TUBERCULOSIS CONTROL IN THE BRAZILIAN N-W AMAZON

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For my Elective, I chose a subject in which I already had a personal interest. I had carried out doctoral research as a social anthropologist among a group of Tukanoan Indians in the Colombian Amazon. Between my first stay, ending in 1970, and a revisit in 1979, I found that these Indians had suffered serious reductions in population from tuberculosis and had become pessimistic about their future. An itinerant medical team had discovered a substantial number of sputum-positive individuals but the strategic problems of administering daily streptomycin injections and ensuring that pills were supplied and taken, proved too much for the lay missionary left in charge and I knew of no case where a chemotherapy course was completed. Day to day experience in Indian longhouses taught me the fate of most medicines received by Indians. These were mainly free samples from pharmeceutical companies distributed by Catholic missionaries who had very little understanding of their proper uses. They were handed on among Indians as unrecognisable, discoloured little packages. I had also been present when a medical team from a distant frontier town (Mitú) visited the longhouse I was staying in and I witnessed the communication gap between traditional Indians who could not speak Spanish and young Colombian doctors who understood very little about Indian society.

Although at first I wanted to return to the frontier town hospital in Mitú, on second thoughts I decided to visit the Brazilian side of the border because I knew that physical communications were easier than in the rapid-filled Colombian rivers and I suspected that, between them, the Brazilian Indian Affairs Department (FUNAI - Fundação Nacional do Indio) and the highly organised Salesian Mission would have arrived at a more comprehensive Indian healthcare system than existed in Colombia. I wanted to find a discrete population for which adequate records of measures taken to diagnose, cure and prevent TB existed and to evaluate the program with particular emphasis on the quality of communication between health-workers and patients and its influence on patient compliance. I was curious to see how the practical problems of case-finding, diagnosis, treatment and evaluation of results would be overcome given the ubiquitous Amazonian conditions of geographical isolation and short financial and human resources. I hoped to use my stay to make some positive contribution in the field of health education towards the control of tuberculosis but I did not want to decide in advance what form this could best take.

As other elective students before me will have discovered, it is one thing to write a project surrounded by library stock describing controlled trials of drug regimes, patient compliance statistics from urban centres and diagnostic flow charts and quite another to gather any concrete information in a remote tropical area in a short space of time. Many days of my six weeks were taken up by arranging to travel, travelling or failing to travel to the next medical centre. Others were spent waiting to see people, searching for patients with wrongly recorded names and addresses and so on. In the end, I came to regard these delays as part of what I was investigating; after all, the difficulties I experienced in finding out about the local tuberculosis program were either those same ones which face lacal healthworkers or were due to defects in the organisation and implementation of the program itself. I was helped enormously by my initial contact with Dr Heitor Dourado and the Medical Faculty of the Universtty of Amazonas in Manáus. If I had not been included in an interdisciplinary students project to take place in São Gabriel da Cachoeira, I doubt that it would have been possible for me (a foreigner and a social anthropologist) to travel in the Brazilian N-W Amazon atall. Beyond the U.o.A., my lack of an official role in the Brazilian institutional system often did seem to stand in my way. Typically I was enthusiastically received for a first visit, during which the standard chemotherapy course, the system of record cards and the ignorance of the patient population and lack of resources would be explained. If I wanted to know things which did not feature in the familiar 'official introductory conversation' goodwill began to run short. No doubt this was partly because people had to patient with my inadequate Portuguese and partly because it was felt that I ought to have been sent by a Brazilian authority, but this was not all. My respondents often found the questions themselves irritating. Sometimes it was because they did not know the answers; for instance, the director of the centre of TBcontrol for the state of Amazonas promised several times to find the number of cases treated in the last year (the simplest statistic I could think of) but it was never forthcoming. Other times it was because my questions concerned subjects which doctors considered to be outside their duties, a point I shall return to.

By the end of my study, I succeeded in visiting a series of people and organisations completing a hierarchical set with the Indians of a remote forest village at one extreme and the Co-director of the TB program for all Brazilian Indians at the other. I was fortunate in that the latter co-ordinated the Indian program from Rio de Janeiro where I had already arranged to change planes on my return but I was unfortunate to have all the elusive statistics about TB in Brazil, which I had persuaded a secretary in an adjacent office to divulge, stolen when I was attacked in a Rio street. Working from general to particular, I visited the Rio co-ordinating centre for Indians, the State co-ordinating centre and TB clinic in Manáus (Ambulatorio Cardoso Fontes), the state-run hospital and Funai medical centre

in São Gabriel da Cachoeira on the upper Rio Negro, the mission hospital in Parí Cachoeira on the Rio Tiquie and the people of Boca de Estrada, two days downstream from Parí by dugout canoe. In this way I saw something of TB control in a range of populations and I was also taken to visit a general hospital in Manaus which had formerly been a specialist TB hospital and accompany a dermatologist in his leprosy clinic held in an abandonned leper colony on the Rio Negro outside Manáus. I spent the last few days of my trip producing and distributing a booklet on TB. The short time I had in each place together with the difficulties in tracing patients made it impossible for me to carry out any systematic set of interviews. An attempt I made to start this with the help of a Brazilian medical student petered out because, like many of the doctors I met in TB work, he thought my questions were irrelevant to the doctor's appointed task of diagnosis and prescription. My report is based on a large number of informal conversations, some of them in private houses, and the exchanges I observed between patients and doctors and nurses in clinics and hospitals. In spite of the lack of reliable quantified information, by the end of my stay I felt that I had heard a representative set of attitudes expressed and had appreciated many of the principle problems involved in implementing the TB control program.

The Health Education Council describes health education as 'any process by which information and advice is conveyed to the lay public, individually or collectively, and which helps them to help themselves to better health' and adds that this amounts to all 'informational' activity related to health. In the context of TB control in Brazil, information is conveyed to the lay public in clinics and hospitals when a diagnosis of TB has been made. Apart from two posters in TB clinics, I saw no written instructions or explanations produced for the public at large or TB patients. One poster said 'A persistent cough might be TB', the other: 'During your treatment make sure you:- take the medicine daily, bring your family to the health centre, return on the proper date, have a monthly sputum test.' Television was apparently used in Manáus to summon patients who persistently failed to attend the clinic and local radio was used in São Gabriel to encourage mothers to bring their children to a BCG vaccination session. A nurse in Manáus told me that she had seen a television program on BCG vaccination which proved it to be ineffective - she said it merely confirmed her own observation that many of her patients had been previously vaccinated. Schools were on holiday during my visit but I was assured that the mission schools in São Gabriel and Parí Cachoeira did nothing in the way of health education. Given this neglect of

potential channels of health education, I concentrated on what patients thought of their disease, how they thought it could be cured, how they thought it had originated and whether thay had understood and completed the instructions about chemotherapy and whether contacts had attended for sputum screening. From the health-workers' side, I was interested in the information I saw being relayed, the understanding of the need to explain the nature of the disease and treatment to the patient the understanding of the patients' beliefs and fears and the efforts made to increase case-finding rates and ensure patient compliance. During the study I also became interested in the activity of record keeping because I spent so much time trying to make deductions from records

In the Brazilian Amazonian context where most treatment is necessarily ambulatory and medical facilities are relatively scarce, it seems to me that health education could contribute to TB control in the following ways:

1. Case-finding: ~recognition of symptoms by patient or relatives
   ~motivation to seek medical help/request sputum smear
   ~convincing susceptible population that TB is an identifiable disease with an effective cure
   ~combatting the social stigma of TB which promotes secrecy
2. Successful completion of treatment:
   ~taking of full correct doses at correct times
   ~returning for next supply of drugs at correct interval
3. Follow up of patients:
   ~persuading patient to attend for check-up at end of treatment
   ~encouraging patient to watch for symptoms in self and contacts.
4. Prevention: ~informing population of value of vaccination
   ~persuading people to attend vaccination sessions

In some places in Amazonia an illiterate Indian may have to travel up to ten days in a dugout canoe to reach extremely limited medical help and therefore the question of patient motivation assumes an even more important place than it does elsewhere. The provisional list of health education objectives is enough to demonstrate that education is really an integral part of any successful TB program. It is unlikely, for instance, that the public will accept that there is an effective cure for TB if inefficient recall systems and inadequate instructions to patients result in self-evident relapses. Again, there is no point in motivating contacts to come for sputum tests or chest x-rays if there are insufficient facilities for screening. Unless health education is exclusively directed to activities confined to the domestic sphere such as diet or personal hygiene, it must be matched to the relevant medical program and, conversely the program should be matched to the level of health education. First I discuss the operation of the TB control

program in the places I visited and then I discuss some aspects of the beliefs, attitudes and behaviour I encountered that are relevant to 'health education' in a broad sense.

Organisation of TB Control in Amazonia

Soon after I arrived in Brazil, I discovered that one of my topics of study:- the factors affecting choice of chemotherapy regime, did not exist The national TB control program has adopted a standard 6month course consisting of Rifampicin and Isoniazid for 180 days and Pirazinamide for the first 60 days Rifampicin (300mg)and Isoniazid(200mg) were combined in red capsules and Pirazinamide was in 500mg tablets. An adult was prescribed two capsules and four tablets daily. Published regulations were available for suitable doses for children by bodyweight, for substituting alternative anti-tuberculous drugs in case of side effects and for alternative regimes in case of resistance The drugs were free to the patient and I never witnessed any shortage although during my stay a newspaper article appeared in the Jornal do Brasil saying that the Central do Medicamentos (the national drug distribution agency) was to stop purchasing all TB and leprosy drugs for one month. Informed opinion differed as to how long ago the present regime was introduced: it was probably in 1980 after the early courses of Streptomycin , Isoniazid and PAS had already been replaced by an intermediate one containing Ethambutol and a smaller Rifampicin component than is now used.

Manáus

Manáus, the capital of Amazonas State is a sprawling river port of over one million inhabitants at the famous confluence of the black waters of the Rio Negro and the white waters of the Solimões. The population has swollen (from 29,000 in 1972) with immigration from the surrounding tropical forest and other regions of Brasil. The vast majority of citizens live in slum conditions. The Ambulatorio Cardoso Fontes in the city centre is responsible for TB control throughout Amazonas and the activities of each state are co-ordinated in turn from the Divisão Nacional de Pneumologia Sanitaria which has bases in Brasilia and Rio de Janeiro. The ACF holds copies of record cards for all TB patients treated within state boundaries but unfortunately I had to give up any idea of using these to show incidence of treatment in the Upper Rio Negro when I learned that they are filed (for the whole state) by patient's name! The ACF also runs an outpatients' clinic for TB and children's respiratory disease to which problematic cases are referred from other local treatment centres. These are cases of drug resistence, those who have abandoned previous chemotherapy and those with highly suspicious symptoms but repeated negative sputum smears Pleural effusions are aspirated and lymph nodes are biopsied for microscopy and persistently sputum-negative patients are sometimes treated after their chest xrays have been

discussed at aclinical meeting

Many new patients come to the AFC after discharge from hospital and are referred on to the nearest health post to their home. A new patient is interviewed by a doctor and then a nurse who advises the patient about separating personal items from those of other household members, sleeping close to a window and not giving up the medicines as soon as the symptoms are alleviated. Theoretically sputum microscopy is done each month for patients undergoing treatment and contacts are listed but record cards suggested the microscopy was often forgotten and the immediate families of some patients I talked to had not been screened. Approximately 800 patients appeared in the treatment ledger for 1981. 17% were listed as having abandonned treatment and 2% as having died. The figures for 1982 were incomplete but the trend was of more treatments abandoned and more deaths and the nurse's own impression was that treatment in 1983 had been less successful than in 1982, with more relapses. It is difficult to tell what proportion of those marked as cured had actually finished their chemotherapy courses because some 'cures' were dated less than six months after the initiation of treatment and were presumably based on negative sputum smears.

São Gabriel da Cachoiera

This is a frontier town on the Upper Rio Negro. The 3,000 inhabitants are mainly Indian or half-Indian but non-Indians, including many immigrants from the N-E of Brazil dominate the professional and commercial life. Being a service town for a vast area of the N-W. Amazon, São Gabriel has a strategic importance quite out of proportion to its few ramshackle general stores and impoverished population. Schooling is run by the powerful Salesian mission; the mayor is appointed by the National Government (this being an area of 'National Security') and the small hospital is administered by the State of Amazonas. Indian affairs are controlled by Funai who provide medical serviced for Indians and TB treatment for everyone since the doctor formerly in charge of the hospital categorically refused to take responsibility for TB chemotherapy. This doctor was from the army because the hospital was built by the army while stationed in São Gabriel for the construction of a road to the Venezuelan frontier. By the time of my visit, the hospital had been turned over to the State who were unable to provide a Doctor. The principal was a male nurse from Manáus who was about to leave because his salary (just over £100 per month) was quite inadequate to support his family in São Gabriel. For want of an alternative, the Funai doctor held a morning clinic for between five and ten patients on most days and an army doctor spent a brief period there in the afternoons. In better times a small operating theatre was used (mainly for hernias, female sterilisations and prolapses). Because the Xray machine was broken, fractures were referred to Manáus (3 hours by plane or 5 days on a cargo boat) and there was virtually no activity in the hospital apart from in the laboratory where an army technician

carried out occasional tests and read Ziehl Neelson stained sputum smears - the Funai microscope being clogged up with fungus.

The Funai team included three health workers: a doctor, a nurse and a paramedic trained to carry out vaccination campaigns and do sputum microscopy. The São Gabriel post covered the rivers Cauaboris (Yanomamo Indians), Içana (Baniwa and Kuripako Indians), the Uaupes and Tiquie (Tukanoan and Makú Indians) as well as the populations along the Upper Rio Negro - altogether an area of over 100,000 square kilometers with an unknown population figure (25,000 was the director's guess). A health post for Indians, the Casa dos Indios, has been maintained by Funai for over a year. Patients and their families may stay in this building a few kilometers out of São Gabriel but those requiring more than drugs or a simple drip are transferred to the hospital.

A third input into São Gabriel healthcare is the Proyecto Rondon, a central government scheme whereby students and teachers from scattered Brazilian universities undertake short research projects or voluntary services in deprived areas thereby participating in the achievement of 'development, national integration and human dignity'. The visiting students hold clinics for all-comers. There is certainly patient demand but the lack of experience of the students, the absence of any continuity or cooperation with the hospital and the bizarre range of drugs available (for instance nothing for intestinal parasites or fungal infections) together with the absence of any proper physical examination resulted in an enterprise which seemed to me to do nothing more than reinforce the patients' desires to take a bottle of medicine home.

The director of Funai in São Gabriel believed that TB was the most serious health problem in his area. He had been actively involved in a number of BCG campaigns but was uncertain of the exact dates, populations and places. The records of these were kept in a distant mission village on the river Uaupes and therefore I was unable to collect any further information about prevention. All TB suspects with positive sputum smears were started on the standard chemotherapy course and told to collect their drugs monthly or two monthly from Funai. Indians from distant rivers were persuaded to spend as long as possible in the Casa dos Indios so that the nurse could supervise their drug-taking but if they insisted on leaving, a decision had to be made about whether to send the drugs to the nearest mission or whether to give them more than two months supply at once. Record cards were filled in for each patient (see fig. 4) and quarterly returns were made about the TB work undertaken. When I visited treated patients in their homes in São Gabriel, I found that only rarely had other family members been screened however, in one case where this had been done, three out of six required treatment. My visits also revealed a number of people who had gone to stay with relatives in Manaus for TB treatment so that the Funai returns do not reflect the total number of inhabitants treated.

Certain points are worth making about these quarterly returns (fig) In 1981, 20% of the people submitted to sputum tests were sputum-positive while for 1982 and 3, the figure is 60% If the smears are being prepared and read properly, this means that household members are not being tested and that the index of suspicion is extremely low. The number of sputum test done to control treatment is also disappointingly small - much less than the number of people recorded as cured each trimester - suggesting that it is unusual to test individuals during or on completion of treatment. That the patient is cured is often an assumption based on the fact that 6 months worth of medicines have left Funai, an assumption that I knew to be wrong in two particular cases of Indians on the Tiquie. São Gabriel ex-patients insisted that they had dilligently finished their courses (although they would be unlikely to tell me if they hadn't), apart from one woman recorded as 'abandoned'. She recalled having attended the Funai doctor's clinic after three months as requested She had expected a sputum test and a further drug supply but was dismissed with no further action Like many others I talked to, this woman had had TB diagnosed after a long wasting illness during which she was treated for something else (anaemia, stomach ulcer and malaria figured among patients' previous diagnoses); TB chemotherapy was only initiated when an axillary node enlarged Her case illustrates the the dilemmas of running a TB program with no diagnostic aids beyond sputum microscopy The policy of the Indian TB program emanating from Rio is that treatment should only follow positive identification of AAFB except in carefully monitored cases of superficial tuberculous lymphadenitis In practice a diagnosis of 'TB ganglionar' with no baciloscopy performed accounts for a consistently high 30% of treated patients in the Funai records Health workers in situ claim that Indians have a special propensity for tuberculous cervical lymphadenopathy but the controllers in Rio ascribe the figures to careless and indiscriminate diagnosis.

Pari Cachoeira

In 1940, Salesians founded their mission centre on the Rio Tiquie, coercing the Tukanoan and Maku groups of the area to abandon their respective longhouse and and nomadic life-styles and to give up their traditional ritual practices. In some cases longhouses and sacred artefacts were publicly burnt by the zealous fathers Today 239 of the 2,619 Tiquie Indians live in Pari under the all-embracing ethnocentric paternalism into which the early authoritarianism has mellowed . The mission's power is ensured by domination of education and religion and close cooperation with FAB (the Brazilian airforce) which controls communications in this frontier jungle region. The imposing mission buildings include a few hospital beds run by an American sister with a nurses training and backup from Funai who visit less than once a year. When the sister feels her limited resources are

inadequate, she arranges for her patients to be flown to São Gabriel. Before the Casa dos Indios existed, Funai would send them on to Manáus where some individuals died in a state of culture shock and despair. Often it proved impossible to trace the bodies or reconstruct what had happened to these Indians and this prompted the mission to press for medical facilities for Indians in São Gabriel.

The hospital in patient book starts in 1974 with 117 cases of 'gripe' (cold/flu) but the diagnoses become more varied with time including snake-bite, alligator bite, 'hepatic insufficiencey' and a number of catchall categories such as 'flu-malaria-dysentery' 116 admissions for TB over 9 years account for 51 separate patients. It is impossible to know if all these really had TB: only a small proportion appear in Funai records (which begin in 1981) and some Tiquie Indians have been treated in Manáus. The records show that Isoniazid, Streptomycin and Tetracycline were freely used in combination for any respiratory symptoms, recalling the Funai directors complaint that after an itinerant TB control team had visited the Uaupes with X-ray facilities in 1959, the missionaries abused all the drugs which were supposed to be reserved for TB. The missionary sister does not make sputum smears: she relies on the rare Funai visits, transfer of patients to São Gabriel, obtaining an 'official' diagnosis from an Airforce doctor aboard a supply plane, or on simply informing Funai that the case is 'ganglionar' for these are the only means of getting Funai to release TB drugs. One mission centre on the Uaupes had a sister with medical traing who did her own baciloscopy but this gave rise to resentment in Rio (in spite of the fact that she had to apply to Funai for all TB medication) because she was said to be 'taking over' and extending her catchment area into the Içana.

Boca de Estrada

This small Indian village, 2 days by dugout canoe from Parí, is composed of a Desana and a Tukano patriline whose members intermarry according to the tradition of patrilineal group exogamy (see fig. 3) As for other Uaupes Indians the subsistence economy is based on bitter manioc, fishing and hunting and gathering forest products. Many traditional Indian artefacts are now supplemented or replaced by manufactured goods brought with earnings from selling bunches of liana (for making brooms) and toasted manioc flour - 'farinha' to traders. Some young men work as migrant labourers, particularly on illicit cocaine plantations over the Colombian border and some young girls become household maids elsewhere in Brazil. I have marked those inhabitants known to have recieved TB treatment but others may have contracted TB. There are, for instance, two teenage children handicapped as a result of mysterious illness which may well have been TB. One has a thoracic spinal kyphosis and the other unstable hemiplegia associated with mental debility.

In Boca de Estrada I discussed TB with the inhabitants learning details of their illnesses and treatment and I took sputum samples from all those old enough

to cough on demand. The elder who acted as my host was in the middle of a chemotherapy course at the time but had inexplicably run out of TB drugs several weeks before and was not aware that he had a further batch to collect from the mission. The people of this village were demoralised by their history of illness which was so infamous that I had difficulty persuading the young men who paddled with me from Pari to stay there at all. Luckily the water level dropped, improving the local fishing so much that they cheered up and stayed out on the river all day. In general these people thought the mission to be well intentioned although they were sceptical about the chemotherapy courses for TB. In common with other Tiquie villagers they considered that Funai let them down.

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Communication and Health Education

So far I have described the framework of the TB control program in Amazonia along an urban-rural continuum. The system puts immense responsibility on a patient population which, whether coming from urban shanty-town slums or remote semi-traditional Indian areas, is culturally and educationally ill-equipped to cope with it. Healthworker-patient interaction is crucial to the success of the program but, at present it is far from adequate. The nature of this communication gap which might be filled by health education is discussed under three headings 'basic communication problems', 'patients' beliefs about disease and treatment' and 'healthworker-patient relations'.

Basic Communication problems

Each groups of Indians in the Upper Rio Negro has its own language and, in the large area inhabited by Tukanoan groups tribal custom dictates that marriage should take place between members of different language groups. In addition many inhabitants of São Gabriel still speak Lingoa Geral (Tupi-Guarani: an Indian language from Eastern Brazil spread throughout the Amazon basin by early missionaries for convenience sake). Altogether there are more than ten non-Portuguese languages in the São Gabriel catchment area. Where Catholic missions are long established, children receive a general education in Portuguese which is often poorly adapted to life in urban Brazil let alone to the tropical forest. As a Tiquie Indian complained to the Russel Tribunal on rights of Indigenous Peoples (Amsterdam 1980), they are taught about Greeks and Phoenecians and encouraged to view their own tribal past with shame. At least two missionary padres who became interested in Indians' language and culture have been expediently removed from the Tiquie by the Bishop in São Gabriel. However, the policy of North American Protestant missions, working principally on the Içana, is to translate the bible into Indian languages and therefore literacy skills are taught in Indian languages.

The nursing sister in Parí was typical in her overestimation of Indians' skills in Portuguese. I did not hear spontaneous conversations between Tiquie Indians in Portuguese and those who were truly fluent were those who had worked, as adults, in a context which required Portuguese. In the São Gabriel Casa dos Indios there were often serious difficulties in communicating at the most basic level with Indian patients; translators had to be found amongst other patients and I felt that little trouble was taken to make sure that the patient had understood questions or been given a chance to describe symptoms. Everywhere I found that missionaries, Funai workers and others lacked a grasp of the different Indian groups, their language affiliation and their traditional relations to oneanother. This has important implications for health education, firstly because it is evidence of a general lack of interest, respect and understanding of the patient population and, secondly, because the opportunity to reach a wider population with literature and broadcasts is being missed. The data I collected on the range of languages individual Indians arriving in São Gabriel spoke and read suggested that Portuguese, Tukano, Baniwa and Yanomami would cover the Upper Rio Negro area most satisfactorarily. The point of using Indian languages for health education literature is that literate Indians can read it directly to non-literate, non-Portuguese speaking members of their parents' generation and the fact that it is written in an Indian language makes it clear that the subject matter is addressed to Indians. There seems to me to be something basically inconsistent in using the language of a dominant invading culture to persuade people whose self-confidence in matters of medicine has been shattered to take a new kind of responsibility for their own health. I was not able to assess the impact of material written in Indian languages since, in the Tiquie region, nothing existed but I have since heard that a booklet I made is now being translated into Tukano and possibly also into Yanomami (by an anthropologist working with a Medécine sans Frontière team).

In Manáus, there probably are language problems in the Funai Casa dos Indios (a larger equivalent of the São Gabriel establishment, but I never succeeded in visiting this). It is difficult to get to and on the day I had arranged a lift, I had the last opportunity to xerox the booklet. In the middle of town everyone spoke Portuguese but the doctors manner of speaking and use of vocabulary made it difficult for many patients to understand and still more awkward for them to ask questions. The sympathetic nurse at the ACF volunteered that it was hopeless to talk 'bonito' (poshl) because it made patients bewieldered and inhibited,

Beliefs about disease and treatment

In traditional Indian society, all life-crises, all ritual gatherings, all illnesses, many technological practices and many occasions where special categories of food are eaten are accompanied by shamanism. The shaman communicates with the mystical world which is otherwise known through a vast corpus of myths about ancestors; meanwhile he blows on a sample of food, body paint, or vegetable medicine in a tiny gourd. He is able to 'see' the mystical causes of the illness and bring beneficial forces inherent in the mythical world to bear upon his clients by offering them the substance he has been blowing over together with an explanation of the causes and rationale of treatment. When I first arrived in the Tiquie, Indians assured me that active shamans still existed but that they are powerless against Wati poari (Tukano for pulmonary TB = Evil Spirit's Hairstuff) and that this disease passes directly from person to person and is not sent by evil shamans. When I talked to people about specific cases of disease, I found that traditional beliefs were firmer than this would suggest.

The story of origin of TB in Boca de Estrada is a good example: Jose (see fig 3) is a lazy man who only fells a small manioc garden each year and does not bother to replant the sticks as he harvests the roots. His sister married an Indian from a distant Uaupes group and his brother-in-law and the brother-in-law's uncle, a famous shaman, made an honorary visit. During this visit there wasn't enough to eat and, worse still, there was no farinha presented to the shaman to sustain him on the long river journey home. He lost his temper, blew evil spells on a cigar and buried it at the river port. Afterwards, at a beer party, everyone became ill and three villagers were actually transferred to a hospital in Manáus by the mission. Later another shaman was called in and he dug up the cigar so that all could see the cause of the trouble. In spite of this story, which is common knowledge among local Indians, people say that members of the previous generation died coughing blood.

I heard of many cases in which people had called for shamanic help both before and during the chemotherapy they had received and cures were partly attributed to the shamans in these cases. My host in Boca de Estrada first fell ill while in São Gabriel and an Indian shaman he met there used a ritual rattle to find the cause. It seemed he had been bathing after menstruating women had been in the river and had consequently been mystically attacked by Fish-Spirits. The same man showed me two specific wild plant cures for TB but, significantly, he had not used them himself. Both had red flowers which were explicitly

compared to the blood of haemoptysis. The bark of one (Leandra rhodofrogon (DC)Cogn)is drunk as an infusion three times a day, the gourd being put outside each night to collect dew. The bark of the other (Aphelandra sp (Acanthaceae)) is used as an emetic to clear TB out of the stomach

Indians explained to me that the nursing sister at Pari was much better than her predecessors because she did not try to prevent shamans from visiting and simulataneously treating her patients The Tiquie population do not see 'Western' medicine and shamanism as an either/or choice Most people try both but there are some more acculturated individuals who would like to see more 'progressive' attitudes predominate One young man told me that he knows how doctors can see microbes and also the inside of your body with X-rays because he has been in Manáus but he thought I should write something for his relatives who wouldn't believe this.

Within the range of modern medicines, Indians also express preferences. Complaints about the medicines from Pari included those that TB drugs were 'bitter', that the sister was mean with them, that they were not effective and that they only secured a short-term improvement.

The most interesting complaint was that the drugs did not correspond to the symptoms. I first encountered this in a young man's account of his mother's long illness. The woman appears in the Pari hospital records for prolonged stays in 1975, 1980, 1981 and 1983 - all for TB and she appears in Funai records as never having had a sputum smear because her disease (treated in late '83) was 'ganglionar' although, in fact, it was pulmonary. When in São Gabriel, the worried son visited one of the two pharmacies and described his mother's illness to the store-keeper On her recommendation he paid dearly for separate medicines for cough, for fever and for chest-pain which, he said, did far more good than the sister's medicine because they were chosen to match the symptoms. This case illustrates several general difficulties in the control of TB among semi-acculturated Indians which are relevant to the role of health education. First, Indians do not understand the relation of a standard chemotherapy course and the varied manifestations of TB. Second, the patient and near relatives play too passive a part in the treatment: free drugs with minimal (and frequently misunderstood) instructions do not engender the same motivation as drugs bought over the counter or shamanic cures. In the pharmacy the Indian has the initiative of the purchaser and appreciates the explanations for his purchases he receives from an untrained shopkeeper. With a shaman an elaborate social transaction involving requests, food and drink, instructions and gifts take place. Since it is clear that Indians should not be made to pay for drugs which they could never afford, the utmost possible should be done to emphasise explanations and make the patient feel that his or her case has been specially considered. Thirdly, a single badly treated case with repeated relapses, besides being tragic for the patient, is very bad publicity for chemotherapy and healthworkers. This particular woman had thrown away her TB drugs on at least

one occasion and it is impossible to know how much of her final six-month course she actually took. She spoke no Portuguese and could not have communicated directly with the missionaries.

In both Manaus and São Gabriel, alternative medicine also palys a part Many patients visit folk-healers for diagnosis and advice about treatment. Chest symptoms are commonly classified as 'peito aberto' or 'open chest' and the most frequently prescribed remedy is mastruço (Chenopodia ambrosioides) often mixed with a special brand of condensed milk and egg. Many former patients thought they knew from whom they had caught TB but the husband of one insisted his wife's illness had come of its own accord. While there appeared to be little social stigma attached to TB in São Gabriel and few patients were concerned that their families were at risk, the nurse at the ACF in Manáus told me that people were afraid to attend TB clinics for fear of being discriminated against and, in particular, of being thrown out of rented accomodation To avoid this many individuals start self-treatment with Rifampicin bought over the counter, but cannot afford to keep up the doses for long I verified that Rifampicin, but apparently not Isoniazid, is freely available (Cr ? 600 for four 300mg capsules in Manaus) A month's course would absorb nearly a third of the minimum wage (about £100/month)

The same nurse knew of many cases where patients had abandoned treatment as soon as they felt better - a practice which would often be disguised in treatment centres by poor record keeping. Sometimes these patients improve so fast on treatment that they do not believe the diagnosis of TB. Others fail to comply for other reasons like the 50year old patient I met who was taking an Ethionamide and Ethambutol course for resistant cases for the third time but was still sputum positive after three months. He explained that the Ethambutol was decomposing and when he put it out in the sun to dry it shrivelled away so he had just been taking Ethionamide.

Healthworker-Patient Relations

The principle obstacle to patient education in the space of the short encounter with a health-worker is undoubtedly the narrow vision that doctors I met had of their own role The doctor holding the clinics in the ACF told me that the Amazonian cáboclo (person of mixed race) understands nothing, is ignorant and has a very low level of intelligence When I enquired what happened if patients failed to attend, I was usually told that this was too bad - they were told what to do but they didn't do it The Funai attitude in São Gabriel was less aggressive but both doctor and nurse insisted that Funai's task was to make a diagnosis and dish out pills: if people didn't take them it was not Funai's fault Again, a nurse in the São Gabriel hospital described how she had pleaded with the former army doctor to keep patients who spoke poor Portuguese in hospital for

long enough to establish some means of communication sufficient to get across the importance of taking medication as prescribed, but she was invariably told that he had done his bit and, if the patients couldn't obey, there was no more to be done. Like the nurse in the ACF she was well aware that doctors avoided conversing with patients, issuing minimal orders which were rarely absorbed o understood: this certainly agreed with my own experience of brusque instructions shouted at mute and beweildered patients. Fortunately in Manáus, many of these were also seen by the nurse who patiently drew a picture of the daily dose colouring in the two Rifampicin capsules red. After my previous experiences this simple act seemed a near miracle.

The patients, for their part, complained about the doctors. They explained nothing; they didn't care about ordinary people and they didn't care about Indians Ofcourse it has been well-proved that patients in general do not remember much of what d octors tell them and it was impossible for me substantiate the numerous claims that patients had not been told they had TB, no-one had explained what TB was and so on Even so the image of the doctor came across clearly. Indians could not imagine a doctor sitting in their houses and the young man who was so upset about his mother delivered a tirade about the Funai doctor, comfy in his São Gabriel office 'with that little whisky and that ventilator fan' People in São Gabriel felt the health services were quite inadequate as is borne out by the number of relatively poor people who were prepared to go to the trouble and expense of a visit to Manáus for treatment. Among others there was a conviction that to enter the hospital was a virtual death-sentence, that drips killed people and so on

In Pari, the missionary sister had much the same complaints as the Indians about Funai. She recalled how she had asked the Funai doctor, during one of his rare visits to leave his motor launch to visit a child dying with pneumonia: first it was too hot, then it rained, then he was in the middle of a card game..... She had eventually come to depend far more on the good will of the visiting airforce crews to fly Indians to hospitals in other parts of Brazil.

The doctor is someone who performs his duty within a standardised TB control program but he is not someone who searches for ways of ensuring that his patients get better. While all grass-roots healthworkers looked to the directors in Rio for instructions on the Indian TB program, the director I met in Rio told me that his job was solely to guide others on how to implement the program and that education was Funai's concern. The point that an informed population would make more effective use of the expensive program was lost on him and he could not arouse enough interest to look through the trial pamphlet I had produced for Amazonian patients in the course of a two-hour discussion. In spite of this he emphasised that the Upper Rio Negro was the most difficult Indian area his team had to cope with.

In six weeks I had seen something of the TB control program in Amazonia and had reflected on how it might be improved without making major alterations in the personel or existing structure. It was a pity that I could not collect more data on BCG vaccination but no-one I met had any way of substantiating claims that BCG programs had been efficient in Brazil and there was no way of knowing what proportion of patients had been vaccinated. Some patients certainly did bear vaccination marks. Superficially, the program in the Upper Rio Negro approaches the reccomendations of the WHO Experts Committee on Tuberculosis in its 9th report "In a logical and efficient sequence of priorities, the first priority would be to provide facilities for direct smear examination of sputum from persons who, of their own volition, present with symptoms and to provide adequate treatment for those who are found to excrete tubercle bacilli In such a program, patients with persistent symptoms, but whose sputum does not contain bacilli should be followed up; treatment with anti-tuberculous drugs would only be given if the diagnosis can be confirmed bacteriologically" In practice the program deviates from this basic prescription in that geographical distances and distribution of health posts makes it difficult for patients to present themselves, follow up is inadequate and treatment is given to a large number of people with lymphadenopathy who do not have sputum tests. I cannot comment on the adequacy of sputum smear preparation, staining and microscopy except to mention that two individuals from Boda de Estrada had sputum smears declared positive by the ACF technician in Manáus (Z-N method), while duplicate slides from the same sputum samples were declared negative by the Addenbrooke's laboratory in Cambridge (Auramine method). The filling in of standardised record cards with copies in the treatment centre, the State archive and the Rio centre should have been a potent means of encouraging testing of patients at the end of treatment and monitoring and controlling the program but, unfortunately, it did not seem to be so in practice. The information often did not include an address with the correct river, let alone village, and, outside Manáus, the space for symptoms, clinical progress and health of family members was rarely completed The controller in Rio and the São Gabriel workers disagreed fundamentaly about the meaning of at least one category on the card ("aldeado") and the way in which Rio copies were classified was evidence of how misunderstandings of simple geography can become the basis of a time-consuming and fruitless indexing system. I came to the sad conclusion that record keeping had become an end in itself instead of a tool for feeding back past experience and information gained into future action. It also seemed ulikely that the statistical information accruing from the archives of cards was put to any use because no-one at the co-ordinating levels knew any figures whatsoever.

With the enormous practical problems posed by geographical distances, cultural divergences, poverty, poor salaries and working conditions for healthworkers, and lack of cooperation between state, central government, powerful Catholic church and isolated protestant missionaries, Funai and Rondon, it is easy to understand the impediments to an adequate TB service in remote Amazonia. The director of Funai in São Gabriel dreams of a wide-ranging boat-service to remote Indian occupied rivers. Funai would supply the boat and microscopy service, the Mayor-the financial support and Rondon-the medical skills. Sputum samples would be collected on the way up river and read before the return journey, when treatment would be initiated and slide shows about TB would be shown. My experience of collecting sputum smears in a remote community suggests that this would be impracticable because it is necessary to arrive the night before taking samples, otherwise the village population disperse to fish or garden at 5a.m. A day per village would mean at least one month to cover the Tiquie alone (excluding many affluents), and it would be difficult to arrange adequate means of collecting two monthly drug supplies etc. This type of expedition would possibly be worthwhile in areas of poorer medical surveillance than the Tiquie but it is doubtful whether the personel could be found to carry it out.

I cannot make any exaggerated claims for my own input, but I hope my efforts may have a small impact. I suggested to the nursing sister in Pari and Protestant missionaries on the Içana that it might be feasible for them to be instructed how to make sputum smears so that these could be read in São Gabriel and drugs returned for positive patients on the next flight. My enquiries in the São Gabriel hospital started some interest and the difficulty I had in locating patients persuaded nurses to start entering patients names and addresses in TB and BCG record books. My interest in the medical history of Boca de Estrada was welcomed in the village but, on the whole, when I returned to Manaus I felt I had experienced much but contributed little. To remedy this I produced two booklets for newly diagnosed TB patients. They were produced in a frantic rush without the time to redraw or revise anything and practical delays made it impossible for me to try them out on the Indian population in the Manáus Casa dos Indios. Rita Loureiro, a well-known Manáus painter did the pictures for the first but I decided the text carried too much of the information and so made an alternative version. These books were circulated to Funai, all the healthworkers I had contacted, a radical Catholic missionary group in Manáus, the State Ministries of Health and Education and an anthropologist working on the Tiquie. I have heard since that they are being translated into Tukano and considered for use among the Yanomami and that the State Ministry of Education may include a booklet based on these in a school series which already includes nutrition and dental hygeine. The anthropologist translating the booklet into Tukano is now working on another about diarrhoea and parasites and so it is possible that health education is being furthered in this neglected area, albeit in a small and tentative way.

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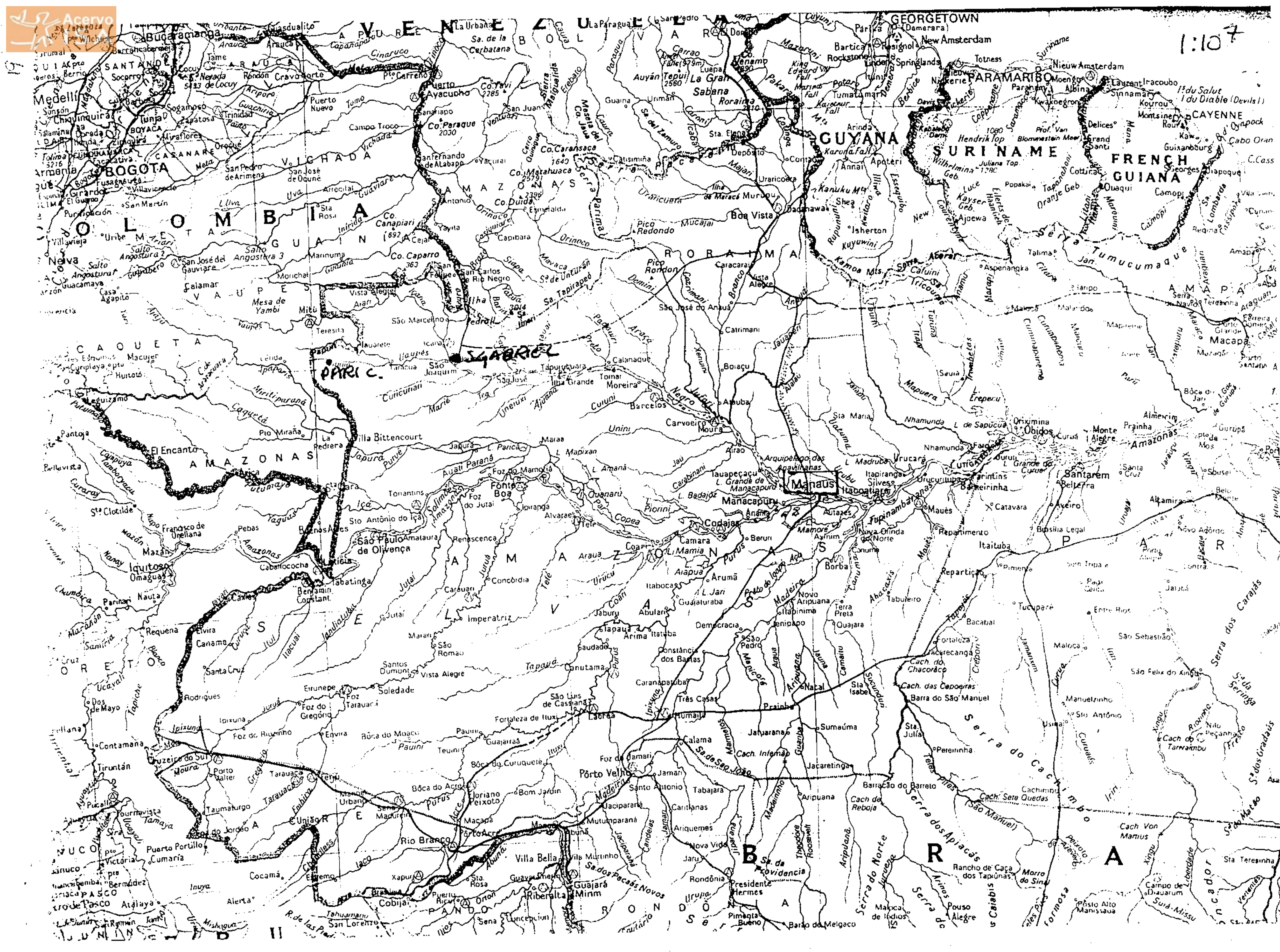
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BOLIVAR
GEORGETOWN
New Amsterdam
PARAMARIBO
Nieuw Amsterdam
CAYENNE
GUYANA
SURINAME
FRENCH GUIANA
Bucaramanga
Medellín
Tunja
BOGOTA
COLOMBIA
Puerto Ayacucho
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RORAIMA
Serra Tumucumaque
AMAPÁ
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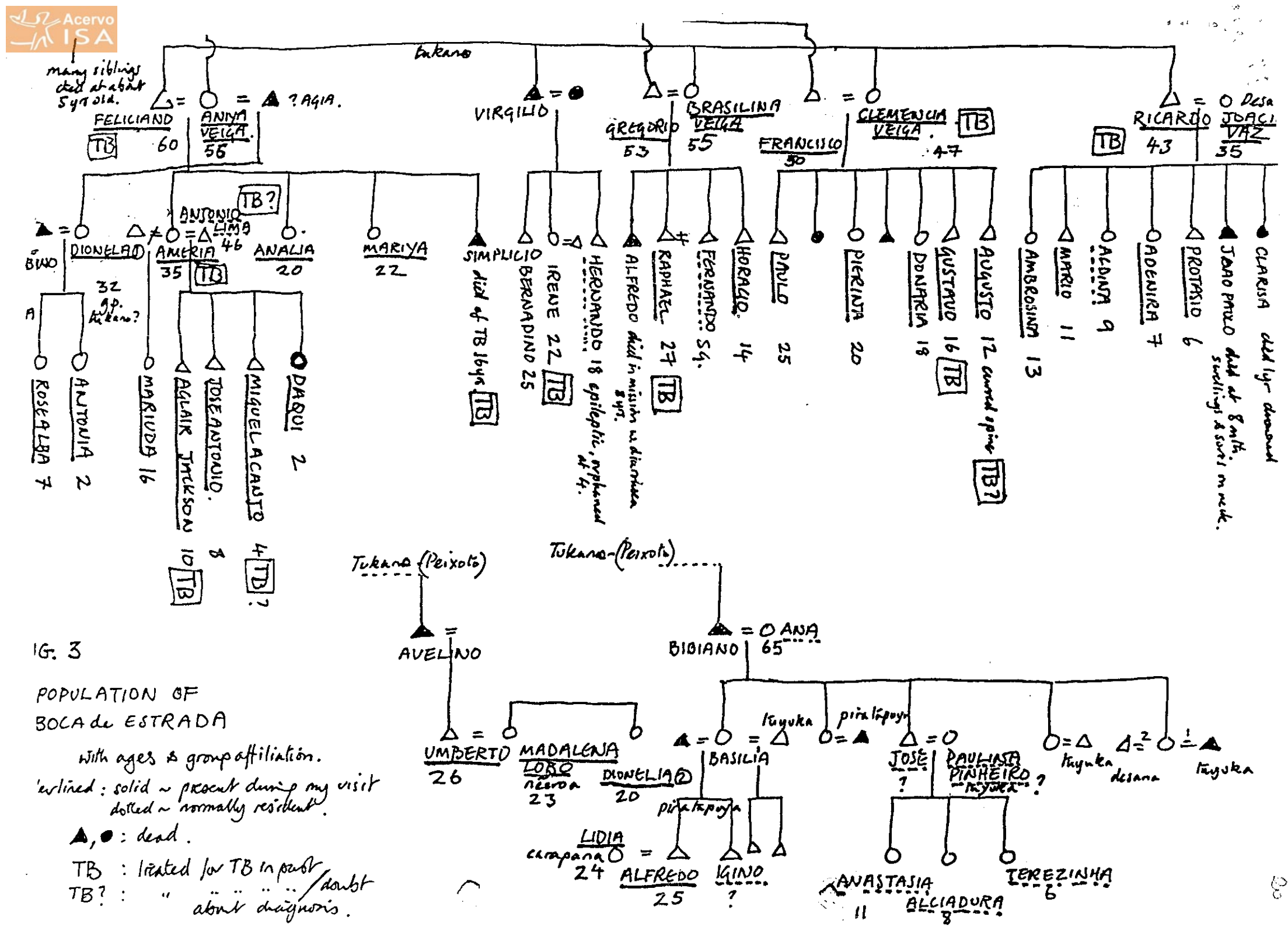

FIG. 3

POPULATION OF BOCA de ESTRADA

With ages & group affiliation.

Underlined: solid ~ present during my visit
dotted ~ normally resident.

▲, ●: dead.

TB: treated for TB in past

TB?: " " " " / doubt about diagnosis.

194.

QUARTERLY RETURNS MADE FOR TB by FUNAI HEALTH POST in SÃO GABRIEL da CACHOEIRA.

Question			1981 QUARTER: 2	3	4	1982 1	2	3	4	1983 1	2	3	4
1	1	Number of patients from last quarter	15	11	13	19	18	13	24	37	45	55	47
2		a) First treatment	14	11	12	17	18	13	22	25	44	52	44
3		b) Repeat treatment	1	-	1	2	-	-	2	2	1	3	3
4	2	Number of patients accepted in quarter	11	7	13	5	8	16	22	24	30	19	11
5		a) First treatment	10	6	11	5	7	14	22	24	28	19	11
6		b) Repeat treatment	1	1	2	-	1	2	-	-	2	-	-
7	3	Number of patients discharged in quarter	15	4	8	6	13	6	9	16	20	27	29
8		a) Cured	9	3	7	4	13	5	7	14	20	24	25
9		b) Abandoned treatment	6	1	1	2	-	-	1	2	-	3	3
10		c) Died	-	-	0	-	-	1	1	-	-	-	1
11		d) Other reasons	-	1	0	-	-	-	-	-	-	-	-
12	4	Number of patients continuing in next quarter	11	14	18	18	13	24	37	45	55	47	29
13		a) First treatment	11	13	16	17	12	22	35	44	52	44	28
14		b) Repeat treatment	-	1	2	1	1	2	2	1	3	3	1
15	5	Number of patients for diagnostic baciloscopy	181	-	48	8	13	27	12	28	21	44	10
16		5i) Baciloscopy positive	20	-	6	4	5	14	12	22	19	15	6
17		5ii) Baciloscopy negative	161	-	42	4	8	13	-	6	2	29	4
18	6	Number of sputum tests done	181	-	48	9	13	29	12	32	23	49	18
19		6i) For diagnosis	181	-	48	1	11	27	12	28	21	44	10
20		6ii) For control of treatment	2	-	-	2	2	2	-	9	2	5	8
21	7	Number of contacts accepted: under 15 yrs	1	-	-	-	-	-	-	1	2	-	-
22	8	Number of contacts on prophylatic chemotherapy	-	-	-	-	-	-	-	1	2	-	-
23		8i) No. of contacts completing " "	-	-	-	-	-	-	-	-	-	-	-
24	9	Number of domiciliary visits	-	-	-	-	-	-	-	1	8	6	-
25	10	Number of intradermal BCG vaccinations	291	-	-	-	-	29	-	-	-	668	-

[N.B. some of these figures are mutually inconsistent.]

1.197.2

PROGRAMA DE CONTROLE DE TUBERCULOSE EM AREA INDÍGENA — DNPS — FUNAI

FICHA DE NOTIFICAÇÃO E CONTROLE DE CASOS

DELEGACIA

POSTO INDÍGENA

ALDEIA

ALDEADO

NÃO ALDEADO

CÓDIGO

DATA DA NOTIFICAÇÃO

/ /

NOME

IDADE

SEXO

OBSERVAÇÃO

DIAGNÓSTICO

BACILOSCOPIA

POSITIVA

NEGATIVA

NÃO REALIZADA

RX

LOCALIZAÇÃO

PULMONAR

EXTRA PULMONAR

MININGITE

OUTRAS

DATA DA ALTA

/ /

MOTIVO DA ALTA

CURA

ABANDONO

ÓBITO

OUTROS

TRATAMENTO

DATA DO INICIO / /

ESQUEMA

INFORMAÇÃO DE CONTROLE DA UAE OU EVS