SUMMARY

When people are confronted with symptoms or complaints of a disease, various ideas and beliefs start to arise, such as; ‘what does this mean?’, ‘what caused it?’, and ‘how long will it last?’ These personal and subjective beliefs are referred to as illness perceptions, and are known to be related to the way people respond to the illness e.g. ignore the symptoms, seek treatment or not. The first part of this dissertation focused on the role of illness perceptions in explaining delay in seeking treatment among individuals at risk for Buruli ulcer (chapter 2), as well as among tuberculosis patients (chapter 3). Delay is a common and serious problem in these patient groups, and one of the main challenges for national programs fighting these diseases. We examined the role of illness perceptions in explaining delay in Buruli ulcer and tuberculosis, quantitatively, by taking into account the factors that have previously shown to be related to delay.

The second part of this dissertation focused on the treatment for patients affected with Mycobacterium ulcerans. These patients are often admitted to the hospital or specialized treatment center for a long period of time. Treatment includes the dressing changes 2-3 times weekly, daily physiotherapy, and antimicrobial treatment. Despite the fact that Buruli ulcer is described in the literature as a painless condition, this repetitive procedure is observed to cause pain; perhaps not for all, but surely for some of the patients. Since clinical studies on the pain experience of Buruli ulcer patients during wound care are currently lacking, this was examined from a patient perspective (chapter 4) as well as a professionals’ perspective (chapter 5).

Clinical researchers are well aware that in order to conduct proper research, a good-quality measurement instrument is essential, since this is related to valid and reliable outcomes and meaningful relationships. On the other hand, a poor quality instrument complicates the interpretation of results and comparison of results between groups, between individuals, or within individuals at different time points. This is especially important when the assessment is performed in less frequently studied populations, such as individuals from rural areas in Sub-Saharan Africa. It could be that cultural factors influence the outcome of measurement. Therefore, the third focus of this dissertation was on the psychometric properties of the Center for Epidemiologic Studies Depression scale.
(CES-D) (chapter 6) and the Pearlin Mastery scale (chapter 7) in a Sub-Saharan African group.

Part 1: Delay in seeking help for Buruli ulcer and tuberculosis

A large group of healthy people at risk for Buruli ulcer from Benin were interviewed about their perceptions on Buruli ulcer, and their potential future delay behavior (chapter 2). We showed that individuals’ illness perceptions were important in explaining delay in presenting to the hospital. We found that people who perceived Buruli ulcer to have a chronic timeline, people who perceived treatment as effective, or people who perceived high control over the disease, had a higher probability of delay. This was found while taking into account previously established socio-demographic and patient factors. Explanation for these findings could be that people who believe an illness to be chronic are more likely to attribute it to causes such as health habits, while people who believe an illness to be acute are more likely to see a virus or bacterial agent as the cause. Furthermore, the overall difficulty of finding effective treatment is an important factor for the late arrival at treatment centers. Thirdly, people who perceive more personal control are more likely to take a situation into their own hands, decide to seek help in alternative treatment or engage in self-medication and therefore, delay in presenting in the hospital.

In chapter 3, a group of newly diagnosed tuberculosis patients from the Kano region in Nigeria was interviewed about the perceptions on their illness, and delay in seeking treatment at the appropriate treatment facility. It was shown that 25% of the patients delayed less than four weeks, 37% delayed four to 12 weeks and 38% delayed more than 12 weeks. Patients perceived their tuberculosis to be acute, and felt highly in control of their illness and treatment. Patients did not fully understand their illness, and associated it with many negative emotions. Causes of tuberculosis such as ‘from God’, ‘taking cold drinks’, and ‘air pollution’ were often mentioned. The majority of patients used two to three other types of treatment before going to the hospital; mostly the Patent Medicine Vendor, self-treatment, herbalist, or mosque. Patient delay was related to unemployment and perceiving negative emotions about the illness. Results of these studies provide directions for future prospective, longitudinal studies or intervention studies, as well as tools for program managers and health care providers in charge of
designing prevention campaigns, aimed at reducing delay in these patient populations (see chapter 2 & 3).

**Part 2 Pain in Buruli ulcer**

In chapter 4, we focused on pain during wound care in Buruli patients. It was shown that pain experienced by the patients during wound care, was low on average, and declined over time after wound care. However, while severe pain scores (scores >6) were reported in almost 30% of the patients, only one patient received pain medication prior to wound care. Higher pain scores were reported by male patients, and by patients who reported fear prior to treatment, pain during the night, or pain caused by cleaning of the wound. It can be concluded that in contrast to the literature describing Buruli ulcer as a painless condition, patients actually experienced pain, for which attention and appropriate intervention should be developed. Future studies could explore possibilities for pharmacological and non-pharmacological interventions to reduce pain. In addition, future studies could be focused on the effect of fear on pain, and examine the development of pain throughout the treatment period.

Secondly, we turned the perspective from the patient towards the health professional. In addition, we reviewed a large number of medical records from Buruli ulcer patients on the prescription of pain medication (chapter 5). Professionals treating patients with Buruli ulcer reported an increase in pain after wound care, which goes hand in hand with the experiences of the patients described in chapter 4. The professionals mentioned several factors regarding the current practice on pain assessment and treatment, which could be important for a future guideline development. Professionals were willing and motivated to improve pain management, and saw the usefulness of developing a standardized clinical practice guideline for pain. Furthermore, in 84% of the reviewed medical records, pain medication was prescribed. Simple analgesics were mostly prescribed, while weak and strong opioids were rarely prescribed, and a large proportion of prescriptions was without an indication. Thus, it is possible that mild pain medication is used for severe pain. It is important to discuss and take into account these factors when preparing and developing a clinical practice guideline for pain management in Buruli ulcer.
Part 3: the psychometric evaluation of clinical scales in Sub-Saharan Africa

After these studies, we also wanted to emphasize the importance of using appropriate and psychometrically sound measurement instruments in our study groups. First, we focused on the CES-D in a study group from Benin and Ghana (chapter 6). It was shown that 17 out of the 20 CES-D items were informative in measuring depressive symptoms. Item 7 ‘I felt that everything I did was an effort’, item 8 ‘I felt hopeful about the future’, and item 15 ‘people were unfriendly’, were less informative in describing the latent trait (depressive symptoms). Reasons for the items to be uninformative could be a possible irrelevance of the content of the item (item 7), the orientation on the future (item 8), or its referral to other constructs such as social competence (item 15). The results in the Sub-Saharan African group were comparable to a Dutch control group, except for the result on item 7. We therefore conclude that, despite large differences in socio-economic, educational, and cultural background between the Dutch group on the one side, and the Beninese and Ghanaian group on the other side, 17 out of the 20 CES-D items were informative in measuring depressive symptoms in both groups. Thus, the CES-D is - with minor adaptations - appropriate to use in Benin and Ghana.

Secondly, the Pearlin mastery scale, measuring a sense of internal personal control, was analyzed psychometrically in four Sub-Saharan African groups. Chapter 7 showed that a new scale, formed by four out of the seven items of the original scale was informative in measuring a lack of internal control in the Sub-Saharan African study groups. This scale included all negatively formulated items, which typically measure a lack of internal control. The rest of the items appeared to be uninformative in describing the latent trait. It is remarkable that two of the non-informative items; item 4 ‘I can do just about anything I really set my mind to’, and item 6 ‘What happens to me in the future mostly depends on me’, were positively worded and typically measure the presence of internal personal control. These two items were also non-informative in the Dutch group. In addition, the negatively formulated item 7 ‘There is little I can do to change many of the important things in my life’ was uninformative only in the Sub-Saharan African group. A possible explanation for item 7 is that this is a more abstract item, referring to a more global issue in life, which might have been less meaningful to
the respondents. Concluding, the Pearlin mastery scale may rather be used as a 4-item version in Sub-Saharan Africa measuring a lack of internal control.

Overall, this thesis provided new data and novel insights on factors related to; delay behavior for Buruli ulcer and tuberculosis; current practice on pain treatment Buruli ulcer from a patients’ perspective, a professionals’ perspective and from information derived from medical records; and the quality of two psychological measurement instruments when they are used among people from Sub-Saharan Africa. Future research is encouraged to build on these findings, in order to -eventually- arrive at evidenced based clinical practice on psychological factors involved in health in this part of the world.