Psychological factors related to Buruli ulcer and tuberculosis in Sub-Saharan Africa
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Publication date:
2015

Citation for published version (APA):
CHAPTER 8

GENERAL DISCUSSION
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This thesis focused upon psychological factors involved in health in the field of two communicable diseases - Buruli ulcer and tuberculosis - in four different countries in Sub-Saharan Africa, namely, Benin, Ghana, Nigeria and the Democratic Republic of Congo. As a first psychological factor, people’s perceptions on illness were examined. We investigated whether certain illness perceptions would affect delay in seeking help for symptoms of Buruli ulcer, or tuberculosis. Second, we studied pain experienced during Buruli ulcer treatment, both from a patient perspective and from a health professionals’ perspective. Third, the psychometric properties of two clinical scales were examined, as these are important for general health, and hence its application in Sub-Saharan African samples was tested. This final chapter reflects on the main findings from this research, followed by the clinical and/or theoretical implications of these findings. Given the different scopes of the three parts of this thesis, in part 1 and 2, the focus was on clinical implications and suggestions for future research in these populations. The third part has implications that impact theoretical and methodological issues.

Main findings and implications

Part 1: Illness perceptions and delay in Buruli ulcer and tuberculosis

The results from the first part of this thesis showed that individual’s illness perceptions were important in explaining variance in pre-hospital delay. This was found beyond and in addition to previously established socio-demographic, and patient factors (e.g. sex, age, religion, ethnicity). These results were found both in healthy individuals at risk for Buruli ulcer (chapter 2), as well as among newly diagnosed tuberculosis patients (chapter 3).

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. These relationships are generally known to exist between illness perceptions and health behavior. However, our finding that a high perceived control over the disease was related to more delay was in contrast with previous studies, showing that higher personal control over a disease is generally related to adaptive outcomes. An explanation for the reverse relationship found in our study, is that individuals who perceive
their condition as controllable, do not feel urged to seek treatment immediately. Another explanation is that these individuals are more likely to take charge, and decide to seek help using another type of treatment such as alternative treatment or self-medication, and therefore delay in presenting at the hospital.

This last explanation is supported by findings from chapter 3, where we showed that the vast majority of newly diagnosed tuberculosis patients seek help by taking refuge to alternative types of treatment before presenting at the hospital. This was mostly a Patent Medicine Vendor, self-treatment, the herbalist, or the mosque. A small proportion of patients (18%) did not choose alternative treatments before presenting to the hospital. The most important predictors for delay in presenting at the hospital were, being unemployed, and perceiving negative emotions about the disease.

The relationship between delay and unemployment suggests that the patients faced inequitable barriers to care, depending on their employment status. This is relevant in Nigeria, where the unemployment rate is very high. The relationship between negative emotional representations and delay is in line with previous studies; negative emotions (e.g. worries about the illness) are known to enhance dysfunctional coping mechanisms, such as avoidance or suppressing feelings and communication, potentially resulting in a prolonged delay.

It should be noted that these relationships were found in cross-sectional studies, limiting the possibilities for causal implications. Especially for the significant relationship between emotional representations and delay in tuberculosis patients, it could as well have been that those patients who perceived the most negative emotions, did so because they delayed the longest period of time.

Two studies used a different perspective, which might have led to differences in findings. The tuberculosis patients who were recently diagnosed with the disease, were asked about perceptions and emotions which appeared at real stake, while the healthy people at risk for Buruli ulcer, had to imagine possible future perceptions and emotions, because they responded to a hypothetical situation. Accurately estimating emotions in a (future) hypothetical situation is known to be very difficult. This could have been the reason why negative emotional perceptions were related to delay in the tuberculosis patients, but not in the people at risk for Buruli ulcer.
Overall, it remains difficult to explain how illness perceptions are related to delay. Previous studies suggested that illness perceptions may not be related to health behaviors uniformly across individuals. Instead, representations may influence behavior at an individual level, resulting in inter-individual differences. For example, for one person, the negative emotions about tuberculosis may facilitate problem focused behavior, leading to an early presentation at a health facility. For another person, negative emotions about having tuberculosis may have a detrimental effect on problem solving behavior, and may therefore result in avoidance and denial of the problem. This could explain why some of the results on the relationship between illness perceptions and delay seem counterintuitive.

Clinical and research implications

The results of these two cross-sectional studies provide a starting point for future studies. According to ‘the increased levels of scientific evidence’, these relationships should first be examined in longitudinal studies, or studies using a prospective (cohort) design. Delay has many negative consequences, such as a worse prognosis, prolonged treatment, and more costs. Moreover, there are practical challenges in designing a prospective cohort study in which people with illness complaints are followed over time. It therefore seems more efficient and appropriate to focus on intervention studies, aimed at using and optimizing existing educational health campaigns.

A discussion on illness and treatment beliefs could be included into these existing campaigns, in order to raise awareness and address dysfunctional illness beliefs. Such studies could provide new insights for program managers and health care providers to develop practical interventions to reduce delay. Another practical implication is to improve the collaboration with traditional healers, herbalists, and with Patent Medicine Vendors in Nigeria. From the results of chapter 3 on delay in tuberculosis, we found that the Patent Medicine Vendor is often the preferred treatment by tuberculosis patients in Nigeria. One other possibility could be to collaborate with these vendors in educational health campaigns, and focus upon and encourage patients to present to official treatment centers in addition to other preferred treatments. This would imply that health care providers would collaborate with these informal treatment providers, to raise awareness, and thereby shorten possible delay. Programs to improve collaboration should be
carefully designed and organized with formal health care providers to prevent frictions and conflicts.

Part 2: Pain during the treatment of Buruli ulcer

In the second part of this thesis, the experience of pain during wound care in Buruli ulcer patients was examined from two perspectives: a patients’ perspective (chapter 4) and a health professionals’ perspective (chapter 5). Patients were interviewed about their pain experience, and health professionals involved in treatment for Buruli ulcer were interviewed about; their perceptions on pain, the current practice with respect to pain management, and the need for a clinical practice guideline for pain management. This is important information, because currently, there are no studies reporting on pain during wound care in this patient group, and there is no information on pain assessment during treatment of Buruli ulcer.

Pain from a patients’ perspective

Pain was reported during and after wound care, and was generally in the midrange, with large variability between patients. Nearly 30% of patients reported high pain scores, while only one patient received pain medication. Pain scores declined over time towards very low scores two hours after treatment. Higher pain scores during treatment were related to pain during the night and pain caused by cleaning the wound. In addition, male patients, and patients who reported fear prior to treatment were more likely to report higher pain scores during treatment.

Pain from a professional’s perspective

Professionals treating Buruli ulcer patients also observed an increase in pain during and after wound care. They were willing to improve pain management, and admitted that it would be useful to develop a clinical practice guideline for pain management. Professionals mentioned several aspects of current pain management, which could potentially increase the success of future guideline implementation, notably, the extensive efforts to accurately assess pain, and the use of the basic principles of the WHO pain ladder. Furthermore, professionals reported to use different strategies to help their patients to cope with pain, such
as counseling (providing information, reassurance, showing empathy) and giving advice. The discrepancy between professionals and patients about pain relief during hospitalization was an important aspect of current pain management that could potentially impede the success of a future guideline implementation. Patients expected to be free of pain, which was unrealistic according to the health professionals. Furthermore, difficulties in assessing and treating mild pain were mentioned, which could both be related to the suppression of pain expression by patients, as well as the Ghanaian culture on the suppression of pain expression. Lastly, the minimal and mild prescription of pain medication, the lack of availability of pain medication, and the lack of a standardized pain treatment were the most important factors that were mentioned.

Research and clinical implications

It should be noted that these conclusions are based on only two, small scale, cross-sectional studies executed in a selection of Buruli ulcer treatment centers. More information is needed, from larger studies, both from a patients’ perspective as well as a professionals’ perspective. Previous studies suggested a recovered sensation at more advanced stages of the treatment process. This suggestion warrants more investigation from clinical studies, using a longitudinal design in order to examine the prevalence and intensity of pain over time, by taking into account patient-, and disease characteristics, and treatment interventions (e.g., antibiotic regimen, surgery, skin graft). Furthermore, the currently minimal and mild prescription of pain medication provides directions for future studies, to examine possible pharmacological interventions to reduce pain. It was also shown that the wound care procedure was associated with fear, which is in line with literature reporting that the anticipation of undergoing painful procedures may elevate fear or anxiety in patients, which increases pain [1,2]. Generally, a moderate to strong relationship is found between fear and pain [3]. Possible future studies are needed in order to disentangle the effect of fear on the reported pain scores by patients. In addition, the options for non-pharmacological interventions to reduce fear prior to treatment could be explored in future research. There is a large variety of non-pharmacological interventions available from the treatment of burns, such as providing information, educating the family, learning positive self-talk, use distraction, and
providing rewards. These interventions could be tested on the effect of reducing pain and fear in this specific patient population and context.

The outcomes of these studies show that the general idea that BU is painless seems incorrect for the wound care procedure. This procedural pain deserves attention and appropriate intervention. This information could be used to develop a clinical practice guideline for pain in Buruli ulcer. A recommended first step [4,5] in guideline development is to discuss the findings of the interviews with experts in the fields of wound treatment and pain management, as well as with local professionals treating Buruli ulcer. Specific issues that could be addressed in this discussion are; how to recognize and treat mild pain, how to deal with the suppression of pain expression by patients, and how to handle discrepancies in expectations about pain relief between patients and professionals. After implementing a draft version of the guideline, quality assessment is needed to evaluate the quality of implementation.

Part 3: The psychometric evaluation of the CES-D and the Pearlin mastery scale

In the third part of this thesis, a first step was taken in examining the cross-cultural validity of two clinical measurement instruments. These were the Center for Epidemiologic Studies Depression scale (chapter 6) and the Pearlin mastery scale (chapter 7), which were examined on their item and measurement functioning using Item Response Theory (IRT). IRT is a method that has several advantages over Classical Test theory methods such as Exploratory Factor Analysis and reliability analysis (Cronbach’s alpha). For example, IRT provides a more accurate estimation of reliability, as well as more detailed information about the unidimensionality and internal consistency of a scale. Moreover, reliability can be estimated for different values of the latent trait, and additional information such as the effectiveness of answering categories, can be provided.

**Item and measurement functioning of the CES-D**

In chapter 6, it has been shown that most items of the CES-D (except for three items) were informative in measuring depressive symptoms among healthy individuals from Benin and Ghana. In other words, most items were useful in distinguishing individuals with severe levels of depressive symptoms from individuals with mild levels of depressive symptoms. These results were similar to
a healthy Dutch control group, except for one item, that was only informative in
the control group. The similarities between the Sub-Saharan African group and
the Dutch group for the majority of the CES-D items was found despite the large
differences in socio-economic, educational, and cultural background. The results
of this study suggest that with minor adaptations, this psychological measure,
developed and used in western countries is appropriate for use in Sub-Saharan
Africa.

There is an ongoing discussion on the use of reversed oriented or formulated
items in clinical scales, since it can lead to several types of bias [6]. In order to
prevent this, alternative CES-D versions have been proposed in which the
reversed scored items were removed [7-9]. Our study showed that respondents
indeed more easily endorsed the positively formulated items of the CES-D than
the negatively formulated items. This is reflected in the high mean item scores
(after reversing) compared to the negative items. Consequently, the positively
formulated items had a relatively great impact on the total depression score.
However, our results also showed that three out of four positive items were
informative in measuring depressive symptoms. Thus, simply removing all positive
items seems too rigorous.

**Item and measurement functioning of the Pearlin mastery scale**

We found that four out of the seven items from the Pearlin mastery scale (items
1, 2, 3 and 5) were informative in measuring personal control among the
participants from Benin, Congo, Ghana and Nigeria, while three items (item 4, 6
and 7) were found to be uninformative. Results were almost similar for the Dutch
control group, except that item 7 was informative in the Dutch group, but not in
the African group.

The four informative items were negatively formulated, and typically measured a
lack of internal control, while two of the uninformative items were positively
formulated, and typically measured the presence of internal control. This could
have been a reason why the four informative items fitted well and were
informative in describing the latent trait in both the African and the Dutch group.
A possible reason that the negatively formulated item (item 7) did not fit well with
the other negatively formulated items in the African group, is that the content of
the item is more abstract, and refers to bigger life issues than the other negatively
formulated items. It could be that this way of framing is less meaningful to the respondents in the African group.

Previous studies emphasized the cross-cultural variability in the salience, manifestation, and expression of depressive symptoms [10-12] and personal control [13]. In contrast to these findings, our studies suggest a high level of agreement in item and scale functioning for both scales, among two culturally different groups. This suggests that item and measurement functioning is less likely to be influenced by cultural differences than reported previously. It should be noted that these conclusions are based on first, small scale studies, and that replication and the testing of other aspects of the validity (external validity) and reliability (test-retest reliability, floor & ceiling effects, and responsiveness) is needed in future studies.

Research and clinical implications

We found that both scales can be used in the studied populations, in an adapted form. However, gaining more insight into the conceptual equivalence of these scales is needed, in order to examine whether all characteristics of the concept which are relevant in the specific context, have been included in the instrument. In addition, the external validity, i.e., the relationship between the construct and other, related constructs, would be an interesting avenue for future research. This is especially interesting for the constructs of depression and personal control, because previous studies showed a high personal control to be beneficial for people’s wellbeing and quality of life. A lack of perceived control is generally related to psychological distress, however, this is perceived from an individualistic viewpoint. Some studies indicate that among members of collectivistic cultures, low internal control is not related to greater psychological distress. Rather, people may still consider that they are in control through an active adaptation to the environment [13]. An alternative explanation is that the observed cultural differences are related to differences in economic circumstances, such as material resources and education [14,15]. This could be explained by the use of a wider range of daily activities, and consequently, more engagement in activities that increase a sense of control by individuals with more material resources and higher educational background. On the other hand, in a lower socioeconomic environment, people are confronted with more uncontrollable situations and
more conflicting relationships, which might lead to a decrease in personal control [16]. A suggestion for future research could be to examine the relationship between depressive symptoms and personal control in more collectivistic cultures such as in sub-Saharan Africa [17], and compare the results to an individualistic culture such as the Netherlands.

REFLECTIONS ON THIS RESEARCH PROJECT

Throughout the design and the data-collection of these studies, several issues about methodology, concepts and operationalization emerged, as well as more ethical issues. In the section below, we will reflect on the most important issues during this research project.

Conceptual and semantic issues

For all scales used in this project, the appropriateness of the measures was discussed with local medical doctors and interviewers. During this process, some misunderstandings of concepts emerged. For example, despite the exclusion criteria of ‘not being treated for any kind of disease at the moment’, it appeared that many respondents suffered from diseases. Especially renal disease was commonly reported, which appeared be a conceptual misunderstanding by the respondents (renal disease was confused with lower back problems). Furthermore, some questionnaires did not cover the entire concept, for example, in the IPQ-R part on causal perceptions, causes such as contaminated water, walking in the mud, aquatic worms, poor hygiene and witchcraft appeared to be important, and were therefore added to the original IPQ-R.

The translation of the questionnaires in countries in which the official language is French or English, but the mostly used languages are the local languages, was important. The English versions of scales were manually translated into French by a medical doctor who is expert in BU treatment (G.S.). This translation was checked after the pilot study, with the interviewers and the Beninoise medical doctors (G.S., Y.B.). We did not use the official French translation of the questionnaire, because of some linguistic differences between the official French translation and the African French dialect. For example, some expressions were too official, e.g. the CES-D item ‘I felt fearful’ is officially translated into ‘Je me suis senti(e) craintif(ve)’, however, for Benin, it was translated into ‘j’avais peur’.
General Discussion

Questionnaires were orally translated from English or French into the local language. During this process, other challenges appeared, for example, that there was no appropriate word for ‘stress’ in the Fon language. A description was therefore developed together with the interviewers.

Operationalization in the field setting

It was decided to use a semi-structured interview instead of a questionnaire because of the relatively low literacy rate in our study populations. We worked together with interviewers, which were selected in collaboration with the local research team, based on their educational background, interview experience, and cultural background. It was desired that the interviewers had a background in social sciences, and that they lived in the country where the study was conducted but not in the exact area where the interviews were held, because we were told that respondents can sometimes be more reluctant to share personal information with someone from the same village. During an interview training, cultural factors were discussed, such as whether it was appropriate to interview in a one-on-one setting.

Furthermore, during one of the pilot interviews (on illness perceptions and delay), it appeared to be important to systematically repeat the Likert scale answers possibilities after each three to five questions, to remind the respondent about possible answering categories. After this pilot study, a discussion was held on the use of Likert scales, in which the interviewers appeared convinced that the respondents understood the answering possibilities.

Finally, it was important to conduct the interviews in a quiet and private setting, since people were often around, and sometimes interrupted or participated in the interview. When interviewing in a village setting, it appeared not to be helpful when the research team attracted a lot of attention during the visit, because it led to crowdedness and excitement. It was therefore decided not to arrive by car but by motorcycle, and not walk around in the village during a visit.

Psychological scales developed in westernized countries, used in sub-Saharan Africa

In all parts of this thesis, the validity of concepts, measured by scales which were developed and used in westernized countries, was an important issue. A question that we started to answer, and that remains to be further clarified by future
studies, is whether concepts such as pain, illness perceptions, depression and personal control are experienced in a similar way, and have a similar meaning to people in non-western cultures. There is ongoing discussion in the literature about the extent to which these concepts are context-dependent; to what extent are these concepts embedded in an individual's personality; and what is the cultural and societal influence on these concepts. Of course, this discussion is different for each of the aforementioned concepts; for example, illness perceptions are highly influenced by environmental and cultural factors, and although this also holds for depression and personal control, the latter two concepts are also related to personality. Thus, the impact of cultural factors could be addressed in future studies.

In addition, it would be interesting to examine whether concepts are expressed similarly, in culturally different countries. Literature about cultural differences in the expression of, e.g., pain and depressive symptoms, describe the suppression of pain expression, as well as somatization of depressive symptoms in certain cultures. Future studies could build on these studies to gain more insight into whether psychological concepts are experienced and expressed similarly. The question, whether the instrument captures all relevant characteristics of the concept in the specific context, and the relationships between the construct and related or unrelated constructs, is an important one. However, this requires the validated 'other' constructs, which are currently lacking. Therefore, a new area of psychological research has to be explored, building conceptual and validation research in this area, in order to arrive at meaningful and interpretable outcomes.

**Generalizability of findings**

One of the new aspects of this study was the quantitative approach of psychological factors (illness perceptions, depressive symptoms, perceptions of control). Previous studies in sub-Saharan African countries often used a qualitative design, with focus group discussions or in depth interviews. Quantitative research provides the possibilities for group comparisons, testing relationships, and depending how the sample was selected - generalization to larger populations. The cultural heterogeneity within and between countries where the studies of this thesis were conducted, was repeatedly discussed throughout this project. One important discussion point, was whether it was acceptable to treat the study groups from Benin, the Democratic republic of
Congo, Ghana and Nigeria as one Sub-Saharan African group. Doing so was advantageous, because it provided more statistical power to conduct quantitative analyses if these groups were combined, as the subgroups were quite small (n ranged between 64 and 128 per group), and data collection was quite difficult and time consuming. Although it was clear that the cultural distance between European countries on the one hand, and Sub-Saharan African countries on the other hand, is probably much larger than the cultural distance between two countries within sub-Saharan Africa, there is also a lot in which these countries differ, e.g. language, religion, ethnicity. For example, only in Nigeria, there are over 250 ethnicities. We therefore concluded that it was not valid to draw conclusions about the outcome of measures, or relationships between variables, for the total Sub-Saharan African group. However, we ignored this heterogeneity for one research question, namely, whether clinical instruments which were developed and mostly used in westernized countries, would be appropriate to use in Sub-Saharan Africa. The reason was that it was less likely to have affected the psychometric analyses. For example, the factor structure, or the extent to which an item was appropriate for, and informative in describing the latent trait (e.g. depression), is less likely to be influenced by country-specific factors, such as religion, ethnicity or language (assuming that items were well translated). In contrast, mean values and disparity on such a latent trait could have well differed per country, due to the heterogeneity in groups.

Conducting psychological research in Sub-Saharan Africa

When conducting health psychological research in remote villages in low-income countries such as Benin, specific aspects of the local health system should be taken into account, because they importantly influence the implications the research might have. Benin for example, faces great health challenges, such as the lack of trained mental health personnel. There is a lack of information on prevalence rates regarding mental health states, and there are insufficient resources to treat mental health problems. During the past five years only one psychiatrist graduated. No psychologists with at least a year of experience in mental health care, and no nurses specialized in mental health care were trained [18]. The budget for mental health in Benin is 70 M CFA (€145,000) per year for nine million people, which is largely insufficient [18]. It was therefore a dilemma whether or not to focus research on psychological factors, considering that basic
conditions such as budget and human resources for mental health are not available. It could be more efficient to put effort in political decisions, such as the expenditures on mental health, instead of, or in addition to, performing research on mental health. On the other hand, people’s psychological state has a great influence on health behavior, such as self-care, self-management and adherence to treatment. This argues in favor of focusing on mental health, despite scarcity of resources. This discussion is not new, however, it is important to take such factors into account when designing psychological studies in low-income countries such as in Sub-Saharan Africa.
CONCLUSION

This thesis provided, first of all, new insights into the role of individual’s illness perceptions in explaining delay, both in presenting to the hospital with symptoms of Buruli ulcer, as well as with symptoms of tuberculosis. Despite limitations on the design and the sample of these studies, the results provide insights for the design of intervention studies aimed at reducing delay in these patient populations, which is important because delay has many negative consequences, such as a worse prognosis, prolonged treatment, and increased costs.

Furthermore, it was shown, that Buruli ulcer patients experienced pain during the treatment of their wounds. Professionals involved in Buruli ulcer treatment confirmed this, and were willing to improve and standardize pain assessment and treatment. Several aspects in current pain management are important to take into account when developing a future guideline for the treatment of pain in this patient group. Factors included the current use of the WHO pain ladder, the reported discrepancy between professionals and patients about pain relief, and the difficulties in assessing and treating mild pain. Also the current minimal and mild prescription of pain medication, and the lack of availability of pain medication were mentioned. Future research should focus upon possible pharmacological and non-pharmacological interventions to reduce pain and fear, as well as on guideline development, in order to standardize and improve pain treatment in Buruli ulcer.

Thirdly, this thesis reported on the psychometric qualities of two clinical measurement instruments by using IRT, which were the CES-D and the Pearlin mastery scale. With minor adaptations, the CES-D, which was developed and mostly used in western countries, is appropriate to use in Sub-Saharan Africa, and the results were largely comparable to a Dutch control group. The results of the psychometric analysis on the Pearlin mastery scale in the Sub Saharan African group were different, as three out of the seven items, including the two positively formulated items, were not informative in describing the latent trait. Results were comparable to a Dutch control group on the two positively formulated items, and it was suggested to use the scale as a 4-item version in Sub Saharan Africa, measuring a lack of internal control.
This thesis provided new insights into psychological factors related to health behavior, pain and fear during medical procedures, and conceptual issues related the use of psychological measurement instruments in Sub Saharan African study groups; insights which are valuable for designing future studies, and evidence-based clinical practice.


References


