2011), it is proposed here to analyse patients' lived experience of allo-HSCT in the context of therapeutic transfer from La Réunion to mainland France.

The case of La Réunion and the other French overseas regions is quite particular since it raises questions about frontiers. La Réunion is located in the south-western part of the Indian Ocean, more than 9000 km from Paris, and has a specific Creole culture. During the Colonial era, La Réunion, an inhabited land, became a French hierarchical plantation-based socially structured colony. Its settlement underwent various phases, including periods of slavery and indentured labour to provide workers for the sugar cane plantations. The various migratory streams and the occurrence of mixed marriages resulted in a process of creolization (Pourchez, 2005a). The status of Department proclaimed in 1946 in response to the move towards decolonization was an important turning-point, as was the epidemiological transition (Catteau et al., 2005b). A new set of social dynamics accompanied the large-scale arrival of executives and civil servants from mainland France, who introduced the Western lifestyle (Benoist, 1993). The postcolonial social transformation resulted in a two-fold picture: the Creole culture, which marks people's private lives which, in matters of health, are often characterized by a medical pluralism and local therapeutic knowledge (Benoist, 1993; Desprès, 2011; Pourchez, 2005b); and the hegemony of the French institutions (Médéa, 2009) responsible for public matters, including biomedical health care. Most of the specialized physicians on the island were born in mainland France and doctor-patient relationships still show some forms of paternalism (Desprès, 2011).

After becoming a French Department, the island acquired de status of Region in 1982, and subsequently that of Overseas Department-Region (DROM) in 2003. This status means that all the sovereign laws and regulations adopted in the French Republic apply on the island, apart from some special derogations relating to French overseas law (Diémert, 2005).

Although the transfer of patients does not involve crossing national borders (this is an intra-national form of mobility), the geographical and cultural distances involved make patients' experiences resemble transnational journeys in many ways. In order to stress this particularity, we will use the expression "overseas therapeutic mobility" to denote movements from one territory to another within the same nation, but which involve crossing geographical frontiers in the framework of the present post-colonial setting.

1.2. Health, cancer and inequalities in La Réunion

In the last 2018 population census, 855 961 inhabitants were recorded in La Réunion (INSEE, 2021). Its residents are entitled to the same rights to health care, health insurance and social protection as the inhabitants of mainland France. However, the poverty rates are high: 43% of the population are living below the poverty threshold; 50% of the population of La Réunion benefit from CMUC (a State-sponsored supplementary health coverage), as compared to 11% in mainland France; and 28% of the labor force was unemployed in 2018 (Hagège et al., 2022). Two of the most prevalent forms of cancer (prostate and cervical cancer) have higher standardized mortality rates than in mainland France (Hagège et al., 2022).

Primary healthcare structures have been firmly implanted here, and although their distribution over the island shows some disparities

(Catteau et al., 2005a), these services are widely accessible, whereas there are much fewer private specialists available than in mainland France (Besson and Caliez, 2016). The University Hospital (CHU) consists of two sites: one in the north (CHU-N) and one in the south (CHU-S). The latter is responsible for dealing with allo-HSCT recipients. Although the island provides most of its own hospital requirements, approximately one thousand of La Réunion's residents were transferred for various specialized treatments to mainland France in 2013 (Besson and Caliez, 2016). Despite the existence of this widely available local healthcare system, inequalities still persist between overseas and mainland France because of the existence of strong territorial and social disparities (Défenseur des droits, 2019; Hagège et al., 2022).

1.3. Allo-HSCT for the inhabitants

Allo-HSCT procedures consist of destroying the patients' bone marrow cells and replacing them with the healthy cells of a compatible donor, usually a member of the patient's family or a volunteer enrolled in an international donors' database. Prior to the transplantation, the patient undergoes conditioning therapy including chemotherapy with or without radiotherapy or immunotherapy in order to destroy all their defective bone marrow cells and prevent the graft from being rejected (Niederbacher et al., 2012). Allo-HSCT is clearly associated with a substantial risk of life-threatening complications such as acute or chronic Graft versus Host (GvH) disorders. Although the allo-HSCT approach gives patients with haematological cancer a chance of remission, it is associated with high rates of mortality and morbidity and a risk of relapse. In addition, it has by now been clearly established that patients' quality of life deteriorates considerably during the course of allo-HSCT (El-Jawahri et al., 2015) or during the post-HSCT period (Niederbacher et al., 2012), especially in patients developing GvH, the main factor associated with impaired quality of life (Pidala et al., 2009).

During the treatment, the patient is placed in protective isolation in order to prevent the risk of infection for a period of 4–6 weeks. It has been reported in the medical literature that many HSCT recipients suffer from the negative effects of strict prolonged protective isolation (Lee et al., 2009) because of the loneliness, lack of freedom and psychological distress it involves (Biagioli et al., 2016).

In the absence of complications, patients from mainland France can return to their homes under close medical supervision, whereas patients from La Réunion are not allowed to go straight home after being discharged from hospital and have to stay near the transplant centre for at least ten weeks more. During this period, patients either stay with members of their family or friends living near the graft centre, or go to a State-sponsored hostel or a medical follow-up centre. Those who can afford to do so can rent more comfortable accommodation at their own expense.

2. Methods

This qualitative study was undertaken as scoping work for a broader research programme, using qualitative and quantitative methods to address the psychosocial consequences of geographical distance on patients and their family carers, the elicitation of patients' preferences to undergo an allo-HSCT overseas, and the economic consequences of the current conditions under which patients are transferred to mainland France.

This qualitative study was approved by the Institutional Review Board of the National Institute for Health and Medical Research (IRB00003888, opinion numbers 19–631). For the sake of personal privacy and data protection, all information about the participants was anonymized under the strictest conditions of confidentiality. Patients and family caregivers gave their consent to participate after receiving both oral and written information about the study.

In-depth semi-directive interviews were conducted between February 2020 and January 2021 with the following participants: 22

allo-HSCT recipients, two of whom had undergone a second transplant after a relapse; and 23 family caregivers, 13 of whom had accompanied the patient during the transfer. In addition, 9 health professionals from the Necker Hospital (NH), the CHU-S's Paris allo-HSCT partner hospital, were interviewed for data triangulation purposes.

Patients were recruited in collaboration with the CHU-S without any selection criteria other than being over 18 years old and having undergone allo-HSCT. The nurse responsible for coordinating the transfer process and monitoring transplanted patients when they returned to their homes suggested to patients during their check-ups that they could meet the interviewer. If the patient agreed to participate, the anthropologist immediately made an appointment. Carer contact information was provided by patients themselves. Although all the allo-HSCT recipients proposed by the coordinating nurse agreed to take part in the interview, the caregivers' acceptance rate was lower. The 22 patients did not all provided caregiver contact information: six of them, did not put the researcher in touch with a caregiver, for various reasons including patients' strong feeling of autonomy so that the caregiver was not even named; non-availability of the caregivers for reasons of work or health; refusal of caregivers who did not want to remember or talk. Some patients gave the names of several contacts, however. The 23 caregivers' interviews therefore related to 16 patients.

The patients interviewed did not all originate from La Réunion: they were mostly from the island ($n = 17$), but three were people from mainland France who had settled in La Réunion; and two were from Mayotte.

Although the interviews with patients, carers and NH professionals covered a wide range of topics, we have focused here only on themes relating to the effects of therapeutic mobility on the patients. The first author, an anthropologist living in La Réunion, conducted the interviews in person at the participants' homes or in a hospital room. However, the COVID-19 pandemic which arose just after the beginning of this study made it necessary to adopt other methods based on telephone and video interviews with some of the participants (6 patients, 8 caregivers and 9 NH professionals).

The interviews were audio-recorded and faithfully transcribed verbatim. Both French and Creole are spoken in La Réunion. The majority of the interviews were conducted in French, with some passages in Creole. The researcher in charge took care to translate the Creole excerpts into French and explain some specifically Creole terms that might have lost their meaning in translation.

An inductive approach and an iterative process based on the Grounded Theory coding method (Charmaz, 2014) were used to analyse the interviews. Using an anthropological approach, we focused on patients' lived experience of the therapeutic mobility and the graft. We have adopted the definition for experience proposed by Kleinman and Seeman (2000:234): "the intersubjective, felt flow of events, bodily processes, and life trajectory which always take place within a social setting". The thematic groups were discussed at interdisciplinary team meetings. The initial results were discussed with the CHU-S haemo-oncology team in order to obtain relevant feedback and correct or confirm the researchers' interpretations.

3. Social inequalities shape patients' experience of therapeutic mobility

Sophie is a 46-year old teacher. She was accompanied throughout her stay by her husband, a physician from Paris. They were sufficiently well-off to be able to rent a spacious apartment near the Necker Hospital. Her family-in-law, who lived in Paris, often came to see her, bringing homemade food. When Sophie was discharged from hospital a few days before Christmas, all the members of her family, including her children, her parents, and her uncles and aunts from La Réunion, came to spend the Christmas holidays with her.

Sylvain, on the other hand, was an unemployed 30-year old. He travelled with his father, who, like his mother, lived on an allowance for

people with no financial resources granted by the French Government. The father spoke only Creole and was illiterate. This was his first journey by air and the first time he had left the island. On their arrival in Paris, the son was transported in a medical vehicle, whereas the father was left alone at the airport and had to make his own way into the city and find the hostel where his accommodation had been booked. Then he had to find out how to use the public transport to visit his son in hospital, 5 km away from the hostel. In addition, the unemployment benefits to which Sylvain was entitled were withheld because the health insurance system was supposed to take over these payments whenever the beneficiaries were ill. However, administrative delays and blockages left this young man with no income for two and a half months after undergoing the graft. His family back in La Réunion had to set up a special solidarity fund to enable the father and his son to make ends meet.

These two cases suggest the extent to which patients' and their families' socio-economic resources can shape their experience of the graft and the period of therapeutic mobility. In what follows, it is proposed to analyse in greater detail the various factors involved in the patients' and accompanying family caregivers' overseas transfer and the patients' treatment.

3.1. The logistics of overseas therapeutic mobility

The coverage of medical transfers includes an economy class return flight in addition to several land journeys: from the patient's home to the departure airport, from the arrival airport to the hospital, and all the patients' transfers from their lodgings to the hospital. Despite the support provided by the French health insurance system, problems still tend to arise which cause the patients much trouble and stress. Apart from some patients whose flights were upgraded for greater comfort thanks to the intervention of a social worker, most of them, such as Simon, aged 62, found the economy class journey most unpleasant: "*They make you travel in a cattle truck, [...] one really needs more space after having spent several months in a goldfish bowl*", said Simon referring to the protective isolation room where he had to stay before the transfer. He added that this 11-h night-time journey had a really negative impact on his state of health: "*You arrive on the mainland, you are completely wrecked, you haven't had a wink of sleep, you are exhausted, and then you are admitted immediately to hospital: you don't feel in the least at ease.*"

Upon their arrival in Paris, further hitches sometimes occurred in the organization of the patients' transport: after the tiring journey, patients already greatly weakened by their medical condition sometimes have to spend several hours at the airport waiting for the ambulance to take them to the hospital. Others complained of the lack of assistance at Paris airport during the return journey.

The services of taxi companies can be used free of charge by patients holding a transport voucher delivered by hospitals. However, many taxi drivers in Paris refuse to accept these vouchers. Post-graft patients therefore often have to advance these expenses. After encountering several problems with taxis, some of them decided to hire a car, drawing on their personal savings for this purpose.

The logistics and formalities required to obtain means of transport were described by respondents as an additional burden over and above their disease. Annabelle, aged 46, should have arrived in Paris with her deaf-mute brother, the donor, for her first transplant (she underwent two allo-HSCTs). Actually, they had to take different planes because of an administrative error. He did not accompany her to the hospital, and did not stay long in Paris. She therefore had to deal with the administrative formalities practically alone: "*It's already so hard to live with this disease, and to go so far away from my family, and to find oneself having to cope alone with the paper-work. [...] I was the one who had to call the taxis and make other calls to obtain the documents and check whether or not they were in order. [...] I was the one who had to manage my admission to hospital all by myself. It's really hard to cope with, it's bad for the morale!*". Coping with the health care system and the bureaucratic demands requires abilities, as well as energy, which patients lack because of their poor

state of health.

According to the healthcare professionals interviewed, the conditions of collaboration between NH and CHU-S have improved. Several bridges still remain to be consolidated, however. The incidents reported by respondents include failure to send a medical transport vehicle to the airport, a last-minute change of flight of which the patient was not informed, patients and their accompanying carers being placed on two different flights, no rooms available at the follow-up care centre, and no transmission of the patient's medical records. All these incidents are so many additional hardships for patients during their period of therapeutic transfer. The logistic problems are sometimes thought to constitute a double ordeal: "*The logistics, too much logistics, too many hurdles to overcome [...] it's already hard to fight the disease, but when you also have to fight the logistics, it's a two-fold punishment*", said Frédéric, a 45 years policeman.

Except for the long flight, all French patients who live in remote areas encounter these logistical barriers. However, the difficulties are greater for Reunionese patients who do not have the same "spatial capital" (Levy, 2003) as mainland French patients, and even more so for those who have never been to mainland France and speak only Creole, and do not enjoy the same ability to use and combine different means of transport and to handle the health care system (Bochaton, 2015; McGrath, 2006). Adapting to new places of care and new living quarters (Kangas, 2010) requires *mobility skills* of the kind described by Sakoyan as "migratory know-how" (2012). Patients have unequal mobility skills, depending on their social (economic, social, cultural and cognitive) resources and their knowledge of mobility acquired through experience and family practices (Ripoll and Veschambre, 2005). The stratification existing between social groups in Reunionese society, which still bears the marks of the colonial era (Médéa, 2009; Desprès, 2011), and the mainland French professionals' lack of knowledge of the Reunionese social and cultural context may exacerbate these difficulties.

3.2. Financial problems

Several patients mentioned the financial problems encountered due to the distance from their homes, which impacted their experience of therapeutic mobility. Although the cost of the patients' medical care, transport and accommodation are covered by the French health insurance system and the accompanying carers' travel expenses are covered by the Department of La Réunion, unexpected expenses can sometimes arise, as the following three situations show.

Adèle, aged 25, hesitated about undergoing the graft. After arriving in Paris with her partner, she refused the operation and wanted to go back home. Her mother in tears on the telephone asked her "*If I come over for the graft, [...] would that make you change your mind?*". Adèle's mother therefore decided to join her daughter for a few weeks to encourage and reassure her. But she had to take out a loan to pay for her journey and that of her younger daughter, who was not yet of age.

The flight of Annaëlle, a 30-year old single parent at the time of the graft, was upgraded to first class along with that of her mother, who was accompanying her, but she had to pay for her little boy's upper-class ticket (about 2000 €) herself, as well the sum of 10 € per day for his accommodation during the four and a half months they spent in mainland France. In fact, Annaëlle should have been able to benefit from financial assistance with her son's travel expenses from the Department, but the heavy, complex administrative procedures she carried out prior to their departure were unfortunately not successful because of bureaucratic obstacles.

Maggy, another single mother, aged 22, was still a student at that time. Contrary to what occurred with Annaëlle, her son's travel and accommodation expenses were covered by the Department. Maggy's mother took an unpaid leave from her work to accompany them. The father, a self-employed carpenter, decided to join and support them in Paris. He therefore closed down his firm temporarily, resulting in a complete lack of income. In the end, instead of the initially expected

three months, they had to stay for eight months because of graft complications. The financial consequences for the family were significant, and they had to take out loans and ask the other members of the family for assistance.

Although the medical transfer to undergo an allo-HSCT is a State-sponsored form of overseas therapeutic mobility, some of the patients interviewed had recourse to their personal savings, while others were obliged to apply for loans, as many transnational mobile patients have to do (Scheper-Hughes, 2011; Connell, 2015; Bochaton, 2015; Kaspar, 2019; Kangas, 2002). Several patients such as Sylvain opened up on-line subscription funds, asking their friends and relatives to help them out by making donations, calling on the well-known Reunionese spirit of solidarity (Ève, 2013). If the situation of the patients from La Réunion does not seem to be comparable to that of people living in capital-poor countries, State-sponsored overseas therapeutic mobility is nonetheless a form of mobility that impoverishes many patients and their families.

3.3. Parenthood and support

Family caregivers are key actors in therapeutic mobility (Kaspar, 2019). Patients having to travel overseas to benefit from allo-HSCT procedures should be accompanied by a family caregiver throughout their stay in mainland France to provide everyday assistance and moral support. Most of the patients interviewed declared that after the graft, their state of health did not enable them to perform daily tasks. According to Jean-Marc, aged 53, there is simply no question of patients coping on their own after the graft: *"It's just not possible. When one has embarked on this bone marrow venture, there are moments when one is completely incapable of managing on one's own [...] Finding oneself all alone [...] can be practically suicidal"*. Previous studies have shown that social support generates psychological benefits that persist beyond the acute phases of HSCT and contribute to HSCT recipients' overall quality of life (Beattie et al., 2013).

Apart from the possibility of financial coverage, it is necessary take into account the fact that adult accompanying carers have to make themselves entirely available, and attention also needs to be paid to the impact of playing this role (Beattie and Lebel, 2011). These people have to drop everything for several months, including their personal lives and possibly also their work, which means a loss of income since carers are entitled to no compensation for absence from work. Accompanying a relative overseas is less problematic for those with no occupational obligations. For carers who have a job, it is more difficult. Some of them had to use special strategies to side-step the regulations. Anaëlle's mother, for instance, found a loophole to accompany her daughter and her grandson by going on "fictive sick-leave".

Some patients cannot be accompanied by a family carer. In this case, the patient either travels alone or has the company of a carer for just a short time. Marie-Olivia, for example, aged 34, was accompanied by her brother Gabriel, who was unemployed. He was able to stay with her for a month, but then he had to go back home to look after his own family. His departure caused Marie-Olivia great distress and the feeling of being "completely alone".

Patients' distress was also due to their worries about members of their family back home. Especially when they had young children, they had to cope with the emotional upheaval caused by leaving them and they worried about how their absence was affecting their children's emotional and practical well-being (McGrath, 2015), especially when the patients were single parents. Marie-Olivia is a single mother of a 5-year old girl and she was mainly worried about her daughter. Marie-Olivia's family was in fact looking after the child, who was able to continue attending school and pursuing her activities. The distance between them had its effects on the child and on the health of the 70-year old grandmother too, since the links of parenthood were disrupted, and as Marie-Olivia stated, it was the Granny "who took over the role of Mummy". Maggy and Anaëlle, the other two single mothers, decided on the contrary to take their children with them along with their own

mothers. Maggy's 3-year old child, who attended school in France, has happy memories of his school in Paris, whereas Anaëlle's 5-year old son is an example of how distance can seriously affect children's schooling. During the four-and-a-half-month transfer period, the child was not enrolled at school. Upon returning to the island, Anaëlle discovered that her son was excluded from his school because of his long absence. He subsequently had to change schools several times, which made his situation as a child with an attention deficit disorder even more complicated.

Issues linked to parenthood and the effects of separation on children's well-being are not restricted to single-parent families. Marie-Amandine was 50 years old at the time of the interview. She had undergone two allografts, one in 2015 and the other one in 2018 after a relapse. She spent 8 and 11 months, respectively, in mainland France. At the time of the first transplant, her 10-year old daughter stayed in La Réunion with her father. When the second graft was performed, the daughter was "disorientated" by the distance between her and her mother: *"She wouldn't set off for school in the morning, she had lost her morale"* said Marie-Amandine. Since she was missing her mother so much, she eventually joined Marie-Amandine in Paris, where some relatives took care of them both.

The narratives of the patients and carers interviewed suggest that therapeutic mobility most severely affects families in which the mobile patient is the wife and mother, as described by previous authors (Pian, 2015). Family structure, parenting and patients' gender may interact in shaping the experience of therapeutic mobility. Being a single parent creates additional disadvantages and may increase the suffering caused by the graft and the medical transfer. However, all the single parents interviewed here were women. This form of gender disparity illustrates how therapeutic mobility reproduces gender inequalities in other ways than through the informal caregiving which occurs within families, as described by previous authors (Kaspar, 2019; Kaspar et al., 2019).

4. "Logics of presence": transferred patients' feelings of disorientation

Patients' experience of overseas therapeutic mobility for the purpose of undergoing life-saving care was perceived as a hope of being cured, and at the same time as an imposed journey: *"The hardest thing is to set off, it's an enforced journey"* said Frédéric with an ironic laugh.

The most difficult issue facing patients is the long separation from their nearest and dearest, with all the uncertainties involved in the treatment. Another important point for Reunionese patients (as defined by originating from La Réunion) is the distance from the mother soil, the birthplace left behind. As Frédéric put it: *"What keeps going through one's head [is] being so far from one's family, far from one's soil, far from one's origins"*. It is proposed in this part of this article to examine what Anaik Pian has called "the logics of presence", which she has defined as follows: "how individuals consider and see themselves in a given space and time, that is, the country where they receive life-saving treatment" (2015:642).

4.1. Remoteness of home, friends and family

Out of the 24 patients in La Réunion who were eligible to undergo allo-HSCT between 2010 and 2014, 8 refused to be transferred to mainland France: 5 of them because they feared being so far from their homes and families (Cabrera et al., 2015).

Long distances between home and the specialized hospital is one of the main problems involved in allo-HSCT (McGrath, 2015). As mentioned above, contrary to patients from mainland France, patients from La Réunion are not allowed to go straight home after being discharged from hospital and have to stay at least ten weeks near the transplant centre. Therefore, their experience of loneliness includes not only the period of strict prolonged protective isolation imposed on all transplant patients, but is extended to the post-graft period, during

which patients are subjected to extremely strict dietetic and hygienic conditions. During this long post-transplant period they cannot see their family and friends back on the island. The presence of an accompanying carer does not abolish patients' need for their supportive family network and the other forms of assistance available in La Réunion. Although her mother travelled to mainland France for a few weeks to encourage her to agree to having the graft, Adèle subsequently regretted having agreed to undergo therapeutic mobility, and regarded the distance from home as the worst constraint involved in the treatment. She said she had agreed only to please her family, and that the nine-month period of absence was an ordeal for her: *"I honestly regret having done it! Because it was too difficult. I didn't have the support of my family. I was practically all alone. There was my partner [...] but I missed my mother's support"*. These patients were experiencing a period of family "scattering" which was not "about family dispersion per se", but about the impossibility of co-presence (Pian, 2015:648).

For the last few years, thanks to the latest methods of telecommunication, patients have been able to keep in touch with their families more easily. NH makes connected tablets available to patients in order to relieve their sense of remoteness. Technological aids help people keep in touch, but digital tools do not replace the loved ones' physical presence.

Like the heavy logistics involved, the distance from home is sometimes perceived like a double ordeal along with the patients' cancer and its treatment: *"It's a double suffering"*, said Frédéric, *"Not only are you ill, but you are in a place where you don't want to be (in mainland France), it's like a double punishment"*.

Because of the geographic distance and the remoteness from home, friends and family, overseas therapeutic mobility is akin to a "medical exile" as described by Inhorn and Patrizio (2009: 906) in the sense that "it is a kind of forced travel from home, which may feel like a major yet undeserved punishment". However, unlike those quoted in Kangas' (2002) study, neither the patients nor their relatives directly criticized the French healthcare centralization policies, except for Frédéric, who regretted that the French State does not invest more in the island's hospital infrastructure, given La Réunion's colonial past: *"We are a small piece of rock. That's when you realize that here you are really left out, although you are attached to France"*. Even if the interviewees expressed few explicit complaints about geographical inequalities in terms of access to highly technical care, most of them regretted not having been able to benefit from the bone marrow transplant on the island. Participants' explicit claims were rather directed towards the local administration and the need to facilitate the administrative procedures and improve the travel conditions and the hospital food (see below).

4.2. Fear of dying alone, far from one's native land and one's family

Patients who have travelled overseas to undergo grafts are unanimous in saying that they did so because "they had no choice". The decision to undergo a graft involving therapeutic mobility, which will be addressed in a future article, is part of a "survival strategy" (Kaspar, 2019). Mobile patients' investment in the "medical imaginary" (DeV-ecchio Good, 2001:397) increases their hopes of being cured, but at the cost of considerable emotional suffering as well as social and financial efforts (Kaspar, 2019). It raises their hopes despite the lack of certainty about the outcome, as Jean-Pierre, aged 70, explained: *"I saw my doctor, who said: 'Well you have one chance out of three of dying, of not making it'. So I retorted [...]: 'I have two chances out of three of coming back home'. Does one really have a choice? One has no choice!"*. Patients face up to the graft hopefully, but the overwhelming fear of dying alone without the support of their family constituted one of the main fears of the allo-HSCT recipients about embarking on therapeutic mobility, "which is sometimes a journey with no return", as the NH psychologist put it. Frédéric described the day of his departure: *"It's like an hour-glass, I mean you are counting the days, but you wish you could slow them down before your departure. You wish the time was longer because you feel you are stepping into the unknown. [...] You think about [...] the risks, and then you say to*

yourself: it would be a pity to take the plane and never come back".

Balancing between the risk of dying far from home because of the transplant and the risk of death from blood cancer if the graft does not take, the allo-HSCT recipients interviewed here had chosen to expand the scope of hope provided by biomedical technology via a last-chance medical journey, as so many other mobile cancer patients have done (Kaspar, 2019).

The death rate in the stem cell graft ward was estimated by one of the graft specialists at 20–30%. The NH professionals interviewed mentioned situations in which patients had died all alone. Étienne, aged 38, had been afraid of dying far from his native land: *"Dying over there [in Paris] is out of the question"* he stated. It has happened that the NH professionals have had patients transported back to La Réunion under emergency conditions when their health has deteriorated, in order to save them from dying alone. This situation is similar to that of the professionals interviewed by Anaik Pian (2012) in the case of foreign female cancer patients who travel to France where they received cancer treatment. When death is imminent, doctors anticipate and tweak administrative procedures, challenging norms and practices in order to allow the patients to die in their own country, near their family.

Fear of dying alone, far from one's native land and one's family is an under-explored aspect of research on therapeutic mobility. McGrath's study (2006) is a noteworthy exception. She has examined how aboriginal peoples inhabiting rural and remote parts of Australia experienced relocation for treatment during their end-of-life care, describing the pervasiveness of the fear of dying alone, far from the homeland experienced by this population, in addition to several other fears also observed in the present study: fear of leaving home; fear of the disempowerment associated with relinquishing the support of family networks; fears about hospital environments and 'high-tech' treatments; fear of cultural alienation for lack of familiar food and ways of being; fear of travel; fear of loneliness; fear of language and communication barriers; and financial worries.

Although the fear of dying alone is a feeling shared by many people around the world, this fear deserves special attention in the case of the therapeutic mobility of populations who have particularly strong ties with their native soil and their culture, as the Reunionese people do (Labache, 2008).

4.3. Culture and the environment

Reunionese patients also suffered during their absence from the lack of several specificities of La Réunion's culture and environment, such as the language, the climate and the food, and said they had started to worry about how they were going to miss these things even before setting off. Like the aboriginal people interviewed by McGrath (2006), the patients interviewed who were born and bred on the island experienced a particularly strong cultural shock and felt completely lost. Anticipating these privations and coping with them are particularly painful for patients who have never travelled overseas, as Marie-Olivia explained: *"I was afraid of not being able to understand or realize what was going on. And then ... there was the language too. We speak Creole more often than French at home. I have difficulty in speaking French properly"*. Other respondents like her were glad to meet other Reunionese people, especially as it gave them an opportunity of speaking Creole, since that was their native tongue, the language of the first process of socialization, and that of intimacy and the emotions (Ghasarian, 2004).

The difference in climate was particularly strongly felt by patients who arrived in France during the winter: *"The climate especially played a role. It's winter over there, [...] it's horrible. It's really bad for the morale"* said Marie-Amandine. As for Frédéric, the plane journey went quite well, but on his arrival in Paris: *"The weather was cold, everything was grey, including the inside of my head"*. Several of the patients interviewed had not been prepared for the Paris climate and had not brought suitable clothing.

One of the aspects most frequently mentioned by the respondents

was the problem of the hospital food and how badly they missed their usual diet, although they admitted that the treatment administered may have affected their appetite and their sense of taste. Patients generally also had difficulty in eating because they had contracted mucocitis and other side-effects of the treatment. In addition, allo-HSCT recipients were subjected to dietary restrictions for a whole year after the graft in order to prevent the occurrence of infections such as aspergillosis. In the patients' minds, eating properly was regarded as a weapon for fighting disease. Food "is important. [...] One tries to fight this disease and if one is given food one dislikes, the battle is over isn't it?" as Marie-Amandine declared, and "If you don't eat, you won't be cured", according to Étienne. Patients described the hospital food served in mainland France as "very poor" or even "disgusting".

Along with language, food is one of the factors contributing most strongly to the feeling of belonging to a culture and materializing that culture (Benoist, 1983; Cohen, 2000). Societies' culinary system is meaningful. It mediates a particular picture of the world and interacts with other aspects of society (Lévi-Strauss, 1958). In La Réunion, both the language (Chaudenson, 2001; Vitale, 2008) and the eating habits (Cohen, 2000; Tibère, 2008; Valentin, 1982) have been forged between tradition and innovation on the basis of complex, multiple social processes of creolization. Most of the traditional dishes in La Réunion consist of rice and fish or meat stews, served with pulses and spicy condiments. As Patrice Cohen (2000) has pointed out, eating in La Réunion is regarded as a basic need for the human body, which strives to obtain a feeling of repletion by ingesting strength-giving food. This belief is attributable to the periods of poverty and food scarcity which have marked the island's history (Cohen, 2000). Rice, which is an essential ingredient, is symbolically associated with comfort and pleasure and has strong connotations with everything contributing to life (Valentin, 1982). The activity of eating, which recruits the senses of vision, smell and taste, also has reassuring effects (Valentin, 1982). Food is therefore intrinsically linked to the islanders' representations of the world and their bodies. When they fall ill, its intake is usually reduced in order to facilitate the digestive process (Cohen, 2000; Valentin, 1982). However, patients undergoing therapeutic mobility are mainly struck by the change of dietary ingredients, which gives them the feeling of "lacking nourishment" and "losing their identity" (Cohen, 2000:334).

These cultural factors are specific to patients of Reunionese origin. Patients originating from mainland France who lived in La Réunion did not complain about the climate or cultural disorientation during their period of mobility. Even if they do not like the hospital food, their objections did not focus on the cultural aspects of the food they were served. The Mahoran patients interviewed expressed even greater distress: these patients were first treated in La Réunion and were subsequently transferred to mainland France for the graft. This meant enduring two mobilities. They were separated from their families and sent far from their island and their culture for more than a year. We only interviewed two Mahorans and cannot therefore generalize, but they seem to have felt less disorientated during their oncological care in La Réunion and often had family members who supported and accommodated them. Their narrated experiences about their stay in mainland France were similar to that of the Reunionese patients.

5. Conclusion

This study based on patients' and caregivers' narratives contributes to research on therapeutic mobility. Overseas therapeutic mobility, which takes place within national borders, greatly resembles the experience of transnational therapeutic mobility, but also includes many differences which make it a hybrid category. Being well-off financially does not relieve patients' suffering, but those who lack financial, cultural and social resources find the experience of medical travel even more difficult and painful. In addition, patients and carers who have never left La Réunion before have to acquire mobility skills. The patients' narratives show how overseas therapeutic mobility requires

considerable logistic and financial efforts and causes them much suffering due to the remoteness of their families and their affective and cultural environment. These circumstances increase patients' worries and loneliness, make them more vulnerable, and give them a feeling of disorientation. In addition to being ill, they have to make a journey which they often feel to be enforced upon them. The two-fold condition of being a sick person with a possibly lethal disease as well as being a mobile overseas patient is akin to a double ordeal. Patients with haematological cancer are already condemned to undergo allo-HSCT, which causes both physical and moral suffering, whereas patients from La Réunion also experience the "social suffering" (Kleinman, 1995:37) resulting from the medical transfer. From the patients' perspective, overseas therapeutic mobility is a kind of "medical exile" beyond their geographical and cultural frontiers.

Contrary to transnational therapeutic mobility, which is often financed by patients and their families, overseas therapeutic mobility is a State-sponsored relocation to a mainland French hospital for highly technical treatment. However, apart from the praiseworthy efforts of the hospital structures involved, the organization of overseas therapeutic mobility is often unsatisfactory because the logistics involved are so complex. There is a gap between the aids to which patients are entitled and what they actually have to endure during their medical transfer, especially the out-of-pocket costs that are responsible for a significant burden on the patients and families with limited resources, as described in other national contexts (Mathews and Ryan, 2017; McGrath, 2016). According to Kaspar (2019 et al.:12), the ability to be mobile makes patients "privileged and disenfranchised at the same time". In the case of French overseas departments, patients are given the possibility of travelling to mainland France for treatment, but this is due to the limitations of local health care and the centralization of specialized treatment. The outsourcing of highly technical care for overseas French citizens confirms the existence of territorial inequalities in France (Huguet, 2020) which have not been sufficiently stressed by previous authors and healthcare policy-makers (Rican et al., 2014). These disparities persist in addition to the social differences which strongly shape patients' and carers' experience of therapeutic mobility and shed light on the cleavages which occur between mainland France and the post-colonial overseas regions. Giving people the right to therapeutic "immobility" may provide a way of attenuating these cleavages.

Credit author statement

Loreley Franchina: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft & Review and editing, **Aline Sarradon-Eck:** Conceptualization, Methodology, Formal analysis, Supervision, Writing – original draft & Review and editing, **Yolande Arnault:** Writing – review & editing, **Anne-Gaëlle Le Corroller:** Writing – review & editing, **Patricia Zunic:** Resources, Writing – review & editing, **Patricia Marino:** Project administration, Funding acquisition, Writing – review & editing

Declaration of competing interest

None.

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