Paying for stories of impairment − parasitic or ethical? Reflections undertaking anthropological research in post-conflict Sierra Leone

Maria Berghs*

Centre for Disability Studies, University of Leeds, Leeds, UK

This article describes how during ethnographic research in Sierra Leone, I was working with people who were used to telling stories of violence about how they got their impairments, which I perceived as ethically problematic and exploitative. I explain how those stories are becoming linked to a post-conflict culture of dependency, patronage and payment. In this context, I explain some of the ethical limitations and struggles I encountered and why, in order to align my research to the community's wants and needs, it was important to engage in more reciprocal and collaborative communal research. I used a social model of disability framework to try and access discourses that the community were using to advocate their issues, and explain some of the limits people encountered by trying to get involved in those discourses.

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Introduction

The West African country of Sierra Leone is recovering from a decade long civil war (1991–2002). This conflict was characterized by the use of 'amputation' as a weapon of war, by all factions, but mainly the Revolutionary United Front (RUF) (Richards 1996). In Sierra Leonean rural culture, power is linked to who controls, exploits and has access to young male and female labouring bodies (Richards 1996; Ferme 2001). Amputation and impairment was thus an efficient weapon of war because it entailed that thousands of people were made 'dependent' (Richards 1996) and the enemy was denied the political and social 'capital' of that labour (Bourdieu 1986, 1991). Amputation during the war was a protest of the youth (Richards 1996; Peters and Richards 1998; Hoffman 2006) against the injustice of a local cultural system that allowed the political elite to treat its youth as labouring dependents, but also acted as a means of inverting such a system by declassifying it (Durkheim 1893/1960; Lockwood 1992). After the war, the healing of the country began with a Truth and Reconciliation Commission (TRC), and a Special Court for Sierra Leone (SCSL) was created to bring to justice those held responsible for the atrocities committed.

While every Sierra Leonean suffered, the many who gained impairments as a consequence of the conflict, such as amputations, have a particularly difficult time finding new roles in society. The sheer number of people who gained impairments represents a considerable challenge for Sierra Leonean society, as well as

*Email: ssmjb@leeds.ac.uk

international rehabilitation and reintegration efforts. While no accurate statistical figures exist on how many people became impaired, the World Health Organization (WHO) (2004, 13) estimates that in Sierra Leone, there are over 7000 'amputees' alone. Associations with trauma and atrocities committed during the war also ensure social attitudes towards 'war-wounded' remain ambivalent (Gbegba and Koroma 2002). This socio-cultural anthropological research project was thus undertaken with members of the Sierra Leonean 'amputee and war-wounded' community over a six-month period, with the aim of trying to find out how they were finding new images, identities and places in society. Doing multi-sited research in a post-conflict environment with a community that had undergone a lot of violence presented many challenges but the most important lay in the realm of ethical response to the community's wants and wishes.

Professional behaviour in the field, as a social and cultural anthropologist, is regulated by a professional code of ethics (American Anthropological Association [AAA] 2009), and one of the most important aspects of that code is to 'avoid harm or wrong'. Moreover, anthropologists (Taussig 1987; Richards 1992; Scheper-Hughes 1995) have also argued for an ethical commitment towards ethnographically describing how communities recover from violence and an obligation for those working in those communities to respond to violence and oppression they encounter.

I begin this article, by describing how I found myself in an ethically exploitative situation, and link that to how people were used to 'telling stories' of violence about how they got their impairments. I then explain how those individual stories are becoming linked to a post-war culture of dependency, patronage and payment. In this context, I explain some of the ethical limitations and struggles that I encountered during my research and why in order to align my research to the community's wants and needs, it was important to try engage in more reciprocal and collaborative communal research. I used a 'social model of disability' (Barnes, Mercer, and Shakespeare 1999) framework to try and access the discourses that the community were using to advocate their issues, and explain some of the limits people encountered by trying to get involved in those discourses.

Telling stories

> I was shown into a room by the organisation and despite my protestations told the interviews would begin and they would send people in. I told the participants that this was voluntary and they could talk freely and confidentially about whatever they wanted as this was the first time we were meeting each other. They were sent in, one by one, and after a couple of introductions, every single person began by telling me a horrific and often violent story about how 'they got their problem' during Sierra Leone's decade long conflict. Everybody thought this was normal and expected way of talking about their impairment. I was in shock.

This excerpt from my fieldwork diaries in Sierra Leone illustrates how situations I understood as exploitative during my research were seemingly normal and expected in a post-conflict situation. Initially, I felt as though I was taking part in a kind of 'dark tourism' (Lennon and Foley 2000) or voyeuristic experience where a new form of 'capital' (Bourdieu 1986, 1991) was created, that of stories, images and bodies of violence. A 'commodification' of the impaired body (Sharp 2000) and an experience of violence to which I was expected to listen and also view, as people also thought

they should show me, a stranger, their injuries, their 'problems', they biographically explained how their lives were violently 'disrupted' (Bury 1982) and how they were still living with the physical, mental and spiritual effects of this 'disruption'.

In post-conflict Sierra Leone, many of the people who participated in my research had previous experiences of being interviewed by international aid and non-governmental organizations (NGOs), for example, verifying who they were, their injuries and their needs. Such information is important to gather in a post-conflict environment and occurred, for example, in the camps for internally displaced people (IDPs), but has continued with other NGOs, journalists and researchers coming to Sierra Leone. Some people in the community had also participated in telling their stories in the TRC process. Therefore in most people's minds, including many of the research participants, they thought that they understood what I was doing in Sierra Leone and what they should say and show during 'an interview'.

Almost everybody I talked to explained 'how they got their problem', their impairment. In the 1970's, in a '..."minority world" (the West, the North, industrialized countries)' (Stone 1999, 4) medical model of disability, such personal tragedy stories were common and apparently also so in a post-conflict West African setting:

> ...there were no dissenting opinions that the 'problems' disabled people faced were caused by our impaired bodies. Sympathetic professionals loved talking about, and encouraged us to talk about our awful experiences. (Finkelstein 2001, 2)

However, hearing these stories in a post-conflict context, I was not sure if people had not somehow internalized the attitudes and wants of international staff concerned with individual urgent medical relief needs or if something else was going on? Sharp (2000, 290) points out that a focus on 'pain and disability' means that more attention is placed on the body and a Cartesian dualistic understanding of the body found in medical discourses leading to a 'dehumanization' or '...persons-as-bodies, a process that ultimately allows for the commodification of the body and its parts'. De Jong et al. (2000) also explain that in Sierra Leone, traumatic events were expressed through bodily complaints.

Adding to the surreal context of interviews would be that fact that local dialects and languages would be speckled with international aid abbreviations, NGO terminology and language. Or for example, illiterate participants who had no 'minority world' (Stone 1999, 4) concepts of time and could not tell me their own age would suddenly mention exact dates and times of when they got 'their problem' and how long they spent in hospital. Later in my research, two participants demonstrated how I should conduct an interview and one participant out in the provinces asked me where my questionnaire was.

A sort of cross-cultural colonization had already occurred, which I had to try and make sense of and which also called into question my own research, which I thought would be focusing more on Sierra Leonean understandings of impairment (Ingstad and Whyte 1995) rather than the 'disability' business (Albrecht 1992) in an African post-conflict environment or such forms of 'creolization' (Hannerz 1987). Tellingly, when I tried to invert professional power relationships and told participants that they were experts and they should be giving me questions to ask their community members to get a sense of what would be important to them and how they culturally understood their impairments, many stated they had never been asked such a

question before. They needed to think about it. Others were unanimous and stated that there was only one real question, all variations on 'How do you survive?' or 'How do you manage?' Many were suspicious of such a role reversal and one person asked me about my experience and if this was the first time I was doing this work. I was at a loss and wondered how telling stories about violence and impairment had socio-culturally become linked to survival or managing?

The socio-cultural context of telling stories

Most of the community is illiterate and so gaining ethical consent (Mason 2002) was done verbally, both on an individual and communal basis. In Sierra Leonean culture, a person is not viewed as an individual 'self' but is part of a larger network of reciprocal exchange in a family, village or communal setting. In order to ensure informed consent, a verbal explanation of the research has to be given to the elders of a family, village or community, as well as educated elites and NGO friends who are best able to understand and explain the issues in local terms. Despite this, community members still thought that 'research' would be linked to having to repeat what happened to them in the war.

Yet, ethically, you cannot interrupt interviews or take away from the importance of what people are trying to tell you. Fuji (2009) explains that there is a lot of interpretation that you need to do when listening to interviews or people's 'stories'. Personal narratives are a means of understanding a group or community identity and 'establishing the status of their members' (Hall and Hall 1996, 183). Denzin and Lincoln (1998, 25) further elucidate that, 'Subjects or individuals, are seldom able to give full explanations of their actions or intentions, all they can offer are accounts, or stories, about what they did and why'. Feminist researchers have all pointed to the importance of personal accounts and experiences in understanding how and why communities are oppressed and have also appealed for more research in this area as it relates to disabled people (Morris 1991; Thomas 1999). Robben and Nordstrom (1995, 3) have also argued that, 'violence is culturally constructed' entailing that one must try figure out not only the cultural context of the stories that people are telling but the context of what is occurring in those stories too. In this first instance, I wanted to understand the socio-cultural context of telling stories.

This was an oppressed and marginalized disabled community and they were narrating their 'stories' in way they had done many times before. Storytelling has a long history in Sierra Leone (Fyfe 1962) but here the focus seemed to be solely on an identity linked to 'personal tragedy', rather than examples of 'affirmation' or celebration of life (Swain and French 2000). Their 'stories' did relate a communal or collective history in individual terms but I was already aware of this through the press, NGOs and TRC narratives about the war. Initially, telling one's story had been empowering, and Hoffman (2005, 339) quotes both Jackson (2002) and Richards (1996) to argue about the legitimacy of storytelling in response to violence as a way of feeling part of a communal order again. It is also true that for many Sierra Leoneans after the war, '... having one's story (re)told on the broadcast constituted a form of legitimacy and verification' (Hoffman 2005, 346).

However, as my fieldwork progressed, members of the community would acknowledge the psychological difficulties related to retelling and reliving what happened to them in the war depending on the context. After building some relationships of friendship and trust, participants related how they could not tell

everything, lied or kept things back depending on who they were talking to. Often they had several different relationships with NGOs, international or religious organizations at one time. Certain subjects like rape or being associated with the former rebels carried strong stigmas and taboos in Sierra Leonean culture while having working children, drug use, watching pornography, drinking and an association with illegal activities were problematic for NGOs, international or religious organizations. Certainly, I later affirmed this stereotype by getting into an argument with one participant over his increasing drug use. I also discovered that some members of the 'amputee' community had lost their limbs by other means (bullets, explosions, accidents, etc.) and not always during the conflict. As Gbegba and Koroma (2002) have elucidated, there are big differences in people's stories according to how 'direct' or 'indirect' their injuries were and this affects what they can talk about because of the way they are morally perceived by society.

That is when I realized what was really socio-culturally important was not always initially mentioned because as Ferme (2001) and Shaw (2002) have found, in Sierra Leone what is hidden from outsiders is often more important that what is said. Fanthorpe (2007, 17) agrees and states, 'Also at work here is a cultural aesthetic of concealment: the idea that overt displays of emotion or intent are morally distasteful and furthermore, court spiritual danger'. For example, there were ex-combatants in those early interviews and none mentioned their role in inflicting violence.

Haanstad (2009, 71) has also explained that the experience of violence can be 'hyperreal, desensitizing, or dissociative' and so great ethical sensitivity is required in trying to figure out what is being told. While stories seemed to be disjointed and people spoke in proverbs or engaged in bodily displays, they were recounting stories of 'personal tragedy' for a reason. Nobody wanted to just tell stories and all wanted a reaffirmation of their identities, bodies and lives and hoped the act of storytelling and not necessarily the content of the story would lead to that. In African culture, storytelling, as well as describing how you have been wronged and forgiving, is a public act and the action is often more powerful ritually than what is being told (Thibeault 2002; Shaw 2002, 2007).

This meant that after they had told their stories, several participants told me that they hoped I would write about them so that there would be more awareness of what was happening in Sierra Leone or so that more people would come to their aid. Others were blunter and asked me what I was going to do for them? When dealing with communities who are poor, marginalized, oppressed and who have suffered violence, there is an expectation that the 'retelling of their memories' or stories should not only 'commemorate' but also provoke 'social action' (Kleinman 2000, 237). 'Social action' in an impoverished post-conflict community can, for some people, also entail you giving them money.

Post war dependency, patronage and payment

The 'amputee and war-wounded' community is a community that has suffered both physical and psychological trauma but also experienced a lot of 'structural violence' due to poverty (Scheper-Hughes 1992; Kleinman and Kleinman 1997; Kleinman 2000). Kleinman (2000, 227) explains that kind of violence means, '...the highest rates of disease and death, unemployment, homelessness, lack of education, powerlessness, a shared fate of misery, and day-by-day violence of hunger, thirst and bodily pain'. In a country situated near the bottom of the United Nations

Human Development Index and swamped with relief efforts after a 10-year civil war, this meant I was always welcomed but people also had very high expectations of what I could give and do for them. This was due to previous experiences with journalists, the international community and the NGOs that they grew to depend on and some lived from.

'Development aid is still often imbued with concept of charity and the idea that the rich north is helping the poor south' (EURODAD and CGG 2008, 8). Perhaps even more so in a post-conflict Sierra Leone where many people have been receiving and living off aid for years. An association with religious or international organizations or NGOs was also a way to help etch out a living for disabled people, and perceived of as normal from their experiences in the IDP camps. As Fanthorpe (2007, 23) explains,

> Young people who have received post-war support from aid agencies, whether in refugee camps, or in their home areas have every incentive to claim further support if the alternative is a hand to mouth existence in rural villages or urban slums.

As well as living from such associations and engaging in the informal economy, many in the community were involved in begging activities. Islamic begging traditions are discerned in the way begging is understood as a culturally accepted way of making a living (Fyfe 1962).

Further fuelling a culture of dependency, is that in Sierra Leonean society, a cultural and political system of patronage also exists in every level of society meaning, '...a huge obstacle to reducing corruption' (EURODAD and CGG 2008, 11). This is no different in the 'amputee and war-wounded' community and as Dixon (2002) has described, it is the elites in a community that are seen as enabling relationships to the NGOs and thus must be rewarded for that by weaker members of the community. This complicates issues of ethical and informed consent (Mason 2002), for it is also the educated elites of a community, who liaise with the leaders or local chiefs that act as gatekeepers and give ethical permission for researchers, journalists and NGOs to enter into a community. 'This naturally causes problems, as all too often contributions end up being used by elites to buy support in patron-client relationships' (Dixon 2002, 3). Richards (2003, 37) describes how people term this kind of 'parallel economy' with goods from humanitarian organizations as, '...the economy of 'hide and seek''.

In one case, in a community I was following, the leader used his access to aid to solidify his power and influence in the community by putting his cronies in positions of decision-making. This lead to a lot of tensions in a community where the educated members, women and youth felt they were being pushed out of decision-making and denied aid. I remember one educated young man who asked me if I had ever read *Animal farm* because that was what it was like to live in his community. NGOs were aware of tensions in certain communities where leaders were not acting to benefit everybody but could not be everywhere at once. Certainly, their policy seemed to be that they should work in strengthening and rebuilding local cultural systems that had been broken during the war. Within those systems they would try to encourage more female and youth roles in decision-making but this did not stop abuse in some communities.

Race, gender, religious orientation, class, ethnicity, age, education, disability and marital status will also affect whether socio-cultural ethical mores will be imposed on

research behaviour or if the 'outsider' status will grant more 'freedom' (Hammersley and Atkinson 2007, 73). As a white able-bodied woman, I was often asked by male elders for money in exchange for access to more vulnerable illiterate and disabled members of the community and their stories. I did not think that this consisted of any form of ethical permission and refused.

Culturally, it is not unusual in a village that a token or 'kola' exchange (Abaka 2005) is undergone when meeting the chief (Ferme 2001; Shaw 2002) as a form of communal entry into community. Asiedu (2008), a fellow researcher in Sierra Leone who was African, behaved in a more culturally sensitive way. He used an African custom of the bridegroom who comes 'knocking' with a gift of alcohol or token to facilitate entry into a community.

However, my status, sometimes associated with NGOs, was different and I got into trouble when giving tokens. In particular, giving money to individuals just ethically complicated my research. In one instance, when members of the community heard that I had given a small amount of money to a man. I was warned that people were used to selling stories and that it was not fair to give to one individual over another. Gatekeepers stated that there were community members who could not gain access to me and hearing I was favouring one person in the community over another would lead to jealousy, resentment and even witchcraft against me by those I had slighted. After these early mistakes, I decided the best course of action ethically was to refuse to give money to any individuals. During my research, I stated that I would make a donation to the community via an NGO of their choice, once I had left, for any member in the community facing an emergency situation. This seemed to be acceptable to the community elders, and in private some of the more vulnerable members of the community told me that they would not have seen any benefit if I had given money to the elders.

This did not mean that some people did not continue to ask me for money. Community members would often ask me to come and visit them and then ask me for money. One woman I visited, who was described by an NGO as being well off, hid all her belongings in two rooms of her house, to make it seem like she was poorer, so I would feel sorry for her and give her money. These experiences added to the feeling that I was participating of a 'commodification' of the impaired body (Sharp 2000) but the fact was that community members had a right to get paid for their stories and images by journalists and researchers. Too often they had been exploited and thus the community now did not allow people to take pictures of them without permission first and others requested money.

Olajumoke (2008), who has also worked in the region, has also described how in a post-conflict society, there is an immediate economy based on people showing 'their injuries', telling 'their story' and having 'their picture' taken. Many in the community also saw getting involved in research and sometimes with researchers as a form of 'political' and 'social capital' (Bourdieu 1986, 1991) that they could access. Certainly, 'images of suffering' (Kleinman and Kleinman 1997; Kleinman 2000) were in high demand as an illustration of the horrors of the civil war in global and local media and part of an economy of violence that was created. Hoffman (2004, 219) also notes violence and 'mutilation' was a wartime '...strategy guaranteed to produce the necessary international aid to secure combatants a post-conflict future'. Indeed, the Sierra Leonean government, and some aid and relief agencies seem to have encouraged the 'commodification' of imagery of violence as a way to rebuild the

nation state and ex-combatants were certainly an assistance priority because of security issues.

Using a social model framework to access communal stories and discourses

Community members in Sierra Leone have a right to make a living and get remunerated as also advocated by the AAA (2009). Research should benefit the communities in which researchers are working in. However, giving money to individuals for violent stories of impairment ignores certain ethical issues. Without doubt, there is the long term psychological harm to traumatized and marginalized people, as well as the perpetuation of a culture of dependency and exploitation. Giving money does not address the social conditions that lead to people thinking that they need to earn a living by selling stories. Added to that is the lack of adequate socio-cultural and psychological training and resources that there were in Sierra Leone to give sufficient culturally and ritually sensitive psychological aid when people become distressed. WHO (2004, 22) states that in Sierra Leone, '...the real magnitude of those suffering from post-traumatic mental disorders remains unknown'. Shaw (2007) has also argued that the post war boom of Pentecostal and Evangelical churches in Sierra Leone is linked to trying to cope with trauma through bodily ritual, not by talking about it.

Ethically and socio-culturally in order not to participate in oppressive practices, it was important to engage in more reciprocal and collaborative research. In order not to harm the community further, I stopped asking individual people's stories and began to focus more on how they as a community were 'surviving'. I worked with NGOs that the community elders recommended as friends and tried to design a simple way that they could access my research, enabling elites, educated elders and NGO gatekeepers to 'follow' me and my research for the community. I also notified everybody that they could always contact gatekeepers or my university if my behaviour was inappropriate or unethical to open up accountability. In order to give back or remunerate the community, it was also agreed that I would make donations to NGOs that were aiding the community. It was also agreed that if I made money from this research in a book form, the community would benefit.

Hunt (1981) has written about 'parasitic' researchers profiting from a disabled community and colluding with the institutional structures that oppress. Stone and Priestley (1996) noted that the one thing that makes disability research ethically different from other researchers examining oppression is that it uses a more 'emancipatory' paradigm. These initiatives were thus informed by a 'social model of disability' approach (Barnes, Mercer, and Shakespeare 1999). In a 'social model of disability', impairment is understood as the biological given of having an impairment, while disability is the social oppression that people with impairments experience. In such a model, research should have as its goal the involvement and 'empowerment' of 'disabled' people (Barnes and Mercer 1997).

Finkelstein (2007, 2) has argued that, '...social models only really make sense in particular contexts'. In this particular cross-cultural context and exchange, nobody had heard of a social model of disability nor were participants interested in my 'system of values' or 'academic biases' (Stone and Priestley 1996; Stone 1997; Humphrey 2000; Mercer 2002). Katsui and Koistinen (2008) seem to have had the same experiences noting that while people were keen to get involved in their research,

they do not always have the time, educational background or inclination to become more informed, participate fully or even take control over the research process.

Stone and Priestley (1996) have also argued that undertaking 'emancipatory research' is a way to align oneself with disabled people to instil social changes and escape an 'exploitative role'. However, Zarb (1997, 51) makes the important distinction that a project is only 'emancipatory' in the sense that, 'the research is actually controlled by' disabled people, and this control features in the 'process of empowerment'. In Sierra Leone, although the research was not controlled by disabled people, the 'amputee and war-wounded' community was already engaged in an economic, social, cultural and political project to try and access different sorts of public stories, narratives, or discourses to change their social status in society (Berghs 2007). In this way research could be ethically aligned to the community's voice and discourses (Caplan 2003). Broadly speaking, I would say that there are four different types of communal discourses that the community felt it was important to get involved in: (1) TRC and reparations, (2) Global and local media, (3) SCSL and justice, and (4) Human rights and laws.

(1) Engaging in the TRC and giving testimony meant an engagement with the government and nation state. The recommendations made by the TRC sought reparations for the injuries that victims of war (amputees, war-wounded, children, war-widows and sexually abused women) had sustained during the war. The community was actively lobbing the government for reparations for their 'problems'. Not receiving monetary compensation and symbolic ritual acknowledgement of their impairments from the government stopped them from 'functioning' in society, effectively making them 'disabled', 'dependent' or 'dehumanized' as described by Gbegba and Koroma (2002). Furthermore, Gbegba and Koroma (2002) argue begging is not just a strategy to survive but also a form of symbolic bodily protest and call for it to be 'recognized' by Sierra Leonean society. Due to the nature of their impairments, sustained as victims of war, the community argued that they occupied a different moral realm, had a different status from other disabled people in Sierra Leone and that this should be made public.

(2) Accessing the discourses of the global and local media, NGOs, religious organizations as well as researchers was a way of gaining a livelihood, but also a means of exerting political pressure on the government and reversing their status in society. It was a means of 'showing' themselves as working and regaining their lost bodily, mental and spiritual places in society. Sometimes in partnership with an NGO or religious organization, they would publicize their activities and the projects that they were involved in the local media. Often they would also hope to attract further funding in this way.

(3) Getting involved in giving testimony in the SCSL was a means of being active in seeking justice for those responsible for the atrocities committed during the conflict. Community members were not always open about being involved in the SCSL despite the fact that there were certain 'incentives' to get people to testify. Other community members were keen to voice criticism of the money spent on the SCSL stating that it should be used for reparations or rebuilding the country. Other narratives of justice involved getting countries like Liberia and Libya, who had been involved in the conflict, to pay reparations.

(4) Lastly, by aligning themselves with disabled people's organizations (DPO's) and with NGOs and international organizations, they are trying to lobby the government for human rights and laws. While they saw themselves as having different impairments from other disabled people and a different moral status, this did not stop working partnerships and friendships. In partnership with other DPOs, some members of the community are trying advocate for a Disability Bill to ensure equal rights for disabled people. The Sierra Leonean government has signed and ratified the United Nations Convention on the Rights of Persons with Disabilities but no laws to protect disabled people exist in Sierra Leone.

All these discourses were important in that they were publicly trying to counter situations of exploitation and dependency that the community found themselves in and were culturally linked to communal 'affirmations' of life (Swain and French 2000). All community members were keen to give and to get more information about these discourses and reciprocated and informed my efforts to get involved in and make public these struggles (Scheper-Hughes 2009).

Limits to social model frameworks: lack of resources, slow changes and risks, rumours and violence

Despite efforts to engage with community concerns within in a social model theoretical framework, there were important limits encountered undertaking such efforts in an African post-conflict setting. Firstly, such communal discourses were located in a 'minority world' (Stone 1999, 4) model and local people needed considerable resources to access this world. Secondly, changing society is a slow process filled with 'broken promises' and not without personal risks for local people, Thirdly, there is always the underlying threat of a return to violence and this underscores the importance of ethically giving back to the community.

Access to discourses means access to resources

Disparagingly, while most community members felt that true social changes would occur by getting involved in differing discourses, they also warned of limits to involvement in discourses that were social and political in nature. The social and political world in Sierra Leone is morally regulated by a patrimonial social system. Yet, these discourses also belonged to the 'minority world' (Stone 1999, 4) and were linked to Freetown and the educated 'development' elites who spoke English (Escobar 1991). While a patrimonial system worked at government institutions where community members needed 'tokens' to gain access to government officials, considerable resources were also needed to travel and gain direct access to NGOs and international organizations based mainly in the capital.

Due to the British administrative colonial history in Sierra Leone (Fyfe 1962), there has been a big divide created between the provinces and the capital, where the colonial government was located, and this remained so after the war. Keen (1998, 321) described how there was considerable 'neglect' of the provinces; most aid projects were mainly based in Freetown during the relief effort and this has been slow to change. To access 'development' discourses you need to have educated elites in your own community and educated elders who speak English as well as considerable

resources and support. For example, in order to access and democratically check back with community members, that their issues were being represented accurately, community leaders had to have the resources (radios) to stay in touch with everyone and travel all over the country. In order to communicate with the people who were running NGOs, and institutions that were not Sierra Leoneans as well as foreign journalists, leaders also had to be able to speak English. In this way power relations are established, in order to access 'development' and 'empowerment' discourses (Escobar 1991). This raises difficult ethical issues of representation and who is speaking for whom (Spivak 1988; Caplan 2003)?

Basic infrastructure in a post-conflict state is still also being rebuilt meaning access and mobility was also affected, especially for those most disabled, and this also had an impact on how democratic and inclusive discourses, as well as research, could be in accessing those people. There were large groups of disabled people out in the provinces that were not accessed, as well as youths, women and children who were not always viewed as having political opinions or insights into such discourses, nor the resources available to the mainly 'big men' who engage in political discourses and debates.

Social changes are slow and not without risks

One of the leaders in the community who had been very important in advocating the plight of his people explained that engaging with all these different discourses was also not without personal risks. Having a high profile and being outspoken meant he had been detained by the previous government and threatened. There exist no laws for the protection of disabled people and within a patrimonial system, it is who you know and what resources you can access that will protect you. It was now rumoured he had been paid off and was corrupt. Preferring a short-term vision of personal gain and safety in a patrimonial system in such a context makes sense.

Instilling social change in a post-conflict society is painfully slow and the results are not always apparent, meaning that people will give up fighting especially because, next to the nation state, a socio-cultural system of patronage exists in which elites are enriching themselves. In Sierra Leone, many of the same economic, social, cultural and political structures that led to the civil war and unrest are now back in place (Richards 2003), but many NGOs are wary of getting politically involved or being critical of the government lest it stops their activities (Dixon 2002; Keen 2005). The lack of real social change, education and unemployment after the many years of fighting, sacrifice and suffering can make people, principally the youth, cynical and bitter. The community described 'broken promises' by the government, NGOs and journalists as the country was moving from a relief effort, where aid and involvement to 'empower' communities had been plentiful, to one based on development where aid agencies were scaling back operations. In Sierra Leone, Keen (1998, 320) also explains,

> A major part of the problem is that aid organizations in a sense, see their interest in promising a great deal, and then when they cannot deliver all that has been promised, disguising this fact. Instead of aid organizations saying they cannot fulfill their mandates in the context of resource constraints or a lack of diplomatic support from donors, we are often seeing the opposite.

There was a wariness of working with researchers for much the same reason and it became ethically important to emphasize the limits of research and to 'manage the expectations' of participants (Pitts and Smith 2007, 28). Yet, as a researcher you are also in a unique position in that you can access and advocate for political change without much risk and without paying tokens for which community leaders are often asked. Dudwick et al. (2006, 31) argue that fieldwork should be ethically linked to the development policies and priorities of a country and this is done by fostering relationships with government officials. In this way they argue, 'findings are used' and access is guaranteed to 'particular regions for research purposes' but my experiences were different.

Undertaking a social model theoretical framework meant aligning oneself with the concerns of the community and advocating the changes they wanted by accessing international organizations, journalists and interviewing NGOs and government members in Sierra Leone. While it was relatively easy to access government officials and advocate community concerns in terms of development policy, this does not mean that you will be taken very seriously or that things will change. 'Disability' policy was only a priority in terms of access to greater development aid through the Poverty Reduction Strategy Papers (PRSP)'s required by the World Bank (WB) and International Monetary Fund (IMF). Similarly, the government would get involved in conferences or events that international organizations, such as the World Health Organization (WHO), would pay for and organize to promote rights for 'Persons with Disabilities' (DWP's). Real changes or laws very rarely followed but the government had to be seen as going through the hoops and adhering to 'minority world' (Stone 1999, 4) conceptions of disability.

'Beware of white teeth, and black heart', one local NGO worker told me because if you have money, the government will be interested. Another NGO told me advocating community concerns to the government was a big waste of time and I should be writing project proposals for them instead as this could inform social changes. In a country without any social welfare or strong legislative system, they argued that it was the NGOs, religious and other organizations, not the government, that inform social changes through projects for the community. Likewise, when I suggested getting the local media more involved, they stated that local newspapers were also affiliated with one of the two main political parties and when asked to cover stories, they too sometimes expected small tokens in return. The community warned of the futility of engaging with the government and of the possible dangers without access to resources to protect oneself.

Rumours and violence: the importance of giving something back

I never took those dangers too seriously but several months into my fieldwork, I began to hear lots of rumours and stories about the security situation in Sierra Leone that meant that undertaking research within a social model framework had a different ethical dynamic. There was a threat of a coup made from the military and while most agreed this was a false threat, it meant an end to visiting any government officials. The community began to warn that things were 'changing' because by-elections were going to be held. One of the leaders in the community ended an involvement in local politics because of safety concerns and the changing political climate. Incidences of political violence out in the provinces became more common

and political and tribal violence also broke out between the two major political parties in the capital.

The violence in March 2009 was very localized, only lasted a few days and the United Nations quickly intervened but the threat of violence that could reach the capital put a new ethical perspective on research. In the Sierra Leonean historical and political context, strong links exist between violence, displacement and 'bodily' loss (Richards 1996; Ferme 2001; Shaw 2002). These events raised a lot of anxieties for the community and some wanted to get more involved in advocating discourses connected to peace, non-conflict and remembrance of the consequences of war. The fact that the political situation can change quickly brought home why people sometimes had short term goals, felt that their individual immediate needs were to be tackled first by money and why engaging with the government politically was viewed so negatively.

This socio-cultural context explains why it is ethically essential to take seriously people explaining that 'survival' and 'managing' is important, and why they get involved in research and telling stories for their survival. It also illustrates that the 'parasitic' (Stone and Priestley 1996; Mercer 2002) connection between collecting stories of impairment and violence for money needs to be ethically reconsidered, and that more of a contribution for the benefit of an entire community needs to be made. While affirming the rights and needs of a disabled community to receive adequate compensation, this should not be at the expense of their current and future psycho-social well being, or at the expense of more vulnerable members within that same community.

Despite the incidences of violence, the community remained hopeful about the reparations they would be receiving as part of the TRC recommendations and the fact the president had symbolically visited one of their communities. There had also been symbolic reparations made out in the provinces and people were happy that their sacrifices during the war would finally be acknowledged by some sort of monetary compensation as part of the reparations process.

Conclusion

Oliver (1992) has argued that power relations cannot be avoided in a research setting, and Coleridge (1993, 209) has warned that no matter how well intentioned or 'sympathetic' a non-disabled person is towards 'disabled' people, 'exploitative behaviour' cannot be escaped, and this was certainly true in this research setting. Despite taking a social model framework, I often felt my research was unethical, exploitative and I was letting the community down by not doing enough. However, I hope that as Davis (2000, 203) has also argued, that I have shown how a significant part of ethnography is to try and break down any simplistic dualistic frameworks that argue in terms of 'them and us' and work towards more fluid, dynamic and complex interpretations even in terms of power relations, community and the limits of engaging in ethical social action in a post-conflict African context.

Acknowledgement

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