INCORPORATION OF KNOWLEDGE OF SOCIAL AND CULTURAL FACTORS IN THE PRACTICE OF REHABILITATION PROJECTS

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INTRODUCTION

Never have I been more aware of the social and cultural factors in the practice of rehabilitation projects than at the time when I had just returned from Zimbabwe. I worked there for four years, in a project on community based rehabilitation and conducted research for my PhD thesis entitled *Kuoma Rupandi, the parts are dry, ideas and practices concerning rehabilitation in a Shona ward.* After my return to the Netherlands, I was in charge of a nursing home, which, in the Dutch setting, also offers rehabilitation services. In the CBR project there were clients who had to walk on hands and feet for miles in order to be able to attend the training and income-generating projects organised. My first meeting in the Netherlands, when I was in charge of the nursing home, was with a group of unhappy residents who wanted me to replace the elevators because the buttons in the elevator could not be reached sitting in an electric wheelchair.

In this article I will assume that the readers all have had similar experiences, whereby differences in social and cultural perception influence the practice of rehabilitation projects. Illustrative as these different experiences and examples may be, I do not want to dwell on them too much but, instead, want to pose some questions that will hopefully bring our discussion beyond the level of individual examples and experiences: What are the social and cultural factors that affect the practice of rehabilitation projects and how can we differentiate between them? On the basis of a number of concrete examples, we will try to analyse how a different interpretation of important social and cultural factors may contribute to communication problems between rehabilitation worker and client, thus hampering the rehabilitation process. Furthermore, I would like us to agree that there is a need to include knowledge about social and cultural factors in the practice of rehabilitation projects. Thirdly we will try to analyse why it is sometimes so difficult to include knowledge about social and cultural factors in rehabilitation projects. Finally I would like to discuss what could be done to overcome these obstacles. With respect to this last point, I would like to play the devil's advocate a little bit, urging the reader to indicate clear priorities and preferences.

SOCIAL AND CULTURAL FACTORS AND HOW TO DEFINE THEM WITHIN THE CONTEXT OF REHABILITATION PROJECTS

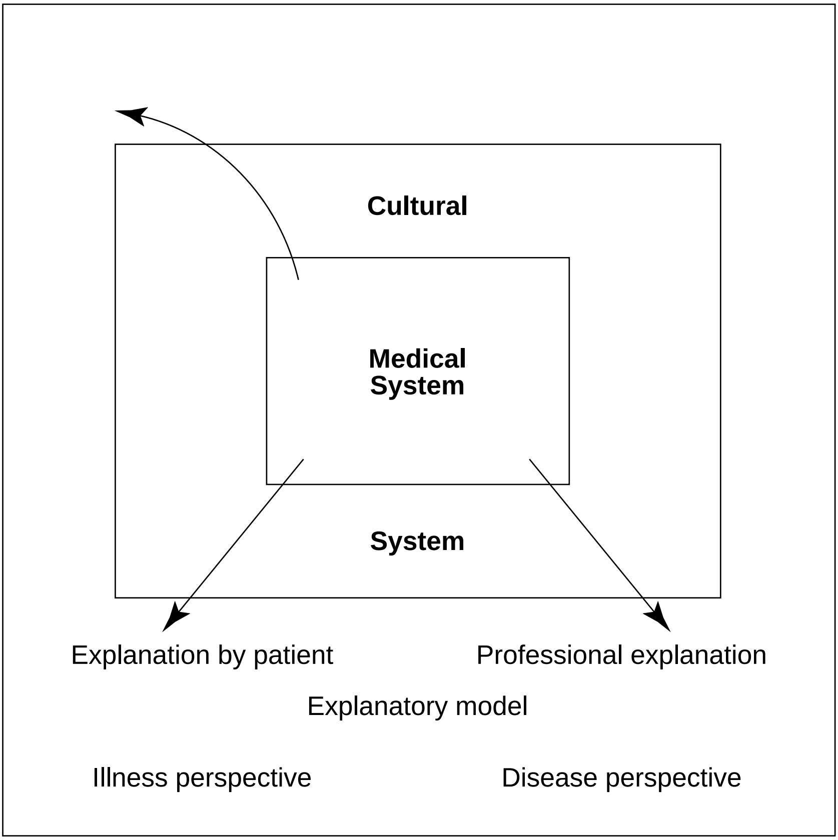
Social factors determine group membership: status, role, position. Group membership determines to a large extent one's perception of the world. Social factors or rather differences in social group membership play a role in almost all client – health worker relationships. It is related to what Kleinman (1980) and others (Press 1980; Eisenberg 1977) have differentiated as the illness and disease perspective, respectively. The explanatory models that health professionals use, whether these are Western style physiotherapists or traditional healers, are different from the perspective of the client. Only when the health care provider is disabled himself or herself and can incorporate the illness perspective into his more professional view, or when the disabled client pursues a professional career in rehabilitation medicine, can the illness and disease perspective be brought together. It is more common however for the two perspectives to differ. In a normal *therapeutic* relationship the client expects from the health care worker the added value of professionalism, summarised by Murray and Chavunduka (1986) as including the following key factors:

- Autonomy towards clients (financially)
- Monopoly in the professional field
- Code of ethics
- Body of knowledge

Cultural factors are related to ideas (knowledge, beliefs, values, norms) with which we structure our experience and order our behaviour (Berger and Luckman, 1976). At the same time, individuals influence and shape culture and the values and norms incorporated therein every time they show their specific choices and interpretations in the form of concrete behaviour; because as individuals we may be guided by norms and rules, but we do not stick to them and that is how norms and rules may gradually fade out and be influenced or replaced by new ones. This is also how traditional ideas about illness and disability will change, when more disabled persons in developing countries are brought into contact with *modern* medical rehabilitation services.

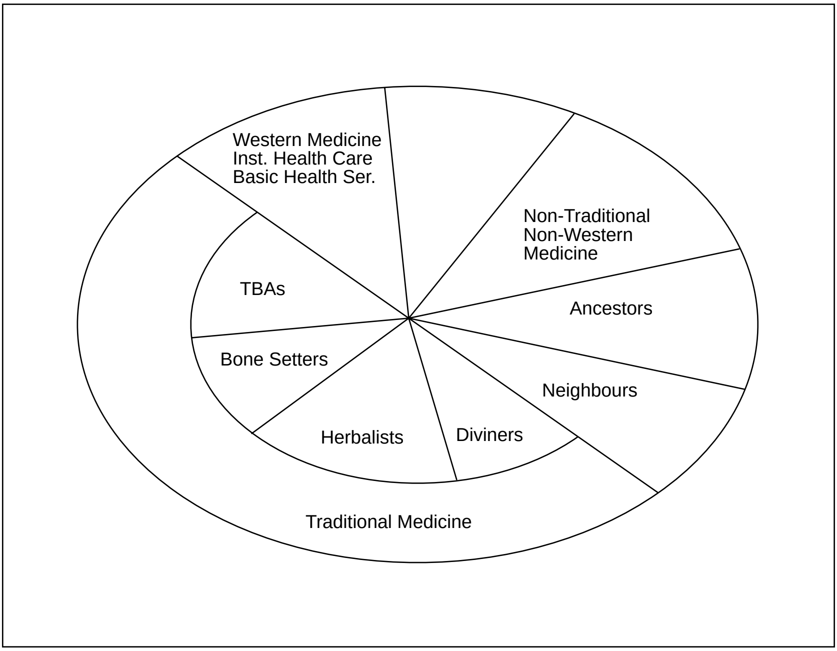
Cultural differences play a role particularly if health worker and client belong to different cultures and to a lesser extent when they belong to different sub-cultures. We will assume that the sub-cultural differences merge with social differences. If health worker and client belong to different cultures their medical explanatory model will have its base in a different cultural mode.

Table 1: Sickness/Folk Perspective (Kleinman)



Each culture has its own medical system. A medical system may be defined as the organised system of ideas and practices concerning illness, a system which is grounded in and derives its structure from a given cultural context (Kleinman 1973: 57). Within one cultural and medical system, different explanatory models may occur. Here we distinguish between the explanatory model from the patient and that of the professional.[1] When a disabled person visits the hospital in the morning and the traditional healer in the afternoon, this does not imply a shift from one medical system to the other medical system. In actual fact these shifts from one type of health care provider to the other take place within one medical system. Within the medical system the different categories of health care may be seen as different pieces of pie from which the client may choose.

Table 2: Different Categories of Health Care



Each medical system has its own *pie*. In Western culture the modern or Western medicine constitutes a larger part of the pie than in developing countries, but in the West our medical system also has different *tastes*, such as homeopathic medicine, acupuncture, ayurvedic medicine, faith healing etc.

Cultural differences play a role particularly when outsiders come to a country to perform rehabilitation services or to develop rehabilitation activities or when people belong to different sub-cultures. The most extreme consequence of this argument is that a person who is a cultural outsider will never be able to perceive and experience the medical system as an insider does. To put it differently, if we had enough disabled rehabilitation workers in each of the developing countries, interpreting disabilities within the context of their own cultural and medical system, the lack of knowledge about social and cultural problems would automatically be reduced.

HOW SOCIAL AND CULTURAL FACTORS INFLUENCE THE PRACTICE OF REHABILITATION PROGRAMMES

When we talk of social and cultural factors, what exactly do we mean? We mean factors that are relevant in one or the other explanatory model. Some examples from the material I collected for my PhD study:

Social and Cultural Factors Influence the Definition of Disability and Determine Who Are Considered Disabled and Who Not

After some time, in my research, it became clear that my taxonomy of disabilities did not make much sense to my informants. When asked to list the disabilities they recognised, in order of importance, conditions were included that would not generally be considered a disability in my system, while other conditions were left out when they should have been included, from my perspective. To give a few examples of conditions that were included: children who got their upper teeth first; throughout my fieldwork area this was considered a very serious disability that would affect a person throughout life; mothers who had borne a handicapped child were considered disabled etc. Function loss, which is an important determinant in our Western taxonomy, only played a minimal role. In actual fact it was not function loss, but the *dryness* of the affected part which determined the seriousness of the disability. These findings are supported in literature about general medical classifications, for instance Pool, 1989.

Social and Cultural Factors Determine the Explanatory Model that Is Used

The longer an illness lasts, and in this respect disability was considered an illness that lasted very long, the stronger the belief that the source of the problem lies in the social environment and not in the human body. Whereas in our endogenous health system we look for the source of evil within ourselves, other medical systems put the source of evil outside the human body. In such a case, the physical condition (e.g. disability) is seen as a symptom of an underlying social problem. The case of Maureen Mapfumo (the name is fictive) illustrates this: Maureen Mapfumo was about 20 years old when we met and she suffered from severe epileptic fits that had caused hemiplegia and blindness in one eye. When Maureen fell ill, around the time when she went to school, the family had consulted several traditional healers, without any result. It was implied that the family did not agree with the diagnosis of the traditional healer. We tried to convince the mother to take her daughter to the rural clinic, so that she could be provided with medicine to control the fits of her daughter. The mother seemed motivated to do so. We actually went along for the first visit and urged the mother to come again after four weeks to get new medication and to adjust the dosage. When we returned it appeared that neither mother nor daughter had visited the clinic. With renewed efforts we talked to the mother and to Maureen once more, but in vain. When we were returning from our third visit, which confirmed our earlier findings, a neighbour walked us back to our car and told us the following story: an uncle of Maureen killed another man in the village, and a dispute arose between the two families; Maureen's family claimed that their man had acted in self defence, the family of the victim claimed it was a brutal murder and they claimed revenge or compensation. The case could not be settled easily and this affected the whole community. When Maureen fell ill, the ancestors on both sides diagnosed this as a sufficient compensation. The family of Maureen will not openly admit it, but they have accepted this verdict. They are afraid that, if Maureen gets cured, the whole thing will start all over again. The case of Maureen Mapfumo concurs with findings by Ingstad (1997), who concluded that for parents of disabled children in Botswana, the disability itself was not shameful but the underlying cause of the disability often was a cause for shame.

Social and Cultural Factors Influence the Definition of Rehabilitation and Its Objectives

In my research, the most important criterion for integration was whether you were married and had children. Our project could provide a disabled person with a sewing machine to make him economically independent, but not however with a lobola (brideprice) to enable him to get him married. There is an example of a project in Africa some years ago, which was quite successful in assisting blind men to become economically independent. The men were involved in various handicraft activities and when I visited their centre I noticed that the handicrafts they produced did not sell much. Nevertheless virtually all the men left the vocational rehabilitation centre after their training period, settled independently in the village and managed to sustain themselves thereafter. Finally it was revealed to me that, while at the training centre, virtually all the men were married off to women who had been divorced or widowed and who had been working in the centre as cleaners. This aspect of the project had never been revealed to the donors however, as they might have opposed this marriage broker role of a rehabilitation project.

WHY IS IT SO DIFFICULT TO INTEGRATE SOCIAL AND CULTURAL KNOWLEDGE THAT EXISTS INTO THE PRACTICE OF REHABILITATION PROJECTS AND WHAT COULD BE DONE TO OVERCOME THESE PROBLEMS?

Incorporation of social and cultural knowledge into rehabilitation practice is a means to an end. In rehabilitation, gaining social and cultural insights will never be ends in their own right; therefore in projects they are bound to get only secondary attention just like gender, ecology, integration etc. This effect is further strengthened by the problems generally involved in multi-disciplinarity and inter-sectorality: the different categories of scientists and health workers involved in rehabilitation do not speak each other's languages, e.g. their questions are formulated in a different language from the answers. Social scientists cannot come with the ten golden answers to the ten most burning questions of rehabilitation workers and vice versa: the goodwill is there but it is more complicated to accomplish than we initially may have thought. Understanding a different social or cultural perspective is a process whose results cannot easily be summarised and conveyed to third parties that have not participated in this process. Some things cannot be learned; they have to be experienced. A lot of the knowledge and experience exists in Africa and Asia, but it has not been written down, it is not published and shared. E-mail and internet offer us possibilities to share and exchange experiences in a less formal way (than a scientific publication that is) and with a much broader audience. In my perception the real problem is not at the level of the individual health worker. Reality will force him/her to struggle along and find practical solutions. The problem is rather at the level of managers who, and I am now providing literal quotes from my own career, "do not need a god-damned anthropologist to run their programme" and who write to you, "if you want this project to be still there next year, you better forget about these cultural hang-ups and come up with some success stories".

What steps should be taken to gain more knowledge and to get this knowledge included both in the design and implementation of rehabilitation projects? This question can be answered in many different ways and in fact during the conference in Bonn (cf. Introduction) many different approaches were discussed. There are more ideological approaches, aiming at greater influence of disabled persons themselves. There are more practical approaches that take into consideration the present organisational and financial constraints. I would like to argue for a combination of approaches. Let us not argue too much among ourselves, but let us try all the approaches that work more or less in the same direction: optimal integration. Conflicts of interests between health care professionals and their clients are bound to occur, but can be solved on the spot or, if the need arises, can be brought forward in forums like the Bonn conference.

From a more practical perspective, I would recommend the following action:

- Train more rehabilitation workers in developing countries themselves.
- Train rehabilitation workers not only in technical skills but *where there is no anthropologist* also as social scientists, as listeners, as observers.
- Strengthen self-organisations of disabled persons so that their needs and problems can be heard as directly from the horse's mouth as possible.
- Social scientists and rehabilitation professionals should carry out research programmes together.

NOTES

1 Kleinman (1980) also distinguishes the folk perspective, which may be seen as some sort of generalised lay-perspective, leaving out the personal influences of the patient perspective.

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