

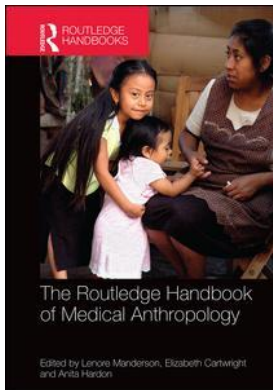
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Changing Childhoods

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Generations of Village Life, 2012. Eate, Vanuatu.
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About the photograph

The burdens of bus fare, arranging for travel, and the requirements of a full day away from work and subsistence agriculture are significant impediments to accessing health care, illustrating a multi-generational battle with poverty where women and young children are most vulnerable. Without monthly visits from a mobile clinic, many children living in rural Vanuatu would not have regular access to biomedical care. Everywhere, intersections of poverty, health, illness, and medicine require new approaches and culturally diverse solutions, informed by ethnographies of children, to improve health care and so health outcomes for infants and children.

—Chelsea Wentworth

Changing Childhoods

*Lenore Manderson, Elizabeth Cartwright
and Anita Hardon*

Anthropology has a long history of neglecting children, both ethnographically and theoretically. Only a few anthropologists have made the study of children central to their work (Abadia-Barrero 2011; Gottlieb 2004; Hirschfeld 2002), and in general, perhaps unwittingly, we have taken on an understanding—from our own settings and from the people with whom we have worked—of children as not yet ‘human,’ that is, as not yet enculturated or socialized (Geertz 1960; Herdt 1981). Such understandings of what children are, and what they can do, are informed by ideas about age, cognitive development and ideation. Accordingly, children are the subjects of patterns of socialization, formal and informal learning, and ritual occasions that ‘make’ them human (Gould and Glowacka 2004), but they are rarely represented as social actors who might contribute to our knowledge of social processes, structures and institutions or to our imagination of social life. In this chapter, we concentrate on children and adolescents, and their experiences of sickness, discomfort, disability, vulnerability and marginality, so to gain insight into how they experience disease and distress, and how these unfold in different family and cultural contexts. In the case studies, we highlight children’s points of view to the extent that we have access to it. Children have their own perspectives on health, disease and agency. Those who work with children argue cogently that adults need to listen to them and grant them power to care for themselves. Children participate in their illnesses, acute, curable, chronic and fatal, with insight and fear, humor and anger, and, ultimately, quite often, with grace.

Anticipating the material we explore here, a number of scholars set the groundwork for contemporary research with young people as key informants. Margaret Mead’s monograph *Coming of Age in Samoa* (1928), based on her doctoral dissertation, was particularly influential. Her descriptions of the relaxed attitudes towards life and the apparent sexual freedom of the young Samoan women with whom she worked was discrepant with American normative behavior at the time of the publication of the book—it was shocking and unsettling to conservative sectors of the public. In many respects, Mead paved the way both for an anthropology of children and an anthropology of sexuality. Much later, both John and Beatrice Whiting (1975) and Sandra Burman and Pamela Reynolds (1986) carried out comparative fieldwork, highlighting the diverse experiences of childhood in different social systems. As children became a more popular topic of research, ethicists and review boards concomitantly began to question whether and how children might ethically participate in research, how such research might be conducted, what children might reveal, and the obligations and boundaries that need to be honored by researchers. Increasingly, medical and other anthropologists have been asked to reflect on the capacity of children

to exercise informed consent, to make their own decisions about participating in research, and thus, to contribute to our understandings of human relationships, social processes and social organization from their points of view. The case studies that we present in this chapter take up this challenge, offering us fresh ways of thinking about children's health and wellbeing, social engagement and resistance.

In *Rites of Passage* (1960), Arnold Van Gennep drew attention to social elaborations of transitions from birth to puberty and beyond, depending on cultural context and local tradition: hair-cutting, tattooing, naming, circumcision and religious ceremonies have been and continue to be held to link children to particular families and faith, lineage and community. Such practices mark sexual and economic maturation, marriageability and civic responsibility. These ideas are not immutable, however. Family structure and composition have changed substantially everywhere with changes in economic production, monetization, industrialization, and urbanization, influencing what children are and what they able to do (Ariès 1962; Reynolds 1991). In all of this, children have increasingly been the subject not authors of their lives, that is, their childhood and the activities in which they might be involved are defined for them. Everywhere children's lives are circumscribed and protected through regulations that follow a consensus of adult views and global norms, based on ideas about age-appropriate development goals, activities, age at marriage, the right to education (and its content, often still gender-biased), and the limits to their employment until the age of assumed agency and autonomy. As Allison James and Adrian James (2008) note, no-one writes of 'the adult' to refer to all adults, yet 'the child' is routinely the subject of international conventions, national policies, and medical, educational, and other social institutions that directly impact on the health and wellbeing of individual children. Compulsory school attendance and strict controls over work are mandated by international conventions and nation states. Multinational agencies advise and governments determine when children should attend health clinics for monitoring, surveillance, treatment and disease prevention. Yet even so, children work as unpaid family labor in and around the home, and formally or informally as waged labor. And as illustrated in the case studies in this chapter, they manage their own and others' sickness, disease, disability and difference; they provide care both to other younger children and adults; and they question the extent to which others govern their lives.

Childhood and the Positioning of Children

The most successful public health interventions of the past two centuries have focused on children. In the last hundred years especially, maternal and child health care, immunization programs to prevent infectious disease, the provision of potable water and sanitation, and nutrition programs have driven down the incidence, prevalence and severity of infections in infants and small children, dramatically reducing morbidity and mortality rates. Although vaccination safety and risk have been part of a sustained critique of the medicalization of childhood, immunization remains a key strategy to control infections that, in children especially, can be fatal or cause long-term disability; it is standard in global infant and child health protocols even in settings where general access to health care is poor.

Clinical metrics feed into parental concerns about infants who might be at one end or the other of growth percentiles, or about a child's attainment of milestones—teething, walking, talking, weaning, sleeping, toileting. These metrics of the 'normal' child and normal development influence the decisions that women make in the care of their infants and small children. Slow weight gain may be interpreted as a sign of insufficient milk supply (van Esterik 1988), for instance, leading to early weaning to bottled milk or the introduction or increase of other food-stuffs. Slow speech development might signal problems in intellectual capacity, leading parents

and children to a circuit of diagnostics, medical and behavioral interventions, and lay advice (Sobo 2010). Although these metrics vary with local norms of infant behavior—ideas about ‘healthy appetite’ or ‘healthy sleeping,’ for instance—global consensus about infant and child health, and global programs that follow from this, are universally applied despite local norms and other unique positionalities (Justice 2000). At the same time, a parent or another caregiver may see no link between clinical advice proffered and their own child’s health, or for financial and other practical reasons, they may be unable to follow the advice. Problems in the procurement of vaccines, the organization of health services, or the capacity of health staff may also lead to the uneven delivery of child health programs. While ‘the child’ is the subject of state and global interventions, advice and monitoring, the health of children is inevitably shaped by local exigencies.

Sickness and Subjugation

Research conducted in the mid-twentieth century, particularly by demographers, highlighted the instrumental reasons that gave children value to families and, in various settings, explained large family size: to maintain lineage and property, contribute to family prestige, provide labor, and ensure care in old age, among other reasons (Nieuwenhuys 1996). Yet, regardless of how the number of children was rationalized, and how and why a child of one sex might be preferred over another, deep affection still binds parents, and other family members and caregivers, to their children. This emotional investment in children—the affective underpinning of reproduction—and the commitment to having a family, influences why people turn to services and their various technologies to ensure conception, safe pregnancy, fetal health, safe childbirth, and secure life outcomes.

Historically, reproduction has been very much a concern contained within families, despite some informal surrogacy, wet-nursing and adoption that extended its boundaries. But from the late twentieth and into the twenty-first century, conception, gestation and reproduction have increasingly been medicalized and commercialized, highlighting inequalities in in-vitro fertilization, non-familial surrogacy, and pre-implantation screening. For example, women involved in commercial surrogacy sequestered in Ghana and India have a very different relationship to their pregnancies, medical services, and the children they bear compared with the wealthier men and women for whom they are incubating (see also Chapters 3 and 15).

In resource-rich environments, the reach of technology into pregnancy includes amniocentesis and chorionic villus sampling (CVS), with other new tests always rolling out into the market. Rayna Rapp (2000) has described how these tests and their results influence decisions about whether or not to proceed with a pregnancy. Where such facilities are available, technologies are used to monitor women throughout pregnancy, capturing changes in health that might indicate compromised maternal or fetal outcomes, using such information to determine or advise on mode of birth, and identifying the need for emergency prenatal or just postnatal surgery or other high case interventions. Highly sophisticated technologies in neonatal wards may ensure that preterm and very low birth weight infants survive, even though many of these infants will experience lifelong medical complications and impairments as a result of these interventions. For most women worldwide, these technologies of surveillance, safety and survival are elusive; for them, even basic emergency obstetric care may be an ideal rather than a right.

Likewise, advanced knowledge of the pathophysiology and management of functional impairments and progressive disease, and developments in surgery, medication, and physiotherapy, have significantly extended the lives and ensured the capabilities of children, from wealthy households and wealthier nations, who are born with a range of medical conditions—hemophilia, cystic fibrosis, osteogenesis imperfecta, severe asthma, spina bifida, epilepsy and cerebral palsy, among

others. These children's lives, depending on the severity of their condition, are disrupted by illness and disability, and they depend on others to ensure and provide appropriate care. Such care is generally provided by women, most often their mothers. Here, there is scope for much medical anthropological work. As an example, Elisa Sobo (2010) has illustrated the complex pathways that parents of children with congenital talipes (club foot) and Down syndrome must navigate between family doctors, specialist pediatricians, clinics and other therapies and rehabilitative services in search of effective treatment and care, evoking foundational medical anthropological work on hierarchies of resort (Holten 2013; Romanucci Schwartz 1969). The visibility of these conditions, Sobo suggests, attracts discussion about interventions and possible action; the clinician is the expert. Children experiencing these conditions are positioned as therapeutic subjects, defined by their conditions as 'disabled,' with possible lifelong social disadvantage depending on household income and access to services.

In clinical encounters, children, parents and health providers interact in particular, scripted ways. Parents or guardians sift out and represent what children feel and experience, including symptoms that they cannot knit in certainty—pain, for example. Parental power is, even so, subordinate to medical authority even when that authority is couched in the most banal terms, as Mara Buchbinder (2012) describes in a paediatric clinic. In her example, patients aged from 5 to 23 years, the majority adolescents, had a range of development disorders, and communication and social difficulties. Clinicians explained persistent pain to children and their parents by talking about 'sticky brains' as a metaphor of the difficulty a child might have in disassociating from pain. Given the access of parents and older children to information on the Internet, we might question the effectiveness of this apparent talking down, and in other contexts, both children and parents are expected to be experts.

Even when children are subject both to parental and clinical control, they are not invisible (Christensen and James 2008). Children can and want to participate in decisions concerning their health. In her book *The Private Worlds of Dying Children*, Bluebond-Langner (1980) illustrates the capacity of very young (3–6 years of age) children with leukemia who know that they are dying, yet who do not reveal this in order to protect their parents. Alderson (1993) similarly argues in her book *Children's Consent to Surgery* that very young children want to be informed about their condition, and are able to absorb the information and make sense of it.

As they age, children are expected to take increasing responsibility for their own health, and in doing so, they gain competence in reading their own bodily signs of illness, and are able to anticipate, for example, an asthma attack or hypoglycemia. While participating in ongoing therapeutic routines and surveillance in addition to school attendance and other activities, children with chronic conditions need to manage the everyday constraints to which they are subject, negotiate the meanings of their illnesses with peers and others, and manage their own and others' anxiety. The routines around illness and self-care, as well as time out from usual childhood activities as a result of episodic sickness, result in a strong sense of 'difference' for some children. This is evident when we consider how this difference manifests in diabetes. In resource-rich environments, homecare technologies allow for blood glucose measurement, and insulin pens and pumps enable parents and children to frame the condition as controllable. Despite this, young people as well as adults (as we discuss in Chapters 6 and 7) may find it difficult to control their health on a day-to-day basis, and may be frustrated by the social, psychological and physical impediments to living a 'normal life.' As Christine Dedding illustrates in her case study below, children may learn to manipulate prescriptions to fit in with their everyday schedules, disregarding certain restrictions, and resenting and rejecting certain aspects of these regimens of care. Like adults, children develop ways to minimize the extent to which illness controls their lives, and often stealthily resist parents' and clinicians' prescriptions, finding their own ways to manage their health and so their lives.

Well children, of course, also find ways to resist the authority of their parents and others: that is part of what being a child is about.

2.1 Children with Diabetes

Christine Dedding

“Must have fallen next to my bag, when I left the house,” ten-year-old Nassar, who had come alone to the clinic, calmly replied to the doctor’s question of why he hadn’t brought his blood sugar device with him to the hospital *again*. Visibly frustrated, the doctor continued the conversation by asking him how things had gone with his diabetes in the last couple of months.

In the past, doctors in the Netherlands asked children with diabetes to keep a diary of their blood sugar levels during the day. Nowadays, this is not necessary, since the blood sugar device keeps a record. The ‘only’ thing children need to do is to measure their blood sugar level several times a day and to bring the device with them to the clinical encounter. Why didn’t Nassar do this, again? This was not the first time that he had ‘forgotten.’ Perhaps he was in a hurry and so forgot. Or perhaps he hadn’t measured his blood sugar levels as often as the doctors had advised him, or he expected that the measurements would not be received well by the doctor if there were too many high, too many low, or too precarious blood sugar readings. Perhaps he didn’t want to be bothered by difficult, boring and unwelcome questions.

The agency of children in clinical encounters is easily overlooked, due to sociocultural images of them as innocent, vulnerable, and not yet competent, and associated with this, the idea that childhood should be a time without concerns (Panter-Brick 2002). There is also the dominant presence of doctors and parents in the consultation room; an assumption that patients of all ages have no real power; and, with the exception of young children, the often subtle expression of agency by children. Young children, contrary to older children and adults, can scream, yell, hide behind their mothers back, fly under the table, or fight if they don’t want things to happen to them or they wish things to be different.

To gain insight into the power and dependency relationships of children, parents and medical professionals, I combined the approaches of participatory action research and ethnography. I invited children with diabetes Type I, between the ages of 8–14, to become co-researchers. My aims were to acknowledge them as social actors, to develop interventions that fit their reality and needs, and to learn what happens if we hand over power to children in a medically dominated domain. In the ethnography, I looked at the interaction between children, parents and medical professionals in clinical settings. I conducted participant observation, interviewed children, parents and medical professionals, organized focus group discussions, and wrote detailed notes of all our formal and informal meetings. As the children could not travel on their own, I picked them up and took them back home, and this offered us many occasions for reflection. With help of professionals, we developed two interventions, a book and a rap, both meeting the needs of young people to educate those around them, including medical professionals, about their perspectives on and experiences with their diabetes. The book is available at bookstores and libraries. The rap has been distributed on a DVD and found its way successfully onto YouTube. More importantly, the children, including the ones who usually didn’t want to talk about their disease, were eager to show their products at their schools, to their relatives and friends.

One of the things I learned during this co-creation process and working closely together is that what is seen as ‘one touch’ of a button of a blood sugar device, from the point of view of medical professionals, means a lot of work for a person with diabetes. It means that you have to have your device with you all the time; to remember to use it; to decide when and where to do it; to think about the social consequences—they will look at me, I will miss parts of the conversation, they might leave without me—and to anticipate welcome and, more often, unwelcome outcomes. An unwelcome outcome means that you have to ask yourself why your blood sugar level is too high or too low; you might need to inject yourself; you either cannot eat or must eat. Even when you have finished this, you are not done. You have to stay alert to whether the action taken was appropriate. If not, the circle starts again. This work, invisible since it mainly takes place outside the walls of the hospital and in the heads of children, disturbs the flow of a normal life:

As usual, I brought cookies and drinks to share when we were working on the book. The cookies were well received; obviously I had made a good choice. Suddenly I saw that Malika, who had stepped aside, didn't have a cookie yet. I asked in a friendly way, 'Don't you want one?'

- Malika (gruffly):* No.
Christine: Don't you like them?
Malika: I do, but then I have to measure first.
Christine: Well, why don't you then?
Malika (angry): No, because then I might not be allowed.
Christine (still ignorant): Then you measure first, and then we'll see together what to do with the results.

The moment I said it, I knew I had made a mistake: neither she nor I could wave aside the outcome. The device, and all that it represents, determines how the cookie tastes. With a high blood sugar level, the cookie won't taste good; with a low outcome, the cookie and its sweetness would be welcomed. A bad measurement doesn't only have consequences for food intake, but it is also an infringement of an ideal—of control, of coping well with the disease, and of being a good patient. After all, since the discovery of insulin in 1921 and with the help of homecare technologies such as blood sugar measurements, insulin pens and pumps, diabetes is increasingly depicted as a controllable disease (cf. Feudtner 2003). Not being able to reach that control, day in, day out, raises various questions for young people: What do I do wrong? What do I have to change? Why do other people manage well? And 'what will my mother or doctor say when they find out?' In anticipation of an adverse judgement, Malika decided to avoid confrontation by not measuring her blood sugar level, and so resisting the temptation of the cookie. While the other children continued working, it took a while before Malika had settled her feelings of anger and frustration. This example of one little cookie shows that 'the work' starts before the device is even taken out of its case.

Children referred to the tasks they have to do in relation to their diabetes as *work*. Furthermore, they referred to this work as analogous to that of a doctor: they observe their body, measure their blood sugar, inject medicines, and make interpretations. Children make interpretations of what the disease means to them, and on how to treat it appropriately, especially in relation to their daily lives. Children understand what medical professionals consider a good blood sugar reading, but this doesn't mean that they don't have their own ideas about it. Based on years of lived bodily experience, they have their own meanings too. Bart and Fatita, for example, are aware that medical professionals strive for a blood sugar level between 4 and 10 (mg/dL), but they themselves consider a result of 4 far too low: "Then you still feel shaky. And then you have to eat something." Ghalid, on the other hand, is happy when his level is below 4: "Yeah I like that, then I can eat extra." Yet he considers 16 good too: "Normally that is high, but I consider it good, (because) then I say that I won't need an extra injection."

The blood sugar levels that medical professionals target are generally determined by the risk of long-term complications (e.g. blindness, amputations, renal failure), but children mainly determine levels on the basis of how they feel and the implications of levels for what they can do and eat. By taking such an approach, children withstand the strong disciplinary power of the health education that they receive routinely, and the classification of symptoms based on medically defined facts and relations. This example of the meaning of measuring blood sugars in daily life and the work it demands gives some context, however limited, to why Nassar might have 'forgotten' to bring his blood sugar device to the consultation room.

Observations, confirmed by children in the interviews, demonstrate that children hardly ever openly question medical discourse and treatment rules in the clinical encounter. The unequal power relationship, dependency, and the controlling presence of a parent in the consultation room, restrict direct and open confrontations with medical professionals. Instead, children choose silent resistance and non-compliance. Non-verbal signs of resistance, such as demonstratively sitting in a slouched position, watching the clock, closing the zipper of their jacket, and answering questions with a jaded 'Yes,' 'No,' or 'OK,' can be read as silent protest. As many children explained, after years of experience, they are fully aware of the questions to expect and of the 'appropriate' answers they are expected to give.

Outside the clinic, children have far more scope to enact their agency and this is much easier to recognize. Children are often out of sight of their parents, playing, attending school or sports clubs,

or hanging out at friends' houses while their parents are involved in other activities such as working, and taking care of the household and other children:

Ghalid is visibly at ease when he explains to me: "I can't eat exactly on time anyway, and I can also inject later. I do that often, I eat first before I inject. You don't notice the difference." When asked why he ignores medical advice to inject before dinner, he explains that his family starts eating without him if he injects before dinner. By the time he is ready to eat, they have finished and his food is cold. When I suggest that he could start injecting earlier, he answers that he does not like to do that. It would mean that he needs to inject quite some time before dinner which implies he needs to watch the clock, needs to know what his mother will cook and at what time she will be ready. Taking all this into consideration would make it impossible to fully enjoy playing football with his friends.

This example shows the agency of children, but it shows also the practical logic behind their acts and the work they have to do. The medical project is just one of many projects in which children with diabetes are involved. An easily overlooked project is how children look after their parents. Most children are well aware of their parents' fears and concerns about their health and happiness now and in the future. This leads them to not always or not explicitly share negative thoughts and experiences about their disease.

Another overlooked aspect, defined by children as a major problem, is general misunderstanding about the nature of diabetes. Children suffer from erroneous ideas about what is in the Netherlands still often called 'sugar disease.' Many people still think that someone with diabetes is not allowed to eat sugar or that they have diabetes because of eating too much sugar in the past. Neither is true, but the image is more persistent than the truth. These misperceptions are difficult to refute for children, especially in confrontation with adults. Adults are verbally stronger and also think they know better. The educating that children have to do is not limited to adults (teachers, trainers, other parents); they also need to explain to their friends what diabetes entails. When I asked Teun how he explains to his friends what diabetes is, his answer was, "well just . . .," followed by a long and complicated medical speech. This, he confirmed, was not understood by his peers. As Zayna explained, "then children don't understand and you get tired. Then you have to tell it again, and then they still don't understand."

To explain a malfunctioning pancreas and the working of insulin is a difficult task, which few adults can achieve. However, the children who do manage—and many do—still experience little benefit. The abstract medical story works within the walls of the hospital, but not outside. Outside children with diabetes need a different story, a story that explains what they can and can't do, what they have to do, and what might happen. They spend a lot of time educating others, finding practical translations for a very abstract medical story, and in legitimizing what they have to do and why. The common misunderstandings about diabetes, and the lack of respect for their own tacit knowledge, were things that they wanted to address in their intervention. The book and rap not only provided clear explanations of what diabetes entails in daily life, but also explicitly stressed the importance of being listened to. In the book, they included a chapter about their idea of what being a good doctor entails. In the rap, they sang 'doctors open your ears, then we will explain how we really feel.' Implicitly, in developing the book and the rap, they sought answers to their own concerns—about sexual relationships, for example, and whether they will be able to have children; on what happens with their blood samples in the laboratory; on how to deal with (over)concerned parents.

★ ★ ★ ★

This case study is not a critique of medical professionals. On the contrary, all the professionals I met were, without exception, very dedicated. They worked hard keeping up to date, collaborating with other professionals, being available during evenings and weekends, and balancing friendliness and being strict in order to both prevent complications in the future and to offer their young patients optimal quality of life in the present. All tried hard to involve children in conversations in the clinic. However, conversations are not only shaped by medical professionals, but also by children, their parents, spaces, technology, managers, policy makers and insurance companies. Also, acknowledging children as knowledgeable social actors makes consultations much more complex: a 'triadogue' is much more difficult to accomplish than a dialogue, especially in the short time period usually available for a consultation.

If we want to understand how children deal with diseases and its treatments, it is helpful to step outside the walls of the hospital. This allows more focus on the daily lives of children. It makes it easier to recognize them as knowledgeable social actors, rather than passive patients who are treated and controlled by adults. Moreover, it raises questions about current approaches to diabetes: the idea of diabetes as a controllable disease; the changes in tasks and responsibilities due to the use of home technologies; the difficulty of incorporating tacit knowledge and of making this available in medical books and patient education material; and questions about how well we are able to support children to deal with this demanding disease and its treatment in their daily lives. In this situation, children have a lot to offer to each other. They can teach their peers about how to deal with diabetes in different settings and find support from knowing that other children suffer from the same problems. If we create a cultural shift in our thinking about children, we might be able to create circumstances in which children can show their competences, practical needs and critiques more openly, so enhancing our understanding of what children are capable of, and of their needs and how these can be met.

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Facing Extreme Illness

The diagnosis of childhood cancer and other serious and often fatal illnesses creates terrible ruptures in the fabric of a family. Diagnosis and disease produce constant breaks in domestic life and in interactions among household members, and between the household and the clinic. Filmmaker Julia Reichert describes her experience of being present in the hospital while filming children living with cancer when she was working on the documentary film, *A Lion in the House*.

Kids are vagabonds, pirates and natural troublemakers, whether they have cancer or not. It was a joy to hang out with these kids, to give them the camera so they could run around filming, to see them play practical jokes on their parents, nurses and doctors. Meanwhile, down the hall, to see these same nurses and doctors grappling with life and death decisions around a family, and to struggle to understand what was going on in each family's emotional life—this was amazing and very moving. A children's hospital is an incredibly vital environment, where every moment matters.

(Reichert 2006)

Like the children living with cancer who are so beautifully portrayed in this documentary film, the children in the following case studies deal with each day, each round of vile medications, and each invasive procedure as best they can—sometimes with stoicism and sometimes with tears. Complex health problems impact at multiple points in children's lives, requiring that they develop an understanding of their health condition; manage pain, treatments and their side effects; deal with stigmatization from others; and come to terms with the deaths of friends made through clinical communities with similar health problems. Illness shapes children's attitudes to and decisions about their education and employment, friendships, intimate relationships, reproductive and sexual health, and their own possible families (Drew 2007).

The children of whom Alice Larotonda writes are in this group. They have uncommon conditions, and regardless of the sophistication of health services in Italy, where her study was conducted, and their access to quality health care, they live their lives with serious impairment and probable reduced life expectancy. The embodiment of their conditions, such as atypical short stature, distinctive morphology or skin depigmentation results in their social exclusion, even though the health problems that impact their daily life may be unrelated to the most visible signs of disease and although they may have similar energy levels and intellectual capacity as other children.

Children born with such conditions survive largely when they live in high-income settings where their families can access and afford high-quality care. Throughout their lives, they may have to interact with multiple clinical specialists to manage their conditions and head off complications. In clinics, as Christine Dedding (above) and Alice Larotonda (below) illustrate, children may resist the intrusions of doctors through their silence and quiet rebellion. While small children may fight and scream, older children are expected by parents and health professionals to show control, to cope with the disease and its impositions on their lives, and to deflect the anxiety of others with whom they share its unpredictability. Sick children are socialized to take responsibility and so to be responsible for the 'social life' of their health, and to take account of their parents' fears and concerns about their health and happiness. Children witness the impacts of their health conditions on others, and so often manage their health as a way of caring for and protecting their parents and siblings as they care for themselves.

Serious diseases are rarely stable. While their unfolding may be familiar to clinicians, this is not so for affected families. Like the children with Type 1 diabetes in Dedding's case study, in Larotonda's example following, both Mattia and Ettore must consistently make adjustments in their everyday lives, manage invasive procedures while they learn in more mundane ways to work with and around their conditions, and negotiate their interactions with other children, family members and clinicians.

2.2 Experiencing Rare Diseases

*Alice Larotonda*¹

Alice: Tell me a bit about yourself, Ettore.

Ettore: Well . . . I do well at school. I will go into fourth grade next year. I can play soccer but only a little, five minutes max, very little actually. Since I have this problem, I get tired very easily, so my parents said I have to adjust to it. We come here (to the hospital) for some check-ups, because I have a disease, one of the rare diseases, called McCune-Albright, so I have to do check-ups. This McCune-Albright (syndrome) makes my bones—how can I say?—more fragile than those of other children. I was born with this disease.

Syndromes such as McCune-Albright are part of a list of pathologies also known as rare diseases. These are defined by the European Union (Fregonese and Aymé 2008: 2) as conditions that affect less than five out of 10,000 individuals. Comprising 5,000 to 8,000 distinct pathologies of different origins (genetic, endocrine, immune, etc.), the category includes a wide group of diseases that are often difficult to diagnose; the majority remain without a cure. Rare diseases are chronic conditions that disrupt the lives of those affected in profound ways. They plunge individuals into a life of complete unpredictability, condemning them to an ever-present threat for their health, while binding them to a constant need for medications and medical screening.

Diagnosed prenatally or during childhood, these pathologies affect social, cultural, and emotional aspects of the experience of children and their families. The difficulty of diagnosis, the lack of treatment, and the challenges of carrying a chronic and debilitating disease generate experiences of disruption and uncertainty, of individual and social suffering entailed in living at the margins of the categories of health and disease, of 'normalcy' and 'difference.'

I conducted fieldwork in an Italian pediatric hospital looking at what having a 'rare' pathology meant to children, their families and their doctors. I participated in medical rounds and examinations in outpatient and inpatient clinics, observing the activity of physicians and other health professionals, and their clinical encounters with chronically ill children and their families. In this way, I met many parents and children, whom I asked to share their stories and experiences of illness.

For children affected by rare diseases, illness seems to be a chronic condition coming in, on, and through the body, entailing physical suffering, impairment or pain. Illness becomes incarnated—personified and tangible—on the child, whose physical appearance can be marked by particular phenotypic traits or malformations. This influences the child's self-perception and the ways in which he or she is considered by others, so shaping individual and social experiences. In my participants' narrations, however, chronic illness was also an experience of negotiation, in which the traditional definitions of 'suffering,' 'difference' and 'normalcy' were called into question. These active negotiations and re-definitions of illness, uncertainty, and difference were more or less successfully elaborated in the everyday social experience of children with rare diseases and their families.

Ettore

I meet Ettore and his parents at the hospital, where he is regularly admitted to undergo routine tests and check-ups on the status of his symptoms. Ettore is affected by McCune-Albright syndrome, which entails "the clinical triad of fibrous dysplasia of bone (FD), café-au-lait skin spots, and precocious puberty (PP)" (Dumitrescu and Collins 2008); his bones are weak and need to be supported, his skin spots require screening, and his endocrine system demands monitoring to prevent PP.

He comes in the examination room shyly, limping, and looking quite unenthusiastic at the prospect of the medical visit. He tries to jump on the examination table, without success. His mother intervenes, but he resolutely refuses help. After a couple of failed tries, he finally succeeds, proudly. Sullen and quiet during the whole visit, Ettore seems quite relieved when the examination and doctor's questioning are over.

After the visit, the physician introduces me to the family and Ettore's parents willingly agree to participate in an interview. The doctor leaves and we all sit in one of the empty, bare rooms of the clinic, where I explain the purposes of my project. Ettore promptly offers to be the one talking about his own experience, "so that [he] can make [him]self helpful." In contrast with his previous shyness, now he is talkative, quite lighthearted in his experience, with a sharp sense of irony.

Alice: So, tell me about this disease you said you have. Do you know what it is about?

Ettore: Yes, my mom and dad told me. At first I did not understand very well, but then they explained it to me. In our DNA there are different patterns, for example: A-B, C-D; basically what happened was A-D and B-C, so to speak. This is why I have this problem.

Alice: I understand. So what does it mean for you to have this problem, in your everyday life? You told me, for example, that you cannot play soccer a lot, because you have to be careful not to get too tired. But is there anything else?

Ettore: I don't play soccer at all. I really cannot play soccer, because . . . well, I *can* kick the ball. The problem is with fouls, because I can get hurt . . . So I don't have to play, because other kids may bang into me and make me fall. I don't play soccer, I can play very few sports. . . .

Alice: I see. Are there other things? What about your leg, for example: I hear you had an operation.

Ettore: Both legs! They operated on both my legs several times, about six times. I had the first surgery when I was two, and then until when I was eight, last year.

Alice: Do you remember these surgeries?

Ettore: About the first ones . . . not really. But I remember from when I was six, until now: I had three surgeries.

Alice: What did they do in the surgery?

Ettore: They fixed my bone. That is, they gave me a plaster, so callus could form again, and become bone. In this case, inside the bone they put a metal bar, inside. So even if it breaks, the bone does not bend, it stays like this and you would have to stay in bed twenty days, if it ever broke.

Alice: So you have to be very careful!

Ettore: Yes, even at school, but not all that much . . . because everybody knows about the disease.

Alice: Really? Who told them about it? Was it you?

- Ettore:* The teacher and I. Well, some of my friends, the ones who were in preschool with me, knew already. The new ones, the 22 new classmates, didn't know, so the teacher and I explained it to them.
- Alice:* So, what exactly did you tell them?
- Ettore:* I explained how come I have this disease, and that they had to be careful not to push me, make me fall down, and so on.
- Alice:* And what did they say? Did they ask any questions?
- Ettore:* Yes, more or less . . . for example: "How did you get it?" "I was born with this disease." Like this.
- Alice:* And did you know the answers?
- Ettore:* Not all of them. Because for example, "what is the cause?" At that time I didn't know about the DNA thing.
- Alice:* Well, that is a hard one! So you told them in first grade, what about now? Are they still curious?
- Ettore:* Sometimes, they ask: "How many times did you break your bone?" and so on. . . .
- Alice:* How did your mom and dad find out about this disease, do you know?
- Ettore:* Because once—I think that's the answer—I fell from my bed, when I was very young, and I broke my bone. So we went to have surgery, and that's how they found out.
- Mother:* Well, that's not exactly it . . . he started limping when he was two . . . so we did some check-ups. And finally, it turned out (to be this disease).
- Alice:* So you have quite some experience with doctors! Do you mind the medical visits?
- Ettore:* No, no. Because the surgeries, in the end, are useful . . . I mean, what would you have to fear? Well, yes, the pain. But then, they are helpful for improving. I mean, they are useful when the bone is broken, to set it back in place, stick it back.
- Alice:* So, thinking it is useful helps you, somehow.
- Ettore:* Yes. But I also have a high . . . what's the name? Pain threshold . . .
- Alice:* Do you still have to undergo many surgeries?
- Ettore:* Yes, I do. Because, as I said earlier, they close my thighbone: when the bone grows it becomes bigger, and they have to change the metal bar. They take it out and put a new one.
- Mother:* It will be stabilized at the end of bone development, around the age of 17. (Turning to Ettore) You still have to be patient. . . .
- Alice:* It seems to me that you are quite at ease with this experience, Ettore!
- Ettore:* Yes, yes! Once the surgery is gone, you don't have that concern any more. Especially when they change the pins, because then you can say: "I have done this, now the next (surgery) is in two or three years."
- Mother:* He really seems quite relaxed. . . .
- Father:* Anyway all of us have problems, even those people who seem not to have any, isn't that so, Ettore? . . . We have this, but other people have other problems.
- Ettore:* Yes, just like this child who is in my class: he has glasses. Even though he says he puts them on because he sees too much! (i.e. he is far sighted).

Ettore's narrative gives insight into different aspects of the experience of children with rare diseases. The troubles of everyday life, the practical and material impairments that the disease causes, the experience of physical pain are contrasted with the protection and care that surrounds the child. Ettore's account is exemplary of how children with rare diseases experience illness *in* the body through physical pain, *on* the body, which can become remarkably 'visible' and 'different' because of the specific features or impairments that are caused by the disease, and *through* the body, as a sensory means for experiencing the world. His narrative, however, also offers some clues about how these experiences of uncertainty and difference can be actively challenged and negotiated.

With the help of his parents, Ettore constructs and negotiates meaning through narrative, so making sense of his predicament. By the age of nine, he has already had six surgeries, but he argues that these procedures are useful to him, and his high pain threshold helps him cope with them. He cannot play soccer, but drawing on his parents' recommendation that he adjust what he does to his own possibilities, he compromises: he can play, but just for a few minutes. He stresses how the problem is not that he is unable to play—even though he limps quite visibly—but that it can be dangerous for him since soccer involves fouls: pushing, falling down, physical contact with other players, are a threat for his fragile bones.

His parents support Ettore in embracing a particular interpretation of his experience: there is a problem, but problems affect everybody. The exceptionality of Ettore's disease is placed in a framework of normalcy. Ettore limps noticeably and his appearance stands out because of the café-au-lait skin spots that cover his body and parts of his face; additionally, long scars from his numerous surgeries cover his thighs. Many children with rare diseases have pathologies that entail tangible bodily marks, specific phenotypic traits or malformation, making the child's physical appearance remarkably 'visible' and 'different.' Ettore's father, however, questions this 'visibility,' maintaining that what one can see from the outside is not always relevant: "even those who *seem* not to have any (problems)" may have some. By attributing normalcy to an experience that might be lived as unique or isolating by Ettore, the exclusivity and marginalization that he might otherwise feel is reduced. Ettore embraces this discourse, and actively re-shapes it with a personal interpretation taken from his own experience: a boy from his class has a problem too, and not because of impairment, but because his sight is 'too good.' Too good or too bad can both range outside of normalcy and thus may be considered problematic. Therefore, indirectly, shaping meaning also consists in molding the body and its characteristics, and in establishing what is relevant and what is not, and what the meaning of these differences is. And as the clinic's psychologist remarked, after all, 'visible' is not what is objectively there; 'visible' is what *one* sees.

Mattia

Mattia is a cheerful 10-year-old, with beautiful olive skin and almond-shaped eyes. Extremely skinny and a bit short for his age, his appearance and features are very different from those of his parents and sister, with whom he shows no resemblance. After a suspected hydrocephalus at birth and an unfounded diagnosis of Silver-Russell syndrome, Mattia was eventually pronounced to be suffering from a serious growth hormone deficiency, and has been under treatment since the age of two. Despite falling sick quite frequently, Mattia goes to school and has plenty of friends, and—in defiance of some isolated episodes of schoolyard mockery—his classmates stand by his side and support him. As the years go by, however, the anomaly of his growth patterns has become increasingly noticeable; his peers are generally taller and more robust. In a pre-teen age when body size comes to gain unprecedented relevance, this is becoming particularly important to Mattia.

Mattia: I wanted to say something . . . I got quite scared when the gastroenterologist told me: "You go see the geneticist, and there are two things: either a problem for which you are normal and you grow up and reach 1.60 meters height, or it is a disease." Well, there I got scared . . . because even 1.60 . . .

Mother: Listen, Mattia . . . Look, I am going to tell you something; if you get to 1.60, you will crow with victory!

Sister: Just like your sister! Then you buy Nike sneakers—the tallest ones—and you gain five more centimeters! (Laughing)

Mattia: No, you know how tall I wish I would become? 1.90 or 1.80 meters!

Mother: Well, that's not possible, c'est pas possible!

Father: Yeah, one meter and a lot of willingness to grow up! (A typical ironic expression in Italian, we all laugh)

Mattia: 1.70 at least!

Mother: Well, I don't know Mattia. . . .

What does being 'different' or 'visible' mean? What does a person's face, body, height or weight tell about him or her? What is at stake in inhabiting different bodies?

Alice: What would happen if you remain small? What would it mean for you?

Mattia: . . . Life! Ok, let me explain this to you. If I remain short, I mean, it's not like I stay there thinking and thinking . . . I stay there a bit, but not much. It's life, and I go on, because anyway . . . I am not sick! I am healthy, only I am short, but other people can also be short. Being ill is different, if you are ill you should really be crying, but if you are just short, you are healthy, basically! . . . 90 percent healthy!

But what does 'short,' 'tall,' 'healthy' or 'ill' mean? The construction of these meanings is negotiable. Mattia's family takes the effort to try and co-negotiate these categories, showing him how definitions can be malleable.

Alice: Mattia, listen, but why do you say you want to be so tall, 1.90 meters? What does it mean to be so tall?

Mattia: Because if you are tall . . . Not too tall . . . Not two meters, because that is not good either!

Mother: Then you cannot find a girlfriend, you find a short girlfriend! At that point, it's better to be smaller! Don't you think? You, very, very tall, with a short girlfriend? (Laughing)

Mattia: Well, what about the opposite, then: me short, and a tall girlfriend?

No matter how unsuccessful, his mother's intervention teaches Mattia something: meanings can shift to shed light on a different outlook.

★ ★ ★ ★

In social interaction, the criteria that determine the positioning of the different actors are not fixed nor objective. On the contrary, they can be negotiated depending on what specific characteristics those interacting decide to attribute relevance to. For children affected by rare diseases, the opportunity of redefinition of these criteria can be fundamental in shaping social relations and granting empowerment. Shifting attention from their 'visible' difference to other empowering characteristics, they get to negotiate their social positioning in interactions, and consequently to challenge—insofar as possible—the uncertainty and precariousness of their whole social experience despite illness. It is arguable, as a consequence, that 'difference' and its perception are subjective and, above all, negotiable, just as 'normalcy' is.

Ettore and Mattia are but two isolated instances of how rare disease can affect children's everyday individual and social experience. Even though the personal, physical and social suffering in pediatric rare diseases cannot be underestimated, what we can take from these cases is the complexity of experience of children with rare diseases, never definitively positive or negative, and always controversial. Children might have an experience of 'difference,' but they learn to manipulate and negotiate its meanings by incorporating and interweaving empowering narratives. Ultimately, their lives stand in ambiguous spaces at the margins between stigma and empowerment, the existential experience of pain and its compensation with the strength and serenity of childhood.

Note

1. The data presented here were collected during fieldwork in a pediatric hospital in Italy. I warmly thank the health professionals, parents and children who made this research possible by accepting to participate and share their experiences. I am especially grateful to Professor Robert Pool for his enlightening advice and support, and to the rest of the Medical Anthropology Faculty at University of Amsterdam, NL. Further references to this work are Larotonda (2012; 2014).

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Cognitive Development

Few anthropological studies have examined intellectual, developmental or mental health problems in children, despite the substantial numbers of children diagnosed with these conditions worldwide. In resource poor settings, families adapt to a child's capabilities as best they can, in some cases with great care, in other cases, with few ways in which they can address the child's needs, by physical constraining or sequestering the child. However, when a child is noticed by or brought to the attention of primary health care workers, doctors or specialist medical authorities, in industrialized countries and in urban settings everywhere, parents and the child may be catapulted into multiple early interventions to support the child's motor, cognitive and social development. In the case study below, Vu Song Ha describes the circumstances of Vietnamese children identified as being on the autism spectrum, with or without formal diagnosis, because their social development, interactions, communication, concentration and behaviors are atypical. Vu is concerned with children living in Hanoi, the capital city of Vietnam, where the facilities and services for education, health care and therapy are far beyond those available in rural areas. Depending on parents' perceptions of the child's capacity and school policy, in Hanoi a child with learning and communication difficulties may be able to attend a mainstream school, but some parents have established special schools for their children to better address their needs. However, understandings of developmental delays and mental illnesses are confused whether or not the child is 'mainstreamed,' and parents may isolate themselves and their children to avoid stigma, blame and discrimination. This is especially so when community members believe that limitations to a child's capabilities are the fault of the parents, the consequences of parental or familial misdeeds, inheritance or 'genetics,' however understood (see also Chapter 14).

2.3 Autism Spectrum Disorder in Vietnam

*Vu Song Ha*¹

I first met Long, an eight-year-old boy, at a group established by parents for children with autism spectrum disorder (*tr ky* in Vietnamese). Like the other six children in the group, Long studied in a mainstream school in the morning, and came to the group for lunch and afternoon activities. In this group, he had individual sessions, in which a private teacher helped him review the morning lessons and do homework. He also had physical, speech and sensory therapies, either in group or individual sessions. After a few days spent with him at this group, I joined him in his mainstream school. My notes follow:

Long went to his school with Miss Loan, his private teaching aide. Long and Loan sat together at a table in the far corner of the classroom. Loan repeated softly what the teacher said, and guided Long to follow the teacher's instructions. In the two lessons of mathematics and Vietnamese I attended, the teacher ignored Long. She walked around the classroom but did not come to his table, invited other students to answer questions or do some math at the blackboard, but neither asked Long nor looked at him. Long talked to himself about advertisements, and Loan kept reminding him to not do so. During the break, Long did not play with other children, but sat at his table and talked with Loan. After the break, Long and Loan moved to the music class. The teacher was cheerful, and Long was excited. He could sing a little with his peers. The teacher asked some students to sing solo, and then asked students to sing as a group. Long sang with them. Then I moved to his physical education class. Again, the male teacher seemed to ignore Long. He called various students to go to the front to perform. Long's classmates in his row went up to perform, but Long stayed there, playing by himself, disregarded by the teacher. I questioned Loan about this, and she said she had told the teacher on the first day of school about Long's condition. He said nothing, but never requested Long to do anything. When Loan thought that Long was tired, she asked the teacher permission for him to skip the lesson, and Long was driven to his parent group.

Among the children with ASD in Hanoi, Long was one of lucky ones, able to go to a mainstream school, even though his inclusion is questionable. His family can afford private school aides and private therapies. Most children going to mainstream schools do not have school aides, and others do not attend mainstream schools either because the school refuses to take them or because their parents are concerned that their children are not capable. Other options for children with ASD of school age are limited—a few special schools for children with disabilities, private centers and parent-run groups. Educational exclusion is only one problem for children with ASD in Vietnam. They are also excluded from health care and social participation.

Educational Exclusion

The Government of Vietnam has made significant efforts in creating a favorable legal framework to support people with disabilities. The Disability Law, enacted in January 2011, ensures the rights of people with disabilities in all aspects of life, including equal access to health care, education, vocational training, employment, residential and government buildings, transportation, cultural activities and entertainment (National Assembly 2010). However, there are significant gaps between law and practices.

Inclusive education programs, based on the principle of integrating children with disabilities into mainstream schools, were initiated in the early 1990s and have had some success in encouraging children to attend schools (Rydstrom 2010; Villa et al. 2003). However, there is no specific policy to support children with ASD in education, and this remains a challenge because of fixed curriculum, emphasis on academic knowledge and achievement, crowding in classrooms (with 40–60 children in classes in public primary schools), and lack of human resources with the capacity and motivation to support them.

ASD was first used as a diagnostic label at major children's hospitals in Vietnam in 2000, and it is still very new for both lay people and professionals working with such children. Many parents and service providers are concerned that ASD is a form of schizophrenia, or that children will become schizophrenic without intervention. Sensory seeking and stereotypic behaviors such as hand waving, rocking, moving and talking constantly are often misinterpreted. Due to the stigma toward mental illness in Vietnam, children with ASD are seen to be threatening and bring shame to the family, and like other children with disability, they are seen as worthless and burdensome. These opinions influence the responses of professionals, as two teachers explained:

These children are very slow. Linh (a child with ASD in her class) cannot take notes. I remind him, but he fails to do so. He also cannot study . . . Teaching these children is very tiring, and frustrating. Linh is good because he doesn't have behavioral problems—he's just slow. Other kids have lots of problems, and don't want to study.

(Secondary school teacher, mainstream school)

These children would be called *thần kinh* (mental, crazy) in a rural area. It's partly correct. Twice I saw them take food out of the waste bin. It was pitiful . . . Sometimes I wish I only had to teach children with hearing difficulties. They have normal intellectual ability, so they can learn what they are taught. Teaching these children with ASD is frustrating. It takes lot of time to teach them a little, and then they forget. At the end of the day, they are still dependent on their families. They couldn't live independently.

(Primary school teacher, class for children with special needs)

The social and cultural values toward childhood, parenthood and disability also disadvantage parents of children with ASD. In patriarchal Vietnam, a couple is expected to have numerous children, including at least one healthy son to continue the male line. Parents are expected to sacrifice their own needs to raise their children properly. In turn, children are expected to please their parents because of the moral debt and gratitude they owe them and their ancestors (Hunt 2005; McLeod and Nguyen 2001), and to provide financial support and care for their parents when they are old (Malarney 2002). Vietnamese culture emphasizes the importance of *gia tộc* (family) and its good reputation. Women are blamed for childlessness, disease, misfortunes in the family, and disabling conditions of their children. Furthermore, beliefs of karma and rebirth construct disability as a punishment for the sins or immorality of previous generations. Although many parents stated that they did not believe in karma, they confirmed that the belief existed and made them

uncomfortable. For example, Hà explained that “some people might say that I had done some (bad) things, so my son suffered. We can’t avoid other people thinking badly about us. We can’t prevent their thoughts. I think someone may think this about me. Sometimes it distresses me.”

Due to stigma, a number of parents feel inferior—they have failed to produce a healthy child. Thus even though parents recognize the difficulties (being excluded, bullied) their children encounter, they are often reluctant to ask for support beyond securing a place for their child in school:

As parents of these children, we are disadvantaged in all aspects. We sacrifice a lot. When our child is of school age, we have to run around, beg for a place in school for him/her. There is no support, no sympathy from society . . . I know that they let my son just sit in the classroom. The class is too crowded, 56 children. My son can’t follow everything [class activities]; however, I think it is good enough. He knows how to function in a group . . . They accept these children. That’s already an improvement.

(Bách)

Health Care Exclusion

There are no routine child development check-ups in Vietnam. Screening, assessment and diagnosis services for children with ASD are extremely limited in both quantity and quality. The government provides no guidance on assessment procedures, and service providers have limited capacity. Health care insurance law indicates that children under six are fully covered for the examination fee and treatment at health care centers (National Assembly 2008), but only a few public facilities provide intervention services for children with ASD. Almost all parents with whom I worked sought support from private early intervention centers or private providers, not covered by medical insurance, and so they paid all costs themselves. As a result, many children with ASD in Vietnam remain undetected and untreated. In addition, other medical specialists (for example, dentists) have no knowledge of working with children with ASD, and so many children with ASD do not get proper health care. One mother recalled:

I am so scared whenever I have to bring my son to hospitals. These children are afraid of crowds; whenever they go to crowded places, they scream and cry. They also are afraid of strangers, and do not stay still and follow the instructions of doctors. Doctors, who have knowledge and experience [in this field], might sympathize with us. However, hospitals [in Hanoi] often are overloaded, so nobody has time to be patient and gentle with these children. So, it is really a nightmare if I need to bring my son to hospital. I never use medical insurance; I often go to private doctors. We do not have rights to [access services], we have to go to doctors who do not have many clients, and who are most easy-going . . . [My son] has a lot of trouble with his teeth, decay and malpositions. We took him to a dentist many times, but had to take him home as the dentist could not do anything with him. So I am the person who takes care of his teeth.

(Nga)

Social Isolation

When I worked with nine children with ASD in a photo-voice project, I found that most of the children’s photos were taken within the home environment. Of 2,142 photos, almost three quarters were taken at home, 6 percent at their grandparents’ homes. Some children studying at parent-run schools took photos there, but few children took photos at their schools even if they had cameras with them. They did take photos at special excursions organized for them, and a few photos were taken on streets or at public places. In general, children with ASD tended to take photographs of themselves and of things, and of people they knew well. At the same time, they had few opportunities to engage in other environments and perhaps minimal opportunities to be comfortable outside of their homes.

Going out with children with ASD is often challenging. Some parents reported difficulties in managing their children’s behaviors, especially in new environments and with strangers. Fear of stigma also prevents some parents from bringing their children into social gatherings. Mai explained:

I only bring my child with me when I am with close friends. You see, this is my feeling of inferiority. A couple of times, I brought my child to attend parties at work. However, I regretted

this, as my daughter has some behaviors not seen as normal by others. These made me feel uncomfortable, inferior . . . It is hard to describe [these feelings] . . .

In addition, in Hanoi, traffic can be extremely busy. People often travel by motorbikes, and public transportation is crowded. Children with ASD are often unable to enter the world outside their family by themselves. Quỳnh's parents recalled that once Quỳnh, a 15-year-old girl, had crossed the street herself on the way home from school. Her entire family was terrified as she just walked onto the road without looking out for traffic. Thereafter, they would not let her onto the street by herself. In the photo-voice project, Quỳnh took photographs from her favorite spot at home, in a glassed-in balcony from where she would watch the street below, crowded with shops, food stalls and people.

Parents' Efforts

With limited support from government and society, parents are the key actors taking care of their children and changing knowledge and social responses on ASD. They are almost solely responsible in identifying and making decisions on assessment, interventions, and education for their children; paying for interventions, health care and education; and protecting their children. In response to stigma and discrimination, and the lack of services available for their children, they employ defensive strategies (such as keeping the child's condition secret and restricting the child's activities and interactions). But they also employ proactive strategies, including home schooling, capacity building for other parents and service providers, initiating various services, and providing public education to address and change social attitudes and policies. Parents build on biosociality (Rose 2006) around ASD, as they work together to demand knowledge and recognition, shape identity, and claim their expertise to fill in service gaps for their children. A number of groups have been established, for example, for parents of newly diagnosed children, parents with teenagers with ASD, and parents using biomedicine. In Hanoi, besides intervention centers established by professionals, three parent-run groups provide interventions for their own children.

The Hanoi Club for parents of children with ASD is a good example of a biosocial grouping. It has organized various training workshops for parents and professionals, held dialogues with school leaders and policy makers in education, disseminated information through its own website, and engaged with the media and initiated public awareness raising events on ASD, for example, walks for autism in 2010 and 2011, in which thousands of people participated.

Conclusion

Although ASD has been recognized as a major public health concern globally, the stories of Long, Quỳnh, and many other children with ASD and their parents, illustrate their neglect in both policy and services, not only because of unfamiliarity with the condition, but also because of stigma and discrimination toward mental illness and disability. The social exclusion of people with ASD reflects the structural violence that operates toward people with disabilities, and those with mental illness, who lack social and economic status and lack power to access to knowledge and services. The biosocial groupings around ADS are helping to make changes, however—negotiating for better services, working for educational inclusion, reframing ASD as a developmental disorder not a mental illness, and countering stigma and discrimination.

Note

1. This case study draws on work conducted on autism spectrum disorder (ASD) in Hanoi, Vietnam from July 2011 to May 2012, as part of my PhD program. I employed in-depth interviews with 27 parents of children with ASD and 17 key informants; participant observation of the daily life of children with ASD at home, in schools, at events, and routine practices of clinics and intervention centers; an on-line survey with 125 parents of children with ASD; and photo-voice with nine teenagers with ASD and six parents. I am grateful to the University of Queensland and the Organization for Autism Research for supporting this work. I thank my advisors Andrea Whittaker, Sylvia Rodger and Maxine Whittaker, and colleagues at CCIHP for their support during my study. I am indebted to the children with ASD, their parents and service providers in Hanoi for sharing their experiences and views with me.

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Coming of Age

Local ideas about sexual practice and desire influence when and with whom young men and young women have sex; these practices vary across time and space (Manderson and Liamputtong 2001; Simpson 2009). Institutional and social factors inform debates about age at first sex and pregnancy. Early marriage and pregnancy (before 18 years of age) and especially very early pregnancy (before 15 years of age) impact young women’s own health and physical development for physiological reasons, as well as disrupting schooling and employment. Yet young women may chose to conceive or continue with an unintended pregnancy while still very young, explicitly to strengthen kinship ties, as Nolwazi Mkhwanazi (2010) has illustrated. In the townships and informal settlements near Cape Town, South Africa, young women live in an environment with some of the highest rates worldwide of HIV infection, and equally concerning high rates of sexual assault, property crime, and violence. Each newborn is a symbol of hope and connectedness, a tangible body that maintains social and familial connections—a compelling symbol for young women.

Early parenting is only one way in which young women and men take on responsibilities for their families and kinship networks. Young people contribute tangibly to economic production, domestically and in the informal labor market, acting in ways that reflect local values of the reciprocity and co-responsibility that exist between parents and children. Such engagement is also often vital. Worldwide, there are unknown numbers of children-headed households; in Sub-Saharan Africa, by 2005 already an estimated 12 million children were singly or doubly orphaned, not only due to HIV/AIDS, but because of war, environmental pressure, poverty and violence, matters that we return to later in this volume. Children may be de facto heads of household too where parents have migrated for work, or when their parents are present but too ill or incapable of caring for others. In her research in Dhaka, Bangladesh, for example, Susan Bissell (2000) followed the lives of a number of children whose waged labor in the garment industry ensured they could keep their families together, providing care for parents or grandparents unable to work and supporting their young siblings to stay in school. But in face of a possible boycott against these industries by the US government, these children lost their jobs. The majority ended up not back in school, but earning less money in more dangerous ways—selling sex, selling snacks, begging, crushing stone to make gravel, carrying heavy loads on the streets and through markets, and working in bicycle factories and as domestic servants. These children were often the sole income earners for their families and while they had some choice about how to make money, they had no real choice that they needed to do so.

Worldwide, many children take on the everyday practical work of caring for others, as determined by family circumstances and individual family and gender-based values. Young girls particularly take on the physical and emotional labor involved in caring for those who are ill. Sometimes the care work is limited—collecting drugs from a pharmacist or local herbalist, for instance (Craig 2002; Granado et al. 2009), but often care is ongoing, with children cooking for, feeding, administering medications, and bathing, dressing and toileting their parents (Jennaway et al. 2015). Young people often hide the extent of their caregiving from others for fear of state intervention and separation.

While many children live their lives in inventive and resilient ways, the pressures they experience can lead to behaviors that might be regarded as inappropriate, pathological or ‘risky.’ Recreational drug taking and alcohol use, eating disorders, cigarette smoking, and interpersonal violence are all areas where young people inhabit an ambiguous terrain between childhood and adulthood. These can also be sites of active resistance and contest, as we explore in Chapter 6. With illness and its prevention, children are the subject of multiple gazes—a clinical gaze, a public health gaze, and a parental gaze. In everyday life, they often have little power over their own lives; rather, they are witness to disruptions that occur around them. This helps make sense of some problematic behavior, including dangerous acts. In situations of poverty and despair, in particular, often very young children drink alcohol; smoke cigarettes; sniff petrol, glue, household aerosols and other substances; and in doing so, risk immediate and long-term health problems including organ failure, brain damage and death. In the same communities, other socially disruptive behaviors and mental health problems, violence and suicide, are present. These children often live in environments where adult mental and physical health is poor, and gender-based violence, sexual abuse and child abuse, suicide, gambling, drug and alcohol abuse, and high rates of incarceration are all endemic (Currie et al. 2013; Gone 2013; Stevens and Bailie 2012). These pathologies are often the long-term outcomes of colonization, persistent structural violence, social exclusion and state neglect. Children’s responses are idioms of endemic social and cultural distress and community suffering.

In the final case study below, Ria Reis illustrates in Suriname and Swaziland how some children respond to and express distress, reflecting the strategies available to them to elicit the concern, care and interventions of adults. Children’s outbreaks of violence, trance, and other unusual behaviors are examples of resort to cultural idioms of distress (Nichter 1981; 2010). Embodied distress is typically linked to powerlessness and resistance, and to a sense of helplessness when individuals are unable to meet social expectations. In the examples below, children are not accountable for their behavior and may feel unable to speak of their distress, and so they use other means to draw attention to it. Away from the school or community, with the medical anthropologist, children in both settings were able to speak of endemic poverty, conflict in the home, abuse and gossip, conflicting identities and feelings of loneliness, distrust, anger and depression. But they had few ways of resolving these problems. Reminiscent of classical discussions of *susto* and *nervios*, their public enactment of distress provided them with a culturally legitimate way to express their feelings, and an effective means of gaining attention and care.

2.4 Children’s Idioms of Distress

*Ria Reis*¹

It was a normal day in a recently renovated high school in the capital city of Suriname. Children were quietly working on a task the teacher had given them, when Robert’s friends noticed he had stopped working and looked very pale. They asked him what was wrong, but he did not respond, staring past them. A classmate called the teacher who found the boy slumped over his desk as if

fainted. She shook him by the shoulder, calling his name. Robert reacted as if he was stung, wildly jumping up, his chair crashing to the floor. He screamed and growled, his face distorted in an angry snarl. While the teacher backed off alarmed, his friends tried to calm him but he fought them off, grasped a chair and violently threw it to the wall. The teacher called out to his classmates to leave the room, made a dash for the door herself, and ran to call the school director. By the time the director came running, Robert was on the floor, sliding across it like a snake. Now there was noise from another classroom, where Suzie had been complaining of stomach pain and feeling dizzy just an hour before. The normally soft-spoken girl began to scream, violently tearing at her clothes and lashing out and shouting abuse at anyone trying to come near her. In a matter of a few hours, four children in different classrooms had fallen prey. Robert was now out in the school yard, where teachers and children were herding in groups, some of the latter crying, others taking pictures of Robert with their cell phones. With the help of some colleagues and older boys, the director took matters in hand efficiently, attending to the affected children and summoning their parents to come and fetch them home, not to be returned before they were well. All other children were also sent home, and the school was temporarily closed while the director called the school board to report the event and seek advice.

How Trance Becomes Epidemic

Epidemics of seemingly contagious dissociative behavior are known to occur worldwide in bounded communities of peers, particularly younger people, in institutions such as schools, orphanages and factories. They have been reported on since the sixteenth century, mostly anecdotally or in the format of medical case studies (cf. Bartholomew and Rickard 2014). However, research remains unsystematic and opportunistic. It mostly takes place in answer to a specific outbreak, involving professionals or academics who happened to be around or were called in to help solve a particular crisis. Different approaches lead to findings that are difficult to compare. Whereas outbreaks come at great costs for individual children, their families and schools, many questions remain unanswered. What motivates children living in vastly different sociocultural contexts to exhibit the same behavior? Do similar experiences or problems underlie epidemics of possession trance? How can insight into children's own experiences, perspectives and strategies contribute to effective preventive and crisis interventions? These questions guided an ongoing multiple case study into children's cultural idioms of distress, in which I collaborated, with local doctoral researchers and small multidisciplinary teams; here I discuss two cases of outbreaks in schools, in Suriname in South America and Swaziland in southern Africa. In each country three recently affected schools were selected and from these we gathered information about past episodes. In Swaziland we also observed children's trance behavior and teachers' responses during an outbreak.

In Suriname, outbreaks in schools of what is locally called 'trance phenomena' have taken place almost on a yearly basis over the last decade, the first report dating from 2006, but there may have been earlier, unreported incidents (Nannan Panday-Jhingoeri et al. 2014). In Swaziland, yearly episodes of *lihabiya*, a cultural syndrome among high school girls, have been reported since the 1980s (Reis 2000: 65). Over the last decade no year has passed without a Swazi high school closing because of what is now called 'demons.'

The description above is typical of outbreaks in both countries. Predominantly girls are affected, but boys can be affected as well, and outbreaks take place at primary as well as secondary level. It always begins with one child feeling physically unwell, having a headache or stomach pain, feeling dizzy, having difficulty breathing, or experiencing strange (temperature) sensations in the body. Some but not all children see or hear things or beings (for instance, animals or dead people) that others can't see or hear. The child becomes unresponsive and observers, both classmates and teachers, undergo a rapid process from feeling concerned and bewildered to realizing something out of the ordinary is going on. It is when a normally nice and well-behaved child bursts out in explosive behavior—e.g. fighting off with seemingly non-human strength peers who want to prevent them running wildly into the bush, damaging furniture or window shutters—that realization seeps in that 'the children are not themselves,' and that some 'thing' may be possessing them. Certain clues in children's behavior confirm this. Some clues are the same for both settings. People report how the child feels uncannily heavy, his or her voice changes, their eyes become red. Both in Suriname and Swaziland, teachers were predominantly of mainstream or Evangelical Christian faith, and likened what they saw to what they knew of exorcist rituals in their own churches or from television.

Children also displayed behavior reminiscent of culture-specific ritual settings. In Suriname people referred to Winti-prey or Jaran Kepang, ritual dances during which descendants of escaped African slaves (Maroon) or of Javanese migrant laborers become possessed by the spirits particular to their religion. In Swaziland some children clasped and moved their stomach as if something was stirring in there (reflective of *nyoka*, the belief in a snake in the stomach that reacts to impurity), or frantically rubbed their arm where they believed they had been marked by the demons as accomplices in their evil work. Swazi eye witnesses described how children often shouted names and this was considered proof of spirit possession: children recognized people they had met while they carried out chores for demons in secret underwater worlds. Imagery in Swaziland was most elaborated, with children relating how 'pastors' whom only they could see had enticed them with promises of wealth, and their narratives were full of references to witchcraft for an informed listener (e.g. having drunk red water and been fed meat that did not taste like animal meat).

In Suriname outbreaks would last for more than a week, in Swaziland some outbreaks lasted for months. Each outbreak caused debates about accountability amongst the adults. Teachers frequently pointed fingers at the families and communities of the children, accusing them of involvement in the occult. At the schools, dormant tensions between staff or between staff and higher levels of management were exposed. Individual staff members were at risk of being singled out as culprit. In Suriname, outbreaks were contained by school management; in Swaziland, such people were sometimes 'chased away.'

In both settings *personalistic* explanations dominate: an evil supernatural force manifests itself, outside of the control of the child it possesses. All adults we spoke to, also in our local teams, shared the strong belief that intentional spiritual evil is present in the world. Those who had witnessed a child in trance act on these notions and on the fear they induce; teachers showed their suspicion or conviction of negative spiritual agency by their involuntary bodily expressions (e.g. fearful expressions, crying, taking physical distance) but also by purposive acts (such as praying or exorcist rituals). The enfolding panic (children running out of class crying, teachers gathering frightened in a corner of the school yard or locking themselves in a room, and only some teachers and students approaching the 'victims') feeds back into the varying levels of distress already experienced, and leads to emotional expressions by children and teachers to different degrees. In the context of this heightened and generalized anxiety, other children's mild dissociative experiences may then also develop into trance and an outbreak is born.

Sources of Distress

That reactions to illness and misfortune may open windows to tensions in social relations is well known, but what was at stake for the affected children? Unlike other reports on epidemics in schools, pressures that specifically related to the school environment, such as the curriculum, the exam period, unfair treatment by teachers, or being bullied by peers, could not be identified. We learned about the drivers of outbreaks from focus groups with children. Both boys and girls pointed at problems in children's daily lives. They suggested children who suffered from trance or demon possession might be an orphan, live in a stepfamily, or have caretakers who drank or quarrelled a lot. They discussed maltreatment, neglect or sexual abuse, poverty, and gossip or conflicts with peers.

I don't think they came from a happy family . . . Because the demons attacked mostly those who came from under privileged families so that it helps them out with their needs . . . I think the ones that are attacked by demons are the ones that stay with guardians and not their real parents and you find that they abuse them . . . When you don't stay with your parents, the people you live with sometimes beat you for nothing. . . .

(Girl, focus group, Swaziland, translated from siSwati)

Problems such as these were widely shared among children in general, but they were acute in the life histories of children like Robert and Suzie, with whom an outbreak had started. In the outbreak we witnessed in Swaziland, all possessed children were single or double orphans. Both in Swaziland and Suriname, some individual children spoke about identity problems, about being torn between a parent's traditional belief and the child's wish to be a Christian, a few hinted at homosexual feelings that were condemned by the majority of the community. All children with whom outbreaks started had experienced trance in the home environment, sometimes long before the outbreak at school.

Teachers, caretakers and key informants all recognized that children in these communities grow up in dire circumstances, but a range of sources of distress on all ecological levels was mentioned.

In Swaziland, the devastating HIV epidemic has deeply affected communities and families. Almost one third of the population of 18–49 years old is infected, and 10 percent of the population under 18 years of age is a (single or double) orphan. Lack of social protection against livelihood and lifecycle risks, high unemployment, food price inflation, and outdated farming methods have caused widespread poverty and increasing inequality. Some 60 percent of the population lives under the poverty line, 90 percent in rural areas.

In Suriname, ethnic tensions fed into seven years of civil war (1986–1992) that caused disruption and displacement in many regions, particularly among Maroon living in the interior South, and among the Indigenous American population of the Savannah. Many families fled to the city or abroad. Some who returned home after the peace treaty found their villages destroyed and their traditional authority structures undermined; they were no longer able to live in a self-sustainable way. Many now live a marginalized life in the cities. Suriname's economy is heavily dependent on fluctuations in mining profits and although poverty is worst in the country's interior, more than half of the urban population also lives under the poverty line.

In the daily lives of children, such stressors at macro-levels translate into stressors in their daily lives. At an individual level, poverty, health care crises, inequity, and a damaged social fabric translate into concrete experiences of going hungry to school, loss of loved ones, and neglect or maltreatment by caretakers who are distressed themselves. Teachers, key informants and children, particularly the girls, also reflected on the fact that children are generally not allowed to express their emotions in the presence of adults because it amounts to disrespect.

Children are not being recognized as human beings. Whatever happens at home, even if one of the parents dies . . . the elders talk alone (while) the child is being left outside. You see, this is still burning in its heart: "What is happening? Why did my mother die? Why did my father die? Why do they not call me? Am I the cause of my father's death, since the family are not talking anything to me about the death of my parents?" These are all the things that pile in the child . . . and cause this.

(Key informant, Swaziland).

Although all actors were well aware of the stressors in children's lives, few children or adults directly connected the social suffering in children's lives with an outbreak. Predominantly occult forces were blamed. This shared understanding allows children to take resort to a cultural idiom of distress. In principle children are not accountable for their behavior, they are not themselves: demons are at work in them. However, accountability in possession trance is not straightforward. Occult forces are everywhere, but their ability to take hold of a person also depends on that person's spiritual strength. Children are considered spiritually weaker than adults, girls weaker than boys, and spiritual weakness allows for evil forces to enter a child. Whereas adults mostly considered children's weakness as a given and looked no further, children's own perspectives helped us understand how, from an emic viewpoint, social suffering causes vulnerability for possession by evil. Boys and girls, but particularly the latter, eloquently described how poverty, conflict, abuse and gossip would lead to feelings of loneliness, distrust, anger, and somberness. These feelings in themselves, and the fact that children are not allowed to express their emotions, contributed to vulnerability to something evil entering them.

Janet: (maybe) that person gossiped this about me and I know it is not like that.

Aminah: . . . and maybe someone comes to you to tell you what is being said and then it becomes . . .

Rosa: then you hear it all the time . . .

Janet: you are not able to get it out of your head, it just stays in your head.

Mariam: you take everything into yourself and if you cannot keep it anymore, then . . .

Iris: then, then they think about senseless things, for instance, Little Busch bridge . . .

Ella: they think of jumping . . . think of suicide . . .

Janet: you just frustrate away.

Ella: plus if you can't discuss it with your parents.

Mariam: you keep everything to yourself, you can't discuss it with anyone, nobody understands you

- Janet: or you're afraid to trust someone
Rosa: especially your parents
Ella: if your parents are strict, you . . . are scared to tell them
Mariam: and you do not want to let the face of your parents fall, so you have no one.
(Girls' focus group, Suriname, translated from Dutch)

A Few Words on Interventions

Swaziland and Suriname are on opposite sides of the globe, and the political and societal challenges they face are very different. Yet at the micro-level, children's social suffering is remarkably similar, as are the structural obstacles for children to express the negative emotions related to this suffering. Possession by spirits or demons offer children culturally shared ways of experiencing and expressing their distress (cf. Nichter 1981; cf. Reis 2013). From an emic viewpoint, responses to outbreaks need to aim to exorcise these forces and enhance children's spiritual strength. Whether or not people accept the presence of demons and evil supernatural force in the world, it is important to intervene in factors that cause children's vulnerabilities and contribute to and compound their suffering. Our findings point to the possibility of preventing or responding to outbreaks of dissociative behavior in schools, by listening to what children can tell us about the challenges in their lives and by providing them with a safe environment to express their (negative) emotions and share their experiences of suffering with actors who may help them. Schools are the perfect arena outside of children's homes to engage adult actors relevant to them.

Note

1. Data were collected through focus groups with children and teachers, and in-depth interviews were conducted with key informants and children and adults who had been part of or witnessed an outbreak. To help elicit children's opinions, a brief vignette was used of a child with dissociative symptoms. I thank Kamla Nannan Panday-Jhingoeri and her team in Suriname; Fortunate and Jabulani Shabalala and their team in Swaziland; Joop T. de Jong for our inspiring collaboration; and the participating children, caretakers and teachers for sharing their perspectives.

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Reis's ethnographic examples of idioms of distress, like Dedding's research with children with diabetes, highlight how anthropologists have worked with children, not only as subjects of enquiry but also as the co-producers of ethnographic accounts. Children's lives are a constant in ethnographic accounts of the family, and individual anthropologists interact with children regularly in clinics, villages, schools and in families, their own and those of their friends and research participants. But few have made children central to their enquiry, and few have questioned how changes in the constitution of the family, with other economic, social and epidemiological changes, have

impacted on children's wellbeing. Across societies, children play multiple roles within their families, in relation to their own health and healing, and in other aspects of social life. These roles disrupt easy connections between youth and powerlessness, age and power. Children create their own ways of being; they should play a central role in medical anthropology in the twenty-first century. In attending to child health, anthropologists need to acknowledge the diverse ways in which children exert agency over their health conditions and disabilities while growing up in different societies. The case studies presented in this chapter suggest that they should not only be informants. They can also be co-investigators, helping anthropologists produce ethnographic insights into the ways in which they live with and confront their illnesses and disabilities, and suggesting ways in which care modalities can help them improve the quality of their lives.

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