The anthropologist as an expatriate native

Anthropological research on and with congenital heart disease(s)

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This paper focuses on the situation that emerges when research within medical anthropology is conducted by anthropologists who are 'native' to the condition they study. Taking myself as an example, I reflect on the impact of my living with a congenital heart disease in relation to my fieldwork with German youths born with similar conditions. Focusing on key moments occurring during and after our meetings as well as during the post-fieldwork writing process, I relay both the advantages and disadvantages of being able to draw upon personal experiences mirroring some of those conveyed to me. I describe the struggle to view my own experiences separately from my young informants' life stories while simultaneously drawing on that very embodied knowledge to gain better insight. Employing the concept of being an 'expatriate' native, I stress the importance of the gap in age and education that invalidates the perceived 'sameness' of memories concerning interactions with classmates and teachers, doctor's appointments, time spent at the hospital and anticipation of surgery. Finally, I explore how the insights gained from my informants changed my own experience of being examined by cardiologists.

[auto-ethnography, limitations, embodiment, narratives, congenital heart disease, chronic illness, Germany]

During the summer of 2008 I met a four-year-old boy awaiting complicated heart surgery. The procedure was necessitated by his congenital heart defect. His condition identified him as a *Herzkind*, a term that is coined by the parents' self-help organisation *Deutsche Kinderherzstiftung* (Deutsche Kinderherzstiftung 2012) and can be translated as 'heartchild' or 'child of the heart'. Not long after our first meeting, I branched into medical anthropology in the course of my Master's degree. As I was introduced to various concepts of the body, health, disease and illness, I visited Yani at his kindergarten several times. We spoke about what to expect at the hospital and discussed the fact that his torso would soon sport a smaller but much redder version of the surgical scar I had. On one memorable occasion, the hot and humid weather had us both ailing with 'circulatory troubles' and for the first time, he had someone with whom to share his misery.

It soon became apparent that the fluid nature of Yani's physical limitations was often met with incomprehension by his social environment. This was especially the case with some of the kindergarten caretakers who did not understand how he could play in the front garden with his friends but then would have to be carried up the eight steps to the house at mealtime. As the time approached to choose a topic for my Master's thesis, my thought processes can be summarized like this: why should I not use my academic training to generate some understanding? Did I not, in fact, have some kind of moral obligation to do exactly that (cf. Ellis et al. 2010: 8)? Did I not owe that effort to all *Herzkinder* whose youth and education did not (yet) give them the same means? Channelling my prior insights into a constructive work about *Herzkinder* became "an intellectual and [deeply personal] challenge" (Goslinga & Frank 2007: xi).

The notion of an anthropologist conducting her studies in an environment to which she can be seen as 'native' is not a new one. Native anthropologists have interpreted their own cultures since the times of Franz Boas (Buzard 2003: 66). Soraya Altorki (1988), Marit Melhuus (2001), Marianne Gullestad (1997) and Val Colic-Peisker count among recent practitioners of fieldwork amongst groups within which they are ethnically native.[1] Colic-Peisker writes about her decision to do the fieldwork among Croatian immigrants living in Austria: "If I was to give them a voice, it might be a more authentic one than what a non-Croatian ethnographer could produce" (Colic-Peisker 2004: 86). I too had begun my Master's mindful of the encouragement given by one of my former professors to practice anthropology in the society into which I was born (cf. Smedal 2001). What had not been clear to me then is that the concept of 'native' in autoethnographic studies need not be reduced to ethnicity or, in a broader sense, nationality. For example, E. Patrick Johnson (2008) has collected countless in-depth interviews with gay African American men living in the southern states of the USA.[2]

Within medical anthropology, "the arrival of the 'body' as a principle of social life" opened up fields of study outside the basis of cultural categories" (Hadolt 1998: 318). One way to approach the subject of ethnography when possessing embodied (Csordas 1990) knowledge about a specific condition is to give autobiographical, in-depth phenomenological accounts. Robert Murphy's "social history of [his own] paralytic illness" (Murphy 1990: 3), Kay Toombs' use of the 'lived body' to give insights into her life as a multiple sclerosis patient (Toombs 1995) and Albert Robillard's (1999) account of the trials of living with amyotrophic lateral sclerosis spring to mind.[3] Still another way for disabled or chronically ill anthropologists is to study people living with conditions similar to their own without making their personal experiences an explicit part of the study, as Karen Mogendorff (2007) and Silke Hoppe (2010) have done in their research with young adults with congenital visible motor impairments and multiple sclerosis respectively. Their presence nevertheless permeates the way they approach the material, and they find themselves in a unique situation of having to navigate between their own experiences and those of their informants. It is one such situation that I will discuss in this paper. I did not feel confident enough to interact professionally with children as young as Yani,[4] but chose instead to focus on those crucial years where the responsibility of weathering the consequences of the condition gradually shifts from parent(s) to *Herzkind*. If nothing else, the shift upon reaching majority at age eighteen is of a legal nature; however, said responsibility often lies partly with the children prior to that point and the parent(s)' sense of responsibility does not end with it. Thus I conducted an explorative study involving seven adolescents aged 15-19 who were born with a variety of congenital heart defects (Hesebeck 2010). Not least because I remembered my own struggles during that time, I wanted to explore how their condition shaped their lives physically as well as socially.

Herzfehler in Germany and the native anthropologist

In Germany, there are about 300,000 people living with '*Herzfehler'* or 'heart defects'. I opt for the untranslated term throughout this paper as it is loaded with emotional meaning for my young informants and myself. According to recent findings, 0.75% of all live-born infants are born with some form of congenital *Herzfehler* (Bauer et al. 2006: 172). They are a category without a group (Brubaker 2002) in the sense that they only in rare cases meet one another, be it in real life or on the internet.[5] The gravity of their heart defects varies greatly, spanning largely harmless holes in the cardiac septum (ASD/VSD) and limited functionality of particular heart valves to false connections between lung artery and aorta (transposition of the great arteries, TGA) or extremely unequally developed ventricles (uni-ventricular heart) (Claessens et al. 2005: 3). While some *Herzfehler* are of little enough consequence to permit a long, healthy life without open-heart surgery, many come with a life expectancy of few years, months or hours if surgery is not performed.

Due to rapid technological developments within biomedicine during the last 30 years, the number of *Herzkinder* reaching maturity has increased immensely. Successful corrections and follow-up surgeries now allow about 95% to live into adulthood (Bauer et al. 2006: 171). However, residual findings cannot be prevented. Heart arrhythmia, inner and outer scarring, the calcification of implanted organic or artificial heart valves as well as increasing pressure inside the ventricles make up some of the lasting symptoms which necessitate lifelong cardiac scrutiny. Additionally, outwardly observable effects like dyspnoea, limited physical capabilities and/or long-term dependency on blood-thinning pharmaceuticals occur (Claessens et al. 2005, Warnes 2005).

I was born with Tetralogy of Fallot, a combination of four different heart defects that I have lived with for 28 years. In terms of medical biography, this has involved three open heart surgeries, several catheter procedures, about six magnetic resonance tomographies (MRT) and several years of taking blood thinning pharmaceuticals. There have been countless check-ups involving three different cardiologists. My current physician is a children's cardiologist since even in Berlin there are next to no adults' cardiologists available who specialise in *angeborene Herzfehler*[6] (Bauer et al.

2006: 171). During school and at university my disability status allowed me extra time during exams for stress-alleviating breaks. On a day-to-day basis 'living with it' continues to involve knowing my limits in terms of physical exertion. If internalised knowledge about the body living with congenital *Herzfehler* were a language,[7] I would be fluent in it. It is this background I refer to here when I call myself a native anthropologist.

My fieldwork was conducted in my hometown Berlin[8] and environs from December 2009 till April 2010. The biographically informed personal and unstructured interviews resulted in insights about a) the adolescents' own understanding of their conditions, b) the varying degrees of conscious awareness of their bodies' limitations as well as c) ways in which their condition informed their relationship to family members, friends, class mates, teachers and medical personnel. My key informants were three young men and four young women.[9] Two *Herzkinder* were in the middle of the *Abitur* phase,[10] one was in her second year as a mechatronics apprentice, the other four were in their tenth and twelfth grades. Contact was mainly established with the help of the *Competence Network Congenital Heart Defects* and two children's cardiologist practices in different parts of Berlin. I met with them repeatedly over a five month period, at cafés or in their homes, sometimes alone, sometimes in the presence (and with the participation) of a mother. All conversations were digitally recorded and supplemented with field notes and the additional purposeful compilation of a wish list[11] aimed at parents, doctors, teachers and classmates. The respective *Herzfehler* varied both in severity, acknowledgement in their daily life, and, surprisingly, in the number of years my informants had known about their condition.

During that period and afterwards, there were several occasions where it became difficult for me to "separate personal sentiments and experiences from [my] research" (Leibing & McLean 2007: 6). Perhaps daringly, I had "deliberately set out to apply my personal experiences or insights to my research" (McLean 2007: 269) by letting my informants know I had a *Herzfehler* from the beginning. In contrast to Mogendorff during the planning stage of her study, I was operating under the assumption that the adolescents and I had shared experiences waiting to be uncovered (cf. Mogendorff 2007: 274). I "earned my insider status" (Colic-Peisker 2004: 87) on account of speaking the language of "shared, unspoken assumptions" (Douglas 1999:xi) – that is, of knowing intimately the procedures of the regular check-ups, hospital stays and the many shades of exhaustion. It gave credibility to declarations such as "... That feels like... I know what it feels like, but how would you describe it?" On the other hand, the quote emphasises how I had to reign myself in at times so as not to steam-roll my informants by way of "self-exposure" (Lovell 2007: 73). Playing on a shared identity thus amounted to a delicate balancing act. I hesitated to cast myself in the role of a potential mentor – indeed, I deemed the idea presumptuous – but I was prepared to 'repay' my young informants' confidences with stories of my own if asked (cf. Shah 2006: 211). As the following vignettes of critical moments during my fieldwork and the subsequent analysis period will show, drawing on personal experience that mirrored experiences narrated to me helped both to encourage responses from my informants and to stifle them. At times it also took a toll on my own psyche.

In that sense, my being a 'native' proved both advantageous and disadvantageous to varying degrees.

The anthropologist as an expatriate native: fieldwork and beyond

"Not to mention [...] the beauty flaws that would be left behind."
(Anne, 19)

The first key moment I want to present lasted no longer than a few seconds in time, yet it had me struggling to keep my own experiences separate from my informant's narration. It also drove home the point that a shared aspect of identity does not ensure that experiences will be homogenous (cf. Murphy 1990: 177). Anne was living with a *ductus aneurysma* and a stenosis at the left carotid. While the "bump in [her] heart" necessitated constant surveillance and the highest rate of MRT-examinations among the seven adolescents, she was the only one of my informants who had as yet not needed surgery. The likelihood that she might need to undergo it one day came up in our discussion. She mentioned a fear of being overwhelmed by two major life changes at once if, by getting pregnant, the pregnancy put a strain on her body that acted as a "trigger". She stressed that she wanted to wait as long as possible before risking surgery that would be "not exactly routine because of the many inconveniences inside my torso." Then she added: "Not to mention the scar, that is the beauty flaws that would be left behind." I felt like I had been hit by a sledgehammer.

Just a week prior, I had had my first official meeting with Hope, a 19-year-young woman who had only known about her congenital *Herzfehler* for two years. She had worn a top that let show the tip of her surgical scar.[12] I, on the other hand, had chosen a round-necked shirt that revealed nothing. When asked about the scar, she said that it did not trouble her now that it had gone mostly white. I had not wanted to flaunt my *Herzfehler* by way of sartorial choices, but now I found myself confronted with a timid "You wouldn't dress yourself like this, then?"

My most notable surgical scar crosses my upper body approximately along the line of my breastbone, is uneven in thickness and took years to pale. The suggestion of fining it down came up once. Twelve or thirteen at the time, I vehemently rejected the idea. It was part of me – an intrinsic part of my "body-self" (Lock & Scheper-Hughes 1987: 7) I would say today – and not to be denied. When I was sixteen, I made the choice that I would not forgo wearing tops with some cleavage just because the tip of my scar might peek out from under it, and to hell with what anybody thought or said. Since then, I have received no more than the occasional odd look because of it. I like to think that I succeeded in normalising the sight in the eyes of my classmates. However, looking back at my younger self I marvel at the bravery it took.

All this flashed through my mind as I was sitting in a café opposite Anne. I did not then have any thoughts about what her statement said about body image and societal conceptions of beauty. Nor did I parse her words as part of a social narrative (Scott 2001: 9ff). My hold on the balance between the two main identities I had brought into the meeting was slipping. The fact that my condition had once been more severe than hers had become an unexpected issue. I felt that she, who had never undergone surgery before, was not entitled to this opinion. Acutely aware that letting any of this slip would not be fair to Anne, not to mention unprofessional (cf. Reis 1998: 305), I did my best to keep the resentment that had risen up in me from becoming part of our conversation's "transference and counter-transference" (Lovell 2007: 67). Intellectually, I knew that she had every right to express concern about an intervention that would have consequences for her own body-self and physical appearance.

I managed to say something about how it should not be a problem to put off the surgery as long as the MRT results remained stable. Though I cannot be certain, I doubt that Anne had any idea that her remark had insulted me – and Hope, but it would not have felt as personal if I had only had her relationship to her scar on my mind. Regardless of Anne's lack of awareness, the impact of my own experience was far from ideal in research terms. The transcript shows that I subsequently changed the subject. Although not pursuing the topic further in my upset state may be viewed as a "wise decision given the circumstances" (Mogendorff in correspondence), I had nevertheless done something I had promised myself I would not do. My aspiration – unrealistic, as it turned out – had always been to prioritise giving my informants free rein to put their thoughts and experiences into words, even – and especially if – these were not the words I myself would have used. Now I had let my emotions put a stop to an aspect of her life Anne had wanted to explore. The same embodied self-knowledge that had put me on nearly even ground with Hope had made me intolerant of an experience that was vastly different to mine. As I discovered, my ability to let the informants decide in which directions they wanted the conversation to go had its limits.

"And I've heard my parents say 'Fifteen, sixteen, that's a good age for the bloke'."
(Sascha, 19)

The second situation I want to showcase occurred when the topic of life expectancy came up in conversation with 19-year-old Sascha. Sascha's *Herzfehler*, being a variant of Tetralogy of Fallot, was nearly identical to mine. When we met, he had recently discovered that the pulmonary valve he had received at age six would have to be replaced. He was very vocal about the fact that my upfront identifying as a Fallot *Herzkind* on the flyer in the waiting room of an acute day ward had played a vital role in his deciding to participate in my study in the first place. Among other things, we were able to discuss the relatively new procedure the cardiologists wanted to try out on his heart instead of risking outright open-heart surgery. The potential of transcatheter Melody valves (Hofbeck 2010) had come up during sessions with my own cardiologist the previous year. For a few weeks I had faced a similar situation as Sascha until MRT results had shown the readings were more stable than a previous ultrasound had suggested.

Sascha told me outright that he would never have spoken to a 'healthy person' about his fears as openly as he did to me, and our conversations showed there was much to be gained from controlled divulgence of my own experiences. However, the situation was not one in which I could indiscriminately relay information. One the one hand, we shared familiarity with the prospect of needing a new heart valve. On the other hand, my university training had provided me with a whole different disposition toward data others presented to me as fact. Yet as with Hope who often confused surgeries with catheter procedures, I was not there to present my prior knowledge as "an unchallengeable 'true picture'" (Hayano 1979, quoted in Buzard 2003: 67). Moreover, I was not and would never again be in the position Sascha was now in. I had had eight years of experience as a legally adult patient. The (mostly) calm apprehension I had felt at twenty-five did not compare to the fear that Sascha spoke of or the fear that I remembered from before my last balloon catheter at age eighteen. In that sense, I had become an *expatriate* native to the challenges he was facing. While our origins were similar I was firmly entrenched in another phase of life by then. I could revisit a similar embodied experience in my memories but not relive them. The realisation how much my own *Herzfehler* experience had changed in recent years went a long way to help me keep our respective experiences separate.

In light of Sascha's very real need for a new pulmonary valve, a conversation about fear of surgery and fear of medical interventions in general led us to the following exchange about life expectancy in relation to Fallot.

> Sascha: "It makes a guy wonder if one should, like, 'Ah, I don't care anymore, I'll quit school and just live the good life' or something like that, but... in the end that's mental, and, well, I don't think about it too often […] So, I'm not like saying 'O God, I'm gonna die soon, I have to do so many things as soon as possible in case I might miss them', it's not like that."
> Ina: "I once read a life expectancy figure on the internet... it made me incredibly angry cause I knew that there was no truth to it at all. And more importantly, what they're going to try with you, they didn't even have that possibility a few years ago […] I recall reading about the first time they did this for another valve […] and telling my mother 'that would be really good for me, if they could do that'."

The exact figure the article in question had mentioned was a detail I did not believe Sascha needed to hear. It had cut short our life expectancies at 'forty'. At the time I had come across it, I had been twenty-one and so enraged that I had written a poem titled "shoot the internet physicians" as a way to express my feelings. Removed from *that* situation by a few years, I used a very abbreviated version of the story to emphasise that thanks to constant technological developments nobody could put an exact number to the years either of us would live to see. My current *Herzfehler* experience became a part of the conversation in a way that helped alleviate at least some of my informant's anxiety. I also believe the exchange engendered a significant measure of trust between us – trust that later allowed him to mention current physical limitations that he had previously been very reluctant to admit to.

"We once went on a long bicycle trip, too."
(Lukas, 17)

The next instance I want to present here is about hearing and reflecting on a story told to me by a boy who turned seventeen during the time I knew him. Lukas was born with a transposition of the big arteries. He had no memories of the life-saving surgeries performed when he was one and two respectively. However, with the exception of Sascha in his current precarious pre-intervention state, he out of my seven informants experienced most limitations in his daily life caused by his residual findings. Primarily, those limitations consisted of exhaustion whenever he strained himself physically.

The first time I went to see him at his parents' house after school, he referred to a class trip where they had taken a train and were set to cover the last miles to the hostel by bicycle. He did not say much about it, but he mentioned being slower than everyone else and the teachers eventually splitting the class into two groups. We had not really come to know each other yet, so I did not pry at that point, but I filed it away for further discussion at a later date. There was more to this story than had been said. My own recollections of several ill-fated class trips were ringing alarm bells. Two weeks later we went over his wish list:

> …And I wish that people would be considerate […] when we do something, go on a trip, that they won't... do anything really taxing without resting. And that, if I like ask for a break that they actually do it with me, take the break.

Apparently, he had talked to his teacher prior to the class trip he had told me about. He had voiced his concerns about being able to cross the twenty kilometres, and the teacher had promised him that the group would rest if necessary. When the weather conditions became less than perfect and the group risked being late at the hostel, this crucial promise seemed forgotten. Lukas' pleas for a rest were ignored and his suggestion to split the group not heeded until it became clear that he could not continue without a friend physically pushing him.

I had been expecting a story like this. Yani's treatment in kindergarten had been an early years version of it. I had had to remind myself when planning to revisit the story that I could be wrong, that it could be dangerous to assume that there was a 'sameness' to our experiences (Hadolt 1998: 318) and to be careful not to put words in Lukas' mouth. But in this case, my unfortunate memories had rightly alerted me to the possibility of similar injustices suffered by others (cf. McLean 2007: 273ff).

"The exhaustion he feels is so strong that it is impossible for him to keep up with his classmates," I wrote in my Master's thesis. "Every additional metre can only intensify it. At the same time, the knowledge about the circumstances – there are still five kilometres to go – serves as a reminder that the trouble is not over yet. His body needs a rest to recover from the previous exertion and to summon enough strength to go on. Any possibility of reaching the hostel in the tempo his classmates can achieve is eclipsed by this need" (Hesebeck 2010: 55).

Every sentence of that paragraph is supported by Lukas' own words, but I strongly doubt I would have been able to phrase it so confidently had I not been able to draw on embodied knowledge that came from having been in Lukas' place. Perhaps I had even been unconsciously looking for a mirror (cf. Mogendorff 207: 279f) to be able to write down such an episode. Yet the notion that the similarities in our stories entail an inherent 'sameness' is an illusion (cf. Hadolt 1998). As with the memories of deciding to wear tops with cleavage or of spending a month in hospital, these memories are not untouched by time. Regardless of how vivid they may seem when brought to mind, they are subject to influence by experiences I have had since then. I cannot trust that simply because I remember something as happening a certain way that it is how I perceived it to be happening back then (Riessmann 2008: 188). Consequently, I cannot claim "the authority of speaking from an undisputed throne of insiderhood" (Buzard 2003: 71). Keeping this in mind became and continues to be a crucial guideline when engaging in conversations with *Herzkind* informants. While I can recognise Lukas' story as something that happened to me in a similar way, I cannot truly know his life as I know my life today. Too many additions to my *Herzfehler*-related biography are setting us apart. I can never again call myself a 'native' without adding the 'expatriate' when writing about adolescents with congenital *Herzfehler.*

The anthropologist outside the field

"You need to come across as more neutral."
(Aresu Czerny, fellow student)

Alsop writes that "the ethnographer tries to connect the personal life of the observed with their social context […] without ever becoming an insider herself" (Alsop 2002: 14). However, noting the limitations observed above, I had been an insider all along. Knowing in advance what I might hear, if not in detail then in general, did not mitigate the way some of the narratives hit close to home. Since my informants' days were taken up by school and extracurricular activities, there were only a few hours left each day when we could meet. This allowed me a large amount of time outside the immediate 'field' of my study to reflect on what I had learned.

Ellis et al. point out that "Researchers do not exist in isolation. We live connected to social networks that include friends and relatives, partners and children, co-workers and students" (Ellis et al. 2010: 6). This proved to be a good thing, as did the fact that I was not geographically distanced from most of them. I must have spent hours ranting at friends, at my mother, and at my computer providing a *Skype*-connection to my brother until at last I felt I could approach the story of Lukas' bicycle trip somewhat objectively again. This continued to be the case once the fieldwork phase was over and the subsequent writing process had begun. While analysing the narratives, I sometimes had to sit back and just breathe deeply when an experience relayed by a *Herzkind* brought forth an unpleasant memory. I also had to take breaks to vent my anger at accounts of unprofessional treatment by medical staff my mother would never have tolerated while I was underage and that I would never tolerate today. That I was not always successful at controlling my indignation became evident during several mutual review sessions whenever Aresu Czerny admonished me that I was still letting my anger at Anne's long line of cardiologists and especially Lukas' teachers shine through.

Though I was unfamiliar with the term at the time, my experiences formed a veritable "shadow biography" (Frank 1979: 85) to the text I was producing, especially since I only put my own experiences to paper when they were an explicit part of the conversation in question. I do not mean to imply that one has to be 'native' to a situation to be affected by typing about others' difficult times. As Silke Hoppe pointed out to me, experiences are recognisable across conditions and so are different forms of suffering (Reis 1998). Yet as a native speaker of *Herzfehler*, I aspired to use my own condition to find words for as many truths as possible (cf. Strathern 2000: 315). Conscious of the possibility that I might let my own experiences take over the analysis, I checked and double-checked that the resulting paragraphs were indeed based on the adolescents' own words (cf. Colic-Peisker 2004: 91). I warrant that both the transcription and the analysis would have been accomplished in significantly less time had I been able to stay detached. Overall, however, I believe that the whole text would have suffered from it.

Expatriate but not in exile

Let me round up this account with a few words about how insights gained from the *Herzkinder* changed my own experience of being examined by my cardiologist. The first time I underwent a cardiological check-up post-fieldwork I had only just finished writing my thesis and was thus still deeply entrenched in thoughts about the body-self during doctor's appointments and the dynamics of doctor-patient relationships (Hesebeck 2010: 21ff, 35ff). The check-up turned into an exercise not only in affirming my current health status, but also in checking if the claims I had made on behalf of my informants held true for me. The different stages of the examination became a refresher course in the *Herzkind* language.

The outcome was a strange one. By focusing on *Herzkinder* other than myself, I had gained words to put to my own experiences that had remained unarticulated before. For example, taking off my clothes in the course of the examination had been something that just happened. After analysing my informants' narratives and reviewing available literature, I had come to think of medical examinations as situations during which the conventions of physical distance are suspended (Young 1989: 45). The removal of clothes takes away a natural barrier between the body and the rest of the world. This is further manifested by the touch of physicians, other health personnel and their equipment. The barrier normally comprised by the conventional distance is simultaneously replaced by the examination room as well as the practice itself. Sitting on the examination table with myself and my cardiologist inside that barrier, I could not help but think of Anne's distrust of physicians and be grateful for the longstanding relationship of trust I could fall back on. The lightness of the electrodes reminded me once more of technological developments ensuring that today's *Herzkinder* will never undergo some of my early experiences with medical equipment of rougher size and that future generations may hardly have to deal with invasive procedures at all.

The discomfort that Anne and Hope had disclosed feeling during ultrasound and stress electrocardiograms respectively had led me to challenge Katherine Young's claim that the patient enters a state of disembodiment during the examination "to preserve the social persona from the trespasses of the examination" (Young 1989: 63). Instead I had argued that the interaction between cardiologist and *Herzkind* heightens the latter's awareness of its fragile health (Hesebeck 2010: 35; cf. Paterson 2001: 93). Listening to my own body while my cardiologist performed the ultrasound, it seemed that the truth was neither completely one nor the other. Although far from terrified at the thought of a possible negative outcome – as Sascha had confessed to often being (cf. McMurray et al. 2001: 53) – I felt on high alert as I waited for my cardiologist to pronounce the readings. At the same time, it was true that while I could feel the sensor touching my skin, I did not perceive the touch as directly related to me. It is a contradiction that recurred half a year later and that I feel warrants future examination. Taking into account my plans to continue working with adolescent *Herzkinder*, I doubt that I will simply go through the motions of cardiologic examinations for quite some time – if ever again.

Conclusion

Medical anthropologists who study conditions they are 'native' to face the unique situation of already possessing embodied answers to questions that may be raised during fieldwork. The insights they bring with them on account of the lives they have already lived with the condition in question may be an asset in relation to some informants yet prove detrimental in relation to others. Constant self-reflection becomes essential both during the fieldwork phase(s) and the subsequent data analysis. While the stories told by informants are generated in the context of interaction between informant and ethnographer, they comprise a crucial part of the ethnographic data that does not always need be questioned in terms of how far it represents 'reality' (cf. Peacock & Holland 1993: 368; Riessmann 2008: 3). The anthropologist's own memories, however, must be held to a higher standard of scrutiny. The concept of the anthropologist as an expatriate native is one I found useful in this regard. Rather than viewing themselves as "full-fledged member[s] of the group under study" (Murphy 1990: 175), anthropologists ought to remind themselves of those elements in their personal illness-related biographies that set them apart from the stories in which they immerse themselves. I have pointed to age, emotional maturity, ability to reflect on presented data as well as level of education as likely indicators of difference between my memories and those of my informants, distinctions which should be taken into account (cf. Hadolt 1998: 318). Anthropologists must be aware of the danger of merging narrations or superimposing one over the other. The circumstances also require openness towards accounts of experiences that might contradict their own. The latter reads like it ought to be a matter of course – however, it may turn out to be more of a struggle than the anthropologist might wish it to be. In addition, the personal experience of living with the condition may be altered by insights gained in the field.

Notes

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The project “Körperliche Grenzen und Identität bei Jugendlichen mit angeborenen Herzfehlern” was carried out with the cooperation of the *Competence Network Congenital Heart Defects*. It would never have been conceived without Yani and would have amounted to nothing without Janine, Lukas, Florian, Hope, Sascha, Anne and Mareike. I am grateful to the participants of the “Ethnography & Self-Exploration” symposium for their comments, in particular to Karen Mogendorff for her thoughtful discussion of this paper’s initial draft.

1 Altorki’s ‘native’ fieldwork was done in Saudi-Arabia, Melhuus’ and Gullestad’s in Norway.

2 Johnson is a gay man himself, a fact that was as crucial in convincing his informants to open up to him as was the fact that he is African American.

3 On a more theoretical level, such embodied knowledge can also serve as inspiration for philosophical musings, as her emerging chronic fatigue immune dysfunction syndrome has done for Susan Wendell’s (1996) feminist philosophical reflections on disability.

4 All but one of the names have been altered. The exception was made at the informant’s specific request.

5 The concept of biosociality applies to my young informants only in the abstract. They took no active part in what Rose and Novas have called “collectivities organized around specific biomedical classifications” (Rose & Novas 2004: 442). A self-help group aimed at young adults with congenital heart defects exists (JEMAH). All seven of my informants answered in the affirmative when asked if they had heard of it, but none of them were members or planned to become members at that point, a situation which may or may not change as they grow older. It should be noted that some of the parents were or had been members of *Deutsche Kinderherzstiftung*, as had mine.

6 ‘congenital heart defects’

7 I owe inspiration to this metaphor to James Clifford’s essay on ethnographic authority (Clifford 1993: 122).

8 I leave out of this account the implications of my German-Norwegian background. While I will not deny that my mixed origin, too, played a role, it is the shared *Herzkind* identity that I want to focus on here. Being born with a *Herzfehler* is but one aspect of both my and my informants’ multifaceted identities, but it is one that often intrudes in unexpected and inconvenient ways and, on such occasions, may supersede others (Hesebeck 2010).

9 To a lesser extent, three of their mothers were also informants.

10 The 13th grade before final examinations.

11 This proved a great starting point for deeper conversations about reality as opposed to an ideal version of the students’ lives and social interactions.

12 See Hoppe 2010 for a discussion of advantages gained by actively influencing the visibility of chronic conditions.

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