

Knowledge of Tuberculosis among Parents/Guardians of Children with Tuberculosis Attending the Outpatient Department of a Tertiary Care Hospital in Karachi

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Abstract: The purpose of the study was to investigate the knowledge and misconcepts for Tuberculosis of the parents and guardians of the children who have this disease. The study is conducted at the outpatient department of the National Institute of Child Health, Karachi. It encompassed 173 parents/guardians who are accompanying their children who are suffering from Tuberculosis and are attending tertiary care hospitals for children in Karachi. A structured questionnaire covering most of the aspects of Tuberculosis was used to collect the data. Descriptive statistics were obtained in terms of frequency percentages. Out of 173 parents/guardians who were included in the study, 128 (73.98%) answered correctly regarding the management and investigative aspects of Tuberculosis. However, only 81 (46.8%) knew the etiology and spread of the disease. The most common misconception was that the spread of the disease is due to sharing utensils and by eating together. In comparison to parents, guardians had poorer overall knowledge. Females, accounting for 102 (59%) interviewees, had poorer knowledge than males, 70 (40.5%). The relation with the adult contact in the same household was 71.6%. The majority of the children 143 (82.7%) belonged to the slum areas of Karachi and 50 (29%) were a part of the Pashto speaking population. Knowledge of the parents/guardians regarding management and investigation aspects of the disease was good in comparison with other studies.

Key words: Knowledge for Tuberculosis • Parents • Guardians • Tertiary care • Demographic perspectives

INTRODUCTION

Tuberculosis is a mysterious disease in the sense that it has a minimal, lethal, infective dose and has natural history of progression of a multitude of complications and eventually death without treatment. However, Tuberculosis (TB) is a social disease, which is preventable and curable, but still poses a leading health hazard in Pakistan [1] as well as being one of the most

common infectious causes of morbidity and mortality worldwide. Approximately one third of the world population, about 2.3 billion, is infected with *Mycobacterium Tuberculosis* [2]. Among 8 million cases of Tuberculosis seen per year worldwide, children comprise 1.3 million or approximately 3-13% of all cases of TB, [3] and approximately 80% of the burden of the disease affects Asian and African countries [4]. TB poses an enormous public health burden in many high incidence

countries, including Pakistan with an estimated population of 161 million ranking eighth on the list of 22 highest TB burdened countries in the world [5]. Overall, eighty-five percent of the total TB burden worldwide lies within the 22 highest endemic countries, including Pakistan [6] which sees an estimated 2.6 million new cases of TB and more than 50,000 deaths per year [7].

Childhood Tuberculosis is the outcome of adult Tuberculosis indicating a linear relationship. Unless we address the issue of TB and control it within the adult population, children will continue suffering from as well as enduring the worst of the disease [8]. Children are at higher risk of infection by adults, including teachers, relatives and neighbors; a lack of knowledge of the mode of transmission of the disease is a critical contributor to continued spread of infection [9]. Accurate data is scarce for TB in children in Pakistan, despite the fact that TB cases remain high among children living in underdeveloped, low-income areas as well as among racial or ethnic minorities. Establishing the definitive diagnosis of TB in a child remains difficult and frequently relies on a constellation of history, clinical findings and bacteriology [10]. The high prevalence of the disease occurs due to poverty, illiteracy, lack of health education, myths and misconceptions, poor follow up, dissatisfaction among patients, scarce patient knowledge about the disease and lethargic behavior of treating physicians. All of these factors may lead to "Default" and hence accelerate the serious burden, drug resistance and perception of incurability of the disease thereby perpetuating the vicious circle of continued infection [11].

The idea of a misconception is an idea that is wrong due to its basis on a failure to comprehend and understand [12] but unfortunately, myths and misconceptions are prevalent throughout society because of lack of proper knowledge and education [13]. The burden of Tuberculosis in children is mainly due to the spread by adults; thus, greater efforts are needed to curb the disease in adults in order to witness a desired trickle-down effect of decreasing pediatric cases. Many myths and misconceptions are associated with Tuberculosis [14]. The socio-demographic determinants are central to the programs and policies for the prevention and control of diseases like Tuberculosis. There is ample evidence in literature that the social and cultural factors either promote and/or undermine the health of men, women, children, families and the general population.[15]

Serious issues such as drug resistance, MDR-TB (Multidrug Resistant Tuberculosis), XDR-TB (Extremely Drug Resistant Tuberculosis) are associated with poor knowledge, myths and misconceptions. As such, it is

crucial to measure these key issues in our local and particularly tertiary care settings, where there are options for adequate counseling and education of the parents/guardians/patients about the etiology, spread, signs, symptoms, diagnosis and reasons for why a lengthy treatment is mandatory. Adequate knowledge about the disease, if imparted upon parents/guardians/patients, can curb the spread of the disease and default for the treatment, which eventually will decrease the morbidity and mortality due to the disease.

The objective of this study was to investigate the knowledge and misconceptions of Tuberculosis (cause, spread, symptoms, diagnosis, treatment and prevention) by the parents/ guardians of the children diagnosed with Tuberculosis.

MATERIAL AND METHODS

The National Institute of Child Health is the only public, tertiary care hospital in the city of Karachi, which has a population of over 19 million. It caters to the healthcare needs of Karachi as well as the interior areas of two provinces: Sindh and Baluchistan. It is a 500-bedded hospital consisting of most pediatric subspecialties including pediatric oncology, pediatric surgery and the facilities for diagnosis and management of childhood diseases. This study was conducted among the parents/guardians of children of the pediatric age group, with Tuberculosis, who are attending the outpatient department designated specifically for Tuberculosis patients, twice a week at NICH, Karachi. One hundred seventy three (173) parents/guardians were included in the study. A pretested questionnaire including 35 questions and important demographic events were recorded via a face-to-face interview by the principal investigator. Information was obtained regarding the knowledge and myths about Tuberculosis by the parents/guardians of children with Tuberculosis. Parents of the old as well as newly diagnosed patients registered in the DOTS regimen under the care of a pediatrician were interviewed in the OPD twice a week. Informed consent was taken from the attending parent/guardian or the attending family member for the interview and the ethical review committee of the institute. Participation was optional and a written informed consent was obtained from all of the attending parents or relatives. The interviewees were assured confidentiality of the data and that this study would have no impact on their treatment by their respective physician. The data was analyzed in SPSS, Version 16.

RESULTS

One hundred seventy three parents/guardians accompanying children attending TB outpatient clinic of NICH were interviewed. The mean age of the parents/guardians of the children diagnosed with, or currently taking the anti-Tuberculosis treatment or with suspected Tuberculosis was 34.30 ± 9.18 years. The attending females made up 73% while the males consisted of 27% with the female to male ratio being 2.7:1.

Children with pulmonary Tuberculosis made up 60% of the patients, while the remaining 40% were extra-pulmonary cases. Surprisingly, among the parents of the children, 50% had no formal education and 30% had only primary education. The parents/guardian females accompanying the children consisted of 60% homemakers, 30% employees and 10% small business owners. Fifty eight percent of the parents/guardians are

earning less than Rps.10, 000/month and 40% are earning between Rps.10, 001-20,000. Eighty-five percent live in small houses less than 120 yards in mostly poor housing schemes of Landhi, Korangi, Orangi, etc. and ninety-two percent are Muslims.

Regarding the mother tongue of the patients, 30% speak Pashto while others in small proportions represented almost all the major languages of Pakistan. The most remarkable misconception found was the belief that the spread of the disease is perpetuated by eating together, i.e. sharing food and serving dishes/utensils. The most alarming finding in this study is the presence of contact of children with the disease within the same household, upwards of seventy-two percent. Information regarding the relationship of interviewees to the children is depicted in Table 1. The results of knowledge regarding the different aspects of Tuberculosis are summarized in Table 2 (Showing good knowledge) and Table 3 (showing poor knowledge).

Table 1: Showing Relationship with Diseased Children

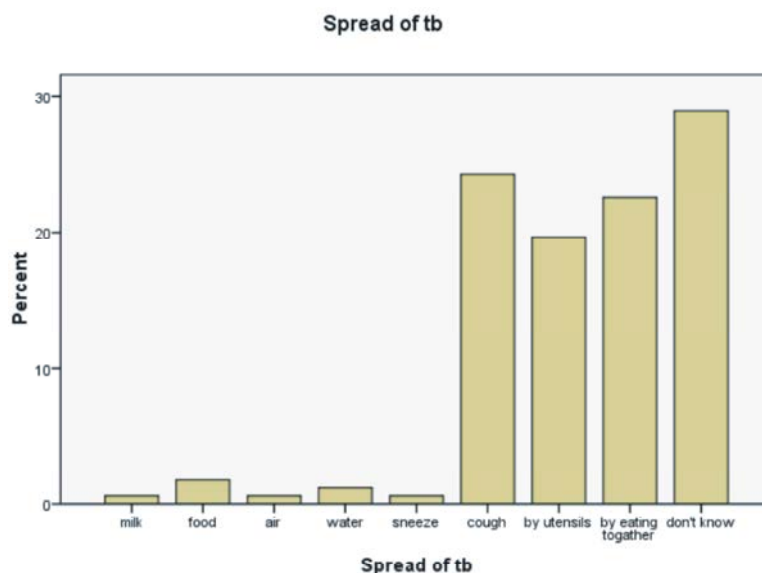
| Valid Relationship | Frequency | Percent | Valid Percent | Cumulative Percent |
|--------------------------|-----------|---------|---------------|--------------------|
| Mother, Father | 128 | 74.0 | 74.0 | 74.0 |
| Uncle, Aunt | 23 | 13.3 | 13.3 | 87.3 |
| Sibling | 12 | 6.9 | 6.9 | 94.2 |
| Grandmother, Grandfather | 7 | 4.0 | 4.0 | 98.3 |
| Nephew, Niece | 3 | 1.7 | 1.7 | 100.0 |
| Total | 173 | 100.0 | 100.0 | |

Table 2: Showing Good Knowledge by Parents/Guardians of Children Who Have Acquired Tb

| S. No. | Leading Question | Parents n = 128 | | Guardians n = 45 | |
|--------|------------------------------------------------------|-----------------|-------------|------------------|-------------|
| | | Correct | Incorrect | Correct | Incorrect |
| 1 | Diagnosis of the child | 91 (71.09%) | 37 (29.0%) | 12 (26.67%) | 33 (73.34%) |
| 2 | Duration of therapy | 99 (77.34%) | 29 (22.66%) | 19 (42.23%) | 26 (57.78%) |
| 3 | Complications of disease if treatment is interrupted | 80 (62.50%) | 48 (37.50%) | 10 (22.23%) | 35 (77.78%) |
| 4 | Disease can be cured with treatment | 111 (86.72%) | 17 (13.28%) | 21 (46.67%) | 24 (53.34%) |
| 5 | Drugs (ATT) should be given altogether before meals | 90 (70.32%) | 38 (29.69%) | 17 (37.78%) | 28 (62.23%) |
| 6 | X-Ray is the key investigation of disease | 117 (91.4%) | 11 (8.59%) | 30 (66.67%) | 15 (33.34%) |

Table 3: Showing Poor Knowledge by Parents/Guardians of Children Who Have Acquired Tb

| S. No. | Leading Question | Parents n = 128 | | Guardians n = 45 | |
|--------|--------------------------------------|-----------------|-------------|------------------|-------------|
| | | Correct | Incorrect | Correct | Incorrect |
| 1 | The disease is highly infectious | 59 (46.09%) | 69 (53.90%) | 9 (20.0%) | 36 (80.0%) |
| 2 | Concept of the spread of the disease | 43 (33.60%) | 85 (66.40%) | 13 (28.89%) | 32 (71.12%) |
| 3 | Presenting complaints of disease | 57 (44.54%) | 71 (55.47%) | 14 (31.12%) | 31 (69.89%) |



Bar Chart 1: Showing Perceptions of Methods of Spread of Disease

DISCUSSION

An old adage states “knowledge is a more powerful weapon than swords and artilleries [16]. Knowledge of the disease plays a vital role in reducing morbidity and mortality. Good, proper, effective knowledge in conjunction with preventive measures can help eradicate the illnesses and disease from the community and eventually from individual countries and someday the world as a whole. Studies show simply knowing the diagnosis and correct preventive dietary measures can reduce the complications of Diabetes by up to 30% [17]. Between the years 1960-1970 in the United States, strong awareness programs for Tuberculosis helped nearly eradicate the disease from the country, although TB again wreaked havoc in late eighties due to emergence of HIV [18]. Widespread poverty, illiteracy and poor knowledge as well as the emergence of myths and misconceptions of TB all help to perpetuate the failure of any preventive program in our country. In order to eradicate the disease from Pakistan lots of effort has been done in past in the form of awareness, screening and management programs, but we have not reached satisfactory levels in the prevention and control of the disease. Pakistan contributes about forty-four percent of the Tuberculosis burden in the Eastern Mediterranean Region [19].

Children, 14 years and younger, are a highly vulnerable group in the population and they are at a higher risk of contracting disease from the infected pool of adult cases [20]. Lack of proper knowledge about

TB is negatively affecting the proper health seeking behavior of patients while sustaining the transmission of the disease within the community [21].

The study was conducted in one of the largest tertiary care, pediatric setting hospitals in the country, with the goal of assessing both the knowledge and misconceptions among the parents/guardians of children with TB. The secondary objective was to compare the results of the study with previous studies done on the same issue and to assess the efficiency of awareness programs. Most of the interviewees of this survey were females because males, in our socioeconomic setting, tend to be busy with earning income for their families, whereas the females tend to stay home, allowing them to tend to health issues of the other members of the family, including the children. Unfortunately, most females do not even obtain the most rudimentary of formal education with the result being that illiterate females are high in numbers and subsequently do not have the proper knowledge necessary to combat the specific illness [22].

The literacy rate was only 20% in this study although overall literacy rate in Karachi is more than 77%. The reason behind this is that almost all the interviewees belonged to “kachee abadis” and slums of Karachi. This lack of education affects the net knowledge for the disease and plays a key role in the unsuccessful TB control programs in Pakistan [23]. This study also shows that parents accompanying the children have a better overall knowledge than guardians do, as the latter has lesser attachment and subsequent lower interest in the welfare of the children they are accompanying.

This will be an additional hindrance for eradication programs because parents leave for their jobs leaving the guardians to look after the diseased children. As such, awareness programs must target the guardians [24]. Greater than eighty-five percent of the cases belonged to slum areas of Karachi where the prevalence of poor sanitation, overcrowding, minimal environment cleanliness, unclean/unsafe water, as well as the presence of all risk factors for the spread and transmission of the disease exist. All of these factors influence the successes and failures of the TB control program, with support by the study done by Pathan and Ilyas in 1988 [25].

A particularly disturbing observation is that more than 30% of the interviewees were Pashto speaking, bearing a greater burden of the disease. Most of our Pashtoon brothers and sisters use naswar for many reasons and their habit of spitting near the bedside and kitchens is the alarming because one major route of spread of TB is spitting and a study done by Aftab, Seema and Fatima in 2009 [26] mentions these findings and observations as well. Out of the 173 interviewees, 124 were presently living in the same household as a TB patient. These observations are both disturbing and eye opening as the majority of the infected children fell victim within their own homes. A study done by Sten and his colleagues in 2009 [27] further elaborates these observations as well.

There are nine major questions regarding TB, all of which were posed to the parents/guardians. The knowledge regarding management and investigation aspects were found to be good. More than 75% answered correctly, which showed marked improvements as compared to studies conducted by Khan A and his colleagues in 2000 [28] as well as Ali, *et al.* in 2003 who found knowledge to be poor overall regarding the same issues. These improvements occurred because of awareness programs, improvements in counseling practices, electronic and print media dissemination of the knowledge, as well as through efforts by non-governmental organization and the extreme diligence on the part of health professionals must be highly lauded.

The knowledge related to the etiology and methods of spread were poor and are major contributory factors in the failure of TB control programs to achieve their goals. The health authorities should therefore focus their time and resources towards those in the slums and “kachi abadis” throughout Karachi and other cities. In this respect, we should coordinate with and task the general practitioners, homeopathic and herbal clinics in these

high-risk areas to help educate the local population, in order to control and prevent the spread of this notorious and costly disease particularly that is alarmingly gaining an increased resistance to current drug therapy.

CONCLUSION

The parents/guardians accompanying the children with Tuberculosis had better knowledge concerning treatment protocols and investigations of the disease, but showed very poor knowledge related to clinical presentations, etiology and methods of spread. This poverty of knowledge is correctable by intensifying awareness programs, particularly in slum areas, as well as through proper counseling in the tertiary care hospitals.

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