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Experiences of Tuberculosis in a Tarai Village, Nepal

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Abstract

In focus is the experience of being a Tuberculosis (TB) patient in the mid-west Tarai of rural Nepal. The information derives from a longitudinal qualitative study between 2005 to 2017 in one and the same community. The findings show few changes in the experience of being a TB patient. The availability of anti-TB medicine free of cost within the government health services was greatly appreciated. The cause of TB, ways and means of transmissions, and the need for preventive measures, however, were not well understood. In the case of Child-TB, the expectation of numerous visits to the government treatment centre for the picking up of medicines was a strong deterrant. In consequence, most child-TB cases were diagnosed and treated within the private sector. The distribution system of the medicines, particularly within the government system, clearly added to the burden of being a TB patient and much would have been gained had the arrangement been more patient-friendly, a difference which most likely had also resulted in more children being treated within the public services rather than within the money-geared private sector. Various misunderstandings about the cause/s of the disease need to be addressed. And, much would be gained was the central directive of "patient support", truly implemented and was a true "two-way communication" to take place.

Keywords: experiences of tuberculosis, misconception about tuberculosis, perceptions of tuberculosis, Nepal

Introduction

The focus of this article is the experience of being a Tuberculosis (TB) patient in rural Nepal. The National Tuberculosis Control Programme was launched shortly after the political change in 1951. It fought a losing battle up until 1995 when Nepal aligned itself with WHO's global policy prescription of Directly Observed Treatment, Short-course (DOTS). The National Tuberculosis Programme (NTP) has since made exemplary progress with anti-TB services widely available through the general health services and through NTP partner organizations. Even so, in Nepal, approximately 40,000 develop active TB annually and 5,000-7,000 die from the disease (Engelbrektsson & Subedi, 2017).

Tuberculosis (TB) occurs not only in the body, but in time, in place, in history, in the lives of men and women, and in communities. The experience, "the lived-in reality of a sickness", as suggested by Kleinman (1985, p.55) and by Atre et al. (2004), is created out of the dialectic between socio-cultural responses and personal signification on the one side (Auer et al., 2000) and the brute materiality of disordered biological processes on the other hand. The objective of the research was to gain insights into the experience of being a TB patient in rural Nepal. The health-seeking process; being on treatment; perceptions of TB; social interaction; and economic costs are the major themes of this article. Moreover, dissimilarities in perceptions of and approaches to adult-TB versus Child-TB (*bal-tibi*) are highlighted.

Methods and Materials

The ethnographic data was derived from repeated social anthropological fieldwork, 2005-2017, in one and the same community in the mid-west Tarai. The community in focus was the Pupara village (Pseudoname) in Bardiya district of mid-west Tarai. Several extended fieldworks were carried out in the village, the first in 2005, the second in 2012, the third in 2013/14, and the fourth in 2017, with short visits in between and after. During the first and third extended stays, TB patients registered in the local government system within the last five to seven years, a family member, and a neighbour of theirs were interviewed, face-to-face, with semi-structured questionnaires and so were guardians of children treated within and outside the government system. Moreover, house-to-house surveys were conducted. In 2013/14, the research also included a follow-up of patients earlier interviewed and some interviews with TB patients from nearby villages. And, in late 2017, there was a follow-up of those interviewed in 2013/14. Moreover, throughout the research period, there were observations

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at local health facilities and formal and informal talks with health staff, key informants, and various community representatives. Informed consent was obtained from all the study participants. Pseudonyms are used to protect the anonymity of persons and places.

This paper is geared towards the qualitative parts of the research and the quantitative components and other information will be published elsewhere. The data generated was analysed thematically with the ambition of particulars being understood as part of a larger socio-cultural whole. Some findings relate to Pupara and the Tarai only but a substantial part is likely to reflect experiences of TB patients throughout Nepal.

Findings and Discussion

Being a longitudinal study, the findings are presented in a time sequence.

Findings in 2005

Local Setting:

In 1974, the government of Nepal opened forest territory next to the border of India to landless settlers. In 2005, there were approximately 1,000 residents in Pupara. The main occupation was farming supplemented by animal husbandry. The landholdings were small and the area was hot, dry, and lacking in irrigation.The forest was all but gone. For firewood, grass, and grazing the villagers went across the border. Many families had a member working in India.When feasible, a son was sent farther abroad. Yet, for most the latter was only a dream as a large sum of money had to be raised for it to come true. A few families had a son in the army or in the police force and a handful worked in local schools.Those who were out of the village were predominantly men.

A large portion of purchases, allopathic medicines included, was made in a small town across the border. Concurrently, on the Nepali side, there were several allopathic options, private and public. One was the government Sub-Health Post (a Sub-DOTS centre since 1998/99) with the Sub-Health Post-in-Charge's private medicine shop next to it. In serious cases, there was the Bheri Zonal Hospital and other medical facilities in the town of Nepalgunj, by vehicle an hour away. Moreover, in Nepalgunj there was the International Nepal Fellowship's (INF) referral centre for TB and leprosy. INF has been supporting TB control in Nepal since 1953 and in mid-western region since 1973.

In the town of Nepalgunj there were ayurvedic government and private clinics but these were rarely if ever frequented by Pupara villagers. However, in some homes, in connection with ill health, attempts were made to comply with basic ayurvedic principles of "hot and cold" and there was some use of herbal salves and ointments.

There were three publically practising shamanistic healers, *dhami/jhankri,* in the village and approximately the same number in neighbouring villages. The Pupara ones was said to do only "simple *dhami* work". They were mainly consulted for sudden cases of illness and when children were ill, "*particularly when they don't stop crying*". One respondent concluded, "*Some call on the shamans, others do not, but all go to India for medicines and treatment*".

In the house-to-house survey (every 4th or 5th house) there was an astonishing wide range of answers to most health-related issues. Some expressed that local government health services were up to standard, others that they were substandard. Some reported visits to shamanistic healers while others stressed that they did not believe in them. Some suggested that TB was increasing, others stated that it was decreasing. However, almost everyone expressed that nowadays, contrary to earlier, TB patients were no longer "hated" (*ghrina garnu/hela garnu*). Elderly residents recalled and commented that in earlier days, TB was regarded as fatal and known as "*khapate"* (the wasting disease) whereas nowadays it is curable and known as "*tibi"*

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Prevalence of Tuberculosis:

In 2005, during the previous five years, 32 Pupara residents had been registered for TB treatment within the local government allopathic health services. The proportion of children with TB was one third. At registration, approximately half of the adults were pulmonary sputum-smear positive, i.e. potentially infectious. Four of the sputum-smear negative cases were Extra-pulmonary (EP) ones. Among the adults there were almost as many females as males. In addition, a few Pupara men were or had been treated outside the local government system, some in India. Moreover, a great number of Pupara children had been TB diagnosed and treated outside the government system.

Adult-TB Situation and Health Seeking Bahavior:

In 2005, most of those locally registered during the last five years were present in the village and were interviewed, and so were household members and neighbours of theirs. Of the 18 adult-TB patient interviewed almost everyone recalled a previous adult-TB case within the family or among close relatives, most of whom had been treated within the government health system. Even so, initially they themselves had rarely turned to the government health sector. The main reason, apparently, was a lack of enthusiasm for the government services combined with not expecting their own troubles to be TB.

For most, the first port of call had been within the private sector, commonly a medical shop. At these, drugs were dispensed per symptom: for fever; for cough; for loss of appetite; for shortness of breath, and so on. Further into the health-seeking process, there were visits to various private clinics and nursing homes. In these, the initial diagnosis was rarely correct.

Only a few testified to having consulted a shaman (the onset had not been sudden). Eventually, some had turned to government health services, mostly to the District Hospital, whereas others ended up at the INF Hospital in Nepalgunj.In the end, most had their TB diagnoses from the INF Hospital.

Before the correct diagnosis, there was increasing

sickness combined with a progressive loss of strength. For some, even to the degree that they had feared for their lives and so had their families. In one or two households, there had been talks about the wisdom of spending more money on a member who was not likely to make it. Thus, to most, according to what was said, it was "a relief" to learn that it was TB, not because it was "a good disease" but because it was known to be treatable and the medicines were free of charge (within the government system).

After the diagnosis, all but one had their anti-TB treatments from the Sub-Health Post. The patients had good faith in the TB medicines and no one reported additional treatments, except one or two for parallel conditions. A few recalled initial problems with the drugs but no long-lasting side-effects, except one female who ended up with jaundice and severe joint pain. Those close to the patients also testified to good faith in the TB medicines. At the same time, it was common knowledge that even with medicines some had not made it. In a recent, quite well-known case the person himself was held responsible as he had not stopped drinking and smoking in spite of being on treatment. Another case, also quite well-known, was explained by the person having been in too bad a condition before the start of the TB medication. And, in a third case, even the family had doubts about him having taken his medicines regularly.

When asked what TB information they as patients received at the time of diagnosis and during the treatment period, the spontaneous reply by almost everyone was, "Nothing!*"* Only two reported to have been asked if there had been previous TB in the family. What they learnt, from day one, however, was that for the first two months they had to come daily to the Sub-Health Post for their medicines and after that once a week for six months. Why daily and why for so long was not understood. Even so, the patients testified to being/having been careful not to miss a single day, because without medicines *tibi* was likely to be fatal. Moreover, if they missed a day or two they were likely to be told off and if they missed more than a few days they might have to start the treatment all over again.

By riding a bike, a man could get himself to and from the Sub-Health Post in less than an hour, whereas a woman, not supposed to ride a bike, had to calculate on double that. To set out daily for the Sub-Health Post while ill and weak was troublesome, bicycle or not, and everyone suggested that it would be far better if the medicines were dispensed for more days at a time. Some women had no option but to bring a child or two along. This was the case for a woman pregnant at the time. Occasionally, however, her husband went instead of her. Another, an elderly woman, told that it was a real treat when her son took her on his bike, or even better, when he went by himself. That someone else on and off picked up the medicines, particularly for elderly patients, was not all that unusual. That this was somewhat acceptable, at least for some, made it even harder for others to understand why the medicines were not given for several days at a go.

The patients were told, "*No alcohol and no tobacco!"* However, this apparently was done without sufficient explanations and without the staff asking if the patient was in the habit of drinking or smoking. And, as common in situations like these, the patients did not raise questions. When specifically asked by the researchers, the majority suggested that the ban on drinking and smoking most likely was "*for the medicines to work well*"! There were serious cut-downs on drinking and on tobacco during the treatments. After the treatment period, however, most of them reverted to a pattern similar to that before the diagnosis.

At the Sub-Health Post, contrary to the key idea of DOTS at the time, the ingestion of the medicines was not observed. Some who had brought water with them swallowed the pills then and there, whereas others walked off with the day's ration in their pocket. Sometimes, there was a crowd at the Sub-Health Post and a delay, but usually not. One woman explained, "*There was not a delay in giving me the medicines but they never asked about my health status. It would have been nice if they had."* She continued, "*When I told them that there was pain in my joints they simply advised me to go to Nepalgunj to have it checked."*

The patients interviewed were as a whole not unhappy with the services but rather the opposite: the medicines were free of cost, they recovered well and never had there been an expectation of government health personnel being particularly engaged with their patients.

Causality Beliefs of Tuberculosis:

In regard to the cause/s of TB, the patients shared the ideas of people around them. The common idea in Pupara, as in nearby places, was that the main cause of adult-TB was "drinking and smoking". At the same time, it was recognised that there might well be other or additional causes, some known and some not. Mentioned in reference to specific cases, some of those were: weakness; taking ganja (drugs); having unclean blood; eating dirty/polluted/spoiled food; lack of regular eating habits; an imbalanced diet; being up late; low hygienic standards; being uneducated. Other causes with less attached blame were: a hot climate; a lack of good food; anxiety; smoke; dust; going/travelling from one place to another; poverty. "*Karma"*was mentioned but not frequently. Even so, the development of TB, it was thought,was not all by chance. Only those with their "defences down"were likely to end up with TB. Some even suggested that in "no way!" can a strong person get TB. Transmission as a likely cause was not spontaneously mentioned. Even so, when specifically asked, almost everyone agreed to TB being infectious.

Beliefs about Transmissions and Observed Practices:

The patients interviewed expessed uncertainties about their own TB being/having been contagious/infectious or not. A young female patient said that most likely her TB was not contagious because, "*I am not all that thin.*" She added, "*Some say it might transfer, others that it is not likely to do so."* Another female, who also admitted that she did not know if her disease was contagious or not,

added, "*People say that it transmits if there is a long and close contact*."

The patients mentioned "*kira"*(germs/minute animals/ insects) more often than people around them. *Kira* were part and parcel of TB and *kira* were part and parcel of TB being contagious. Our finding was similar to the findings of Baral et al. (2007) in their large scale knowledge, attitude and practice study on TB. Yet, the matter was not well understood. Neither were the implications of the presence or absence of *kira* in a test result. Thus, precautionary measures, mainly in sleeping and eating arrangements, commonly initiated by the patients themselves, were installed not only in the homes of those with potentially infectious TB (sputum-smear positive cases) but also in the homes of those with non-infectious TB (sputum-smear negative cases) and in both circumstances upheld far longer than ever needed, often to the end of the treatment.

To the question,"*Do/did members of your family and others around you think that you are/were contagious?",* some replied that they did not know what others thought but indicated that most likely at least some believed or had believed their TB to be contagious. Others said that people around them definitely thought so. At the same time, most testified to no or no greater changes in the behaviour of others towards them. This tallied with most interviewed neighbours suggesting that they did not hesitate to sit close to a TB patient as long as they were or had been"on treatment". The only remaining restriction, it was said, was not to partake of food from a patient's plate. A few neighbours said that they would not keep a distance openly but would do so when not offensive, not necessarily because of a fear of transmission but because a general feeling of unease. An elderly Brahmin woman concluded, "*We used to talk to patients sitting at a distance as if they were 'lower caste people' but in these days we sit close to them."* At the same time, the mother of one patient bluntly stated, "*People are angry with those who get TB*".

The Child-TB Situation:

Within the last seven years, there had been far more Pupara children (mostly infants) on anti-TB treatment than adults. The house-to-house survey indicated at least twice as many! Like the adults, most were diagnosed outside the government system. However, unlike the adults, most also had their treatment within the private sector

Spontaneously, only a few of the custodians mentioned visits to shamanistic healers. Such consultations, however, were common. One mother even said that a government health worker had advised her to take her infant daughter to the *dhami.* The general idea seemed to be, "*Sometimes they get cured, sometimes not, and if not we bring them to a hospital*".

In the investigated cases, the first allopathic port of call for half was a medicine shop across the border, for the other half a similar enterprise within the district. Government health centres were also visited at an early stage. The initial diagnosis, however, wherever made, tended to be anything but TB, mostly pneumonia. Thus, there were repeat visits and visits to more than one health establishment. This was the case of a mother with a child diagnosed at the age of eight months who said,

> *My son had fever, vomiting and did not eat well. I took him twice to B-gaon(across the border), then to the Health Post, and then to a private clinic but he was not cured. He was better in the months of Magh and Phagun but got worse in Chaitra. At that stage, a neighbour advised me to take him to 'the Child Clinic' in Nepalgunj and this I did in the month of Baisakh and after a X-ray, Dr X said that he had tibi of the lungs*.

In the end, most of the children were diagnosed in the Child Clinic: a private facility with a child specialist (Dr X) in Nepalgunj.

There were no routine referrals from the private sector to the public one, although some private institutions were and are providing DOTS under NTP. Some families, primarily those who had or recently had had a member on TB treatment from the Sub-Health Post, had their child-TB treatment from there. The rest- the great majority - had it within the private sector, approximately half from "the Child Clinic" in Nepalgunj and the other half from geographically closer private facilities, the Sub-Health Post-in-Charge's medicine shop included.

Some health-workers suggested that the government staff were happy with the young being diagnosed and treated privately, as child-TB is only supposed to be 5-15 percent of all TB cases. Moreover, an efficient TB programme should not have more than 50 percent non-infectious cases and most child-TB cases were and are non-infectious.

The common undertstanding as to why most of the children did not have their TB treatment free of charge from the Sub-Health Post was the expectation that the medicines had to be picked up daily, whereas this was not so within the private sector. There was an additional incentive in a widespread belief that whereas the government's adult-TB medicines were "good", this was not necessarily so with the *bal-tibi* medicines.

The child-TB medicines were inexpensive and widely available. Even so, some Pupara families could ill afford the cost. One mother said, "*About Rs. 2,500 were spent all in all, vitamins and the travel up and down included. We went three times. I didn't have enough money, so I pawned my jewellry for Rs.1,200*."

Causality Beliefs of Child Tuberculosis:

Poverty/a lack of good food, an unhealthy environment/ climate, dirty water, and mothers alone and working long hours, were suggestions as to why so many Pupara children ended up with TB. Meanwhile, some health workers hinted at a possible over-diagnosing.

When asked what cause/s the parents perceived for their child's TB, the answers were almost as many and varied as those suggested in the adult cases, except alcohol and tobacco not being in the picture. In one case, however, the mother suggested that the vapour from her brewing of alcohol was a likely cause of her son's TB. However, she added, "*It also depends upon the strength of the body and the*

amount and the quality of the blood." Some explanations were quite imaginative, thus one grandmother suggested, "*If a mother takes spicy and oily food her child can get TB. I also think that lipstick can cause TB. And, the mother not eating eat well and using cigarettes is yet another reason."* Several suggested that the TB might have started already in the womb and this with or without the mother having or having had TB. The latter explanation was mostly tied in with the mother's physical condition having been weak.

Beliefs about Transmissions and Observed Practices:

Two-thirds reported a previous adult-TB case in the family. When specifically asked, most acknowledged that the child's TB might be because of a transmission within the household. The idea of such a transmission, however, was rarely spontaneously suggested and hardly ever as the only cause. When asked, "*How can TB transfer from an adult to a child*", the common suggestion was by the child eating or drinking something touched by the adult. One mother stressed that, "*One time can be enough*" and continued to tell that her toddler, by mistake, had been given water touched by the grandmother (on TB treatment) and, "*that combined with him being a weak child was probably why he got TB."*

Bal-tibi, it was said, was *tibi* but different from adult *tibi*. The children were not expected to be a danger to others except if someone by mistake would eat the child's food left overs. Thus, in one household, in which both father and an infant daughter were on treatment, both from the Sub-Health Post, there were precautionary measures in the household in relation to the father but none in regard to the daughter.

The children were not blamed for the disease. In some cases, the mothers were but not severely so. Infants were expected to be sick on and off and *bal-tibi* was common, bad, and somewhat costly but treatable, i.e. great worries before the diagnosis but not necessarily so after the diagnosis.

Findings in 2013/2014

Local Setting:

Pupara in 2013/14 was more affluent than in 2005. A major reason was money made outside Nepal but also investments by the government in irrigation schemes. Even so, like before, most households had a member or two working outside Nepal, and thus still a lot of comings and goings and of male absences. Moreover, some families had moved in and others had left. There were now nearly 300 houses with about half being extended households. A few, but only a few, it was said, had conspiciously more than others and "the really poor" were less than 25 percent.

There were worries about too much drinking, some of which was blamed on local unemployment. Even so, health-wise there were improvements, particularly among the young. Vitamins had been distributed through UNICEF-initiated nutrition campaigns and since some years, infants were routinely BCG vaccinated. Moreover, there were less children per family and, according to the Female Community Health Volunter (FCHV), because of that there was enough food for each child and thus stronger children. She added, "*There is less pheumonia among the young and because of that perhaps less bal-tibi*". Meanwhile, rumours suggested that NTP representatives had advised "the Child Clinic" in Nepalgunj to be more restrictive with TB diagnoses.

In 2013/14, when illness struck, shamans were consulted but perhaps less than previously. Medicine shops on the other side of the national border were still visited but so were a couple of new ones inside the border, close to the village. According to government staff, the latter were popular because of their great willingness to give injections. Meanwhile, the number of health establishments in Nepalgunj had swelled and the Pupara villagers turned to these when illhealth persisted. And, when seriously ill, the sick ones were increasingly brought to Lucknow, India.

The Sub-Health Post was better staffed than previously. A former Clinic-in-Charge had returned and it was commonly recognised that its services had improved. Even so, except for minor health problems, for those with money to spare the Health Post was still not likely to be the first port of call. In 2012, the Sub-Health Post became "a Health Post" and itsTB services upgraded to include sputum tests.

Prevalence of Tuberculosis:

The Health Post staff reported no greater changes over the years in the TB ratio within their catchment area as a whole (the VDC). The Pupara FCHV, however, suggested a sharp decline in Pupara itself, particularly in child-TB.

In 2013/14, during the last five years, no Pupara child but eleven adults had or had have TB treatments from the VDC Sub-HealthPost/Health Post. Ten of those were interviewed and so was a member of their household and a neighbour. A household member and a neighbour of one absent patient (India) were also interviewed. Moreover, five adults from neighbouring villages on TB treatment at the Health Post were included in the study. In addition, as before, custodians of child-TB cases were contacted and interviewed.

Two of the adult patients interviewed in 2005 had left the village and one had died in an accident. The others, including three who had previously been absent were followed up in 2014. Three reported a lack of health, which they associated with their previous TB. One of the three had had three TB treatments, including one in Lucknow, India. Even so, he still had pain in his neck and feared that his TB was back. The other two had developed asthma, which they suggested had developed because of the previous TB. Even so, the general opinion among those from the 2005 cohort was that the anti-TB medicines had been effective and permanent cures had been obtained.

Adult-Tuberculosis Situation:

Of the 16 adult patients (seven females, nine males) in the 2013/14 cohort, ten were pulmonary sputum-smear positive, two pulmonary sputum-smear negative, and four were EP cases. The youngest was 19 years old at

registration, and the oldest, 61 years old.

A few of the adults interviewed had been in India or otherwise abroad at the start of their TB. Being ill, however, they had returned home sooner rather than later and thus the main part of their health-seeking had been in Nepal. However, some had not and that in spite of having to pay for their TB treatment. A main reason, it was said, was for others not to learn about their TB.

Early in the ill health, a few had tried home-made concotions and a somewhat larger proportion had consulted shamans. Most health-seeking efforts, however, as in the 2005 cohort, had been within the allopathic sphere and again more within the private sector than within the public one. Each household, it seemed, had blazed its own route. Asbroek et al. (2008) report similar observation in their research.

In 2013/14 in Pupara, the key characteristics of "the common type of TB", pulmonary TB, were widely known. Even so, like in the previous cohort, most health-seeking processes were drawn out. A young woman told, "*Yes, my father-in-law suffered from TB. He had medicines for eight months. Now, he is dead. My three children had bal-tibi and another died before being diagnosed."* Her symptoms, however, were different from theirs and the health-seeking efforts were geared towards gastric problems. Fifty thousand Nepali rupees were spent. Due to the continuous coughing and an obvious weight loss, the next-door neighbour claimed to have suspected TB at an early stage but had chosen not to say anything.

Experiences of Being on Treatment:

In 2006, the "Stop TB" strategy was launched. In this, the former key directive of "direct observation of treatment" was replaced by "supervision and patient support". The latter to be marked by effective two-way communications between the healthcare providers and those receiving treatment.

Two years later, the routine anti-TB therapy was shortened to six months. "The intensive phase" with compulsory daily visits to the treatment centre, however, was extended to the whole treatment period. When implemented it meant more work for staff and increased inconveniences for patients (Kirwan et al., 2009). However, in the VDC Sub-Health Post/Health Post, like in many other health centres, the central directives were modified and so the treatment period was shortened but without "the intensive phase" being noticeably lengthened. Even so, like earlier, the TB patients were unhappy with the many compulsory visits to the Health Post. An elderly male patient, who during "the intensive phase" in vain had twice asked for more than one day's medicines was so upset that he had stopped talking to the Health Post staff altogether.

In 2013/14, in Pupara, as in the area at large, there was no longer a cultural ban on women riding bikes and, thus for some the loss of time was less. The irritation over the many compulsory visits, however, was not only about practicalities but also that the many visits to the Health Post signaled to others that the condition was likely to be TB.

The former Clinic-in-Charge, remotely posted for some years, was back and, as mentioned, there was more vitality in the Health Post services.Yet, the DOTS components of "patient-adapted information" and "patient support" had seemingly not been taken to heart. However, as of late, TB patients were told to cover their mouth when coughing and when speaking to others. The Health Post waterjug was not clean and most patients, like before, took off with the medicines in their pockets.

The staff, it was said, preferred to make their encounters with TB patients as short as possible. Meanwhile, the patients, like earlier, did not expect the staff to be particularly engaged and, apart from being upset about the many required visits, most patients, like before, were happy with the services and with the anti-TB medicines.

In two cases, the treatment was prolonged because of delayed "sputum conversion" (from positive to negative). One of the two, an elderly woman, told that at the time of the diagnosis, she had been utterly weak, thin, and "*kalo"* ("black", a sign of being seriously ill). "People said that I was surely going to die". She was not worried about the extension of her TB treatment but rather the opposite: "*the longer, the better*." Another elderly female patient, an EP case, willfully extended the therapy. The Health Post, she told, stopped her treatment after six months but she did not regard herself as cured: "*They told me that there was no law saying they had to provide me with more medicines*." Her two sons in Nepalgunj took over and for the next 12 months they provided her with TB medicines from a private clinic (cost 3,500 NRs per month).

Causality Beliefs of Tuberculosis:

In 2013/14 like in 2005, the general idea was that the cause of adult-TB was "drinking and smoking". In regard to individual cases, however, as previously, the range was wider and more often than not multi-layered, commonly with "weakness" as a key component. To the question if anyone can get TB, a majority of the respondents in words and gestures expressed, "*maybe/perhaps/who knows?"*. Some, however, suggested that even if everyone can end up with TB in real life it only happens to those who are not careful about their health.

A patient might have one set of explanations, a household member another, and the neighbour a third. Thus, a middle-aged female patient suggested that her TB was a carry over from her son who had been diagnosed before her. He lived in Kathmandu but had come for a short visit. Her husband did not mention the son or his TB, but said that while he and his wife were in India, she was too fond of "*ram"* (alcohol). The *ram*, he said, ruined her heart and liver and because of that the TB occurred. Meanwhile, the next-door neighbour suggested, "*Just like alcohol and tobacco, very spicy food ruins the stomach and thus leads to jaundice and TB."*

Beliefs About Transmissions:

The possibility and probability of the disease being a transfer from one person to another was suggested more

frequently in 2013/14 than in 2005. Seldom, however, was it mentioned as the only cause and hardly ever with the index case outside the family, "*close links*", it was said, were needed for a transmission to take place. At the same time, there was the notion of TB being more seated in some kinship groups than in others, not necessarily because of transmissions but mainly because of "*bad Karma"*.

Like those in 2005, the patients interviewed were not certain if their TB had been/were transmittable or not. And, if transmittable, they did not know for how long. Meanwhile, as previously, in most homes safety measures were installed and again upheld far longer than ever needed. Some instigated a few measures, others several. Some were strictly upheld, others not. Moreover, in one and the same household, some precautions were more strictly upheld by some members than by others. The most frequently observed safety measure, in 2013/14 like in 2005, was "*no food from the plate of the patient*". Some claimed that this was an instruction from the Health Post.

In relation to transmissions "casual encounters" were not perceived as a danger. One patient, a young man, highly sputum-smear positive at diagnosis, had a small grocer's shop in the village. He claimed to have received no information about whether he was contagious or not. Even so, some precautionary measures were initiated in the home but none in the shop. People knew about his TB, yet customers kept coming. His mother's explanation was that TB is so common in the village that no one bothers about it.

Whereas most patients reported marginal if any social problems because of TB there were those who suggested otherwise. The latter were chiefly patients presently on treatment whereas those looking back rarely recalled any negative attitudes or behavior, and definitely none beyond the completion of treatment.

For most of the patients interviewed the influences and effects of TB were temporary. However, for some they were not. The latter was obviously the case for a middle-aged male patient who was treated for TB not once but twice. Before him an elder brother had passed away in TB and he himself was not able to believe that his own TB was gone. There was also a young woman with bone TB, whose treatment was coming to an end during the 2014 interviews. She said, "*This disease has brought big changes into my life – we have lost a lot of money and previously I was not disabled but now I am!"* And, there was the young man whose treatment was completed three years prior to the interviews. We did not meet him as he was in India. His family, however, reported that he was far from well. The reason, his wife suggested, was that they were poor and had not had enough money for "fish and meat" while he was on treatment and because of that he never recovered fully. "*Again, he has chestpain*", she said, "*but not only he - now I also have chest pain!"*

Child-TB Situation and Health Seeking Behavior:

In Pupara the number and the proportion of *bal-tibi* cases had dropped drastically! Even so, much of what was learnt in 2005 was still applicable. Thus, yet again, it was found that most child-TB cases in addition to being diagnosed outside the national program were also treated outside the same.

In 2013/14, contacts for longer interviews were established with 13 families in which there had been *bal-tibi* within the last seven years. The children, seven boys and six girls, all BCG vaccinated, were two years or younger at the time of the diagnosis. Two were on treatment. The symptoms, according to the custodians of the 13 children were various combinations of fever, diarrhoea, vomiting, loss of appetite, lethargy, a preference for cold places/wet things, coughing, irritation, and crying.

In relation to the young age of the children, the health-seeking processes outside the homes were lengthy, half of them two months or more. Shamans were contacted and allopathic help was sought within the private as well as within the public health sectors. With each failed treatment the child's condition worsened and the worries and fears of the parents increased. Before the TB diagnosis, within the allopathic sector, children were treated for pneumonia, malaria, measles, jaundice, worms, urine infection, and so on.

After a series of unsuccessful medical and/or shamanistic consultations and treatments, someone was likely to suggest that it might be *bal-tibi,* occasionally with a suggestion of where to turn for help. Eventually, all the children, except one, were TB diagnosed within the private sector, half at the aforementioned "Child Clinic" in Nepalgunj.

In contrast to the adults, the subsequent anti-TB treatments, as pointed out, were also within the private sector, some from the Nepalgunj "Child Clinic". One mother told that she wanted to have the treatment closer to home but the Nepalgunj nursing home where the child had been diagnosed (not the "Child Clinic") had insisted upon the treatment being from the same place as the diagnosis.

Only one of the 13 children had have their anti-TB treatment within the government health sector. Unfortunately this very child had a relapse and so, six months after the first treatment (from the area PHCC), he had a second round of TB therapy. This time, however, the treatment was from the private sector. According to his mother "*...the government medicines had not worked".* However, she also suggested that the first treatment might have failed because she had been "*dry*", and without mother's milk the son had been weak and skinny.

After the start of treatment, with one or two exceptions, the recoveries were quick. Even so, the parents, with one exception, meticulously continued with the medicines and some arranged for an extra month or two to ensure "*a complete recovery*" or "*just in case*". In addition, two of the children had more extended anti-TB medication because their recoveries were slower than others and one child had it because he had been without the medicines for "*a couple of days*".

Since the children did not have their treatments from one and the same place there were differences, not in the anti-TB regimen, but in the amount of additional drugs/ supplements, the frequency of medicine collections, and in

the number of check-ups. Thus, the efforts and the financial costs varied.

Besides the expenditure for medicines and supplements (vitamins, iron tablets, Baby Tone, and the like), there were costs for travels, snacks, and so on. Two households reported that they had spent Rs.5,000 or less, three to between Rs.5,000 and 10,000, and the rest Rs.10,000 or more. Three-quarters of the families testified to not having had enough money at hand and loans had been taken, some with a high interest (from non-relatives).

Only one of the mothers claimed to have been unaware of there being free TB medicines within the public health sector. The standard answer, like in 2005, as to why they paid for something, they could have for free was the difficulty of daily visits to the Sub-Health Post/Health Post. They were working, there were other childen in the family, and it simply was too much of an effort. Moreover, again like in the previous survey, free medicines, it was said, might not be as good as those paid for and besides, the child-TB medicines were not all that expensive.

Among the parents, as in the community as a whole, "physical weakness" was suggested as the main cause of *bal-tibi*: "*first weakness and then TB*". A weakness more often than not blamed on a lack of "*good food*". The health workers' instruction to ensure that the child had high quality, nutritious food during treatment reinforced the idea. Some blame landed with the parents. Bad hygiene, dust and smoke were also mentioned as causes. Whereas, some residents suggested that, "*it just happens by itself*", an elderly grandfather concluded, "*Child-TB is because of malnutrition, adult-TB because of carelessness*".

Beliefs About Transmission:

Whereas, adult-TB was supposed to be transmittable, child-TB was not. However, there were inconsistencies in the reasonings and a lack of understanding of the mechanisms of both. Thus, a person would suggest that his/her child's TB did not transmit because *bal-tibi* did not transmit, yet a few minutes later the same person would report that since the *bal-tibi* diagnosis no one had been given or had taken food from the child's plate. And, some of those who suggested that the child's TB could have originated from an adult-TB case did so in spite of the prior TB case having being before the child was born. And, in one case the person was dead before the birth of the child.

The children recovered quickly. However, several parents remarked that physically not all *bal-tibi* children caught up with their peers. "*Perhaps*", it was said, "*because the food provided during their TB treatment had not been good enough*".

Findings in 2017:

For several years, for the VDC as a whole the registered number of new TB cases at the Health Post had been 25 to 35 with three to five being from Pupara. In 2017, however, with still two months to go, there were eight new Pupara registrations, all adult cases.

In late 2017, the patients interviewed in 2013/14 were followed-up. One had died, three had left the area, and one was not found. Of the remaining eleven, five were abroad (for work), but their homes were visited and at least one family member was interviewed. The man who had died, had in 2014 testified to a complete regaining of health. However, a year later he developed asthma and this, according to his wife, was the reason for his death. One of the TB cases on treatment in 2014, had had a relapse and was presently on her second round of TB treatment. This time, however, not from the government but from the private sector. Of the remaining ones, half testified to physically doing well whereas half suggested post-TB weakness, chest pains, and coughs (asthma in two cases).

The custodians of child-TB cases interviewed in 2013/14 were re-interviewed in late 2017. Two of the 13 families had left the village. Of the remaining ones, seven reported that the child had done well. Four maintained that this was not so; the child was thin, had stomach troubles/ lack of appetite, and was more often sick than others. Three of them suggested a direct link between the lack of good health and the *bal-tibi* episode whereas one was not sure about the connection.

All testified to no social problems because of the *bal-tibi,* neither during nor after the treatment. Even so, seven of the eleven children had not been told that they had had TB, not because of omission but rather by choice.

For most of the families, in the run up to the diagnosis as well as during the treatment, there had been considerable expenditures. In 2017, however, all of that was in the past: loans had been repaid and, presently they testified to being no worse off than others.

In most households there had been no more TB. In three, however, there had been. In addition, one of the children had been *bal-tibi* diagnosed not once but twice.

The 2017 follow-up indicated that in most cases the negative effects of *bal-tibi* were gone. In some cases, however, as mentioned, parents still worried about the physical condition of the child. At the same time, in Pupara, there was a widely known older case which had taken a nasty turn, a warning, it was said, not to play around with *bal-tibi*.

In the follow-up, we asked, if the custodians, if they knew of others, adult or child, presently affected by TB in their immediate neighbourhood. Almost everyone answered in the negative. The FHCV did the same, "*one or two, at the most three cases*", she said.

Summary and Concluding Remarks

The data from Pupara 2005-2017 shows few changes in the experiences of being a TB patient. In regard to most adult patients, this meant a drawn-out health-seeking process with progressive illness, worries, and costs, not because of inactivity but rather by faulty conclusions and misdiagnoses. The TB diagnosis, when reached, tended to be a relief but not all happiness. *Tibi* was "a big disease" and a somewhat shameful disease (Chang and Cataldo, 2014). The circumstance of good anti-TB medicines being available free of cost within the government health services was greatly appreciated. Yet, to get the medicines, there

had to be frequent visits to the government health centre which was an arduous circumstance and a likely social give-away. Similar findings are found in other study sites of Nepal (Harper, 2005). During the medicine pick-ups the communication was sparse between healthcare provider and patients and thus wrong ideas about TB prevailed in spite of the many visits, the notion of a TB patient being somewhat at fault for his/her condition included.

In the community, the mechanisms of TB transmissions were not well understood and separation measures were installed in most patient homes (sputum-smear positive and sputum-smear negative alike) and kept up far longer than ever needed and this in spite of a potential transmission between household members most likely having taken place well before the diagnosis. Meanwhile, in regard to outsiders, except a ban on food from the patient plate, few, if any, precautions were taken.

Seldom, if ever, was the disease talked about or discussed outside the family. Others, however, suspected and guessed. Even so, everyday social interaction was at large maintained even if sometimes tainted by hesitation. Suggestions of *tibi* presently being "a highly stigmatising disesase" was strongly refuted by everyone and examples of "enacted stigma" were hard to come by. Even so, there was a fear of transmission and some anger for the patient having had "his/her defences down". Negative reactions, however, were temporary. Some "self stigma" (Goffman 1963) might remain together with some economic problems but not for long. For most, TB was "an episode", an unwanted, gruesome, and costly interference in their lives, but it passed. In some cases, however, there were continuous effects, physical as well as economic.

And, then there was child-TB. In the eyes of the community, adult-TB (*tibi*) and child-TB (*bal-tibi*) were and are phenomena apart, with the former primarily connected with individuals having been careless about their health, whereas *bal-tibi* was "all over the place" and the children innocent victims. Moreover, while adult-TB could be dangerous to others, *bal-tibi* was presumed not to be. However, everything was not white or black, and the idea of *bal-tibi "happening by itself*" was moderated by remarks about the evils of poverty and possible negligance by some mothers. Furthermore, in spite of strong convictions about *bal-tibi* not being contagious, the food leftovers of a *bal-tibi* child were not distributed,"*just in case*".

There was a drastic drop in the number and proportion of those diagnosed over the years. In the community, the plunge was primarily explained by improved living conditions combined with routine infant vaccinations, making more resilient children. The possibility of a previous overdiagnosing was mentioned, but not frequently.

Child-TB medicines were free of charge within the government services but unlike the adult-TB medicines they were not supposed to be as good as those privately purchased. Moreover, the thought of numerous visits to the government treatment centre with or without the child for the picking up of the medicines was a strong deterrant (Parmar et al. 2018). In consequence, most *bal-tibi* cases, in contrast to most adult-TB cases, were not only diagnosed within the private sector but also treated within the same.

Usually, there was a quick recovery and that basically was the end of the *bal-tibi* episode. For some, however, there was less strength than expected and hoped for. Concurrently, however, as mentioned, the common assumption was that those who ended up with *bal-tibi* had originally been weaker than others. After cure, in most cases the fact of a child having had *bal-tibi* was of little if any consequence. Even so, most parents choose not to inform the child about him or her having had *bal-tibi*.

In Nepal, much has been accomplished in the battle against TB. Thus, effective TB medicines, are widely available, and free of charge within the government sector. Yet, the route/s to the diagnosis are commonly long. The distribution system of the medicines, particularly within the government system, adds to the burden of being a TB patient, and much would be gained if the arrangement was more consumer-friendly, a change which could result in more children treated within the public rather than within the money-geared private sector (Paz-Soldán et al., 2013). Various misunderstandings about the cause/s of the disease, the mechanisms of transmissions and potential contagiousness need to be addressed. Much would be gained are the central directive of "patient support" (based upon two-way communication) truly part of the experience of being a TB patient (Paz-Soldán et al., 2013).

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