

Conception of Kala Azar medicines

Literature review for an anthropological study of patients' perception of and experience with Kala Azar and its treatment in Bihar, India



An informant, who had the illness experience of his grandchild written down on a paper, reading the consent form, © MJ

August 2013

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MANAGED BY THE VIENNA EVALUATION UNIT

Literature Review

This paper reviews literature for the anthropological study of patient's perception and experience of treatment for Kala Azar in Bihar, India. The review will start with a thematic focus. Two studies on Kala Azar will be presented, one study on treatment perception in general. Then follows a conceptual elaboration on medication intake. The summary will give an idea about the gaps in literature and the contribution that this study might make to the field of research.

Knowledge, practices and Kala Azar

Little work has focused on conceptions of Kala Azar (KA) and its treatment. This section will discuss two studies relevant to the research topic. However, both studies are not grounded in anthropology.

Knowledge, attitudes, and practices (KAP) about Kala Azar in two villages in Nepal – Titaria and Haraincha, is the focus of a study published by the WHO in 1998. The authors (Koirala et al. 1998) investigate patient's knowledge on transmission of the disease and how they thought the disease could be treated and prevented. Qualitative and quantitative methods were used to gather data – interviews, discussions and structured questionnaire.

According to the study, participants had little knowledge about the disease. Most did not know how Kala Azar is transmitted; a small number believed mosquitos transferred it. As prevention measure participants cited that infected people should be isolated. Isolation was understood as avoiding sour, hot, fatty food, and not sharing clothes or food with infected people. Only a small number associated fever and change of skin colour with Kala Azar (Koirala et al. 1998:488). Most respondents believed KA could be treated effectively with western medication, while only a small number thought ayurvedic remedies and treatment by healers would help. Predominantly, participants indicated to seek help at government health facilities. Also local private doctors, hospitals and “traditional faith healers” were consulted. Difficulties associated with the government facilities were long waiting time, weak rapport between doctor-patient, transportation problems and costs (Koirala et al. 1998).

The weakness of this article is the method used to explore the topic. Several anthropologists criticized knowledge, attitude, practice (KAP) surveys (among others Nichter 1993). According to Launiala (2009), KAP is a tool mostly utilized by (public) health researchers to gain a general picture on participant's knowledge on treatment and prevention. This knowledge is usually only related to biomedical concepts, giving little attention to the emic perspective on illness. Knowledge is translated as scientific based truth and contrasted to beliefs, which are considered as obstacles to “appropriate behaviour and treatment-seeking practices” (Launiala 2009:5). Anthropologists do not differentiate between knowledge and belief (Pelto and Pelto 1997 as cited in Launiala 2009:3).

Further, KAP surveys only provide descriptive accounts on people's practices. They do not elucidate on actual daily practices and reasons behind them. For example, merely descriptive data is given account while why and when certain treatments are sought remains unexplained (Launiala 2009:5). In addition, KAP surveys frequently aim to change people's behaviour, assuming a relation between knowledge and practices. “Several studies have, however, shown that knowledge is only one factor influencing treatment-seeking practices ...” (Launiala 2009:5).

Finally, KAP surveys often bring about “don’t know” answers, also observable in the article above. This is mainly because many surveys fail to translate questions about knowledge into “meaningful local categories” that participants can understand (Launiala 2009:7, see also Stone and Campbell 1984).

The discrepancy between knowledge and behaviour is brought to the forth by Munguti’s (1995) article on health-seeking behaviour of Kala Azar and Malaria diseased people in Kenya. The author demonstrates that aetiological beliefs are not related to health seeking behaviour. Many people affected by Kala Azar or Malaria tended to seek help at western health centre’s regardless of what they thought was the cause of disease (Munguti 1995). Those who used medicinal plants did so because of their effectiveness, availability and affordability.

Instead of aetiological beliefs the author emphasizes that social and structural factors influence illness and health-seeking behaviour. His findings show that accessibility, efficacy and quality, availability and costs of the medicine have an effect on which treatments are sought. High prices of medication were often the biggest constraints to the use of the most effective medicine. Many different forms of treatment were applied when one was perceived as not efficacious (complimentary not contradictory usage). The multiple uses of different forms of therapies resulted in additional costs.

“In the search for cure, households with kala-azar tended to utilise many of the health resources available to them. Clearly, the problem was not one of awareness of the appropriate form of treatment, rather, the inability to purchase the treatment” (Munguti 1995:21).

Due to the limited number of qualitative studies on Kala Azar in general and on treatment and Kala Azar especially, the inclusion criteria and search terms were expanded from “Kala Azar and treatment perception” to chronic diseases and treatment perception (e.g. TB), adherence (compliance, concordance), treatment-taking behaviour and treatment trajectories.

Treatment perception

Britten (1994) investigates on patients perception of medicine in order to find reasons for “non-adherence” to treatment. 30 patients of 10 doctors that either presented to the medical practice regularly (“attenders”) or did not attend for a minimum of two years (“non-attenders”) were selected for the study (Britten 1994). Interviews with participants from south and south west London brought up themes such as perceived properties of the medication, general opinion on medicine and self-reported drug use.

The author divided the characteristics that patients attributed to the medicines to negative and positive properties. Some medicine such as penicillin was very much appreciated for its benefits and its acceptance was associated with the long time that it is already available on the market. Negative connotations were articulated due to the damage that medicines might cause on the body. Drugs were associated with a lowered ability of the body to fight infections on its own. Especially antibiotics were considered as weakening the immune system. Further, participants note that despite alleviating symptoms, medicines do not tackle the cause of disease.

General opinion on the intake of medicine differed widely. For some it was a “taken for granted” activity, others preferred not to take medicine when possible or avoided strong drugs. Some participants feared intake of medicine for a (life-) long period and preferred low-

dose or “low level” treatment (Britten 1994:466).

According to Britten, positive opinion on medicine could be associated with stronger adherence to intake (decision to consult = decision to take medicine). Those with negative attitude towards medication often did not take medicine as prescribed. They stated they forgot (especially for those that have to be taken at certain time intervals) or devised the intake according to the gravity of the symptoms. Others applied medication whenever they considered it was needed. Likewise, the opposite view was expressed – instructions were followed, as participants did not feel having enough knowledge to devise dose and intake. Those having a negative opinion on medicine took them when they recognised familiar symptoms (the author mentions as example sinusitis and hay fever), which they were used to treat with medication, in case of heavy pains or when they recognised severity of the disease (Britten 1994:467).

Although the author gives account to the perception of treatments by the patient, the analysis seems narrow. As no specific medication was selected and treatment for acute as well as chronic conditions was included, the findings seem to generalize and only touch on important topics without going into depth.

Treatment-taking behaviour

A number of articles aim for an understanding of treatment non-adherence¹. Most often these studies chose “treatment-taking” behaviour as conceptual focus and elucidate factors that influence “adherence”. Although implied in the term, the actual intake (how the medicine is actually taken, e.g. amount, interval, right application etc.) of the medication is given less importance in the revised studies.

Dowell and Hudson (1997) give account for the patient perspective on treatment taking in order to move beyond a compliant or adherent patient to a “concordant” relationship between doctor and patient. They use the concept of concordance to signal the need of moving beyond the established terms “adherence” or “compliance” and its underlying assumption of the patient as conducting irresponsible behaviour.

The authors develop three types of patients, those who “reject, passively accept or actively modify the prescribed regime” (Dowell and Hudson 1997:372). Passive acceptance of treatment, especially for medication that is taken for a long period, was associated with “loss of autonomy”, and implied the acceptance of the illness, which might ultimately challenge a person’s identification. This means that denying illness goes hand in hand with changing or stopping medication intake. “Emphasizing a drugs importance could, paradoxically, reduce the amount taken” (Dowell and Hudson 1997:374).

The authors argue that patients form an opinion on their treatment by consciously or subconsciously testing how the medicine works on their body. The reaction of the body on stopping treatment for example made patients restart their medication intake (Dowell and Hudson 1997:371). However, patients also seek advice for medicines quality from other doctors, acquaintances and the media. Thus, choices are made on how and if a treatment is applied by testing out its need and quality. This self-evaluation might lead to reject, accept or adjust treatment.

Munro et al. (2007) give a broader overview on factors affecting treatment-taking behaviour

¹ However, “adherence” does not account for a patient centered approach, “the dynamic nature of adherence behaviour and the power imbalance implied by these terms” (Bissonnette 2008:634).

through a meta-ethnography of qualitative studies done in medication adherence and Tuberculosis (TB) around the world. Despite the long course of TB treatment, concepts and factors revealed by the authors might be valid for the study on Kala Azar.

Munro et al. (2007) selected 44 papers out of 7814 and outlined the different causes of non-adherence that emerged in these studies. The authors identified four major topics influencing treatment taking that are interlinked with each other: structural factors (which often constrain the agency of the patient), including poverty and gender discrimination; the social context (emotional and financial support); health service factors; and personal factors.

It is suggested that during the period of medication intake, decisions are continuously made and reasons for adherence or non-adherence might shift throughout the course of treatment. Thus, it is often not a single but multiple factors influencing treatment-taking behaviour.

Among these four major themes, several sub-themes are identified. The authors mention for example aspects such as accessibility of health care facilities (distance, transportation) and the implied financial burden for the family, problems at the facility (waiting time, lack of privacy, doctor-patient relationship etc.), and availability of medication. The implications of treatment adherence on monetary resources - direct, hidden, transport costs ("Financial burden of treatment") - were cited as a factor that influence intake by several of the examined studies. The long period of treatment may lead to choose between work and treatment, especially in male respondents. Poverty was frequently named as a reason for non-adherence (Munro et al. 2007:1240).

Apart from structural factors, patients also devised the way of taking medication according to their own standards. Patients often stopped treatment because they felt an improvement of their condition and thought they were already healed. The same accounts for the other way around. Not experiencing an improvement might lead to the abandonment of treatment at an early stage. However, participants also cited to continue treatment because of symptom relief. Two aspects seem to be important in this regard. First, the active engagement of the patient in finding out if the treatment works for them. Dowell and Hudson (article see above) conceptualize this procedure as a "testing process" by which participants consciously and subconsciously try out how the medicine works on the body. Second, that the patient might have a different perception of recovery than the doctor assumes (patient's perception of recovery).

The authors also identify aspects such as knowledge about the treatment and its duration, belief in the medical system, efficacy of medicine, fear of diagnosis, concurrent intake of TB medicine with other medicines, and pregnancy as factors that influence the intake of medication. In addition, personal characteristics and aspects such as religion, ethnicity, gender, age, illiteracy and personal motivation were identified to influence treatment-taking behaviour of patients.

Finally, the social context - the extent to which the family, community, and household supports the patient has an impact on adherence. This support might be financial and/or emotional.

The article is strong in presenting a broad overview of the key factors that influence treatment taking of TB medicine. No or little account has been given to rumours, emotions (fear) and texture of the medicine.

Munro et al. emphasize that most literature is "conceptualized from a biomedical perspective", leaving out the emic perspective on disease. The elaboration on this view is essential to understand why patients take the decisions to stop treatment. The authors

identify gaps in qualitative studies of adherence, among others, the role of gender in shaping experiences of treatment intake and, although mentioned briefly, the impact of real, anticipated and culturally interpreted side effects on treatment continuation.

Side effects

Etkin (1992), a pioneer in ethnobotany and ethnopharmacology, explores side effects embedded in their social and cultural context. She argues for “incorporating cultural context of use in the assessment of drug efficacy, introduction, and administration” (Etkin 1992:99). In biomedicine side effects are known to be associated with unwanted effects in addition to the therapeutic outcome. Through user surveys those effects that most frequently appear are attributed to the drug. However, these surveys include only few women, elderly and children (Etkin 1992).

Social and cultural context where the medication is taken most often generate a different understanding of side effects. For example, secondary effects might be appreciated and anticipated as part and sign of the therapeutic process (e.g. vomiting, skin manifestation, diarrhoea etc.). “In any event, these effects represent a symptom set explicitly primary to the functional effectiveness of a medicine, whereas typically they are secondary to the goals of biomedical therapeutics” (Etkin1992:103).

In reference to her own research in West Africa, Etkin proposes that taste of the medicine is often associated with a therapeutic outcome. Hausa for example believe that pregnant women should not take bitter medicines due to “gastro- and uterotropic effects” (Etkin 1992:104). Characteristics of the drug, like smell, taste, texture etc., may be interpreted as reflecting the power of the medicine. “And throughout the developing world, the misplaced belief in the superior efficacy of injection is legion” (Etkin 1992:106, the topic of injection is focus of several studies as for example Hardon & van Staa, Whyte & van der Geest).

Side effects may be perceived as indicators of authentic medicine. In Nigeria, the bitter taste of a medication may tell the difference between the genuine and the counterfeit. “The interpretation and management of ‘side effects’ is one of the several key axes along which therapeutic expectations have been, and continue to be, refined” (Etkin 1992:108).

Due to the circulation of drugs in the informal sector, people often choose other brands of medications according to its associated effects and presentation of the medication (size, color etc.). This of course raises the issue of resistance. Drug resistance in malaria and cholera is partly due to the usage of drugs because of their “full range of effect, including ‘side effects’ (Etkin 1992:107).

Associated to this issue is the patients understanding and translation of the therapeutic process. Etkin gives the example of swallowing medicine instead of injecting it. Thus, it might be of interest to consider how treatment is actually taken. Prout (1996) elaborates on the metered dose inhaler – an inhalation therapy for asthma - how it is designed and instructed to use and how patients in practice translate the understanding of the intake.

Translation practices

Prout (1996) examines the experience and practices of medication usage. By applying an actor-network approach he focuses on the treatment pathway of the metered dose inhaler (MDI). He elucidates the network of actors that stand behind the device, for example, from the laboratory and all people who develop the medication to the doctor who prescribes the treatment. Eventually, the medication is taken far-off the laboratory and is intended to work with its users – the patient. However, “a device is ... never simply inserted or diffused into a

setting but is always subject to (...) processes of translation during which humans interact with it, each configuring and reconfiguring the other in unpredictable and often unexpected ways” (Prout 1996:202). It was discovered that patients incorrectly and thus inefficiently utilized the metered dose inhaler although it was described as an “easy to take” medicine by its’ inventors. A typical error was e.g. not breathing through the mouth but through the nose, however people also forgot to take off the protection cap or applied it directly on the chest. Prout refers to these actions as “antiprogrammes” (as by Latour) (Prout 1996:209). Patient’s use of the medication differs either unintentionally from the requirement (“programm”) of the intake – because of “a different understanding of the mechanism of therapeutic action”, or intentionally – overriding medical advice by applying the medicine how it seems the easiest (Prout 1996:209).

One attempt to strengthen the ability of users to take the medication “correctly” was the providence of written instructions that stated step by step the procedure of the intake. However, these guidelines presume literate users who understand the instructions and translate them into appropriate action. Only a small number was able to apply the inhaler correctly after reading the instructions. Further oral explanation only moderately raised the number of correct applications (Prout 1996) (→ knowledge ≠ practice).

Prout illustrates how “a device is (...) never simply inserted or diffused into a setting but is always subject to (...) processes of translation during which humans interact with it, each configuring and reconfiguring the other in unpredictable and often unexpected ways” (Prout 1996:202). This aspect is well linked with Locks and Vinh-Kims (2010) claim that the impact of any biomedical technology differs significantly according to the context where put into practice.

Our position is that biomedical technologies are not autonomous entities, the effects of which are essentially uniform whenever they are put into operation. Professional choices about the use of specific technologies – when exactly to put them into practice, and how to interpret the results and effects that they bring about – are combined with broader societal variables including culturally informed values and constraints, specific local and global objectives, economic disparities, and inconsistent or non-existent regulations. These variables ensure that the far-reaching effects of biomedical practices of all kinds are understandable only in context, notably at sites of implementation (Lock and Vinh-Kim 2010:5).

Conclusion

In summary, no anthropological research has been done on Kala Azar and treatment perception in India. Many studies aim for an understanding of treatment “non-adherence” by focusing on theoretical concepts such as treatment taking behaviour, treatment trajectories (these longitudinal studies mostly for chronic conditions were not included in the review, however should be mentioned in the interest of completeness e.g. Riemann and Schütze 1991, Johnson et al. 2008), and treatment perception. Many of these studies do not differentiate between chronic and acute conditions or do not focus on a specific treatment. Further, the treatment-taking as a procedure itself is often left out of analysis although it might be important in order to grasp how patients understand and translate the intake of medication.

Addressing the gap in literature, the upcoming research will examine the social and cultural dimensions of treatment use, among Kala Azar diseased people in Bihar. Despite the focus on perception and usage of 4 (biomedical) treatment modalities, the research aims to be open to local knowledge and aspirations (cf. Lock and Vinh-Kim 2010). Such anthropological

knowledge of treatment perception is academically important as it gives insights into the (positive and negative) effects of biomedical technologies on an Indian population. Accordingly, the study will contribute to closing knowledge gaps about contextual information of medicine usage (intake) and medical beliefs in part of the Bihari population.

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