

Published in final edited form as:

Int J Tuberc Lung Dis. 2004 December ; 8(12): 1484–1491.

Tuberculosis and nutrition: disease perceptions and health seeking behavior of household contacts in the Peruvian Amazon

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Abstract

SETTING—Households of TB patients in the Peruvian Amazon.

OBJECTIVE—To investigate how knowledge and beliefs of household contacts about TB affected health seeking behavior.

DESIGN—Interviews with 73 patients finishing treatment and 79 of their adult household contacts.

RESULTS—Contacts were knowledgeable about free screening and treatment, but contacts who noted weight loss, not cough, were more likely to be screened for TB ($P=0.03$). Forty-two per cent reported that TB was prevented by nutrition, 28% by separating eating utensils, and only 19% by avoiding a coughing patient. Only one household contact reported being stigmatized. Stigma centered upon nutrition, and only 12% knew of the association between TB and HIV. Only 14% had a BMI <20, yet 30% reported regularly going to sleep hungry. Free food packages were reported to be the most important reason for treatment adherence by 33% of patients.

CONCLUSION—Contacts misperceived TB as a nutritional disease and did not fear airborne transmission, which should be corrected by public health education. Weight loss, and not cough, led to screening. Stigma appeared to be minimized because risk was perceived as personal, through malnutrition, rather than exposure-based. Nutritional incentives that utilize these beliefs may reduce diagnostic delay and enhance treatment adherence.

Keywords

diagnostic delay; nutrition; stigma; TB

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Tuberculosis (TB) continues to rank among the world's most serious health problems despite the availability of effective chemotherapy.¹ Authorities estimate that 8 million new cases of TB occur every year, causing 3 million deaths.^{1,2} Psychosocial factors are dominant forces in health seeking behavior.³⁻⁵ Salient among such factors are the health beliefs of patients, the understanding and information people have from family, friends, and neighbors as to the nature of a health problem, its cause, and its implications.⁶ Studies of TB patients have shown that cultural-based explanations that patients give to symptoms can be strong barriers to early diagnosis,^{5,7,8} and that knowledge about the health beliefs of patients can be used to tailor TB control programs to screen, diagnose, and treat patients more successfully.^{3,6,9,10}

Early case detection and treatment is the cornerstone of short-term TB control, while improvement in socio-economic conditions is a long-term solution.⁹ The World Health Organization (WHO) has widely implemented the DOTS strategy, a TB program that improves treatment completion and outcome. Although 155 (of 210) countries implemented DOTS in 2001, only an estimated 32% of cases worldwide were detected and treated.¹¹ Late case detection and sub-optimal adherence to treatment regimens remain barriers to successful TB control.¹¹ In many instances patients seek treatment only when their condition is much deteriorated, making their therapy more costly and reducing the chance of cure.¹² Furthermore, even in the context of model DOTS programs, approximately 10% of patients still default from therapy.¹¹

Transmission of *Mycobacterium tuberculosis* usually occurs due to inhalation of infectious droplet nuclei produced by a coughing patient.¹³ Household members are at a particularly high risk for TB because of their close contact with patients,^{14,15} and numerous studies have provided evidence in favor of active case finding in this population,^{16,17} i.e., active seeking out and TB screening for household contacts of newly diagnosed TB patients. Nevertheless, active case finding of contacts is not widely implemented,¹¹ and little is known about the beliefs and attitudes that affect health seeking behavior among high-risk household contacts.

Iquitos is the largest city in the Peruvian Amazon; it has a population of 337 000, with a high incidence of TB infection of 106 per 100 000 population.¹⁸ The staff of the National TB Program (NTP) recommend that all household contacts attend the nearest health post for free screening, which consists of sputum microscopy for those individuals able to produce a specimen. Case finding in this endemic region is otherwise passive. The aim of this study was to describe the knowledge and attitudes of household contacts towards TB disease, TB patients, the NTP, and to evaluate how these beliefs and nutritional incentives affected their health seeking behavior. A structured questionnaire was used to interview household contacts and TB patients to investigate these issues.

MATERIALS AND METHODS

The study had national and international ethical approval and all participants gave informed written consent. Data were collected by means of interviews in the participants' homes. All interviews were carried out by the same investigator (MB), who recorded anthropometrics and used a structured questionnaire to guide discussion and gather information regarding demographic data, health status and beliefs, socio-economics, and nutrition.

In July and August 2002, 108 consecutive pulmonary TB (PTB) patients were identified from medical records and visited in their homes, 6–7 months after starting treatment. This corresponded with the final month of treatment or the first month following treatment completion, with the exception of seven patients whose treatment was prolonged due to previous default from therapy or to multidrug-resistant TB (MDR-TB, resistance to at least isoniazid and rifampin). Of these 108 patients, 17 had moved out of the region, two

addresses did not exist, three declined to participate, three had died, and four lived alone and were not suitable for this study. The remaining 73 patients were interviewed with a questionnaire concerning diagnostic delay, nutrition, and opinions regarding nutritional incentives. All patients were more than 14 years of age at the start of treatment. Sixty-seven were diagnosed by direct sputum microscopy and six were smear-negative and diagnosed on the basis of symptoms and chest radiograph. Patients were treated at the Hospital de Apoyo in the center of the city of Iquitos and medical health-posts in the urban shanty-town of Belen and in the surrounding peri-urban city districts of San Antonio and San Juan.

Household contacts were interviewed if they were more than 14 years of age and had lived with the patient for at least 1 month prior to their diagnosis and for the entirety of their treatment. Of 246 eligible contacts, 115 could not be located despite three home visits. Of the remaining 131 eligible contacts who were found, 79 consented to participate in the study. No more than two contacts consented in any household.

Statistical analysis

Categorical data are specified as % (*n*), and as % (*n*/sample size), where data are available for only a subset of the study population. Normally distributed data are expressed as mean \pm standard deviation. Non-Gaussian data are expressed as a median (interquartile range [IQR]), and groups were compared using the Mann-Whitney test. The χ^2 (Yates corrected) and Fisher's exact tests were used for analysis of categorical data. A *P* value <0.05 was considered as indicating statistical significance. Statistical analyses were performed using v10.0 SPSS software (SPSS Inc, Chicago, IL, USA).

RESULTS

Demographics

A total of 79 household contacts in 73 households were interviewed: 70% (55) were females, and the mean age of contacts was 42 ± 17 years (range 15–80). In relation to the patient, 28% (22) were partners, 24% (19) were parents, 18% (14) were children, 14% (11) were siblings, 15% (12) were extended family, and one was a maid.

Of contacts interviewed, 14% (11) had received prior treatment for PTB on average 6.9 ± 7.4 years previously, ranging from one contact on current treatment to another who had been treated 25 years previously; 53% (39) of households had members other than the patient who had been treated for TB in the past.

Six per cent (5) of contacts were illiterate, 29% (23) had only primary school education, 49% (39) had at least attended or graduated from secondary school, and 15% (12) had attended university or vocational school. Male contacts had a significantly higher level of education than female contacts (*P* = 0.02).

Contacts spent an average of 18 ± 6.6 h in the same house as the patient, of which 12 ± 7.6 h were spent in the same room as the patient. Forty per cent (32/66) of contacts shared a bedroom with the patient during treatment. There was no significant association between gender and hours spent in the same room as the patient.

Beliefs

Family health and screening—Twelve per cent (9) of patients sought treatment within 2 weeks after the onset of cough, as recommended by the NTP, and 88% (64) waited longer. Patients waited a median of 2.0 (IQR 0.92–3.0) months before seeking treatment (Figure 1). Sixty per cent (47) of household contacts reported that they had been examined or screened

for TB since the patient was diagnosed. Twenty-two per cent (17) of contacts had a cough (two of whom also had hemoptysis) for more than 2 consecutive weeks' duration in the previous year, raising the suspicion of active PTB. Of these contacts with respiratory symptoms, 77% (13/17) visited the health post for TB screening, but this proportion was not significantly greater than the 56% (34/61) of contacts without such symptoms ($P = 0.1$).

Contacts who noted weight loss within the last year had a lower body mass index (BMI) ($P = 0.04$), and more often had a BMI < 20 , consistent with malnutrition ($P = 0.04$). The 67% (4/6) of contacts who noted weight loss were more likely to also have chronic respiratory symptoms than those who had not noted weight loss ($P = 0.02$), but contacts with a lower BMI were not more likely to have prolonged respiratory symptoms. Those contacts who noted weight loss had a significantly greater chance of being screened for TB ($P = 0.03$). No other symptoms, including cough, fever, chills, nocturnal diaphoresis, fatigue, or back pain were significantly associated with being screened for TB at the health post.

Gender was not significantly associated with being screened for TB, and nor was it significantly associated with the prevalence of respiratory symptoms or weight loss.

Symptom knowledge—Contacts were first asked to name all symptoms that they knew to be suggestive of TB (Figure 2A). A list of symptoms commonly associated with TB was then reviewed with them, and contacts identified symptoms that they believed to be indicative of the disease. Cough was offered 53% (42) of the time, and weight loss and anorexia were offered respectively 46% (36) and 39% (31) of the time. Cough was recognized as a symptom of TB 89% (69) of the time, only 3% more often than weight loss. Only 5.1% (4) could not identify at least one symptom of TB, even when offered the list.

Infectiousness—Eighty-two per cent (65) of the contacts believed that TB is transmissible from a TB patient to another person. Using a 5-point scale, contacts were asked how much they worried about contracting the disease from the patient: 32% (25) were very or extremely worried; those who believed that TB is an infectious disease were significantly more worried about contracting the disease from the patient ($P < 0.001$), while 11% (9) of contacts noted that while they believed TB to be infectious, they were less worried about contracting the disease because they had learned that patients were less infectious after starting antibiotic therapy. Gender was not significantly associated with knowing that TB is an infectious disease.

Of the 65 contacts who knew that TB is an infectious disease, 61% (25/41) reported that they believed TB was transmitted by sharing eating utensils, 44% (18/41) by coughing, 36% (15/41) by conversing, 4.9% (2/41) by kissing, 2.4% (1/41) by sex, and 2.4% (1/41) by sleeping in the same room as a patient.

Prevention—The method of first asking an open question, and then reviewing a list of possible answers, was also employed when contacts were interviewed about the prevention of disease transmission: 28% (22) of contacts stated that TB prevention stems from eating well, and 42% (33) reported that separating eating utensils could prevent TB. Only 19% (15) stated that avoiding coughing individuals could prevent TB. A similar majority of contacts selected eating well and separating utensils from our list, rather than avoiding coughing individuals as possible ways to prevent TB transmission (Figure 2B). No contacts suggested that working in moderation helps protect against TB, yet 53% (42) of contacts identified from our list that TB can be prevented by avoiding excessive work. Interestingly, many stipulated that this was because a rigorous work schedule often does not allow enough time to eat.

Program knowledge—Eighty-six per cent (66/78) of contacts believed that TB can always be cured, and 97% (76/78) knew that TB is at least sometimes curable. Ninety per cent (68/75) of contacts knew to go to the closest health post for screening, 8.0% (6/78) incorrectly thought screening was only offered at hospitals, and only one contact did not know whether the hospital or health post offered screening; 81% (63/78) knew that screening was free. Ninety-five per cent (73/77) of contacts knew that the screening test involved giving a sputum sample, 68% (52/77) believed incorrectly that a chest radiograph was necessary as well, and 46% (35/77) believed that a blood test was also necessary, probably because patients with fever are routinely tested for malaria.

Stigma associated with TB

Interaction with patients—Six point three per cent (5) of contacts admitted to avoiding the patient because of their disease: two slept in different rooms, two ate separately from the patient, and one generally avoided the patient. These contacts nevertheless stated that they offered support to the patient during treatment. Overall, 80% (63) of all contacts stated that they supported the patient during treatment. Data on the nature of the support were available for 40 individuals: 48% cooked for or helped to feed the patient, 18% accompanied the patient to the health post, 18% collected medications for the patient from the health post, 10% verbally encouraged treatment adherence, and 15% helped fulfill the patient's household duties; 20% of all contacts stated that they continued to treat the patient normally after learning of the TB diagnosis.

Interactions in the community—One household contact reported difficulty finding work because co-workers feared contracting TB from him; 74% (57/77) continued working as usual, 12% (9/77) were able to find more work to compensate for the patient's lost income, and 13% (10/77) left school or work to care for the patient. Sixty-four per cent (50/78) of contacts claimed they would help neighbors with TB, 24% (19/78) reported they would continue to treat them normally, and 12% (9/78) asserted they would avoid them because they were frightened of contracting the disease and wanted to protect themselves.

Shame—Forty-two per cent (32/77) of contacts stated that they were ashamed of having TB in their family. Those ashamed of having a relative with the disease believed that impoverishment predisposed to TB ($P < 0.001$); 10% (8/77) of contacts said they were ashamed of TB because friends and neighbors would gossip about them, and 6.5% (5/77) asserted that they did not tell friends or extended family members about the patient's condition because of fear of being abandoned.

The last 33 interviews included questions about whether contacts recalled hearing gossip about TB: 64% said patients were thought to be malnourished, 24% said patients were thought to live in squalor; 15% stated they had heard none, and only one contact thought the patient would also be likely to have human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS). No one specific type of gossip correlated significantly with being ashamed of having a relative with TB.

TB and HIV/AIDS—Forty-two per cent (33/78) of contacts believed that a person with HIV has a greater probability of having TB. These contacts were both significantly younger ($P = 0.03$) and more educated ($P < 0.001$). When asked to specify the nature of the relation between HIV and TB, only 12% (9/78) noted correctly that HIV patients are more susceptible to TB infection because of impaired immunity; 73% (57/78) did not know, 6.4% (5/78) noted that TB is curable while HIV is not, and 8.9% (7/78) of contacts erroneously believed that the two infections were always concurrent. Those individuals with a higher

level of education were significantly more likely to know the correct association between HIV and TB ($P = 0.02$).

Nutrition

Anthropometrics—The mean BMI of contacts was 25 ± 4.2 kg/m² (range 16–35 kg/m²). Fourteen per cent (11) of contacts had a BMI <20 kg/m², suggestive of malnutrition, and 10% (8) had a BMI >30 kg/m², suggestive of obesity. Patients reported going to sleep hungry 2.9 ± 6.8 nights in the past month, 30% (24) of contacts reported going to sleep hungry at least once in the previous month due to lack of food in the household. Contacts who reported going to bed hungry were significantly more likely to note weight loss ($P = 0.002$) and have a BMI suggestive of malnutrition ($P = 0.04$).

Food packages—The NTP of Peru aims to give each patient monthly food packages that contain vegetable oil, rice, beans, canned tuna, and milk. Patients reported that one packet feeds an average family 19 ± 11 days. Patients received on average 2.2 ± 1.4 food packages over 6 months of treatment, and 11% (8) received none. Some packages were reported to be incomplete: 73% contained canned tuna, 74% contained beans, and 37% contained milk. Patients reported that they ate on average $22\% \pm 12\%$ of this food, while contacts ate $77\% \pm 12\%$ of the food. All families reported that they had not sold any of the food. Sixty-nine per cent of the patients who received at least one food package reported it was an incentive to adhere to treatment, and 33% said that it was the most important reason they adhered to treatment.

DISCUSSION

This study reveals that while household contacts have considerable knowledge about TB diagnosis and treatment, many misconceive TB as a nutritional disease and do not fear airborne transmission. Accordingly, only those with weight loss, but not respiratory symptoms, had a significantly greater chance of attending the health post for TB screening. Social stigma appears minimized in this nutritional context; most contacts were sympathetic to patients and none abandoned them, and only one contact reported being stigmatized by co-workers for having a relative with TB. While most contacts were not malnourished, approximately one third reported regularly going to sleep hungry because of lack of food. Free food packages were a strong incentive for patients to remain adherent, despite the fact that no patients received the intended amount.

Numerous studies have shown that household contacts of TB patients are at a particularly high risk of developing TB,^{14,15} yet little more than half of the contacts studied attended for screening despite efforts to screen them soon after the patient was first diagnosed. Diagnostic delay has been shown to lead to more serious illness by the time the patient presents,¹⁹ and to increase infectiousness within the community.²⁰ Despite a decentralized health care system that maximizes health care access and limits diagnostic delay on the part of health care workers,^{20,21} nearly 90% of the patients in this community still had a delayed diagnosis due to late presentation. Prompt diagnosis in this endemic setting would reduce the spread of TB and limit the burden of the disease.

There are conflicting reports on how gender affects diagnostic delay.²² Seventy per cent of the contacts interviewed were female. This bias is best explained by the fact that contacts were interviewed in their homes during daylight hours, and females presumably work domestically more often than males. Nevertheless, gender alone was not associated with significantly longer patient exposure, which perhaps reflects the fact that female contacts did not have a significantly greater prevalence of TB symptoms. Studies have shown that females are at a higher risk for diagnostic delay and case under-reporting²³ due to less

education,²¹ feared social stigma,²⁴ and heavy workload, combined with lack of mobility.²⁵ While female contacts had a significantly lower level of formal education than males, there was no gender difference in the level of knowledge about TB symptoms, diagnosis, and treatment. Furthermore, males were no more likely than females to be screened for TB.

Educational background has been shown to be an important determinant of patient disease knowledge and adherence; those with a higher level of education usually know more about TB,⁸ and poor treatment adherence has often been associated with a low educational level.⁵ While most household contacts in this study were poorly educated, with nearly one third being illiterate or only primary school educated, nearly all knew that TB is curable and that the closest health post offered free sputum screening tests. Despite this widespread knowledge, contacts with prolonged respiratory symptoms were no more likely to be screened than healthy contacts. Only those who noted weight loss were significantly more likely to be screened, perhaps because TB is misperceived as a nutritional disease and airborne transmission is not feared. Contacts cited weight loss and anorexia almost as often as cough when asked to describe symptoms of TB, and more believed that prevention stems from eating well and separating eating utensils than avoiding a coughing patient. Previous studies have found widespread beliefs that TB transmission occurs via eating utensils, principally in uneducated populations.^{8,26,27} Slightly more than half of the household contacts interviewed reported that other members besides the patient had been treated for TB in the past. Hence, the dichotomy between the extensive knowledge about the TB program and misconceived TB pathology is likely a reflection of widespread experiential education that stems from the high prevalence of the disease in a population with little formal education.

Social stigma associated with TB is a common concern among patients in developing countries,^{4,24,26} and patients are often abandoned²⁶ or socially isolated.^{8,24} In contrast, in the current study, contacts were sympathetic to patients, perhaps because TB risk is perceived as personal, through malnutrition, and not exposure based. Only one third of contacts were 'very' or 'extremely' worried about contracting the disease from patients, usually from sharing eating utensils. Accordingly, 40% of contacts slept in the same room as the patient, and none moved out. Moreover, 80% supported patients throughout their treatment, most often by cooking for them. Needham et al. reported that TB patients often spend extra money on additional or special foods to treat symptoms before seeking a diagnosis,²⁸ and Liam et al. found that patients who mistakenly believed that TB is spread by sharing eating utensils also expressed little fear of social stigma.⁸ Thus, while previous studies have described the perceived importance of adequate nutrition and contagion in TB prevention and transmission, the ramifications on social stigma are not well recognized in the literature.

Several studies have shown that TB patients in HIV endemic areas are stigmatized for presumed co-infection with HIV.²⁷ The proportion of TB patients with concurrent HIV infection in Iquitos was estimated in 2000 at between 0.8% and 1.7%,¹⁸ and is relatively low in comparison to many other regions. Accordingly, only 12% of contacts, who were significantly younger and better educated, knew that HIV infection predisposes to active TB infection. Importantly, less than 10% of contacts erroneously believed that the two infections always occur simultaneously. Social stigma associated with TB in this population seems minimized because airborne transmission is mistakenly not feared, and because few know of the relation between HIV and TB; only one contact reported losing his job because co-workers feared contracting TB from him. Accordingly, household contacts are an empathetic population, with over 60% reporting that they would support a neighbor with TB. Nevertheless, many are still ashamed of having a relative with the disease. Thus, while

actual stigma seems minimized in this nutritional context, the fear of stigma, a well-established cause of diagnostic delay,^{6,24} is still prevalent.

While anthropometrics revealed that most house-hold contacts were not malnourished, the fact that one third reported regularly going to bed hungry attests to the widespread poverty in this population. It is well known that low family income is associated with diagnostic delay and poor treatment adherence.^{5,28} Farmer et al. have even proposed that the economic constraint of poverty is the most significant factor in treatment failure.¹⁰ They demonstrated that financial incentives led to 100% treatment adherence despite associated stigma and poor understanding of TB etiology in an impoverished Haitian population. The NTP of Peru aims to give patients a monthly food package that usually feeds patients and their families for several weeks. While most patients received a fraction and other patients none of these packages, nearly one third reported that it was the single most important incentive to remain adherent.

Malnutrition is common in patients with TB,²⁹ and immunological and epidemiologic studies suggest that malnutrition contributes to TB susceptibility.^{30,32} Furthermore, nutritional supplementation strengthens anti-tuberculosis immunity and has recently been shown to accelerate patient recovery on TB treatment.³³ These scientific discoveries are strikingly similar to the beliefs of the undereducated population studied, who also associated TB susceptibility principally with malnutrition. Education about TB respiratory symptoms and airborne transmission from coughing patients may encourage health seeking behavior and should be a priority. Nevertheless, the current predominant belief that TB is a nutritional disease may provide important opportunities for public health promotion within the cultural context. Specifically, nutritional incentives have great potential utility in this population to simultaneously augment anti-mycobacterial immunity whilst utilizing community perceptions to encourage early TB diagnosis and treatment adherence.

Acknowledgments

This study was principally supported by the Fulbright Commission (USA) through a fellowship for MB, a Voluntary Services Overseas (UK) Fellowship for CF, and by a career development fellowship in clinical tropical medicine from The Wellcome Trust (UK) for CE.

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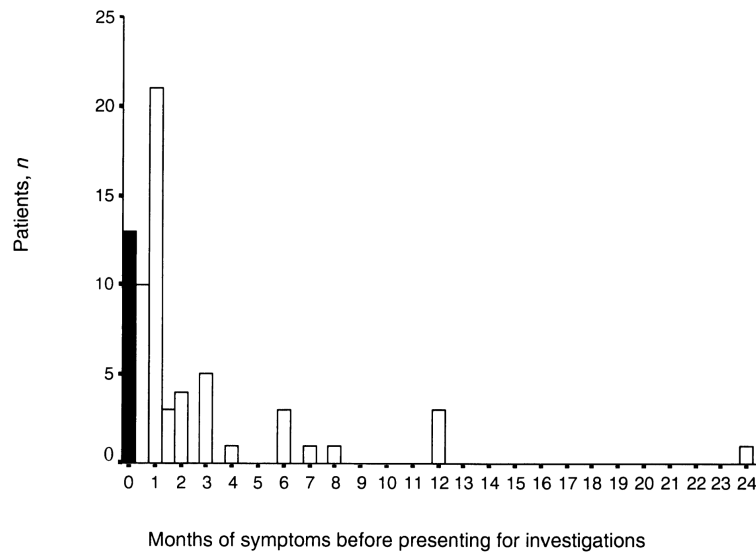


Figure 1. Diagnostic delay in TB patients ($n = 73$). The duration of respiratory symptoms prior to each patient presenting to the health care system for medical investigation is shown for the study population. Individuals who presented immediately after the first 2 consecutive weeks of respiratory symptoms, as recommended by widely publicized public health policy, are shown in black. Others who delayed diagnostic investigations until later in their illness are shown in white. Median duration of symptoms prior to pre- sentation 2.0 (0.9–3.0) months. TB = tuberculosis.

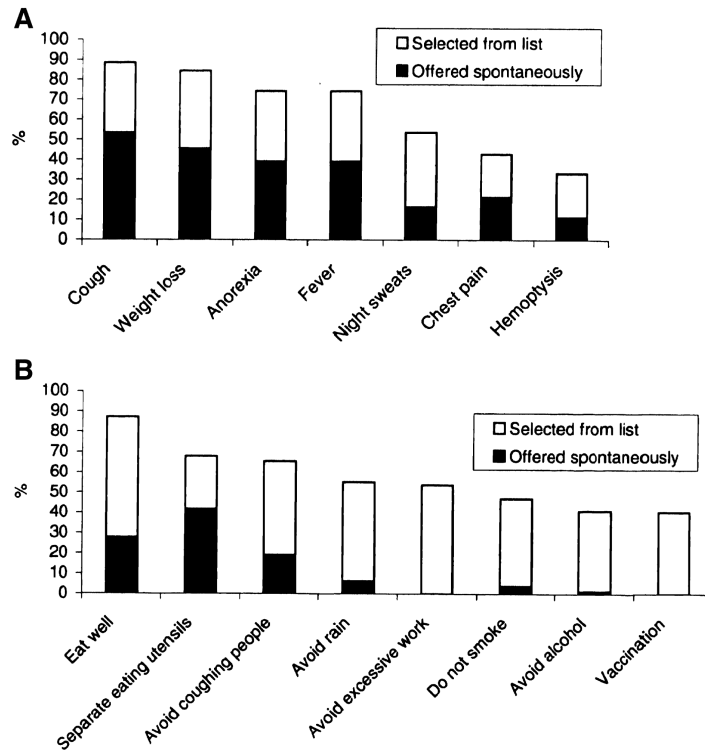


Figure 2.

A. Perceived symptoms of TB ($n = 79$). Contacts were first asked to name all symptoms they knew to be suggestive of TB (black). A list of symptoms commonly associated with TB was then reviewed with them, and contacts identified symptoms that they believed to be indicative of the disease (white). **B.** Preventive strategies against TB ($n = 79$). Contacts were first asked to name all the preventive strategies they knew that protect against TB (black). A list of preventive strategies was then reviewed with them, and contacts identified those that they believed protected against the disease (white). TB = tuberculosis.