Epilogue 1

Epilogue 2
A reflection on positionality and knowledge processes in transdisciplinary research

“Is it time to retire the concept of stigma?”
“I am not shy... so I don’t have leprosy, right?”
Abstract
The SARI project aims to reduce stigma and improve the lives of people affected by leprosy in Cirebon District, Indonesia. The project team includes staff from different scientific disciplines from universities in the global North and South. Members of society participate in several ways in the project. The SARI project is transdisciplinary in the sense that frames, approaches, and methods from different disciplines and local knowledge are combined to co-create knowledge on the reduction of leprosy-related stigma. In this short story I reflect on my own positionality: my baggage and position in the research. I share several realisations about the path I have travelled to where I am today – a researcher in the SARI project – which I believe could be relevant for others. It highlights that understanding one’s own positionality should be encouraged in transdisciplinary research as it can help break down barriers for knowledge processes.

Introduction

The voyage of discovery consists not in seeking new landscapes, but in having new eyes. Marcel Proust

The path to where I stand today – a researcher in a transdisciplinary study named the SARI project – is marked by realisations regarding positionality and knowledge processes I believe could be relevant for others. These realisations were a result of frequent reflections. My aim is to exemplify a reflection on positionality and to illustrate why understanding one’s own positionality should be encouraged in transdisciplinary research.

Although this short story is not about the concept of positionality, its history, definitions and uses within scientific traditions as sociology and anthropology I would like to explain how I, coming from development studies, understand the concept. As Sumner and Tribe wrote:

It is not possible to conduct research about developing countries without carrying a lot of what is probably best referred to as “baggage.” (2008: 43)

Besides defining what this baggage is and reflecting upon it, positionality embodies to me situating the researcher in the research (see also Sumner and Tribe 2008). Reflexivity is thus needed. Eyben described reflexivity as “the ability to step out of your identity and interrogate how that identity shapes your understanding” (2006: 5). Before starting my own interrogation about my baggage and position in the research, let me start by introducing the SARI project.
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Introducing SARI
In 2010, the SARI project was initiated to address stigma and improve the lives of people affected by leprosy through three interventions in Cirebon, Indonesia. In total about 600 persons affected by leprosy are currently enrolled in the project. Key activities facilitated by the SARI project are the development of a micro-credit system, providing lay and peer counselling, the development of a participatory video, and events in villages that aim to bring into contact people affected by leprosy and community members. The project team includes staff from different scientific disciplines (public health, medicine, disability studies, psychology and development studies) from universities in the global North and South. Members of society participate in several ways in the project, for example through a disability-inclusive team, partnerships with local actors and participation of people affected by leprosy.

The SARI project is transdisciplinary in the sense that frames, approaches, and methods from different disciplines and local knowledge are combined to co-create knowledge on the reduction of leprosy-related stigma. Within a knowledge co-creating process “different perspectives on the issue come together in a learning process, whereby in the course of the interaction implicit knowledge is made explicit, and new knowledge is construed, shared and tested” (Regeer & Bunders 2009:14). The learning process in the SARI project is facilitated by the Interactive Learning and Action approach (Bunders & Broerse 1991). During the first phases, also referred to as the reconnaissance, among others, a broad view of the issue under concern and its characteristics is obtained. In the SARI project this was done through an exploratory study in which the often implicit and sometimes hidden experiences of people with leprosy and other actors were captured. A first stigma-reduction plan was made based on these findings and implemented. This first plan and subsequent plans were followed by observation and reflection of the team leading to new knowledge, and hence new plans and action. Along the way SARI has broken down barriers to knowledge co-creation by dealing with feelings of powerlessness of some participants, getting everybody to the discussion table and creating a real commitment to listen to and understand each other.

My baggage
I will share my baggage or in other words, where I am from, who shaped me, where I was educated and some other key events in my life before elaborating on the implications of this for the SARI project:

I was born and raised in the city Arnhem, the Netherlands and grew up in a white middle-class family with two younger brothers. Our neighbourhood was predominantly white, although some of my best friends came from ethnically mixed families. My parents are nurses and exciting stories about their work were discussed at the dining table. My parents dreamt of working in a developing country and my father’s five week holiday to Thailand when I was 8 years old are just two examples from my childhood that stirred my interests in other countries and cultures.
After secondary school, I studied physiotherapy. At that time action learning was the new method of teaching that stimulated reflection upon daily practice during my internships in a hospital and private practice in the Netherlands and abroad in Mumias, Kenya. After graduation I went to Nigeria for a couple of months and worked with children, persons affected by leprosy and disabled young adults.

A few years later I obtained a Master of Science in Public Health Research. I gained most of my scientific education at the Athena Institute, VU University. Athena’s scope is transdisciplinary research to solve persistent and complex problems in society and this is reflected in their teaching and internship positions. I was particularly interested in participatory methods and used these during my internships in Bangladesh and Vietnam.

Awarded with several grants, I chose the Institute of Development Studies (IDS), University of Sussex, in Brighton to obtain a second master and continued focusing during this Master of Arts on topics such as participation, power, gender, reflection and learning. I also explored the Dutch development cooperation and the tight links with the former colonisation of Indonesia.

A few years ago, my mother developed a hernia in her spinal cord and suffered a stroke, as a result, she is now a wheelchair user.

Why is this personal testimony important? Would my contribution to the SARI project and also the findings have been different if I would have been a man instead of a woman? I believe so. Would it make a difference if my parents were historians, accountants, retailers instead of the nurses that they are? Yes, it would. My gender, race, family history, nationality, sexuality, class, disease history all have a part to play in shaping my positionality – they make a difference. Describing what exactly constitutes this difference and especially the magnitude of this difference is a difficult endeavour. What follows are some initial reflections on how my background shapes our research.

I feel more connected to the topic disability, because my mother is disabled and because we as a family occasionally come across mistreatment of society. Related to this connection are the approaches I favour; a rights-based approach. I am, however, not disabled myself as many of my colleagues, nor do I have any personal experience with disability in a development context what would have created an even stronger and profounder connection.

I am aware of the Dutch colonial history in Indonesia. Hence, I had to learn how to deal with the personal struggles I experienced due to felt inherited ‘mea culpa’ of being a colonizer when overseeing and managing the fieldwork. It made me cautious and I chose a non-authoritarian management style. At some point SARI’s research assistants, also for other reasons, asked for more structure and coordination of their superiors.
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For transdisciplinary research, one’s professional discipline probably matters most as it determines who one knows (Barnes, Brand, Charlton, Snow, Father Damien, Chambers, Goffman\(^1\^6\)), what one reads (I remember well my struggles with anthropologic text at the start of my studies at IDS and that of some of my peers with economics or graphs), how one thinks and frames (in boxes, feedback loops, percentages, chaos, concepts, models, arguments), and how one analyses and writes. Differences between disciplines can be vast. How vast became clear to me during a lecture ‘medical anthropology’ at IDS:

I was looking forward to this lecture: medical anthropology. After classes on colonialism, economy and politics I welcomed a more familiar subject. I thought. The lecturer decided to compare medical anthropology with public health and she did not conceal her dislike about the latter field. She stereotyped and presented public health as bad, very bad.

Getting familiar with aversion towards my field of interest was a great lesson I realise now, but at that time I felt offended.

Situating the researcher (me) in the research
This section describes my position and some of my roles in the research.

Within the SARI project, first and foremost, I am a PhD student straddling two disciplines. My journey through academia entails that I search for frameworks and theories, collect empirical data to describe or explain the phenomena stigma, it’s possible reduction and the process that was required. The journey is also one of personal development in many fields other than academia. I have several ‘practitioners’ tasks as I am responsible for the implementation of one of SARI’s interventions. For me personally, being a ‘researcher’, with some ‘practitioner’ tasks is delightful.

I am also an outsider. I differ in economic, social and cultural status from the ‘researched’ and all of my Indonesian colleagues. Although I speak basic Bahasa Indonesia, wear batik when appropriate and spend about forty per cent of my time in the project area, I remain an outsider.

All these positions and roles matter because they have their strengths and shortcomings. I overlap disciplines (public health and development studies – in itself a multi-disciplinary field) and thus can establish linkages, but it also causes internal conflicts especially when I am pushed or push myself to choose (for example to answer the question: Can we measure stigma? Yes or no). As an outsider I have to accept that I will not fully comprehend many aspects such as the culture, history and identity of the project.

\(^{16}\) These are all key persons to the different disciplines of the SARI project (disability studies, public health, development studies, medicine)
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participants, however, I also shed new light on issues by asking different questions and by thinking in unconventional ways. I am closely involved with the implementation of interventions and want them to be successful: since this would mean that the participants (several who I got to know personally) are having a better life and that the SARI team might have a paper in a journal like the Lancet. Does this make me biased? Yes, it does. Yet, I am content with being biased towards this cause. It does not, however, make me want to present the results of the SARI project in a partial manner. It makes me a driven but not an insincere researcher.

**Positionality and knowledge processes**

Generating new academic knowledge, for instance, on new methods for assessment and new ideas around key concepts has been a very challenging process. At times in the SARI project I have wondered whether the differences between disciplines are surmountable. As the co-creation of knowledge does not happen naturally, a strong (perhaps extraordinary) commitment of the team is needed also to continuously make the time and resources – that are often scarce – available. There also seem to be more invisible limitations, such as, disciplines being hegemonic or perceived so by other disciplines.

A thorough understanding of one’s baggage and own discipline, its strengths and weaknesses – also as perceived by others – has been vital for me. It helped me to give meaning to internal conflicts and make productive use of it. It also helps me to put into context the different perspectives on an issue, and although I believe I do not establish linkages in the project, I facilitate the interaction now and then. It also made me more conscious towards my own – sometimes limited – perspective on a problem, issue or phenomena. As I believe in the foundations of transdisciplinary research, this automatically triggers and motivates me to understand other perspectives. I also recognize more easily a default type of response when I come across a conflict. Instead of protecting my own fields again I try to listen more sincerely to others and do a genuine attempt to understand other perspectives.

**Conclusion**

Reflection in this case on positionality might, as Shutt writes, “appear an act of vanity”; the experience is, as she also writes, instead “deeply discomforting” (2006:79). After submitting the abstract for this short story I wondered why on earth I have put myself up to this challenge. Of course I know it: I believe in openness and reflexivity within academia and in walking your talk. Inner discomfort is part of the first stage of reflection, and for myself, exploring areas of discomfort have in retrospect been worthwhile endeavours. However discomforting, I had to do it.

I hope to have illustrated that reflection on positionality in transdisciplinary research is valuable and as result members of transdisciplinary teams will ask themselves more often: What baggage do I bring to the project? How does my background influence the research? Where I am situated in our research? How can this make a difference? And
then make productive use of these insights and share their realisations with their team members. This is in particular important in transdisciplinary research were the nature of involving different academic disciplines and stakeholders could results in more and more complicated conflicts and where the ultimate goal of knowledge co-creation is perhaps more demanding. I believe that a thorough understanding of one’s baggage and scientific discipline, and being aware of the strengths and shortcomings of one’s position in the research can help break down barriers for knowledge processes and help us seeing things differently.
Epilogue 2
“Is it time to retire the concept of stigma?”

The question posed in the title of this epilogue was the title of an editorial in the journal *Stigma Research and Action* (Tal 2011). After studying leprosy-related stigma experiences and working for over four years on interventions to reduce leprosy-related stigma, I would like to share my thoughts on this question.

There is debate about the definition of stigma. What does *stigma* mean? What does *stigma* mean to me? If I say: “the man affected by leprosy I just met for an interview experiences stigma”, I might be saying that he got fired from his job as a cleaner in a hospital or that he resigned to avoid trouble. Or he might have been forced to live away from his wife and children. He might have decided to stay in his house most of the day, because he is ashamed. He might have concealed leprosy from his wife, because he is worried she would leave him.17 It could be one of these social or psychological experiences or a combination of them. Stigma is a very broad term. There is a wealth of words in our vocabulary that would provide us more accurate description of this man’s experiences: *discrimination*, *social exclusion*, *shame*, *devaluation*, but I (and others) regularly refer simply to *stigma*. Staples called the concept of stigma “a lazy shortcut” (Staples 2011:91). My first point is that scholars, myself included, can easily (unconsciously) create ambiguity by using the concept of stigma.

Conceptual models aim to convey the fundamental principles and basic functionalities of the system they represent. Similarly, conceptual models of stigma such as the ones applied in this thesis (Weiss 2008; Link & Phelan 2001) intend to simplify the concept. This raises the question: “When are these simplified models appropriate and when are they not?” There is a valid reason for simplification. In this thesis, I have argued that in order to assess stigma quantitatively, there is a need to reduce the complexity. Quantitative measurements allow us to compare and contrast the findings of groups and help us generalize the results from a sample to the wider context. Simply said, a set of questions leads to a total score and when the total scores of a group of individuals are added up and divided by the number of people in that group we have an estimate of the extent of stigma experienced in that group. By making this assessment complex, we risk missing our target. The way in which one conceptualizes and investigates the construct of stigma influences forms of intervening and how we engage with those affected by stigma (Parker & Aggleton 2003; Harris 2011). Now things get tricky, because the way we intervene and the way we engage with people should not be based on simplified categorizations. Stigma is a very complex construct and it is not simple to intervene in the stigmatization process. For stigma-reduction interventions, I argue that we first need to abandon the simplified conceptualizations and appreciate the

17. All these examples are from the SARI project.
complex responses a disease like leprosy evokes in those affected, associated and not affected by it. Then, later on in the process one might need to simplify the complex reality somewhat in order to make choices and get things done. Appreciating the complexities first will help tailor the interventions to the unique needs of the persons involved and help maximize the benefits. In summary, my second point is that scholars (myself included) risk over-simplifying or making excessive use of over-simplified conceptualizations in situations where awareness of the complexity is appropriate.

Then – perhaps worse – there is the risk of inappropriate objectification. Recently, an anonymous reviewer made comments on a manuscript I had submitted to a scientific journal, that “defining people as ‘stigmatized individuals’ – while I recognize this is the aspect of their identities the author is most interested in for the purposes of this study – is inadequate as a description of who they are.” Which is very true. Once diagnosed, people with leprosy are not synonymous with people affected by leprosy or with stigmatized individuals. I adapted the sentence accordingly. Harris noted that “the tendency to use the word stigma as synonymous with negative experience may well contribute to these negative outcomes by validating the perspective of the stigmatiser; rendering the stigmatised voiceless, subordinate and invisible and denying the possibility of alternative outcomes” (Harris 2011:137). Emphasizing positives outcomes and peoples’ resilience or agency, like I have done a number of times in this thesis, is also very important. Hence, we must take care not to classify certain people in a particular manner, as we might contribute to the experience we want to reduce or prevent. Sometimes, researchers do need to objectify, but very often there is no need to do so. In line with this, my third point is that we as scholars do sometimes objectify inappropriately.

Why are processes of imprecision, simplification and objectification happening? Staples argues that “too many of us who work on leprosy do so within the narrow confines of our own disciplines without referencing – or even being aware of – a wider body of research that should inform our thinking and make for better policy” (Staples 2011:92). To speak for myself, I indeed needed to learn about the wider aspects when I entered the field of leprosy and stigma research. A wealth of information exists from a variety of disciplines and, not surprisingly, I started with reading material from my own fields (public health and development studies) and that of my supervisors. Fortunately, our transdisciplinary team inevitably encouraged me to read beyond the boundaries of my own disciplines. So, after a while, I started to read and engage with work pursued in, for instance, disability studies, anthropology and psychology. Simultaneously, the fieldwork and analyses of data raised their own questions that stimulated the search for answers. It took more than four years to reach my current level of understanding and to be able to write this down.

So should we retire this vague concept called stigma that is at risk of causing oversimplification and objectification? Or is there some value attached to the term? Stigma is a fundamental human experience. The overarching aim of stigma research is to
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understand this experience in order to prevent or reduce the negative social and physical outcomes associated with stigma and its proxies. In order to achieve this we need powerful and overarching words. I think stigma is such a word. I am proud that, because of the project I was part of, the theme of the 62th World Leprosy Day celebrated on 25th and 26th of January 2015 in Indonesia included the word. The precise theme was: “Hapus stigma! Kusta dapat disembuhkan dengan tuntas” or “Remove stigma! Leprosy can be completely cured”. At the national level, finally proper attention was paid to this real and important experience of people affected by leprosy – an experience that, for many affected people, is worse than the disease itself. One participant in the SARI project once made it very clear to me that the disease leprosy was not his problem and that his severely impaired hands were not the problem, but that others’ attitudes and how this made him feel was his problem. During World Leprosy Day, some people in the audience very bravely shared their sometimes heartbreaking experiences of leprosy and stigma. A concept that encompasses all these experiences is needed in this context, and stigma fulfils this role.

I do not believe we should retire the concept of stigma. It has an important value for the reduction all the negative consequences associated with stigma. Several scholars have raised similar points or made commendable contributions to this subject (Harris 2011; Staples 2011a; Tai 2011; McCordic 2012; Corrigan & Ben-Zeev 2012). In conclusion, scholars need to be more careful how they apply the concept of stigma, write and talk about those affected by stigma in a thoughtful and dignified way and be aware of the role they play in transmitting this message to current and future academics, policy-makers, other practitioners and persons affected by stigmatized conditions.