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# Mending Little Hearts 'For Life'?

## Promises of a Cure and Experiences of Chronicity in a Context of Unequal Access to Paediatric Heart Surgery

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## Abstract

Congenital heart defects (CHDs) are the most common type of major birth defects worldwide. Yet globally, access to high quality treatment is very limited and uneven with most patients living in places without adequate diagnostic or treatment. Based on ethnographic engagement with Beninese and Togolese children undergoing surgical treatment in Switzerland through a humanitarian medicine programme, this paper explores the multiple temporalities and experiences of chronicity at play in the lived experiences of families with children with CHDs in a context of profound health inequalities. These temporal experiences encompass the various promises of a cure made to them, ensuring continued investment in their child's health, experiencing a sense of rebirth, and navigating the potential risks of future complications. The article highlights how families facing CHDs in underserved regions encounter distinct forms of chronicity compared to those in more privileged areas. It identifies four kinds of chronicity in the families' lived experiences: symptom-related, procedural, follow-up, and emotions-related.

## Keywords

Congenital Heart Defects, Chronicity, Temporality, Children, Humanitarian Aid.

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# Introduction: Chronicity is not for everyone

Congenital heart defects (CHDs) are the most common type of major birth defect worldwide (Van der Linde et al. 2011). Paradoxically, despite the high rate of people affected by CHDs and although they are at the heart of issues surrounding the concept of chronicity, given their congenital nature, only a few medical anthropologists (Worthington 2015; Svensson 2020; Vaucher 2023) have explored the perspectives of children and families living with CHDs. Research about young patients and their families’ experiences of CHDs (McMurray et al. 2001; Chiang et al. 2015) or of children undergoing congenital heart surgery (Alderson et al. 2022; Thomi, Pfammatter and Spichiger 2019) is mostly found in medical and nursing studies.

The spectacular progress of cardiac surgery since the 1950s is limited to so-called ‘industrialised’ countries. While within the latter, the emphasis is now on improving the quality of life of adults living with a CHD operated on during early childhood, ‘the rest of the world still needs to develop basic access to congenital cardiac care’ (Tchervenkov et al. 2008, 64). Globally, an estimated 90% of patients live in places without adequate diagnostic or treatment of CHDs (Zheleva and Atwood 2017). Those fortunate enough to be born in a setting with access to high quality treatment, and those who manage to gain access to treatment through humanitarian actions, are the exception.

Global inequalities in access to health infrastructures have many consequences for children affected by CHDs living in the global South and their families, including ‘disproportionately high morbidity and mortality, generating critical developmental challenges’ (Dearani et al. 2016, 1010). In this context, many non-governmental organisations (NGOs) set up programmes aimed at helping children as early as the 1960s. This foreign aid takes two main forms: medical transfers (Brousse et al. 2003; Heinisch et al. 2019), and surgical missions (Worthington 2015). Despite variations in the forms of aid offered, all are ‘interventions designed and financed in the North, with the aim of helping populations in the South. It is the invariant basis of all aid’ (Olivier de Sardan 2011, 415).

This paper follows the call set forth by Lenore Manderson and Carolyn Smith-Morris (2010) to question the biomedical understanding of chronicity, to address the complexity of patients’ and families’ experiences of illness in different contexts. Drawing upon ethnographic fieldwork in Switzerland, Benin and Togo, it explores families’ lived experiences of CHDs—a condition with an unclear chronicity

status—in a context of health resources scarcity, where families are referred to an international NGO for medical evacuations.

Pierre, a retired intensive care doctor involved in the selection of cases for a Swiss NGO programme addressed to children from ‘disadvantaged settings’, in the terms of the NGO, shares his thoughts with me over the phone about the ambiguous chronic nature of CHDs:

> One could consider these patients as chronically ill, if we consider that they will have to be followed until their old age, even if they are perfectly well. But long-term follow-up does not mean that their situation is getting worse. Sometimes, patients have a perfectly normal life, but they still need to be monitored.

Pierre’s words reflect the full ambivalence of the notion of chronicity when attached to the trajectories of children living with CHDs, an ambivalence that is further strengthened in the case of children living in countries with limited access to heart surgery. While the American Heart Association (2023) insists that CHDs are malformations, abnormalities, and not diseases per se, and while the terms ‘chronic disease’ and ‘chronicity’ are not used by the families, nor by the NGO staff I met, they are increasingly associated with CHDs in the medical literature since the end of the 1990s. ‘Centres specializing in the management of congenital heart defects in adulthood’ are gradually emerging, in order to meet the needs of a ‘new cardiological population’ (Blanche et al. 2013, 1142)—called GUCH, for Grown Up Congenital Heart Disease (Trigo Trindade, Friedli and Beghetti 2003, 403)—that keeps growing: people who have become adults thanks to medical and surgical advances, and whose health now requires lifelong medical monitoring by doctors specialised in CHDs.

However, as it stands, in a global world where access to treatment is still highly unequal, it appears that chronicity is not for everyone. Several researchers working in low income countries have shown that ‘there is nothing inherently chronic about conditions’ (Manderson and Wahlberg 2020, 430–1), that chronicity does not depend on the natural course of a disease, but rather on the (lack of) availability of life-saving and prolonging treatments, the possibilities and priorities of health systems as well as national and international policies, resulting in extremely uneven experiences for individuals, families, and communities across the globe (Manderson and Smith-Morris 2010, 18; Smith-Morris 2010, 21; Chabrol 2018). A tension emerges here relating to differing experiences of chronicity based on health infrastructures. On the one hand, chronicity is accessible only to those who survive (those fortunate few who have access to live-saving care). On the other hand, chronicity is endured by communities who are not invested in by NGO or governmental programmes.

As Carl Kendall and Zelee Hill (2010, 178) observed in the context of HIV/AIDS in South Africa, the ‘new chronicity’ related to access to treatments ‘has created a tiered system of haves and have-nots’. For the millions of children without access to paediatric heart surgery, CHDs remain life-threatening conditions. These children do not experience the *positive* or ‘new’ form of chronicity—an extended life span without disabling symptoms—that is now linked to the lives of Western GUCH patients. In fact, only those with *operated* CHDs have the opportunity, so to speak, to experience chronicity in the way health systems for GUCH patients frame it. Meanwhile, other less theorised forms and experiences of chronicity affect patients and families living with CHDs in countries with limited access to cardiac care.

Through descriptions of treatment trajectories as they unfold from diagnosis, throughout surgery and in the time that follows, this paper focuses on experiences of chronicity among Beninese and Togolese families supported by a Swiss child welfare NGO programme. By looking at the different temporalities at play in the discourses and practices of those involved in caring for the children in this specific setting, the article identifies four kinds of chronicity experienced by these families—symptom-related, procedural, follow-up, and emotions-related—and explores how they intertwine throughout several families’ transnational care trajectories.

The differences between the families’ trajectories, which mainly depend on the child’s age at the time of their medical travel, the time elapsed between the diagnosis of CHD and medical care, the course of surgical interventions, and the families’ place of residence—more or less distant from urban centres and healthcare infrastructures—have an influence on their overall experience of their child’s care through the NGO programme and their experience of the forms of chronicity discussed here. Depending on these factors among others, one form of chronicity may last longer or take precedence over others.

# Research Context

This article builds on ethnographic research in Benin, Togo, and Switzerland, between July 2018 and March 2020, following the experience of 81 Beninese and Togolese children who, for lack of medical and technological infrastructure and insufficient trained personnel necessary for their heart surgery, benefited from a humanitarian medicine programme run by a Swiss child welfare NGO. The NGO organised the medical ‘transfer’ or ‘evacuation’ of more than 200 children, aged a few months to 18 years old, from so-called ‘disadvantaged families’ to Switzerland

each year, without any family member, for their surgical treatment, until 2022.[1] The NGO headquarters representatives justify the absence of parents mostly through an efficiency rationale, related to the number of children operated on each year and partnerships with Swiss hospitals. Other reasons include political concerns related to assumptions about the aspirations of families to migrate to a high income country, as well as logistical reasons such as the absence of facilities and staff to house and support families. A last argument is that the absence of a parent, especially a mother, could unbalance the household in the home country, and deprive it of a source of income.

During their stay in Switzerland, children aged zero to two years old are hosted in foster families, while children aged two to 18 stay in a housing facility, together with about 40 children from eight different countries and suffering from different conditions, who are all part of the same NGO programme. Within the facility, the children are cared for by an interprofessional team of social educators and nursing staff. The children follow French and math lessons, participate in educational and recreational activities according to their age and learning level, and receive pre- and post-operative care (Vaucher 2020). After a convalescence period of about two to three months, the children return home and are monitored ‘for life’, says the NGO, remotely by Swiss medical teams as well as in their country by local partners.

I accompanied the children through various stages of their trajectories, following the programme’s hectic pace. This involved travelling with them by plane and car between countries and institutions, navigating hospital corridors, or moving across playroom floors, which is why my approach can be described as an *itinerant ethnography*. It was also a *sensory* and *embodied ethnography* (see Pink 2015), as I shared life experiences, sensations, and emotions with the families and everyone involved, communicated through gestures, tears, or silences as much as words. Finally, I define my approach as *involved ethnography* since I played significant roles alongside the children throughout their journey, being their constant companion in a programme marked by numerous handovers between different volunteers and caregivers. Additionally, I collaborated closely with families, NGO, and medical teams to address their needs and try to improve the programme. This included organising feedback sessions and creating tailored tools for each group of actors.

The analysis also draws on semi-structured interviews with 13 children aged four to 16, and 11 parents. Discussions during interviews and observations were mainly held in French. When the families and NGO staff spoke other languages, such as

[1] The NGO has stopped being involved in the programme since, but the latter has continued in a very similar form in collaboration with other NGOs and associations.

Fongbé and Ewé, staff members or a relative carried out a summary translation for me. The interviews were recorded and transcribed. While encounters between families and staff in Benin and Togo were not recorded, I was able to take very detailed notes on my laptop, since I had a desk in the same office as the NGO staff. During my observations in hospital settings, I took handwritten notes. The level of detail in my fieldnotes varied significantly depending on the presence (in Benin and Togo) or absence (in Switzerland) of parents with their children. When the children were alone, I often played an important role during the medical visits, such as holding a child on my lap or reassuring them, which prevented me from taking systematic real-time notes.

This research raised many ethical questions, primarily related to the absence of parents from their children during moments of physical, psychological, and social vulnerability. Their absence had an impact on my position as a researcher, involving significant emotional and physical engagement on my part (Vaucher 2024).

# The Temporalities of Access to International Aid

## Late diagnosis and late parents

I meet Lilly,[2] eight months old,[3] and her parents—Dorian, wine merchant, and Salomé, who sells natural soaps at markets, both in their twenties—for the first time one afternoon in July 2018, when they come to the NGO office in Cotonou, the economic capital of Benin.

Before they enter the room, social worker James—a cheerful and energetic Beninese man in his early thirties, who had been working as an assistant project manager for the programme for six years at that time—tells me that he will ask them questions about Lilly’s eating and sleeping habits, to complete her file, ‘as she will be travelling [to Switzerland] soon’. He warns me that ‘it is a very young couple, and they don’t want to know the date of Lilly’s departure’. James and I, in turn, know the date of her flight, scheduled eight days later. James also tells me that ‘Lilly’s mother has delayed the procedure. She didn’t bring the necessary documents, because she was afraid that, as soon as the application would be ready, Lilly would have to leave the country immediately.’

Two days later, when I invite Lilly’s parents to participate in an interview, I learn that the couple lived together at the birth of their daughter, but when Lilly’s

[2] All original names have been replaced by pseudonyms.

[3] At the time of data collection.

diagnosis was confirmed, the family setup changed: Dorian hosted his mother and siblings from Ivory Coast for several months, while Salomé, along with Lilly, moved back in with her parents to receive her mother's support. The two homes are located about 30 minutes from the capital, in opposite directions. This arrangement lasted until Lilly returned from Switzerland.

Dorian confirms James’ impressions: ‘When we filled out the forms, we knew that they were going to give us a date [of departure], and that she was going to leave. She’s our first child and it’s a little difficult’.[4] While sometimes the procedure can take a long time—on average six months between the first contact with the NGO and the child’s departure—in Lilly’s case, things moved very quickly until the moment she could travel. The waiting time between the diagnosis, the constitution of the file and the actual departure of a child is extremely variable from one family to another. These variations depend both on the intricacy between care trajectories and social trajectories of families (Béliard et al. 2018, 3), the relationship between the child’s age, the time of diagnosis, and the complexity of their condition, and hospital waiting lists (especially for children under two years old, for which places are more limited).

The benefits of ‘early surgical repair’ of CHDs from an early age have been demonstrated in the late 1980s (Neirotti 2004, 343). However, for many children, the probability of having access to corrective surgery is extremely low, and if they have access to it, ‘they do not receive timely repair interventions’, ‘contrary to practice in developed countries’ (Heinisch et al. 2019, 2). The ‘delayed’ diagnoses are mostly attributed to the ‘limited paediatric medicine infrastructure and a lack of specialized medical centres’ (ibid.). Another structural factor that contributes to longer intervals between the children’s first symptoms and the use of biomedical infrastructures is the families’ place of residence, knowing that, in Benin and Togo, the only two trained paediatric cardiologists at the time of my research were based in the two economic capitals, in the south of the countries. Despite the fact that important structural factors limit families’ access to hospitals and medical infrastructures, and that the NGO programme was developed precisely to respond to the shortage of trained personnel and advanced technologies, the NGO files and the NGO staff narratives tend to overestimate the responsibility of parents in relation to what they term ‘delays in diagnosis’, ‘delay in presentation’ of the child to medical and hospital structures, or ‘administrative delays’, impeding what is considered ‘timely’ humanitarian and medical care.

As such, ‘delays’ in procedures were often attributed to parents, especially mothers, as I followed their regular encounters with the NGO staff, and consulted

[4] All quotes have been translated from French to English by the author.

the files submitted to the NGO headquarters in Switzerland and drafted by the West African teams. Across the files, parents were frequently deemed 'late' or 'slow' to react to their children's symptoms or to provide the documents that the NGO staff needed to put a file together. For example, the youngest of three siblings, living with her two parents in a village about fifty kilometers from Cotonou, six-year-old Maya's file states that

> Maya's illness appeared after her first birthday. Her parents, unaware of the condition, and believing that she would get better over time, did not seek medical attention promptly. But by the time she was five, the symptoms persisted, and the medical examinations revealed a Tetralogy of Fallot.[5]

In an article on 'patient delay' in the case of adults' cancers, Christina Dobson, Andrew Russell and Greg Rubin (2014) show how the term 'delay' is 'pejorative and judgemental', attributing blame to the individual. The use of certain terms such as 'late' or 'slow' may indeed have implications on the perceptions that different actors in the NGO programme have of parents and can shift responsibility from structural components to the parents' behaviour or willingness with regards to caring for their child.

The files crafted by the NGO workers do not, however, only mention the parents' 'delay'. Rather, they oscillate between two positions regarding the temporality of family procedures. On the one hand, the NGO staff produces normative evaluations relating to the so-called therapeutic and/or administrative slowness or delays of parents. This position participates in differentiating serious from less serious parents with regards to the medical follow-up of their child, recalling how time is a disciplinary and moralising technology (Benton, Sangaramoorthy and Kalofonos 2017, 458). A second posture is made visible through the NGO workers' attempts to be empathetic, understanding, and their justifications of parents' behaviours. This empathetic attitude is facilitated by the local NGO employees' knowledge of the supported families' socioeconomic situations and their long-term close contact with them. Eight-year-old Samy's file illustrates this ambivalence:

> Samy's parents separated when he was two years old. From then on, he stayed with his mother who dedicated herself to taking care of him. The first signs of his condition appeared when Samy was three, but his mother trivialised them. It wasn't until 2016 [when Samy was six] that she took him to a doctor to investigate his breathing difficulties. Cardiological tests revealed a Tetralogy of Fallot. Due to financial constraints, it took a long time for the file to reach us.

[5] A 'moderate' type of CHD characterised by four different heart malfunctions (hypertrophy of the right ventricle, pulmonary stenosis, ventricular septal defect, and overriding aorta).

The ambivalence in the files reflects the position of the NGO workers, who are torn between their empathy for the families, and the pressure to prepare files that persuade the NGO headquarters of the children’s need for assistance. Indeed, to meet the programme’s selection criteria, the files must highlight both the medical urgency of the situation, the families’ destitution, and the parents’ ‘motivation’ to do everything they can to improve their child’s health.

As Nancy Worthington (2015, 240–1) shows, research in public health and anthropology indicates that in ‘developing countries’, delays in medical diagnosis and treatment are related to factors such as limited access to healthcare and families’ financial constraints, but also to fear of negative outcomes, cultural beliefs, and distrust of biomedical institutions. She argues that despite facing these challenges, the Honduran families she met typically sought biomedical care promptly for their children with CHDs. Similarly, my own research reveals families’ relentless efforts to address their children’s condition through extensive geographical, financial, and social mobilisation, and combining various therapeutic options. However, discrepancies between medical protocols, NGO practices, and families’ care trajectories result in their efforts being perceived as slow or late, despite years of struggling to access appropriate assistance.

This section underscores the entanglement of institutional and familial temporalities in the experience of families navigating CHD care in Benin and Togo. The notion of ‘delay’, often applied to parents, reflects a misalignment between the rigid timelines of humanitarian medical programs and the lived realities of families facing structural, financial, and emotional barriers. The dual posture of NGO staff—oscillating between moralising assessments of ‘seriousness’ and empathetic acknowledgment of socioeconomic challenges—illustrates the tension between institutional priorities and on-the-ground realities. These dynamics reveal how families’ sustained efforts to care for their children—despite significant structural barriers—are reinterpreted as deviations from idealised timelines.

## Time to experience symptoms . . . and to worry

Late diagnosis of CHDs means that, if they survive, the concerned children must live with disabling symptoms and without treatment to relieve them for several months or years, which has a significant impact of their quality of life, schooling, and leisure time, not to mention the emotional and logistical impact on the rest of the family.

During our first interview, Salomé begins by sharing how she became concerned about Lilly’s health:

> From the moment she was born, I noticed her chest was slightly swollen, and her breathing was a bit rushed. ( . . . ) When she was four months old, she stopped eating and began losing a lot of weight. One morning, she started coughing, and I thought: ‘This is getting bad’. I called the hospital, and they said to come. While I was going, she was having trouble breathing. She was hitting, as if she was wrestling. She was barely breathing. We ended up spending six days in the hospital. They gave her oxygen for a day or two. ( . . . ) After that, we saw a cardiologist. He provided care, ultrasounds, and prescribed medication. He confirmed it was a heart defect. We asked him if there were any other options [besides surgery], and he said ‘No, when there is a hole[6], you have to close it, that’s all.’

For most of the families I met, support from the NGO represented a last resort solution, after enduring long and trying care trajectories, marked by numerous appointments with traditional therapists, paediatricians, and cardiologists. Due to limited infrastructure and equipment, as well as the high cost of procedures, prenatal screening is rare in West African countries, and CHDs are frequently diagnosed ‘late’ in a child’s life. This results in a prolonged period of living with an undiagnosed condition before being referred to a specialist. In contrast to children born in Switzerland or other Western countries, who are typically operated on shortly after birth, the children I met generally suffered from multiple symptoms of their CHDs. These included breathing difficulties, delays in growth and functional development, lack of appetite associated with weight loss, repeated infections, general weakness, pain in the rib cage, bluish extremities, oedemas and, for some, seizures (called ‘blue spells’). In this context, symptoms are related to the lack of on-site treatment options. This experience of chronicity is thus driven by structural factors that delay diagnosis and, therefore, medical treatment, leading to dramatic situations which simply do not occur in countries with access to paediatric heart surgery. As 13-year-old Constance’s father explains a few months after his daughter’s return to Benin, after 59 days spent in Switzerland: ‘We went through very difficult times [he starts crying]. We didn’t even know how long she would live. We completely lost hope. Her condition progressed to the point where she could no longer stand, walk or go down stairs.’ Constance’s father here refers to his daughter’s overall weakness, as she weighed only 32 kilograms for 1.60 metres when she arrived in Switzerland. As a result, Constance had to travel on oxygen, accompanied by a nurse. During an interview, Constance tells me that her CHD was diagnosed when she was 10, at a time when she felt tired even when lying down.

[6] CHDs such as ventricular septal defects are often described as *holes*, which can be *closed* with surgery.

Lilly’s father, Dorian, recalls the moment they were told that the surgery could not be performed locally: ‘They told us that Lilly had to be evacuated, as they are not able to treat this here.’ As in Lilly’s case, it was typically during the first consultation with a cardiologist, after the CHD diagnosis was confirmed, that families learned about the NGO offering support abroad.

Getting in touch with the NGO involved a lot of paperwork to be completed within a limited time. As Salomé puts it, ‘the process was super stressful, and I even wondered if we should really do it, if it was worth it’. Alongside the administrative procedures, concerns about the child’s health persisted, as Salomé emphasises:

> A heart is no small thing. What stresses me out is that at any time, something could happen. We have no idea what is going on inside. Of course, there are the drugs, but we are not reassured at all. When I sleep next to her at night, I see how she struggles, and that’s hard to accept.

Lilly’s case was considered ‘simple’ and ‘timely’ and was therefore quickly accepted by the NGO headquarters. Unlike Lilly, some applications are rejected even after going through an initial medical screening in Benin and Togo. For these applications, ‘it is too late’, according to the team responsible for reviewing and sorting the files. The surgery is deemed ‘too risky’, or the close follow-up after complex surgery required in such cases would not be possible in the child’s country. In other cases, some children die while waiting for a medical transfer.

However, having their application accepted by the NGO does not prevent parents from grappling with a mix of doubts, worries, and questioning, as their child’s departure date approaches. As Salomé puts it:

> We have to do it, because one way or another, putting aside that we don’t want to be separated from her, she needs to be well, she must be in good health, she needs to be cared for ( . . . ). When I think about that, sometimes it gives me the courage to keep moving forward. It must stop. We must do it for her. We have to think about her and her future. That’s why it’s worth it.

Dorian adds:

> But on the other hand, there is uncertainty, where you just don’t know. We were told that [the stay] could last three months. But the surgery can last, and there can be complications, and it can extend beyond six months. ( . . . ) Nothing is easy, everything is complicated.

As Lilly’s parents point out, just when a surgical solution is on the horizon, and while one form of chronicity—that of the symptoms—is about to end, another form of chronic experience takes its place. This emotional form of chronicity is made up mainly of worries and uncertainties about the future.

## A long-term investment

After the families have established contact with the NGO in Benin and Togo, the local staff conducts initial socioadministrative assessments by interviewing parents and inspecting their homes. The goal is to determine the level of commitment and motivation, particularly among the parents, in improving their child’s health. This assessment focuses on whether they are likely to adhere to the recommended medical follow-up once their child returns home. Through their questions and observations, the NGO workers specifically aim to assess whether investing[7] in one child rather than another is justified, given that the number of children selected for the programme each year is significantly lower than the number of children with CHDs requiring surgical treatment. This forms part of an ethics of triage in medicine, which becomes increasingly complex as demand exceeds supply, leading to real dilemmas. To address these dilemmas pragmatically, various resource allocation systems have been created, based on criteria such as age, social utility, long-term prognosis, and patient and family engagement, which are often combined (Lachenal, Lefève and Nguyen 2014).

Within the framework of the NGO, providing surgical treatment for a child is often viewed and presented as a long-term investment that must be made worthwhile. This ‘presages the accumulation of debt by those receiving medicines in settings of scarcity’, as Benton and colleagues point out (2017, 464). When parents visit the NGO premises for the first time, they are generally warned, as social worker James explains to two-year-old Bignon’s parents:

> [NGO name] will invest money on the child. So, when the child returns, it is essential, mandatory, that you do the follow-up. You will have an ultrasound every six months. If there is any problem, if something needs to be corrected, [NGO] will take the child back and fix the issue, even if the child is 30 years old. But if the follow-up is not properly carried out and a problem arises, [NGO] may refuse the file. You will continue like this until the doctors tell us it [the CHD] is cured. It’s a requirement that obligates you to do the follow-up properly.

The parents’ commitment to follow-up is thus established as a condition not only for immediate care—since, as part of the file submission, parents are asked to sign a written commitment form ensuring they will adhere to follow-up—but also for potential care in a distant, hypothetical future, should the child ever require another surgical intervention, referred to as correction or revision surgery. This means that parents and older children must remain constantly vigilant for any signs of the disease and strictly adhere to follow-up guidelines. Similar to what Benton and

[7] The costs relating to surgery and hospital stay are covered by the Swiss university hospitals, whose humanitarian funds are largely financed by the state. In turn, the NGO covers travel and accommodation expenses.

colleagues (ibid.) have observed, compliance is framed as a way for patients and their families to repay their debt to the NGO.

According to James, although NGO staff systematically have the child’s medical follow-up commitment form signed, the form serves ‘a deterrent function. We never take real action in the event of a lack of follow-up’. However, for parents, the requirement to commit, through their signature, to ensuring their child’s health follow-up may seem, at the very least, surprising. This sentiment is reflected in the reaction of two-year-old Ruben’s parents—respectively rectoral agent and customer adviser, living in an urban environment, less than 20 minutes by motorcycle from a university hospital—who find such parental investment self-evident:

> Mother: ‘All the effort you put in to enable him to travel, and then he returns, and you neglect him? No! I didn't do all this for nothing’.
>
> Father: ‘Even if there were no follow-up conditions, we would have done it anyway, because after all, he is our child. Parents always want the best for their child’.

In addition to the follow-up commitment form, families are also required to make a financial contribution of approximately €30—described by the NGO staff as ‘symbolic’, although some families are unable to raise the amount—if the child’s file is accepted by the NGO headquarters. This financial contribution is intended to ‘guarantee the parents’ follow-up and demonstrate their commitment to ‘saving their child’, as James puts it.

The commitment form’s ‘deterrent function’ and the parents’ required ‘symbolic money investment’ thus place families in a position where they must demonstrate ‘trustworthiness and cooperation’ (Benton, Sangaramoorthy and Kalofonos 2017, 9), or even ‘perform deservingness’ (Huschke 2014). These performances are not expected of families in a context of easier access to care.

As revealed in this section, structural inequalities in access to CHD care extend beyond medical constraints to socioadministrative practices, shaping families’ relationships with the NGO as they negotiate their children’s survival. By framing care as an ‘investment’, the NGO operationalises a form of ‘deservingness’ tied to parental compliance and symbolic financial contributions. Simultaneously, the parents’ adherence to follow-up protocols becomes a form of moral and practical repayment, reflecting broader dynamics of care as a debt-laden exchange in resource-scarce settings.

## Promises of a Cure

Parents’ pledges of long-term investment are matched with the promises of a cure formulated by both NGO and medical staff. When we enter the consultation room for a pre-departure check-up with a travel doctor[8]—a Moroccan woman in her fifties—she immediately notices that Lilly is quite small for an eight-month-old. She reads her file: ‘4.8 kilos, 63 centimetres’, and comments, thoughtfully: ‘What impresses me is the parents’ strength. Entrusting your baby . . . But it’s for a good cause. With the certainty of a cure.’

Much like in this consultation, the words addressed to parents by the NGO and medical staff are filled with hope and promises about the potential outcomes of heart surgery. The NGO staff act as trusted guides for the families, offering much more than administrative assistance both in preparing for and during the trip. They provide reassurance, health advice, and support throughout various procedures. Along with their emotional and practical support, they help create and sustain *promises of a cure*—or of a future healthy child, ‘like any other’—to which the families hold on. These promises contribute to a temporal regime oriented towards the future and its anticipation (Adams, Murphy and Clarke 2009).

On the day of two-year-old Joshua’s departure, as his parents arrive at the NGO office to finalise travel arrangements and sit before James in silence, James tries to reassure them, with little success: ‘When it’s over, he’ll be back. We bought a round-trip ticket for three months. I know it’s not easy, but it’s for his health. He will leave, and when he comes back, he will be healthy. It’s painful, but you’ll get used to it in a few weeks.’ Joshua’s parents do not react. James adds: ‘It’s going to be fine. Everything will be alright.’

As I followed the children along their journeys, I observed that promises of a cure were conveyed to them by several other actors, such as health staff at university hospitals, and educators at the housing facility where they stayed in Switzerland.

During a preoperative consultation at a Swiss university hospital, six-year-old Duma[9] sits on the examination bed, as a cardiologist gestures towards a heart diagram, explaining to a group of students the surgical procedure that will be performed on Duma: ‘It is a rather simple surgery. The surgeon will remove that and close the VSD [ventricular septal defect] with a patch of pericardium. And then, he will be cured.’ She then turns to Duma and says: ‘Won’t you? For life. And he

[8] A doctor specialised in travel medicine must carry out a final medical check-up a few days before a child’s departure, to determine whether the child will need oxygen during the flight.

[9] The data I have regarding the living conditions and family structure of the children I met are very heterogeneous. While for some, like Lilly or Ruben, I was able to speak with their parents and consult their social files, for others, like Duma or Bignon, I have no information beyond their age and diagnosis.

will be able to play sports, to run.’ Duma does not speak French. He sits silently on the examination bed, looking at the doctor while moving his legs.

In this situation, the cardiologist pushes the promise of a cure even further, by giving it a definitive temporality, described as *lifelong*.

Finally, promises of a cure and a healthy child are also conveyed by other parents. When I accompany Salomé, Dorian, and Salomé’s mother to the airport on the day of Lilly’s departure, two other parents of children who have previously benefitted from the programme are also present, offering social support through a local association. Ruben’s mother, whose child travelled to Switzerland two years earlier, tells Salomé that ‘she [Lilly] will come back big and strong. You won’t even recognize her. ( . . . ) You must be strong. I see that you have that strength in you’.

While waiting for the volunteer who will accompany Lilly on her first flight, Lilly swings between her parents’ arms, refusing to be carried by anyone else. Salomé comments: ‘She understands that something is going on, with everyone watching her.’ After a long wait, the volunteer arrives and greets the family. Salomé explains the treatments to be given to Lilly during the flight, before the time for separation comes. Sarah, the project manager—a Beninese woman in her fifties, with training as a midwife and clinical psychologist, and nearly twenty years of experience working for the NGO—says: ‘We must go now, you must give her.’ Salomé hands Lilly to the volunteer. Sarah, the volunteer, and Lilly enter the airport terminal, and we watch them leave through the window.

When I visit Lilly in a Swiss university hospital about a month later, a picture of her parents is displayed on the bars of her hospital bed. She is cheerful and appears in great shape. A nurse informs me that her surgery went smoothly and that she will soon be able to return to Benin. In Lilly’s case, the promise of a cure was fulfilled.

The promises of a cure, expressed by NGO staff, medical professionals, and even other parents, create a hopeful narrative that sustains families through the emotionally and logistically challenging experience of seeking CHD surgery abroad. The assurances of a healthy future for the children serve as a source of courage for the parents, reinforcing their commitment to this arduous journey. At the same time, these promises also function within a temporal framework that prioritises the future. Families are encouraged to endure present sacrifices—emotional, financial, and logistical—for the anticipated reward of a healthy child. However, the definitive nature of these promises raises questions about complexities and uncertainties inherent in medical care.

## A Second Birth

I see Lilly, her parents, and her grandmother again in Benin eight months later, in April 2019. Lilly, now 18 months old, is chubby and joyful. During the interview, she walks around the room, taps on the table, scribbles on a piece of paper, says a few words, and alternates between her parents’ laps. Looking back on Lilly’s health, Salomé says: ‘[The NGO] has really contributed to a miracle.’

When I meet several children after their return home, most of them, along with their parents and the NGO staff, clearly distinguish between the children’s condition before and after their surgery and medical travel. As Salomé puts it, recalling the day of Lilly’s return to Benin, after spending 36 days in Switzerland:

> When I saw her arrive, she had completely changed! She had grown up; she was very, very pretty! She was very kind too, very alert, more cheerful, we could tell. She could do anything. We could see she was very happy, and she ate very well. We really saw a very positive change in her. She has completely caught up, now she’s even exceeded the weight and height for her age.

Three months after her return to Benin, 13-year-old Constance goes so far as to describe her experience as a second birth: ‘It’s like I was born again. Because whatever I couldn’t do, now I can do.’ As noted by Matthew Wolf-Meyer (2014, 146, 155), cures have an ‘implicit linear trajectory’. Their delivery is a ‘historical marker’ and serves ‘as a rupture between past and future’, thus placing individuals ‘into a new spatiotemporal regime’.

The feeling of being born again sometimes applies to parents as well, since many of them suffer both psychologically and physically from the anxiety caused by their children’s illness, departure, and surgery. At this point in their trajectories, the families’ experiences are thus entangled between concerns that can even affect the parents’ wellbeing, and aspirations for the future tied to the numerous promises of a cure made throughout the journey and embodied in the returned child.

Along with their concerns, the children’s medical travels also impact family plans. When I ask them if they want to have more children, Salomé tells me: ‘Yes, but not now. We missed a few months or her life; she couldn’t do what she was supposed to do at seven months, so now we try to spend as much time as possible with her.’ While they were trying to ‘kill time’—in their own words—when Lilly was away, her parents are now making up for *lost time* by enjoying every second spent with their daughter.

## Cured, But Not Really

Despite the success of many heart surgeries, reality is more complex than what the promises of a cure suggest to families, and their experience of chronicity does not necessarily end after the children return home. Often, the families’ ‘chronic homework’ (Mattingly, Grøn and Meinert 2011), as well as their ongoing emotional and care work continue long after.

Even with proper treatment, ‘living with a CHD is not equivalent to being cured and many children are in need of life-long follow-up’ (Holst et al. 2019, 1082). Indeed, the fact that children survive longer with CHDs means that for the few who access treatment (viewed from a global perspective), a broad range of complications can emerge over time (Bouma and Mulder 2017, 908). Such complications include reduced long-term survival for patients who have undergone surgical or catheter-based treatment compared to the background population, as well as a life entailing reduced exercise capacity, risks of deteriorations, and the need for further surgical interventions (ibid.; Lüscher 2017).

As shown by Nancy Worthington (2015, 20), these risks and complications are more frequent, and the prognosis worse for children living in low income countries due to difficulties in accessing diagnosis and treatment, leading to ‘late’ presentation and intervention, greater comorbidities that may influence the outcome of surgery, and limited insurance coverage. In the context of the Swiss NGO programme, a second ‘medical transfer’ is required for more than 15% of children suffering from CHDs.

In accordance with medical guidelines in the field of CHDs, the NGO has set up a ‘lifelong follow-up’, with regular medical check-ups every six months or annually, including auscultation, ECG, and echocardiography. This follow-up is conducted in collaboration with public hospitals and private clinics in Benin and Togo, as well as remotely from Switzerland by the operating teams. Recommendations for further examinations or surgeries can be made through communication between the medical teams and the NGO offices in Benin and Togo, facilitated by the NGO headquarters. If additional interventions are needed, children can be transferred again within the programme, even into adulthood.

While surgery may, in many cases, represent the end of the chronicity of the symptoms and treatments, as well as the end of a period of seeking therapeutic options, the experience of families at that stage remains marked by the chronicity of follow-up care. Contrary to the promises of a cure that have been conveyed to them multiple times, these regular check-ups remind families that their child is not yet considered ‘out of the woods’ and that it is therefore important to remain vigilant for any signs of a problem that they were told had been ‘fixed’. Marie Svensson

(2021, 4) analyses these outpatient follow-up encounters as spaces where families engage in ‘prognostic calibrations’, defined as the ‘families’ continuous and often fraught attempts to come to know, adjust to, and reconcile biomedical prognoses. ( . . . ) Prognostic calibrations, therefore, help to highlight the anxiety, high stakes, and uncertainties ( . . . ) that persist despite continuous attempts to establish routine, a sense of security and certainty’.

Indeed, families must now live with the insidious threat of potential future risks, concerns about their child’s present and future health, and hopes that the child will not require another surgery. They must constantly manage their child’s medical follow-up while also finding ways to express their gratitude to the NGO that played a crucial role in saving their child’s life. All these dimensions of the families’ experience can also become chronic: they can persist over time—‘for life’—or reappear cyclically, during follow-up encounters, home visits by NGO staff, the child’s birthdays, or the annual commemoration of the date of their departure or surgery. Families thus live in an almost constant intertwining of joy and suffering, hope and fear. These are some of the ‘chronic paradoxes’ described by Marie Svensson, Ayo Wahlberg and Gunnar Gislasson (2020), which do not disappear once the surgery has been performed, and the child is back.

Although most of the risks of complications related to CHDs listed above are not disclosed to the families in the programme, the indication for lifelong follow-up prompts most parents to closely monitor any signs of health issues in their child, as 10-year-old Maria’s mother tells me: ‘As soon as we feel the slightest fever, I take her to the doctor. I must watch everything very closely.’ Maria’s mother, a shoe seller, has been a widow for over a year at the time of our interview and raises her two children alone. She is threatened with eviction from her home because she has not been able to pay the rent for almost eight months.

Interestingly, while many families do believe their children are completely cured after their return, the majority still harbour concerns about their children’s health years after the surgery. For instance, three years after six-year-old Yael’s return to Benin, his mother tells James: ‘With Yael, I am never completely at ease. When he runs outside, I run after him to stop him.’

Despite the success of most heart surgeries, the experience of chronicity often persists for families and children, as CHDs require lifelong follow-up to monitor potential complications. As a result, families find themselves caught in an ongoing cycle of vigilance and uncertainty, balancing both practical and emotional labour.

## Barriers to Lifelong Follow-Up

The medical and emotional journey continues after the children return home following their surgery and medical travel. Salomé explains:

> First, [Lilly] came home with medication. We continued until the box was empty, and a few months later, we went to see the cardiologist for a check-up, as we had to do it every six months. At the end, he said 'congratulations', and that we could return in a year.

Not all families can easily secure this 'long-term investment' or ensure consistent medical follow-up over time, as Lilly's family did. Nor do all children experience such positive outcomes after their check-ups. The NGO's plan for lifelong follow-up faces challenges, including the geographical distance between the place of surgery and the families' homes, which can disrupt the continuity of care (Weinberg et al. 2022). Additionally, some families lack the financial resources to adhere to their child's recommended medical follow-up.

As I accompany James on a follow-up visit[10] to the home of eight-year-old Kenan, who benefitted from the programme about two years before, he greets Kenan and his mother and says: 'We haven't heard from you in a while.' It seems that Kenan's last medical check-up, of which the NGO team received reports, was over a year ago. James asks if they can schedule a check-up for the following week (he will arrange the appointment), 'to make sure everything is okay. He then asks: 'Did he stop the treatment?' The mother nods. James presses further: 'Who stopped it?'

She explains that they stopped it themselves because they 'didn't have enough money to buy more once the box was empty.'

James advises her: 'When you go for the ultrasound next week, ask the doctor if Kenan needs to take any medicine. It is not for you to decide to stop.'

The mother argues that 'it has already been a long time since [they] stopped'.

James warns her about the risk of relapses: 'You see him like this, but we can't tell how his heart is doing. Personally, I see that he has not gained any weight.'

The mother asks: 'So should I get him checked every year until he is grown?'

James answers that she should go for the check-up 'to find out if you can stop. Maybe it will be every five years, or maybe he won't need to go anymore. Or maybe

[10] NGO workers in Benin and Togo usually plan a home family visit once every year after the child's return. These visits aim to provide social monitoring for the child and their family, but they are also an opportunity to remind parents about the importance of medical follow-up.

he will need to go until he’s older. We can’t know unless you take him for a check-up.’

This situation highlights the ‘threats of complications’ faced by patients when they do not adhere to medical prescriptions related to their chronic condition, and how they are perceived by medical teams as lacking autonomy (Ferzacca 2010, 160).

In fact, some families in situations similar to Kenan’s, who lack the financial resources for ongoing medical care, may hesitate to request further assistance from the NGO. This reluctance often stems from a sense of indebtedness for the invaluable support they have already received in saving their children’s lives. As a result, some children are classified as ‘lost to follow-up’ by the NGO within just two years after their return.

Another reason for the lack of assiduity in taking treatment or attending medical appointments is that some children feel better and, as a result, no longer see the immediate need for continuing treatments and follow-up care. During an interview with 16-year-old Victoria’s mother—a very religious woman who raises her three children alone despite her own delicate health—she shares that her daughter has not been taking her treatment regularly since her return six months earlier because she ‘feels cured’. According to Susanna Trnka (2017, 15), compliance is ‘not (just) a question of discipline or knowledge, but ( . . . ) predicated on the implicit way that patients view themselves and their (illness) experiences in time.’ Unfortunately, Victoria’s chest scar became infected, and her mother is ashamed to have to ask James and Sarah for additional support.

The post-surgery journey is complex, as families face challenges ensuring long-term medical follow-up due to financial constraints, geographical distance, or the perception that the child is cured. While some families, like Lilly’s, successfully manage follow-ups, others struggle, with children like Kenan becoming ‘lost to follow-up’ when resources run out. Feelings of gratitude and indebtedness to the NGO further deter some families from seeking additional help.

## Conclusion: Different Experiences of Chronicity

Social scientists have long been interested in the lived experience of chronicity—or *chronic living* (Manderson and Walhberg 2020)—but few anthropologists have explored the experiences of children with CHDs and their families globally. This article contributes to the limited anthropological literature on this subject.

It examines how global inequities in access to healthcare and the timing of treatment shape the experiences of children with CHDs and their families.

Specifically, it focuses on how the circumstances and timing of diagnosis, as well as the biomedical interventions undertaken (namely open-heart surgery and heart catheterization), create specific experiences of chronicity for Beninese and Togolese families supported by a Swiss child welfare NGO.

The ethnographic data presented in this paper highlights the multifaceted nature of chronicity as it is framed and experienced within the context of NGO work and family life. While NGO workers and medical teams often frame chronicity through the lens of ‘promises of a cure’, this framing contrasts with the lived experiences of families, who face the emotional and administrative burdens of chronicity. The paper thus suggests that various forms of chronicity interweave in the experience of these families. Some experiences of chronicity are shared with families in countries with established healthcare systems, while others seem more specific to those in less privileged contexts, particularly families supported by the Swiss NGO.

A first form of chronicity—*symptom-related* chronicity—arises from the *absence* of necessary medical technology, infrastructure, and personnel. From a ‘Western’ perspective, where chronicity is often linked to the ‘victory’ of biomedicine, this finding is counterintuitive. It means that, while children in countries with access to heart surgery experience few or no symptoms due to early intervention, those in countries with limited treatment options often endure debilitating symptoms for years, until they receive foreign aid, or pass away. Paradoxically, the shortcomings of healthcare systems in these countries make the children’s condition and families’ efforts appear ‘late’ or ‘too late’ from the perspective of both the NGO and medical staff.

Once the families engage with the NGO and their child’s treatment is planned, a second form of chronicity—*procedural* chronicity—sets in. This form refers to the ongoing medical and administrative procedures families must navigate to secure care. It involves a continuous, exhausting struggle to prove their needs to medical authorities, NGOs, and public administrations, and appears typical of populations in and from countries with limited access to care.

The third type of chronicity is long-term biomedical *follow-up* after heart surgery, a familiar aspect for CHD patients worldwide, though it begins later for the children in this study. This form of chronicity, which is linked to the successes of biomedicine, includes ongoing treatments and measures to prevent complications or further surgeries.

Finally, a fourth kind of chronicity emerges from the continuous uncertainties, worries, hopes, and fears that families have regarding their children’s health: the chronicity of *emotions and emotional work*. This form of chronicity persists throughout the entire caregiving process. As Arthur Kleinman and Rachel Hall-

Clifford (2010, 248) put it, ‘chronic disease is distinctive because it does not end, but rather it becomes entangled in people’s work, families, and life stories. For patients and families, chronic diseases entail a radical restructuring of time.’ As this paper has shown, the families’ concerns and vigilance regarding their children’s health ‘do not end’ either. As Kendall and Hill (2010, 194) argue, ‘chronicity ( . . . ) is a social, not a biomedical fact’.

Among these four forms of chronicity, only the first—*symptom-related*—is specific to families living in underserved regions. However, I argue that the Beninese and Togolese families in this study experience all four forms of chronicity under different conditions than those in wealthier parts of the world. These families, supported by the NGO, must repeatedly prove themselves and their need for treatment aimed at ensuring their child’s survival, in a challenging context of family separation. These aspects of their family care journey, in turn, shape their experience of chronicity. I argue that experiences of chronicity can differ in both nature and temporality. In terms of nature, some children treated early in wealthier countries do not even experience symptoms of their illness, while some children in Benin and Togo may live with disabling symptoms of an unoperated heart defect for over a decade before receiving help. In terms of temporality, the forms of chronicity do not follow the same order, nor do they unfold along the same timeline in different healthcare contexts.

In this sense, this article contributes to existing research on the biomedical transition from acute to chronic illness in low income countries (Kendall and Hill 2010) and adds to the understanding of ‘chronic paradoxes’ (Svensson, Wahlberg and Gislason 2020) by showing how some of these paradoxes—such as alternating hopes and worries, or the constant threat of complications—are shared across contexts, while others, like the challenge of affording post-surgery care, are context-specific. By examining the ways in which chronicity is experienced in a specific resource-poor setting, this study contributes to the understanding of how social, economic, and political factors shape the lived realities of chronic illness.

While chronicity is often reduced to the lasting or irreversible nature of a condition that requires ongoing care (Fainzang, Hem and Risør 2010, 20), this study broadens its understanding to include dimensions beyond biological markers and medical treatments. These additional facets of chronic experience include the ongoing administrative and medical procedures families must endure, as well as the emotional labour that persists over time, both before, during, and long after the children’s medical travel and heart surgery. By expanding the concept of chronicity, this study highlights how experiences of chronicity—even for the same condition—can differ across contexts with varying healthcare access. Understanding this variation is crucial for the theorisation of chronicity in medical anthropology.

## Authorship statement

The article was conceived and written in its entirety by the author.

## Ethics statement

The doctoral research project on which this article is based has received ethical approval from the regional ethics committee.

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