Chapter 2
Theoretical concepts
“I am not shy... so I don’t have leprosy, right?”
This chapter presents the theories used to conceptualize the research described in this thesis. The chapter begins with the theories related to the concept of stigma. These include the definition of health-related stigma, the different types, levels and components of stigma, the causes of stigma, the context, concealment and agency. Taking this together, I conclude that stigma is a complex and persistent problem. This obviously has implications for stigma reduction. I elaborate on aspects that are believed to facilitate the reduction of stigma: understanding stigma in its local context, addressing causes of stigma and multi-level and multi-faceted approaches.

2.1 The concept of stigma
Goffman – in his seminal work on stigma – adopted the term *stigma* from the ancient Greeks, who used it to refer to cut or burned marks made on the skin of criminals, slaves and traitors in order to visibly identify them as tainted or immoral people, who were to be avoided and shunned (1963). He described stigma as an “attribute that is deeply discrediting” (1963:3) and that reduces the bearer “from a whole and usual person to a tainted, discounted one” (1963:3). His conceptualization of stigma was followed by more than 50 years of development in the body of theory and research, from which I selected several definitions and theories.

2.1.1 Defining health-related stigma
Conceptualizations of health-related stigma have been developed over time by scholars from different scientific disciplines (e.g. psychology, psychiatry, public health, sociology, anthropology) and sometimes for specific health conditions (Link & Phelan 2001; Parker & Aggleton 2003; Weiss et al. 2006; Corrigan et al. 2005; Bos et al. 2013; Sermrittirong & van Brakel 2014). Important critiques are the individual focus of many conceptualizations that neglect processes and structures and the many theories that are not informed by the lived experiences of the persons who are stigmatized (Link & Phelan 2001; Scambler 2006; Manzo 2004; Parker & Aggleton 2003). Some scholars even argue that the concept of stigma has become no clearer (Manzo 2004; Staples 2011a). Despite these critiques and the remaining work that evidently needs to be done, I selected a definition of health-related stigma that fits best the purpose of this thesis. Weiss underlines that stigma is a social process and not merely an attribute and that it can manifest itself in different forms. Health-related stigma is:

A social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group [identified with a particular health problem]. (Weiss et al. 2006:280)
2.1.2 Types, levels and components of stigma

Weiss (2008) also developed a model in which he clarifies the different types of stigma that are exhibited in those who stigmatize and those who are stigmatized. Weiss extended the Hidden Distress Model of Scambler (Scambler 1998) and distinguishes six types of stigma, three from those who stigmatize and three from those who are stigmatized. Those who stigmatize show accepted, endorsed and/or enacted stigma. Endorsed stigma refers to justifying and supporting exclusion but refraining from being actively engaged in it, while accepted stigma means not endorsing, but not speaking out against the process (Weiss et al. 2006). Enacted stigma is often called discrimination. Those being stigmatized may exhibit anticipated, internalized and/or enacted stigma (Scambler 1998; Jacoby 1994). The latter refers to the experience of discrimination, and is also called experienced stigma. Anticipated stigma, also called perceived stigma, refers to a person with a stigmatized condition who behaves or feels a certain way (e.g. excludes him or herself) due to anticipated responses from others. Finally, internalized or self-stigma4 is characterized by “negative feelings (about self), maladaptive behaviour, identity transformation or stereotype endorsement” (Livingston & Boyd 2010:2151). The conceptualization of Weiss is not unopposed. Staples, for instance, argues that the boundaries between stigmatizers and stigmatized are “more blurred than a dichotomy between the two might suggest” (Staples 2011a:94). For instance, health professionals can stigmatize persons affected by leprosy, but they might be stigmatized by others because of their close association with the disease (Harris 2008).

A different categorization comes from Livingston and Boyd (2010) and Bos et al. (2013) who based their work on Corrigan et al. (2005) and Herek (2007). They defined three levels of stigma and use different names to describe each. In my view the most useful are: structural, social and individual. Structural stigma exists at the macro level and is defined by Pryor and Reeder (2011) as the “legitimatization and perpetuation of a stigmatized status by society’s institutions and ideological systems” (page 793). Social stigma is interpersonal and exists at meso level. It connects to the category “those who stigmatize” of Weiss (2008) and it comprises according to Bos et al. “the cognitive, affective, and behavioural reactions of those who stigmatize” (2013:2). Individual stigma exists at micro level and includes internalized stigma as defined earlier and stigma by association (or Goffman’s (1963) courtesy stigma). The latter entails “social and psychological reactions to people associated with a stigmatized person (e.g. family and friends) as well as people’s reactions to being associated with a stigmatized person” (Bos et al. 2013:2).

A third categorization comes from Link and Phelan (2001). They explored the processes from the side of the stigmatizers and give more in-depth insights in the processes that

4. Personally, I prefer not to use the term self-stigma as it gives the impression that people affected are to blame for the stigma, obscuring the fact that it is the product of social processes.
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lead to stigma. They define stigma as the co-occurrence of five components: labelling, stereotyping, separation, status loss, and discrimination. They explain each component as follows:

In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labelled persons to undesirable characteristics—to negative stereotypes. In the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of “us” from “them.” In the fourth, labelled persons experience status loss and discrimination that lead to unequal outcomes. (Link & Phelan 2001:367)

The importance of power for these processes is emphasized by Link and Phelan (2001), who note that “for stigmatization to occur, power must be exercised” (page 363).

2.1.3 Interrelatedness

The different types, levels and components of stigma are interrelated. The interrelatedness has been addressed by Bos et al. (2013), who argue that public stigma is at the root of internalized stigma, stigma by association and structural stigma. Link and Phelan (2001) describe that stigma mechanisms are mutually reinforcing and underline the persistency of stigma. They stated:

It is the existence of multiple stigma mechanisms and multiple stigma outcomes that helps explain why stigma is a persistent predicament — why, on average, members of stigmatized groups are disadvantaged in a broad range of life domains (e.g. employment, social relationships, housing, and psychological well-being). (Link & Phelan 2001:380)

With multiple stigma mechanisms, Link and Phelan refer to the different ways to achieve discrimination (structural and direct) and many ways stigmatized individuals can be “encouraged to believe that they should not enjoy full and equal participation in social and economic life” (Link & Phelan 2001:380). If the mechanisms used at a certain moment and in a certain context are addressed (stopped or “become embarrassing to use” (Link & Phelan 2001:380), new mechanisms can be created that replace the old ones. Parents might, for instance, discourage their children to play or be near to a child affected by leprosy. If this strategy becomes ineffective, they might ask the head of school to send the child affected by leprosy away from school. In addition, multiple stigma outcomes also contribute to the persistency of stigma. Link and Phelan state that “the effort to eliminate one bad outcome, ironically produces strain that lead to another” (Link & Phelan 2001:380). For example, disclosure of a leprosy status to close family members might release the burden of carrying a secret and lead to support of some family members, but can also lead to negatives attitudes and behaviours of other family members. Hence, the interrelatedness of types, levels and components makes stigma a persistent problem.
2.1.4 Causality of stigma

Causes of stigma vary from one disease or condition to another (Rao 2010). The causes for leprosy-related stigma are summarized by Rafferty (2005) and more recently by Rao (2010) and Sermrittirong and van Brakel (2014). The causes are shown in Table 2.1 and include beliefs about causation, external manifestations and fear of transmission. Rao concludes that “leprosy stigma is deeply rooted in religious, social, economic and cultural domains” (2010:118).

Table 2.1
Causes of leprosy-related stigma including examples (based on Rafferty 2005; Sermrittirong & van Brakel 2014; Rao 2010)

<table>
<thead>
<tr>
<th>Cause</th>
<th>For example:</th>
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<tbody>
<tr>
<td>Religious and cultural beliefs about causation</td>
<td>Curse, punishment, karma, witchcraft</td>
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<tr>
<td>External manifestations</td>
<td>Odour, skin condition, impairment</td>
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<tr>
<td>Fear of transmission</td>
<td>Hereditary</td>
</tr>
<tr>
<td>Perceived as death sentence</td>
<td>Perception leprosy is progressively disabling</td>
</tr>
<tr>
<td>Association with ‘inferior’ people</td>
<td>Sinners, poverty</td>
</tr>
<tr>
<td>Public health and related interventions</td>
<td>Compulsory segregation</td>
</tr>
</tbody>
</table>

2.1.5 Stigma is context-specific

Several scholars have highlighted the importance of understanding the context for the conceptualization of stigma (Pescosolido et al. 2008; Link & Phelan 2001; Scambler 2006; Parker & Aggleton 2003; Staples 2011a). Staples clearly describes the relevance of context. He focuses on the intra or interpersonal level and states:

Put simply, we need to understand the everyday life worlds within which people stigmatise and are stigmatised, because, contrary to how stigma might be presented as a constant, it is not something uniformly applied to leprosy affected people across different contexts. At different stages of the life cycle and within different networks of relationships discrimination takes different forms. (Staples 2011a:92)

Link and Phelan (2001) and Parker and Aggleton (2003) also acknowledge the importance of context, but focus on a different level with concepts as history, culture and power. Link and Phelan, state that stigma is dependent on social, economic and political power. Parker and Aggleton note:

It is vitally important to recognize that stigma arises and stigmatization takes shape in specific contexts of culture and power. Stigma always has a history which influences when it appears and the form it takes. (Parker & Aggleton 2003:17)
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Hence, both the dynamics at the intra and interpersonal level as well as the aspects of history, culture and power influence the experiences of stigma.

2.1.6 Concealment versus disclosure
A fundamental dimension of stigma concerns the degree to which the disease or condition can be concealed (Bos et al. 2013) and whether disclosure is voluntary or involuntary (Stutterheim et al. 2011). Concealment and disclosure influence the experiences of the disease in many domains of people’s lives (Chaudoir & Fisher 2010) and are important concepts used in several chapters in this thesis. Goffman wrote:

Does the stigmatized individual assume his differentness is known about already or is evident on the spot, or does he assume it is neither known about by those present nor immediately perceivable by them? In the first case one deals with the plight of the discredited, in the second with that of the discreddable. This is an important difference. (Goffman 1963:4)

Interestingly, some people affected by leprosy can conceal their disease, while for others the disease is evident. Sometimes the disclosure is voluntary and sometimes involuntary. The relevance of concealment for leprosy specifically is illustrated in the studies by Kaur and Ramesh (1994) and Vlassoff (1996) in India and by Heijnders in Nepal (2004). The latter study revealed the concealment strategies of people affected such as telling stories, avoiding situations or temporary withdrawal. Individuals who manage to conceal a stigmatized condition face stress and psychological challenges as shown in studies on HIV/AIDS (Pachankis 2007; Stutterheim et al. 2011). Pachankis (2007) calls for more research in this field as his study suggests that “there are unique consequences of possessing a concealable stigma that are not necessarily shared by individuals who possess a visible stigma” (page 341). Also Chaudoir and Fisher (2010) state that it is imperative that researchers “understand the conditions under which disclosure can lead to beneficial consequences and those that can lead to detrimental ones” (page 252).

2.1.7 Agency
People living with a stigmatized disease or condition are sometimes portrayed as an object, as passive or as victims (Howarth 2006), whereas they do make active responses to their stigmatization (Misir 2013). Howard (2006) underlines the importance of acknowledging how stigma acts to deny agency and she suggest to re-assert agency in stigmatized relationships. In line, Misir (2013) draws attention to the downplaying of the knowledge and capabilities of stigmatized individuals in both individual as structural models of stigma. His work focuses on HIV/AIDS stigma, but this seems equally valid in the field of leprosy. He notes that:

Actors are knowledgeable about their culture and capable to act and resist; this understanding of action theory, therefore, makes PLHA [people living with HIV/AIDS] agents who are part of a human agency. (Misir 2013:5)
To be able to acknowledge the capacity to act in this thesis, I will discuss in more depth the concepts of agency and structure. Giddens work on structuration theory has been influential in sociological research (Giddens 1979; 1984). According to Giddens, actors and structure (traditions, institutions, moral codes, established ways of doing things) are in a dialectical relationships; inseparable and mutually dependent. Actors and the way they act are influenced or empowered by structure, and the repetition of individual acts reproduces social structure. Valuable in the context of this thesis is the possibility for change, as Giddens believes structure can be changed when people start to ignore facets of the structure, replace them or reproduce them differently. This is, however, very difficult and happens largely unconsciously.

There has been a long-standing debate among scholars on how to define agency. I took the work of Ortner (2006) as the analytical basis in this thesis. She wrote that agency in an abstract sense might seem to be a property of social subjects: “Some people get to ‘have’ it and others not; some people get to have more and others less” (page 151). But that in fact agency – in her view – is not a thing in itself, nor is it equivalent to the capacity of individuals to act independently or the exercise of free choice. In contrast, Ortner underlines that agency is part of a process and that social subjects are embedded “in the webs of relations that make up their social world” (page 152) and in that sense, social subjects act never fully free or independent. Ortner adds that it useful to distinguish between what she calls “agency of power” and “agency of projects” (page 151).

Both the agency of power and agency of projects are relevant for understanding how people respond to stigmatization.

2.2 Assessing stigma

Stigma theories influence the way stigma is assessed “by determining the content of stigma assessments and thereby identifying what lies within the stigma construct” (Yang et al. 2007:1531). Measuring stigma is challenging (Cross et al. 2011a), but important. The importance is clearly summarized by Link et al., they stated:

The effectiveness of any such efforts [initiatives to combat stigma and discrimination] will rest on our ability to understand stigma processes, the factors that produce and sustain such processes, and the mechanisms that lead from stigmatization to harmful consequences. Essential to the scientific understanding of stigma is our capacity to observe and measure it. (Link et al. 2004:511)

To understand how leprosy-related stigma affects the lives of people affected or associated with the disease, it is essential to obtain perspectives from multiple participants and to use multiple methods. Multiple informants are necessary according to Yang et al. (2007), because single informants may be inadequately aware of how other actors
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perceive leprosy. For example, stigmatized individuals may be scantily aware of the views of community members and vice versa. In addition, multiple mixed methods are favoured by several scholars (Van Brakel 2006; Bos et al. 2013; Yang et al. 2007), but currently quantitative methods are more frequently used to assess stigma than qualitative methods. Link et al. (2004) in their review on methods to assess mental illness stigma found that quantitative methods were the most common type of research method used (76.3%), followed by studies applying qualitative methods (13.8%). Also, the review of Van Brakel on measures to assess health-related stigma described only three (out of 63) studies that used qualitative methods (Van Brakel 2006). Options for qualitative methods include participant observations, in-depth interviews and focus group discussions (FGDs) (Staples 2011b; White 2008; Harris 2011; Varkevisser et al. 2009). Options for quantitative methods include scales of which several have been developed. Frequently used scales to assess aspects of health-related stigma are SDS (Link et al. 1987), EMIC-CSS (Weiss 1997), P-scale (Van Brakel et al. 2006), Berger stigma scale (Berger et al. 2001) and Internalised Stigma of Mental Illness scale (Ritsher et al. 2003).

For the study described in this thesis several qualitative methods and the EMIC-CSS and SDS were selected as promising tools. These two scales were, however, not yet culturally validated in the study context. The framework for cross-cultural equivalence testing used in this thesis to test the validity of these two scales, draws on the work of Herdman et al. (1998; 1997), Terwee et al. (2007) and Stevelink and van Brakel (2013). In Chapter 9 this framework is discussed in more detail.

2.3 Stigma-reduction theory

Stigma-reduction interventions can address this complex and persistent problem of stigma. Stigma-reduction theory is not well developed. Parker and Aggleton (2003) noted that existing stigma theories are of little use in the design of effective programmes and interventions. Likewise, Bos et al. (2013) argue that stigma interventions are lacking sound theory and methodology. In her work on racial stigma, Howarth even questions whether “a dominant regime of stigma [can] be challenged, contested and changed” (2006:449). She argues that there is room to “unsettle, challenge and potentially transform representations and practices that stigmatize” (page 448), but that this can only be done through a collective enterprise, through coming together in dialogue and debate. She underlines the importance of agency. This chapter’s conceptualization of stigma as a complex and persistent problem has implications for stigma-reduction interventions. What scholars know or have hypothesized is that understanding the local context, addressing the underlying causes of stigma and multi-level and multi-faceted approaches will facilitate the reduction of stigma. I address all three in more detail below.

2.3.1 Understanding stigma in the local context

Yang et al. (2007) underline the importance of understanding everyday lives for stigma-reduction and also draws attention to understanding the local setting. They stated:
Although stigma may share features across contexts, what is most at stake in local settings constitutes the receptive field that shapes how stigma is felt. Rather than prescribing interventions without knowledge of their local effects, focused interventions based on observation of the everyday lives and the actual difficulties that stigmatized individuals face may better address how stigma threatens what is fundamentally at stake. (Yang et al. 2007:1533)

Opala and Boillot described the failure of certain public health campaigns in Sierra Leone and also encourage the understanding of worldviews:

[Health professionals] may succeed at altering people’s behaviour to some extent by introducing dramatically effective drugs, or by directing health education efforts to ‘progressive’ people already open to outside influences, but as long as the traditional world view persists largely unaltered, some changes in behaviour are very difficult to effect. The only way health workers can overcome those limits is by appealing to their patients within the framework of their world view – by shaping a message consistent with their traditional way of thinking. (Opala & Boillot 1996:17)

So, in efforts to reduce stigma, the perceptions, ideas and opinions of a diversity of local stakeholders should be the starting point. Different worldviews and mind-sets will help in appreciating and taking into consideration the complexities the concept of stigma poses. Chambers (2010) describes several general factors contributing to mindsets, and understands that mindsets are informed by:

- Training, education, professional norms, ideology and personal life experiences.
- Paradigmatically, it interacts with (influences and is influenced by) concepts and ontological assumptions, values and principles, methods, procedures and processes, roles and behaviours, and relationships. (Chambers 2010:7)

Within the factor personal life experiences fall one’s personal, perhaps, lived experience of disability and stigma.

2.3.2 Addressing the causes of stigma

Parker and Aggleton underline the importance of starting with an understanding of the “deeper social, political and economic causes of stigma and stigmatization” when designing stigma-reduction interventions (2003:21). Likewise, Link and Phelan state that any approach must address the fundamental causes of stigma. The approach:

- Must either change the deeply held attitudes and beliefs of powerful groups that lead to labeling, stereotyping, setting apart, devaluing, and discriminating, or it must change circumstances so as to limit the power of such groups. (Link & Phelan 2001:381)
The causes and reasons of stigma are often different between conditions and sometimes even for one condition across different cultures. Rao studied the differences and similarities of causes between conditions and stated:

While the experienced or enacted stigma may be the same for all health related stigma, in terms of isolation, discrimination and social participation restrictions of the affected persons; the concept and origin of stigma varies from one disease to another. An understanding of the cause of stigma is, therefore, essential to formulate effective strategies for its reduction or elimination. (Rao 2010:117)

This is particularly relevant for the content of, for instance, education messages or the testimonies, which need to address different issues for different diseases.

2.3.3 Multi-level and multi-faceted approaches
Heijnders and van der Meij (2006) identified five levels at which stigma-reduction interventions can address stigma, each with its own aim as illustrated in Table 2.2. The intrapersonal level is the micro level mentioned earlier, the interpersonal and community level connect to the meso level, and the organizational, institutional, governmental and structural to the macro level.

<table>
<thead>
<tr>
<th>Levels for stigma reduction</th>
<th>Stigma-reduction interventions at this level aim to:</th>
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<tbody>
<tr>
<td>Intrapersonal</td>
<td>Change individual characteristics such as knowledge, attitudes, behaviour, self-concept; improve self-esteem, coping skills, empowerment and economic situation.</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>Establish relationships between members of the patient’s interpersonal environment (family, work environment, friendship network).</td>
</tr>
<tr>
<td>Community</td>
<td>Increase knowledge regarding health conditions and stigma, increase community development skills and develop support networks within specific groups.</td>
</tr>
<tr>
<td>Organizational and institutional</td>
<td>Change to modify health and stigma-related aspects of an organization.</td>
</tr>
<tr>
<td>Governmental and structural</td>
<td>Enforce the protection of rights of people affected with a stigmatizing illness.</td>
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</table>

It is increasingly recommended that, to be successful, stigma-reduction interventions should be oriented towards multiple levels and facets (Heijnders & van der Meij 2006; Brown et al. 2003; Cross et al. 2011a; Link & Phelan 2001). Link and Phelan even state that positive outcomes of a programme that focuses on one specific behaviour and group will erode over time. This is because:

There exists a flexible package of mutually reinforcing mechanisms linking the
attitudes and beliefs of dominant groups to an array of untoward outcomes for stigmatized persons. (Link & Phelan 2001:381)

In sum, the above has shown that stigma is a complex and persistent problem, which can be studied from different angles. Scholars have articulated different types of stigma, different levels at which stigma operates, different components, their inter-relatedness and different causes of stigma. They have also underlined that stigma is context-specific, how concealment can influence it and articulated the importance active responses to stigmatization (see Table 2.3 for an overview). Vital to the understanding of leprosy-related stigma is our capacity to assess it. It is essential to obtain perspectives from multiple participants and to use multiple methods. Finally, I hypothesize that understanding leprosy-related stigma in the local context, addressing the causes of stigma and multi-level and multi-faceted approaches are essential for stigma-reduction interventions.

Table 2.3
Overview theories concept of stigma

<table>
<thead>
<tr>
<th>Categorizations, mechanisms or related concepts</th>
<th>For example:</th>
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<tbody>
<tr>
<td>Types of stigma</td>
<td>Perceived, internalized, enacted, endorsed, accepted</td>
</tr>
<tr>
<td>Levels at which stigma operates</td>
<td>Individual (micro), social (meso), structural (macro)</td>
</tr>
<tr>
<td>Components of stigma</td>
<td>Labelling, stereotyping, separation, status loss and discrimination</td>
</tr>
<tr>
<td>Causes of stigma</td>
<td>Beliefs about causation, external manifestations, fear of transmission, perceived death sentences, associations, public health interventions</td>
</tr>
<tr>
<td>Context</td>
<td>Everyday life of individuals but also culture, history and power</td>
</tr>
<tr>
<td>Interrelatedness</td>
<td>Multiple stigma mechanisms and multiple stigma outcomes</td>
</tr>
<tr>
<td>Concealability</td>
<td>Voluntary and involuntary disclosure</td>
</tr>
<tr>
<td>Agency</td>
<td>Active responses to stigmatization, agency of power and agency of projects</td>
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