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Chapter 9

The Invisible Work of Care and Emotions along the Trajectories of Beninese Children Traveling to Switzerland without Their Family for Heart Surgery

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INTRODUCTION

Among the studies on medical travel (Roberts & Scheper-Hugues, 2011; Marsters, 2012; Bochaton, 2010; Lunt et al., 2015), very few of them concern the medical mobilities of children (Sakoyan, 2010; Vindrola-Padros, 2011; Massimo et al., 2008), and even fewer relate to the movement of children residing in countries of the Global South (Johnson & Vindrola-Padros, 2014). As noted by Vindrola-Padros & Bages (2016), the relevant literature is even more sparse when it comes to documenting how the children themselves experience their own medical travel, with most studies accounting for the experience of family members or health professionals.

Furthermore, while a part of the medical travel literature focuses on the liberal choices of Western people to travel abroad in order to get cheaper, higher quality, or even more restful treatment for their disease or that of a relative, Roberts and Scheper Hugues (2011:2) remind us that many people who travel for medical reasons come from economically disadvantaged backgrounds, and are “desperately seeking life-saving drugs and therapies and corrective surgeries that they cannot get at home,” as is the case with the patients my research concerns. As such, the work of Kangas (2007:295) also highlights the fact that “technological medicine is more than a consumer good. Wrapped up with life and death, it is an emotional and moral good as well.” Studying medical travel thus also means considering the health

inequalities that exist between the different medical travelers around the world (Faist, 2013).

Finally, while the scarce literature on children's medical travel attests to the fact that children are generally accompanied by at least one family member during the course of their travels (Vindrola-Padros & Bages, 2016; Massimo et al., 2008), in the context of my research, children aged 0 to 18 travel alone, without any relatives. I have not yet found any other study that focuses on the medical travel of children without family members.

At a time when the presence of significant others—especially parents—is valued in the field of pediatrics (Lombart, 2015; Massimo et al., 2008; Mougel, 2013, 2007) and considering that the detrimental influence of a prolonged separation between children and their parents—especially in situations of illness and hospitalization—has been shown (Bowlby, 1980; Spitz, 1945), caring for these children creates unprecedented situations, practically as well as emotionally. Indeed, medical travels affect not only the young patients/travelers themselves, but also their kin, their friends, the health authorities in both countries (Vindrola-Padros & Johnson, 2015; Kangas, 2010), NGO workers, health professionals, volunteers, or other children they meet in health facilities. In this chapter, I would like to explore how the care and treatment of these children thus constitute the heart of a complex network of emotions and care work for all the actors who support them at all stages of their biographical and therapeutic trajectories.

While the literature on medical travel has mainly focused on the reasons for travel, the flow of patients around the world, or certain difficulties caused by such travel (Sobo 2009 in Johnson & Vindrola-Padros 2014), this chapter will examine the emotions experienced by the constellation of actors who plot the course of Beninese children's medical travels to Switzerland, and the work of care that both arises from these emotions and sometimes causes them, depending on the situation. The nature as well as the temporality of these emotions differ according to the individuals concerned.

The purpose of this chapter is to highlight that, in parallel with the cultural, political, medical, institutional, or even economic challenges that fall to the humanitarian specialized care program in question, and underlying the gigantic coordination work which makes it run, the emotions and care work of the different actors in a child's medical trajectory form another layer which is less often investigated and less recognized. While the surgeons' work is generally in the spotlight (without wanting to devalue it), I suggest that the emotions and care work of all the actors involved in the medical travel of children, which go beyond protocols and are not necessarily seen, recognized, or discussed by the work teams, also constitute a driving force of the program and should be made more visible.

Among the actors who participate in the medical trajectory of the children accounted for in this chapter, I would like to emphasize that the children themselves provide considerable (care) work as part of their own journey in care. By considering children as social actors (Christensen & Prout, 2002), and accounting for their emotions, care work, practices, and perceptions, I wish to contribute to acknowledging that “they, too, tailor global health, humanitarian, and biomedical systems of knowledge and practice to their particular circumstances” (Hunleth, 2017:4).

RESEARCH BACKGROUND

My doctoral thesis in the field of medical anthropology, from which this chapter stems, is devoted to the experience of Beninese children suffering from congenital heart defects, as part of their care by a humanitarian specialized care program in Switzerland. The program has existed for sixty years, has changed little since its creation, and has never been subject to an in-depth study. This program consists of welcoming children from so-called disadvantaged families from a dozen countries in West and North Africa, for surgical operations in University hospitals in Switzerland (and in rarer cases, in France and Spain). The program was created in response to a health context in which the treatment of these defects is limited by the impossibility of access to a surgical operation, due to the lack of local technical resources. It is thus thanks to non-governmental medical humanitarian aid organizations that the therapeutic projects of these children can be undertaken (Brousse et al., 2007), knowing that each medical transfer abroad generate very high costs. Beside this, while pediatric heart patients receive timely intervention in Western countries, children suffering from heart defects in West Africa are “diagnosed very late due to limited paediatric medicine infrastructure and a lack of specialised medical centres,” also delaying their surgical intervention (Heinisch et al., 2019).

Upstream work is carried out by the collaborators of local delegations with the aim of evaluating the economic and social situations of families applying for the program. Once the application has been accepted, all the children's medical travel is covered by the NGO and by partner associations. Therefore, the families do not contribute financially to travel, accommodation, food, medical, or surgical costs. However, they spend significant sums of money, given their economic situations, during the medical and administrative procedures surrounding the application.

Children up to eighteen travel alone, without any family member. They are accompanied by different volunteers during their flights and movements while in Switzerland, and live in a residential care facility for children,

along with about forty others, during their approximately two- to three-month stay.

Within this program, I was interested in the ways in which these children experience their illness, their heart operation, and their travel to Switzerland; how they communicated and cohabited with the various actors who crossed their path as part of their medical and social care, including other children; and how they developed communication strategies and adaptive behaviors in environments which, for several reasons, are not familiar to them.

My fieldwork within the NGO specialized care program took place between July 2018 and March 2020. My approach included participant observation as well as semi-structured interviews with children, their parents, NGO workers, and volunteers, at all stages and in all the places traveled by the children as part of their therapeutic itinerary in Benin, in Switzerland, and in-between during the flights, as well as the analysis of internal documentation and written correspondence between different agents of the program. In view of the fact that I was subjected to multiple movements in the same way as the children whose trajectories I studied, and that I made observations including during their mobilities, I consider this special kind of multi-site ethnography as an *itinerant ethnography* (see Laurier et al., 2008). The data were subject to inductive thematic analysis, making it possible to highlight both longitudinal and transverse axes concerning the children's trajectories. Pseudonyms are used for all persons quoted in this chapter.

By the end of the data collection phase, I collaborated more closely with the NGO officials, in order to discuss ways of translating my research findings into changes in practice and policy, sharing the opinion that social sciences can contribute to improving the conditions of research subjects, in this case children and their families (Vindrola Padros, Pfister & Johnson, 2015), but also volunteers and NGO and health professionals. The modalities we have discussed include a summary of my observations punctuated by suggestions for improvement, discussion groups and training for volunteers, and thematic workshops for reflection on the professionals' practices, depending on the needs and interests of each work team.

FROM THE FIRST SYMPTOMS TO THE ANNOUNCEMENT OF THE DIAGNOSIS

Although each history of a child's disease and medical travel are experienced in singular ways by the children and their families (Vindrola-Padros & Bages, 2016), for the majority of the families I met during my fieldwork in Benin, the NGO specialized care program seemed to represent a last resort option after having already been through a long and trying care journey. These trajectories

were generally punctuated with numerous appointments with different physicians in several medical centers, progressive referral to cardiologists, and then orientation to the NGO program, which only meant the beginning of another journey that would also include its share of formalities, time, and concerns.

The announcement of the diagnosis of congenital heart defect was always a very emotional moment for parents and other close kin. The shock caused by the announcement of a disease requiring intricate surgery was coupled with the announcement that it would require treatment abroad as part of the NGO program, and finally that the medical travel would require separation between the child and their family for a few months. Ruben's mother recounts the shock she experienced when her child, who was only a few months old at the time, was diagnosed with a heart disease:

I did not understand anything. My child was in my arms, and I was so disoriented I almost dropped him. The doctor repeated to me: "with what your child has, he has to have surgery. He must be operated on to stay alive." I learned that my baby had a hole in his heart, and that he needed to have an operation, in order that he would live!!! There are no words to describe how I felt, I was wrecked. There are really no words. I wouldn't even wish it on my enemy.

These different announcements and the mixed emotions they caused sometimes delayed the administrative procedure of asking for help from the NGO, as the parents often needed time to make the decision. Doubts assailed them during the procedures leading to the child's departure, as the mother of Lilly, eight months old at the time, testified: "It was super stressful and I even thought about whether to do it or not, if it was worth it." It is by putting aside her own emotions that this mother managed to make the decision to allow the medical travel of her daughter, as she explained, one week before Lilly's departure: "We must do this for her. We must think of her, of her own growth. That is why it is worth it to keep going with the procedures."

Since the diagnosis of congenital heart defect was not very well-known in the general population in Benin, a feeling of guilt was common among parents, especially among mothers, who wondered and were often judged as to the origin of their child's disease. During the same interview, one week before Lilly's departure, both her parents shared with me their doubts and questions about this. While this couple reassured themselves by telling themselves that they had undergone all the recommended medical examinations and dietary restrictions during the mother's pregnancy, Ruben's mother testified in more detail to her feeling of guilt, produced by the accusations of those around her, including her husband:

I asked the cardiologist what caused the disease; was it because of my diet during pregnancy? Had I made a mistake, had I taken a medication that I shouldn't have? What happened? He reassured me and told me it had nothing to do with my diet, that it was a natural phenomenon. I also thought that maybe it was a divine punishment. I asked myself, why me? Does heaven blame me for something? You know, in Africa, it's hard to explain to people that your first born has a disease. My mother-in-law told me: "Look inside yourself and ask yourself, my daughter, whether it is possible that before meeting my son, you did stupid things . . . And if this is the case, it is normal that your child has this problem." And with many people, even if it is not in their words, you feel in their behaviour that they blame you for something. At first, you know, I'm not going to lie to you, when we got married, my husband didn't want a child right away. After some negotiations, he got me pregnant. So, when the child was born, like that, sick, it was a shock for him. At first, he didn't want a child, I practically forced him, and then the child came, but sick. Immediately he started to accuse me: "You see, it's because you were in a hurry. We did not wait for the right time. You weren't patient. It wasn't God's time, but you insisted." He made me feel guilty for a while.

Although the cardiologists explicitly told the parents that they had no responsibility for their child's disease and that congenital heart defects happened by accident everywhere in the world, it did not prevent the fathers as well as those around the family from making the mother feel guilty afterwards, or even during the same appointment in the presence of the cardiologist.

Despite the great concerns generated by their child's disease and by their future medical travel, parents mostly felt lucky to be offered the opportunity to heal their child, as Ruben's mother explained: "The fact that my child would heal gave me the strength to complete all the formalities for him to travel. Since this opportunity existed, I told myself that I would not miss it. For nothing in the world should I miss it. Other mothers would have liked to have had this opportunity for their children. If I had this opportunity and did not take it, I would be ungrateful to my God." As Sobo (2015:224) suggests and as the above quotation seems to highlight, "undertaking medical travel can serve as a demonstration of social position [. . .] [and as a way to] create and maintain [one's] identities as 'good' relatives."

Many concerns arose as the child's departure date approached, in particular relating to the length of their stay in Europe, and the way in which parents and children would experience separation, as Lilly's parents explained:

Father: On the one hand, there is uncertainty, we do not know. Because they [NGO employees] say it is often three months. But the operation can last, and it can go beyond six months, even one year. Up to a year, well I wonder if

your child, who left while she was a baby, will recognize you. Nothing is easy, everything is complicated, anyway.

Mother: Absence will always be absence. We will try to endure it in our own way. Because for me, well, she is my hobby. I do practically nothing at all, we are together all the time. So, I will try to kill time, look for something to do so as not to feel her absence too much.

SUPPORT AND SOLIDARITY NETWORKS

Benin is one of the rare member countries of the program where an association has been created, on the initiative of the local employees of the NGO and of parents whose children have traveled previously, in order to support families in the process of separation during the child's medical travel. As such, on each departure and each return to Benin, families whose children had benefited from the program in the past and ex-officio members of the association were present at the airport and supported the families of the children who were about to leave or return. Support was expressed by families sharing their stories, memories, or photographs of their children, before and after their medical travel, and by distracting parents with anecdotes, or by comforting them. Ruben's mother shared what the association changed for her, as she was preparing for her son's departure, in these words:

Knowing that, from now on, you have people who have had the same experience as you, who have cried as you have, for the same cause, who have fought, who have hoped, finally who have triumphed, people who practically shared your story, who have lived the same things as you, you tell yourself: they are my family. Because you have a lot to tell each other. It is a family, from now on. And each time I see them, I am happy, I feel at home.

A GENDERED FACET OF EMOTIONS

During my observations of the preparations related to the departure of a child, I noted that the interpretation of emotions as well as their management by the people around the parents were gendered in structure. Indeed, more attention as well as more support seemed to be given to the mother of the child, rather than to the father, an attitude relying on the perception that the mothers' emotions were more legitimate than those of the father. When the parents of two-year-old Joshua came to the NGO office, on the same day Joshua would leave for Switzerland, the father told the NGO employee that he had no appetite since he knew his child had to leave for medical reasons.

The employee answered: "You have to imagine what the mother is going to go through, because the child stayed with her all the time." Despite the fact that the father's emotions were not legitimized in this conversation with the employee, the latter however took them into account at the end of the interview, when he said: "I do not want to take the risk of having you drive in this state, so we will drive you to the airport tonight." As such, I had the impression that attention to the fathers' emotions was reflected more in actions to protect them from reckless acts, while attention to mothers' emotions was expressed with empathetic questions, and physical or verbal reassurance.

The perception that the separation was more difficult for the mother than for the father was shared by the members of the association who accompanied six-year-old Maya's family on the evening of her departure. A father whose child had traveled to Europe previously explained to me that the members of the association were also here to "distract the parents, to bring a little joy in this difficult moment." He added: "Above all, you have to talk with the mother a lot. Because she is the one who carried and fed the child, and even if it looks like she is listening, in reality she is absent, she is thinking about her child, and she will shed tears once she is home. Even now she is in the car, shedding tears."

During my fieldwork at the airport, I noticed that the fathers' emotions, while more discreet, were still observable. In most situations, the emotions of both parents were contained and rather discreet in the public area which is the airport. Social conventions seemed to prevail over the expression of negative emotions, as in the case of Maya's departure when her parents continued to talk and smile when spoken to, although staring blankly.

BEHIND THE SCENES OF EMOTIONS

While the emotions of the children and the families are obvious and recognized as legitimate, despite their efforts to hide them in public most of the time, the emotions of other actors are considered less so, and require constant emotional labor (Hochschild, 1983). This is the case for the NGO employees in Benin as well as in Switzerland, but also for the volunteers, for the health professionals in both countries, and for me, as a researcher.

Managing One's Own Emotions as Well as the Emotions of Others

The professionals who worked for the NGO in Benin supported the families on a daily and long-term basis. They accompanied them in their administrative procedures, during medical appointments, and supported them morally

through their trajectory. They personally knew the parents, the child in need of medical care and their siblings, sometimes the grandparents or other members of the family, and they developed friendly and sometimes almost familial ties. They kept in touch before, during and after the child's medical travel.

The occasions when the emotions of professionals appeared to me most clearly were the days of children's departures, which generally occurred once or twice per week. To avoid emotional exhaustion, the professionals in Benin had deliberately decided to take turns.

On the day of Lilly's departure, after NGO employee Sarah has taken care of relaying Lilly to the volunteer who will accompany her during her flight, she comes back to the family and says that "everything went well" and that she will call them the next morning to inform them of Lilly's arrival in Switzerland. We say goodbye to the family and leave. Directly after, on the way to the carpark, Sarah tells me it was a really tough departure. She says that the baby girl cried a lot, that they passed her from arm to arm, that she was disoriented. Once in the car, Sarah sits at the front, leans forward, puts her hand on her forehead, and sniffs. I put my hand on her shoulder and ask her if she is okay. She takes a moment to answer and says: "I'm fine." When she turns around, I see that she has tears in her eyes. Then she adds: "you must be able to hold out in front of the family." The 10-minute drive then takes place in total silence.

This excerpt shows that the professionals had to deal with their own emotions as well as with the emotions of others, and that they repressed the expression of their own emotions in front of the families. But this emotional labor had consequences, as the professionals took their emotions home with them. One week after Lilly's departure, as Sarah was about to coordinate another departure, we left the office together. In the street in front of the building, she told me: "I hope that tonight's separation will go well. Last week, it really wasn't easy for me. I didn't sleep all night because I was imagining how things were going for Lilly."

Furthermore, the professionals' emotions did not arise only at children's departures, when they had to manage the separation between a child and their parents. Their emotional involvement was constant. One professional, James, summed it up: "We are not only dealing with files, they are not papers. We are dealing with humans." James told me about the difficulty of their daily work, and said it's emotionally exhausting, and that sometimes he wonders if he should quit. He told me about situations where families come to the office and their child's case does not meet the NGO criteria and where he has to refuse their application, and about the mother kneeling in front of him and imploring him. He said that in front of families he holds out, but that sometimes in the evening he can no longer hold it all back.

Just a few days later, when I arrived at the office in the morning, another employee, Raphael, informed me that he had just received a call from parents to inform them that their child had died, while his medical transfer to Switzerland was scheduled soon after. He then told me: "Now there is no one to comfort us." Many cases showed that taking care of families' emotions weighed on the NGO professionals, who would have benefited from emotional support, too. In Switzerland also, the NGO employees' emotional burden was high, although in a different way, as they were not confronted with the children's families. However, NGO workers went to greet the children at the airport on the day of their arrival and drove them to the hospitals. While I accompanied Sandra one day as she was driving a child to the hospital, she confessed to me: "You have to be strong. You get used to it as you go. But there are still situations that affect me. Recently, I collapsed when I learnt about the death of a child." As I followed her work, I saw signs of her progressive exhaustion. Although not seeing the children very much, the NGO workers knew all the details of their medical trajectory and got attached to them, sometimes visiting them at the hospital although their professional function did not require them to do so.

Experiencing the Limits of Their Function

Both in Benin and in Switzerland, health professionals experienced the limits of their function when they were confronted with difficulties in caring for the children within the humanitarian medicine program. In Benin, the shortcomings of the health system were felt above all in relation to the lack of necessary equipment as well as skilled personnel for the treatment of congenital heart defects. To make up for the lack of on-site training, doctors who wanted to specialize in pediatric cardiology were often trained in Europe, as is the case with a cardiologist who told me about his frustration with local resources: "We encounter many difficulties related to the imprecision of diagnoses, due to the lack of specialized training and adequate equipment." But limits were also felt due to the contrast between the willingness of the cardiologists and the slow administrative pace of the NGO: according to the same cardiologist, "one problem is the delay between the submission of an application and the child's medical travel. Sometimes the children die in the meantime. It is a huge burden for us."

In Switzerland, the emotions of health professionals stem more from the fact that hospital partnerships with humanitarian programs require them to take care of children who do not necessarily speak the same language as them, and who are not accompanied by their parents. Massimo et al. (2008) have reported similar difficulties in verbal communication in the context of caring for foreign children in an Italian pediatric oncology service. During

my observations in hospital settings, the nursing staff kept asking me if I had information on the eating or sleeping habits of these children or on the way babies were usually carried, revealing both their perception of a shift in cultural practices, and the absence of a link in the care chain. An intensive care unit manager shared her thoughts with me: "The biggest problem with these children is the fact that we lack an intermediary representing the child, a link between the child and us, namely the parents, as we have for the other children we welcome in the unit." The caregivers also told me that they felt empathy, even pity, for these children who were hospitalized without their parents. To compensate for the perceived lack, the caregivers adopted parental postures, filled with tenderness toward these children. For example, as she prepared to undergo a cardiac catheterization exam, three-year-old Clementine was carried in an anesthesiologist's arms. A nurse passed by and kissed her on the cheek. Clementine snuggled against the anesthesiologist's shoulder. This observation shows that both caregivers and children adapted to the absence of parents: caregivers by adopting a more parental posture, and children by seeking physical contact with caregivers.

Despite the fact that the caregivers appreciated the mutual tenderness with the children, they mostly felt helpless and had feelings of guilt over the fact that they could not be around the children all the time, despite the children's needs. This was especially the case for nurses. Nurses also developed protective and advocating attitudes toward the children and granted them small privileges, more so than was the case with children accompanied by their parents during their hospital stay. On one of my first days of observation in the baby unit, I asked two nurses if the children cared for by the NGO were considered the same as the other regular patients. They immediately reacted very strongly, saying that these children "had many more rights than the others," and that the nurses "had a much more parental attitude towards them": "we are their advocates, too." They said that they took them with them during their lunch breaks and in the nurses' office, defended them against the doctors, for example, by asking if it was really necessary to have them do blood tests every day, and that they were also more forgiving with them.

The Thankless Care Work of Volunteers

When traveling by plane to and from Switzerland, the children were accompanied by volunteers from a different NGO. Due to the lack of time and the administrative procedures to be completed, volunteers generally met the children they would accompany only about 15 minutes before going through the security gates with them. Sometimes they did not even meet their family before leaving with the children. When leaving in stress due to a flight delay,

one volunteer confessed to me: "I would have liked to meet the family before. When it happens like this, I feel like a child kidnapper."

Time and organizational constraints had a direct effect both on the volunteers and the children's experience, and thus on the way the journey unfolded. For the children, as they sometimes did not have time to get used to the person who would accompany them, the beginning of the journey sometimes took place in panic and tears, which put volunteers in uncomfortable positions, especially with regards to other passengers on the flight. This discomfort was compounded by the fact that other passengers were not aware of the exact situation, and allowed themselves questions, comments, and judgments. On his arrival at Geneva airport when entrusting 18-month-old Imany and nine-year-old Laura to the NGO employee, a tired volunteer confided: "On the plane, it was difficult; at the beginning, Imany cried a lot. Everyone was looking at me, and people asked the flight attendants why I was the one taking care of these children, and why it wasn't a woman who was traveling with them. People thought I was stealing children." Once again, this shows the gendered perceptions attached to care work, as well as the feelings of the lack of legitimacy of the volunteer work.

The journeys in Switzerland, for example between the children's place of accommodation and the hospitals, were also dealt with by volunteers. Although they spent limited time together, volunteers and children nevertheless developed a certain attachment, which made separation sometimes difficult for both parties. In the long run, volunteers, like professionals working for the NGO, learned to "armour themselves," as they put it.

Unraveling the Researcher's Emotions

Several authors have addressed the fact that the researchers' emotions are not sufficiently considered in the analysis of the research process, and that they do not testify enough to the part played by emotional dimensions in the production of knowledge (Brannan, 2011; Pirinoli, 2004). In a recent article (Vaucher, 2020a), I reflected on how the researcher's reflexivity regarding his or her own emotions during fieldwork could contribute to an approach that is both epistemological and ethical. In this previous article, I focused mainly on the emotions related to my research posture, namely a kind of dissonance between my "researcher identity" and my "personal identity," at the same time questioning the fact that there are two clearly distinct identities.

Here, I wish to focus more on the emotions I experienced in contact with the children during the days spent with them, and in particular in the context of observing the care and examinations they underwent in a hospital setting. My emotions were closely linked to the very committed posture

I adopted during my fieldwork, as most of the time, I occupied the role of a reference person, or even a parental substitute for the children. Very quickly at the beginning of my fieldwork, I noticed that I experienced a kind of emotional empathy toward the children whom I accompanied, as I frequently had tears in my eyes when watching a child cry during a blood test or a vaccine. I interpreted my reaction as a response to the fact that I was aware of the entire social and medical trajectory of these children, and was, therefore, able to imagine the depth of their emotions, which I perceived as going beyond the mere moment of the blood test or injection. Gallenga (2008:4) suggests that the notion of empathy should be inscribed at the heart of the definition of anthropology, or considered as an ethnographic method, as one of the main aims of anthropology is to produce knowledge about others.

I mostly experienced sadness as well as helplessness when I visited young children in the baby unit, and found them sitting in their crib, watching for any movement in the hallway. Several times, when I took them in my arms, they immediately snuggled against my neck, searching for skin-to-skin contact, and quickly fell asleep to the sound of my lullabies. I also felt terribly sad when I tried to play with a child who was apathetic due to medication, or suspicious because they mistook me for a member of the healthcare team. Feelings of guilt very often inhabited me, surfacing almost each time I had to leave the hospital at the end of the day and leave a child alone. As my fieldwork progressed and I could no longer bare the imploring gazes of children when I left their room, I got into the habit of leaving during their naps. This strategy spared me painful separations, but not the feelings of guilt. Indeed, on the train back home, I wondered what the children would think when they woke up, whether they would feel betrayed or that I had abandoned them.

Despite my great emotional fatigue after the days I spent in hospitals, I noticed that the emotions I experienced guided me in the field, leading me to occupy roles and functions that I would not have occupied without them. Thanks to this fully committed position, I had access to unexpected situations which offered me additional insight into my research object. One day when I had only planned to observe the arrival of two-year old Kenzo at the airport, the tenderness and the joy I experienced in the presence of this boy, who had an apoplexy crisis and who had to be transported by ambulance to the hospital, but who was still playing with a teddy bear and laughing in the ambulance when his life was threatened, as well as the fear I felt for his medical condition, led me to accompany him to the emergency room, to spend the whole morning with him, and finally to access the operating room where I was able to attend his entire heart operation. This was the one and only time I was admitted in the operating room.

Finally, despite the fact that positive emotions seemed more difficult to circumscribe in my fieldnotes, I must nonetheless do them justice, as I have experienced many of these as well. The next excerpt shows one of these situations:

I visited two-year old Nayel at the intensive care unit, three days after his operation, and I found him motionless and listless in his bed, his eyes open just a crack. At the same time, a volunteer musician entered the room, and came to play kalimba music at his bedside. Nayel began to move his fingers gently while looking carefully at the musician, as if he were playing the same instrument himself. While continuing to move his fingers to the sound of the music, he started to move his legs under the blanket, struggling to keep his eyes open. His nurse approached and the three of us stood at his bedside, smiling at this moving scene, in a soft and benevolent atmosphere.

CHILDREN'S EMOTIONS BEFORE THEIR MEDICAL TRAVEL

In general, children were surprisingly absent in the process surrounding the preparation of their travels. Indeed, although they were systematically present during the medical and administrative procedures, little or no room was given for the expression of their thoughts or emotions. This was partly due to local perceptions in West Africa that the child does not have the right to speak unless asked to, as well as to the idea that the child should not be involved in "negative" situations, as the NGO professionals and some parents explained to me. Previous research has shown that in West African cultures, children mostly have to ask permission to speak in the presence of adults, a posture described by Jaffré et al. (2009:244) as the child being "'the s/he" of an interaction; the one people are talking about, but to whom no one is talking." [author's translation]. As a result, the face-to-face interviews I conducted with several children represented rare opportunities for the children to speak about their personal experience in relation to their disease and their medical travel.

One week before her departure, Victoria, 16 years old, told me: "I am happy to go there, to be healed and come back home safe and sound. I hope that the doctors there will be nice." Although Victoria's speech was full of hope regarding her recovery, the fear of separation from her family, especially her mother, quickly became apparent: "When my mom doesn't see me, she is sad. For me, it is the same: when I don't see my mom, I am sad. I pray God will give me the confidence to stay alone and not worry about my mom so much. And I pray for her that my older brother's wife can come and stay with her for a while."

Surprisingly, fear about separation outweighed fears about her disease or her future heart surgery. This excerpt also shows the gendered aspect of domestic work and recalls that when a child leaves the country for some time, the separation is not only difficult for the parents emotionally, but it can also be difficult in practice, since children, even when sick, provide daily domestic work. The work of Hunleth in Zambia (2017:136) has shown how children can also assume household and nurturing work when their relatives are sick, and that a gendered sense of responsibility can be observed at a young age.

During interviews, sometimes conducted retrospectively after the child's return, some children expressed their joy of traveling to Europe, sometimes equating their medical travel with a touristic trip, such as Antonio, 14 years old, who I met in Benin almost one month after his return from France: "I was happy to leave because I had never seen France before. I had heard of it, and of the Eiffel Tower. So, I went to France for my operation . . . and some memories."

CARING FOR EACH OTHER DURING THEIR MEDICAL TRAVEL: CHILDREN'S EMOTIONAL AND CARE WORK

As shown above, the start of the children's journey was often tormented. While the youngest were frequently anxious and cried a lot, the older ones mostly hid in silence. When children recounted their experiences to me, they often remembered their fear of flying, as 14-year-old Agatha remembered: "When I had to get on the plane, I was afraid." This fear, while expected in children who have never taken a plane before, also arose in other less obvious situations, like, for example, when the children were afraid to get in an elevator or to take an escalator in the airports and held on to my arm nervously.

In another publication (Vaucher, 2020b), I described the care practices that the children deployed among themselves during their stay in Switzerland within their residential care facility. The care interactions between children of different ages and different nationalities included forms of socialization with the rules of the hosting facility and life in the community in general, practical help, aesthetic care and hygiene, moral support, tenderness, solidarity, translating and mediating the words and moods of other children, or expressing interest and concern for other children, and their medical trajectory. The article sheds a light on a model of socialization and care between children and shows that children can be both recipients and providers of care. This observation is similar to that of Vindrola-Padros & Johnson (2015:1) who underlined that children could be both "independent agents looking after their own health and well-being and family dependents with competing responsibilities [. . .] [such as providing for] younger siblings." In the context

of my study, the children's competing responsibilities complexified as they could relate both to their family of origin and to the "strong sense of kinship" they developed toward their "temporary surrogate family" (Ackerman, 2010:418) constituted by other children experiencing similar life situations in Switzerland.

I have observed that these forms of care could also be found at other stages of the children's trajectories, for instance, during flights or at the hospital:

At 16-year-old Victoria and two-year-old Safira's departure, more than an hour after the plane took off, Safira is still struggling and yelling stridently. I show her magazines, try to sing her a song, rock her, nothing helps. She screams and struggles for no apparent reason. Victoria looks at me helplessly and says to me: "She is afraid." After a while, Safira puts two fingers in her mouth and falls asleep for a moment but is quickly disturbed by a flight attendant who brings the meal trays and she starts to cry again. Victoria takes her in her arms, and places Safira's fingers back in her mouth the same way she saw her do it earlier. Safira goes back to sleep. Victoria keeps her on her lap for a moment and then manages to put her in her seat without waking her.

This excerpt shows both mediation care work, tainted with a probable projection of her own feelings when Victoria interprets Safira's cries as fear, and practical help and solicitude to soothe Safira. Similar care work between children was observed at the hospital, as shown in the two following excerpts:

10-year-old Laura and 18-month-old Imany are undergoing an initial health check-up at the hospital on the day of their arrival in Switzerland. As a doctor tries to take Imany's temperature, she screams and struggles, pushing away the doctor's arm. Laura, who was sitting on her own bed, gets up, approaches her and tries to comfort her by tapping on her stomach gently.

Despite the fact that care from girls, and from older children toward younger ones was more frequent, I also observed situations of care from boys, and from younger children toward older ones, as in this scene:

On the day of nine-year-old Theo and two-year-old William's arrival in Switzerland, and while undergoing their initial check-up, William walks happily through the hospital corridors, plays and laughs with the caregivers, while Theo looks serious, remaining motionless and mute. We go to the dining room, where William starts to eat with appetite and pleasure. Theo barely tastes his plate, head down. William looks at him and says: "Eat! Come on, eat!" Theo sobs while eating a few pieces of pasta, drinks a very small sip of water, and then leaves his entire meal tray.

The care practices deployed between children also extended to care toward adults, and in particular their families, despite the distance.

When he has been in Switzerland for two months, 10-year-old Jacob is sitting at his desk in the classroom, and when I sit next to him, he spontaneously tells me: "I am worried about my mom, that she has problems with her work, because she is alone taking care of us. My father does not work."

As other authors have shown before, children experiencing illness and/or medical travel perceive the economic, emotional, and social burdens they place on their families and the consequences this can generate, sometimes leading to feelings of guilt (Vindrola-Padros & Whiteford, 2012; Vindrola-Padros & Brage, 2016; Couturier, 2019).

CHILDREN'S MIXED FEELINGS

The first days after the arrival of a child in Switzerland were often difficult, with children having to get used to new places, new faces, sometimes to new languages, and practices. Sobbing attacks and difficulty falling asleep were thus frequent in the children's residential care facility. Mixed emotions animated the children, between the joy of discovering that they were not alone in their situation, the sadness of missing their families, and the fear of going to the hospital and seeing the date of their operation approaching. During an interview with ten-year-old Maria, three days after her return to Benin, she recalled her fear of undergoing heart surgery and how the educational staff reassured her: "When I was at the house [residential care facility], they [educational staff] said that they [at the hospital] were going to operate on me. I was afraid. And the people who work at the house they told me not to be afraid, that it would not be complicated, they said don't be so sad."

Memories related to the operation itself were rare in children's speech. However, they frequently spoke of their surprise or fear when they discovered their chest scar, as well as the boredom and sadness of being alone at the hospital. It was sometimes also difficult for the children to understand why the other children hospitalized in the same service were visited by their parents when they were not. The following excerpt of my hospital fieldwork shows this confusion:

As six-year-old Mila and I move from the service playroom to her room, we meet a group of people in the corridor: a child, his parents, and a nurse. Apparently, the child is about to leave the hospital. The father takes him in his arms, and the

child seems very happy. I try to motivate Mila to move towards her room, but she remains frozen, next to me, leaning against the wall, and seems to want to observe the scene. When everyone leaves, she asks me, with the little French she masters: "Why mom and dad? Me also mom and dad leave?" I explain to her that unfortunately not, that she will see them when she flies back home. As I have to leave, I then accompany her to the nurses' office. She sits on a nurse's laps and snuggles against her chest.

Over the time spent in the residential care facility, the children developed friendships with other children, as well as attachments to the educational, nursing, cooking, and cleaning staff. Therefore, when the time came to leave the hosting facility in order to return to their country of origin, farewells could sometimes be as painful as arrivals.

THE RETURN OF THE CHILD: FROM JOY TO DIFFICULTY

When the children returned to Benin, the first emotions experienced by parents and other family members were joy, followed by surprise in relation to physical and capacity changes noticed in the children. During an interview, Ruben's mother remembered the day of his return to Benin:

I asked permission to quickly come home from work. When I got home, I prepared everything, I cleaned everywhere, I went shopping and bought him a lot of clothes, and I made him garlands, everywhere I wrote "welcome back, my child," "mom loves you," "I'm happy," "Now I am a mother," as if he could read! [. . .] When I saw him at the airport, he was chubby and beautiful! I said: "Ruben, is that you?" He didn't even look at me! I said: "It is mom, I am here." I wanted to take him in my arms, first he didn't want to, and then—you know here in Benin we have litanies, everyone has a litany here, so I reminded him of it, and at that moment he opened his arms to me. I was very happy.

As in this excerpt, it was frequent that the children did not jump into their parents' arms immediately upon arrival, as could be expected, and were a little wary at first, especially when they were babies or young children. Returns were sometimes not as happy as one would imagine due to the relationships the children had developed in Switzerland, and the difficulty of this new separation for them, as was the case for 10-year-old Maria, who arrived in tears at Cotonou airport, when she met with her mother and brother, and said she was sad to have left a friend in Switzerland, and that she would have liked for her to have come back on the same flight.

After a few days, children sometimes found it hard to get used to local rhythms and customs, reminding us that "medical travel is an inherently cross-cultural exercise" (Sobo, 2015:225).

Four days after six-year-old Marc-Antoine's return to Benin, he and his mother come to the NGO office for a return interview. While I knew Marc-Antoine as a rather talkative and joyful boy in Switzerland and during the journey back to Benin, I immediately notice that he is discreet and silent at the office. While his mother speaks with the social worker, James, Marc-Antoine sits motionless, his head lowered to the ground. The social worker asks the mother: "How have you found him this weekend?" She answers "fine" but looks pretty desperate. James enquires: "Did something go wrong?" She answers: "He won't eat. Nothing." James reassures her: "It takes a little time to get used to our meals." The mother also says that Marc-Antoine asked her why people in the neighbourhood were staring at him, and that she told him it was because he had changed. The mother concludes: "It is not easy."

As we can see, for the parents and family members, the pain due to the child's absence, and the joy of having their child back, was sometimes quickly replaced by distress or annoyance when they realized that their child had changed, sometimes in relation to educational models that contradicted their own. Six months after 16-year-old Victoria's return to Benin, her mother told me about her perception of the changes in her daughter since her return: "She has changed completely! In all ways. Ah! She has completely changed. Really, even when she speaks now, she speaks without thinking, just like that. Where is the respect, really? This is why I get angry often. I ask: 'what is going on? Since you came back, what's wrong? There is no more respect, what is that, what is happening?!'" Three days after 10-year-old Maria's return to Benin, her mother also told me how her daughter had developed new habits since she returned from Switzerland: "She got used to brushing her teeth after breakfast. When she wakes up in the morning, I say: 'Maria, come and brush your teeth' and she answers: 'No mother, I have to eat first. When I finish eating, then I will go brush my teeth.'" Victoria's and Maria's behaviors both challenged their mothers' authority. Furthermore, they show a circulation of educative and hygiene standards.

During the interviews after their return, children told me how happy they were to be healthy and to be able to do things that they could not do before because of their disease, as thirteen-year-old Constance explained, twenty-five days after her return: "Before, I couldn't walk, I was lying down all the time. Now I'm walking well. Just before coming here today, my mom asked me to go buy some supplies, and I am very happy about that. It's like I've been born again. Because everything I could not do, now I can do it."

Constance's speech shows that her joy also came from her rediscovered social role, as a young girl capable of helping her parents with domestic tasks, which once again highlights the part played by children in care work. However, although they said they were happy to be back with their families and to see their classmates again, some children also expressed a will to return to Switzerland. Six months after her return, a little embarrassed, Victoria told me: "Since I have returned, it has been good. But sometimes I also want to go back there. I miss the friends I had there and the other people, too. And sometimes the food, also." The desire to return was also present in younger children, as in the case of six-year-old Marc-Antoine. One week after his return to Benin, during a follow-up appointment with a cardiologist, Marc-Antoine's mother told the doctor: "He says he wants to go back already." During my interview with Marc-Antoine a few days later, as I was telling him that I would go back to Switzerland in four days, he said: "I will return, too. I will leave, too."

We see with these last excerpts that despite the recovery of their children, parents still experienced concerns after their return. When we visited their home during a social follow-up about one year after six-year old Marek's return to Benin, his mother told the social worker that Marek was so rowdy and active that she was worried about his health and was afraid that his disease would resume.

CONCLUSIVE PERSPECTIVES: A COMPLEX EMOTIONAL NETWORK

In this chapter, I mainly focused on the emotions of children, their families, NGO professionals, and myself. However, all those who work closely with these children during the preparation of their medical travel, their actual stay, or the long-term monitoring of their medical and social trajectory, undertake a complex work of care, dotted with diverse and varied emotions. We have seen that important emotional work was undertaken within the work of giving care, by all actors toward each other during the trajectory of these children: by NGO professionals in Benin toward the families, by parents toward their children and by children toward their parents, by children among themselves, by medical, nursing and educational staff toward the children, and by myself toward the children. Each of these agents in the children's trajectory managed their own emotions at the same time as the emotions of others, recalling Strauss's understanding of the concept of a disease's trajectory as referring to the work deployed to follow the course of the disease, as well as the repercussion that this work and its organization have on all those involved in it (Strauss, 1992: 111).

According to Sakoyan (2010) in the context of the medical travel of children within the Comoros archipelago, inequalities can be found both in relation to accessing medical care (which refers more to the concept of *cure*), and in relation to social recognition and psychosocial *care*, such as benefiting from the presence of significant others, or having the possibility to communicate in one's own language. In the context of my study, it seems that, through their interactions with other children as well as with all the people who participated in their trajectory, some children have succeeded in reducing inequalities in terms of *care* as a mirror reaction to the filling of the need for access to the technical *cure* of their disease which the program addresses. However, as I indicated at the beginning of this chapter, it should not be overlooked that the very existence of this program is marked by profound inequalities in access to care which inevitably shape the children's experiences and which they are not able to respond to.

As such, it is important to notice that, although some of the emotions discussed in this chapter related to the diagnosis of a heart defect in children, and were, therefore, not directly related to their medical travel as such, many other emotions and situations of care arose specifically from this unequal access to care and to the specific context generated by it, and would probably not have occurred if the children were operated on in their own country. This is the case of all the emotions generated by the separation of children from their families, and the parental substitution work that resulted from it, as well as the emotions and additional work created by cultural differences and language barriers.

From a perspective of care ethics, this chapter reminds us that both autonomy and vulnerability concern all those who participate in the medical journey of children (Tronto, 1993). Zielinski (2010:636), relying on Tronto's work, recalls that the more care practices become visible, institutionalized, and recognized in society, the more attention to the needs of others will be favored, working as a virtuous circle in which the social recognition of care plays an educative part. This chapter thus contributes to the visibility of the care work and emotions of people, both adults and children, in the context of medical travels, with the hope that medical institutions and NGOs will consider the fact that care work and emotions contribute to the running of medical travel programs as much as protocols and technology do.

Finally, this chapter provides insight into different ways of considering childhood in general and childhood on the move (Vindrola-Padros & Brages, 2016). Indeed, it highlights traits other than the usual notions of vulnerability, dependence, and incapacity associated with childhood and children, by showing that they are also capable of taking care of themselves and others, adults and children alike, and that they develop many skills and strategies in order to adapt to their situation in a cultural and linguistic context different

from their own. These skills include language skills, as they generally learn many French words and expressions adapted to each context in a few weeks, as well as cultural competences (Sobo, 2015) and educative skills, as they show a rapid understanding and adaptation to local manners and educative practices in their temporary home in Switzerland, and then readjust to the cultural and educative manners of their country when they return from their medical travel. As such, this contribution confirms that children are not passive objects of hospital and medical care, but that they can be actors in this setting (Mougel-Cojocar, 2007). In the absence of their parents, children are thus capable of taking care of themselves, of their own medical trajectory, as well as that of other children.

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