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TUBERCULOSIS DIAGNOSIS AND TREATMENT;
QUALITATIVE STUDY ON THE COPING MECHANISMS FOR ECONOMIC CONSEQUENCES

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ABSTRACT... Pakistan is eighth among countries with high burden of tuberculosis (TB). In Pakistan free-of-charge TB diagnosis and treatment services are available. The objective of qualitative exploratory study was to understand how TB patients and their families cope with the lost earnings and increased expenditures (other than diagnosis and treatment cost) related with disease and its treatment. The research methods included literature review, focus group discussion using vignettes and in-depth interviews with TB patients. The study was done in the rural areas of Lahore District with the support of district and local health facility staff. The study revealed that, Results like in many other developing countries, TB patients rely mainly on financial and physical support of family members and friends. Conclusion The study also highlighted the need for developing institutional mechanisms to help patients cope with economic consequences of tuberculosis.

Key words: Tuberculosis, exploratory study, coping mechanisms, Tuberculosis, treatment, diagnosis

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INTRODUCTION

This research aims to study the economic consequences of TB diagnosis and treatment and the mechanisms that TB patients use to cope with economic difficulties. This study has attempted to inform modifications in current TB care delivery arrangements and to evolve strategies for assisting TB patients to cope with economic consequences of TB diagnosis and treatment.

As TB case treatment is comparatively more cost effective than many health interventions, it is widely accepted that all countries, even in those who are at low levels of expenditure on healthcare, should invest to cure nearly all cases of tuberculosis that report to health services[1]. Detecting 70% or more of TB cases and successfully treating at least 85% of them is required for achieving tuberculosis control[2]. Multiple issues related with providers and consumers (patients) are known to affect the achievement of the required case finding and treatment outcome targets for effective TB control. The provider issues mainly relate to inadequately resourced and poor quality of health care, whereas patient issues relates mainly to his/her adherence to the 6 – 8 months treatment protocol.

This poor patient adherence leads to death, multi-drug resistance, chronic disease and continued transmission[3]. Incomplete treatment therefore poses a serious risk both for the individual patient and the community, and subsequently contributes to global failure in controlling the disease. It is therefore essential to identify approaches to tuberculosis case management, which are conducive towards ensuring patient compliance to the therapy[4].

Multiple studies in Pakistan and elsewhere have indicated TB association with reduced earning ability and/or opportunity and increased expenses. The patient and his/her family have to cope not only with the medical and administrative requirements of the treatment process but also the changed economic circumstances of their respective families. The patient ability to cope with these requirements may vary with patient gender and age, rural or urban location, family circumstances and assets, and social responsibilities and support network. A study

in Thailand suggests that the inability of poor patients to cope with the economic consequences of diagnosis and treatment cause low detection and treatment completion rates[5].

A follow-up survey of trial patients revealed that costs, occupational concerns, time, and poor health were the four top barriers to patient complying with treatment requirements[6]. A study in Bombay, India found that males were more worried about financial difficulties, loss of wages, poor job performance and consequences of long absences from work[7]. Another study in Pakistan found that psychological, financial and materials support of kinship networks was positively associated with an improved treatment adherence[8].

This is important to learn about TB patients and their family experiences of coping with the economic consequences of TB diagnosis and treatment. The study was meant to qualitatively study TB patient experiences of coping with the economic consequences of TB diagnosis and treatment. The male and female younger and elder patients living in selected rural areas were studied through semi-structured interviews. The exploratory study tried to answer the following five questions:

1. What are the economic consequences of TB diagnosis and treatment in Pakistan?
2. What coping mechanisms (individual and societal) are available to TB patients in Pakistan?
3. What coping mechanisms (individual and societal) are preferred by various patients living in rural Pakistan, and why?
4. What has been the patient experience with any particular coping mechanism that he/she tried?
5. What are the lessons for making the care delivery arrangements patient friendly?

The exploratory study used the “travel cost” and “incidental expenses” as indicators of direct disease related costs. The “foregone earning or working opportunity” indicated the opportunity cost to the patient.

Operational Definitions of the Terms Used in the Study are attached in Appendix A

Coping mechanisms

These mechanisms refer to any arrangement that a patient makes to deal with the economic consequences of TB diagnosis and treatment i.e. decreased earning or increased costs. In most cases, individuals and families are forced to seek possible ways of coping with the economic consequences arising from the physical ability limitation and/or disease related costs.

In this study the coping mechanisms were categorized into two groups i.e. individual/ family mechanisms and societal or institutional mechanisms. The individual/ family mechanisms include; Household members’ participation in labor force, Change in lifestyle, Deferred investment – financial investment and child education, Loans from formal or informal sources, Selling the family assets, beggary and Insurance i.e. risk reduction measure before getting the disease. The societal mechanisms comprised of; Government-run support networks, Individual philanthropist, social rehabilitation and food supplementation. These two categories of coping mechanisms, as used in the studyare briefly defined in appendix B.

In addition to above, some other relevant experiences may include: a) conditional cash transfer i.e. patient is offered cash incentives on achieving certain landmark(s) in his/her treatment process, and b) advocacy, communication and social mobilization for better informed and enabled patients and communities.

The study tried to combine learning through three main methods i.e. review of relevant documented experiences, focus group discussion with community, and interviews with selected young and old male and female TB patients living in rural areas of Lahore district. Access to patient list and addresses were managed through the district and health facility staff.

METHODOLOGY

The qualitative exploratory research was conducted with TB patients from rural areas of Lahore. The "triangulation" approach for the study included: a) the review of the national and international literature to inform the baseline understanding about TB disease and care context as well as the challenges faced and coping mechanisms adopted by TB patients and their families, b) focus group discussions with TB patients and c) in-depth interviews with TB patients.

The main focus of the exploratory study included: a) economic consequences of tuberculosis in terms of patient ability and opportunity to earn, as well as direct and/or opportunity costs related with disease and its treatment, and b) two main categories of coping mechanisms i.e. individual/ family mechanisms and societal or institutional mechanisms.

Two focus group discussions were held with TB patients (i.e. one male and one female patients) living in the selected study population. Each focus group discussion comprised of 12 participants (TB patients). The focus group discussions were facilitated, by the researcher, with the help of "vignettes" and "checklist". Vignettes are stories about individuals and situations which make reference to important points in the study of perceptions, beliefs and attitudes. The focus group participants would be asked to respond to written scenarios with what they think the characters in the story should and would do and why? And, if appropriate, what they themselves would do in such a situation. The expected output of the focus group discussions were: a) list of economic challenges that TB patient might face, and b) list of mechanisms available for the patient and his/her family to cope with these economic challenges.

In-depth semi-structured interviews with ten TB patients were conducted following the two focus group discussions. The interviews were done with 6 male and 4 females which were further categorized in the following five categories of TB patients: a) 2 married males – with regular job, b) 2 married males – daily wager, c) 2 male youth, d) 2 married females – housewives, and e) 2 female youth (unmarried).

The researcher transcribed the notes taken during the focus group discussions and interviews. The researcher then collated the transcribed data into various categories and groups of information. On the basis of collated transcribed data, the researcher then interpreted the key comments, issues, explanations and suggestions made by various respondents.

RESULTS

The study showed that majority of TB patients face economic consequences in terms of increased disease related expenses and/or lost income. Due to availability of free treatment (no payment made for investigation and anti-TB drugs), many patients reported to have paid significant:

Direct costs for treatment related transport and special foods.

"Due to my poor health, I was not able to earn enough for my family livelihood" (male - daily wager)

"I faced difficulty in paying for our travel to the health center" (female – housewife)

Indirect cost in terms of reduced or lost earning.

"My employers fired me because of my reduced ability to work and perceived risk of infection to their family" (female – house servant)

Majority of TB patients reported to have adopted one or more mechanisms to enable their families to cope with the economic consequences of TB and its treatment.

Many male and unmarried female patients reported their family members (including father, mother, brother, sister, wife and children) started working to cope with economic consequences of disease and its treatment. However, none of

the married female patient reported her in-laws family member started working for her disease or treatment. The nature of work that the family members got involved include skilled labor such as driving, sewing, embroidery etc. as well as non-skilled labor such as household servant, construction labor, work at restaurants or shops or factories. For many patients this option was found not feasible because of the non-availability of an individual or an opportunity to work.

"To meet day-to-day household expenses, my wife started working as kitchen helper at chaudhry's house" (male – micro-entrepreneur)

"My mother started doing embroidery to supplement my travel and food cost" (female – housewife)

Few married women (either herself a TB patient or a wife of TB patient), along with their children, were reported to have lived with their parents for six months or more mainly to help husband cope with the economic consequences and/or to reduce the disease risk to his family members.
"My brother in-law has taken me, my wife and two children to his house, so that he can support us till I get cured and start working" (male – daily wager)

"I was shifted to my parent's house, so that other members of the in-laws family can be protected" (female – housewife)

For married women patients who continued living with her husband family, generally the set of her household responsibilities (cooking, washing, cleaning etc.) remained unchanged, with a minimal support (if any) from other women members of the household. However, support from the daughter (mostly) and mother of the woman TB patient (occasionally) was reported for their routine household chores.

"My husband is not able to afford even a part-time servant, so my elder daughter (twelve years of age) has been sharing the daily household chores" (female – housewife)

Many TB patients reported stopping child schooling to save on education related costs and to make child work for his family to cope with the economic consequences of disease and its treatment. The boys were engaged mainly in earning activities whereas girls were engaged mainly in assisting their mothers in household chores.

"Due to my illness, the elder son (14 years of age) stopped going school and started working at a town restaurant to earn for family livelihood" (male – agriculture worker)

Many TB patients reported taking loans to cope with the economic consequences. The families in general were found more prepared to borrow money for male TB patients (mainly of productive age-group) and less for female TB patients. The main source for such loans has been the siblings, relatives and friends. None of the TB patents reported paying any interest on these loans. Some patients reported feeling humiliated because of their dependence on loan from relatives and friends. However, none of the TB patients reported their relatives and friends suffering from financial exhaustion.

"I have borrowed money from my brother to pay for the shelter and food of my family. He had saved the money for his daughter's marriage, which has now been postponed at least for a year" (male – daily wager)

Many patients also reported difficulty in getting loan from relatives and friends. This has mainly because: a) fewer of their relatives and friends had "spare money" to borrow, and b) uncertainty about patient's ability to repay loan in certain timelines. This shows that such borrowing arrangement was actually more difficult for those who had least financial ability (i.e. needed most).

"I faced difficulty in borrowing money from my relatives and friends, because most of them had not made much savings in the last few years" (male – factory worker)

Most TB patients from rural areas were found not able to report any institution (e.g. bank) and/or its requirement for their borrowing money to cope with economic consequences. Many individuals felt that such institutional facility, if made available, would be more acceptable because of lesser dependence on relatives and friends. However, few also showed reluctance to an interest-based loaning facility, if made available to TB patients and their families.

"We consider 'interest on loan' as not permissible in our religion. So we would not borrow money if payment of interest is involved" (male – agriculture worker)

Many TB patients reported selling family assets to cope with economic consequences. These assets include livestock, jewellery, piece of land and/or house, and household furniture or even utensils. In one case, mortgaging of family assets (i.e. jewellery) was also reported to cope with the economic consequences. The families in general were found more prepared to sell assets for male TB patients (mainly of productive age-group) and less for female TB patients.

"My family had to sell a piece of land to meet living expenses during a year of my illness" (male – agriculture worker)

Few patients reported their receiving (on request) some financial assistance from the respective landlord, employer and/or politician. However, none of the male and female TB patients reported "begging" as the approach adopted to cope with the economic consequences of disease and its treatment.

"Begum sahib provided financial assistance and relaxation in duty hours, so that I get treated and my three children get supported" (widow female – house worker)

None of the TB patients reported "insurance policy" as a source of his/her family support to cope with economic consequences of disease and its treatment.

A greater proportion of TB patients were found not aware of the possible financial assistance through Bait-ul-Mal and Benazir Income Support Programme (for women only) to cope with economic consequences of disease and its treatment. None of the TB patients reported to have availed any assistance from these two sources, mainly due to lack of knowledge and perceived difficult access.

"We poor lack the 'sifarish' that is required to get financial assistance from these government schemes" (female – housewife)

More respondents were found aware of Zakat, as a possible source of their financial assistance. Few respondents reported to have availed the assistance, but their family was found registered with the Zakat facility prior to the diagnosis of TB.

None of the TB patients reported to have availed any vocational training and skill-building scheme through programme facilitation. However, a couple of women were found to have attended vocational training classes before the diagnosis of TB. None of the TB patients reported to have availed any food supplement or other social support scheme through programme facilitation. However, one woman was found to have availed food supplementation, through world food programme, as a part of maternal and child health care initiative. Many of the TB patients felt that any such scheme, if introduced, would help families to cope with the economic consequences of disease and its treatment.

DISCUSSION

In this study TB patients were fo und to have faced economic consequences, in terms of increased disease related expenses and lost income. This finding is quite in line with experiences in other parts of the world. For example in Vietnam, poor people were found less able to seek TB treatment for fear of losing earnings and even their job.

In this study the core social network (mainly family and friends) has come out to be the main source of help for TB patient to cope with the economic

consequences. Both for unmarried and married women, the parents and peers remain the main source of social support to cope with economic consequences. The support has mainly been in the form of labor, money, and responsibility for family well-being. Experiences in other developing countries also suggest families taking responsibility to cope with the burden of disease related costs in a number of ways. In Malawi, the extended family remains the most important social safety net to provide care during illness. However, in Ethiopia, the involvement of social support structures beyond relatives (i.e. TB clubs) seems to have been important and successful[9].

In this study many families were found to have compromised their prospective investment in child growth to cope with immediate economic consequences. Similar experiences of children in disease-affected families leaving school have been reported in Malawi[17], India and Uganda[10].

In this study many TB patients reported selling family assets and/or borrowing money from families and friends to cope with economic consequences. Similarly studies in Thailand and other developing countries showed that the high costs of TB triggered "asset selling" and "borrowing" to mobilize substantial sums of money. Both asset sales and borrowing undermine the future income streams and threaten the sustainability of the household economy[21].

In this study, a significant lack of institutional arrangements was found for patients and families to cope with economic consequences. In Malawi, the personal insurance schemes, pensions and worker's compensation only catered for a very small percentage of the population[17]. However, experience in Moldova showed positive results with national insurance for TB diagnosis and treatment[23].

CONCLUSION/ RECOMMENDATION

The ability to cope with economic consequences plays a major role in achieving the treatment success as well as ensuring long-term wellbeing of TB patients and their families. This coping is too important to be left to TB patients and their families. The government and society has responsibility to evolve institutional mechanisms for facilitating the coping of TB patients and their families. There have been few small scale experiences, but further research and interventions are needed for coordinated national response to these challenges. It is recommended that the future research may include the urban locale and facilities to understand their set of coping mechanisms for economic consequences of TB treatment and diagnosis.

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APPENDIX A

Ability and opportunity to earn

The ability to earn refers mainly to the "physical" ability of an individual to carry out certain earning activities. These activities may vary in the level of skills and hardware required. The opportunity refers to the "chances" an individual may get to make use of his/her mental and/or physical abilities and earn. Tuberculosis is a disease that can affect both the ability and the opportunity of an individual patient to earn.

Tuberculosis is known to cause wasting of muscles and general weakness (i.e. weight loss). This affects patient's physical ability to carry out strenuous activities. The patient may find it difficult to manage his/her work and even the daily life social responsibilities. In advanced cases, the patient may become bed ridden i.e. higher level of physical dependence. This limitation of physical ability generally leads to patient either reducing the number of working hours or changing his job/ work so that he/she can manage with relatively less physical ability. In case of female patients, not directly engaged in any income generation activity, the saving family makes by their doing the household work (i.e. cooking, washing, cleaning etc.) is compromised.

Tuberculosis is also known to be associated with stigma. The person labeled as TB patient generally has to face a non-encouraging social response from his/her friends and communities. This also includes the possible risk to his/her job opportunity. In many cases, employer sends the person on forced leave without pay, and asks him/her to report back when cured. For an unemployed TB patient, the chances of getting employed are also significantly reduced. The stigma also affects the self-confidence and trust in others, which further affects the patient ability and opportunity to earn.

This changed circumstances, generally implies reduction in economic resources of the family. The study used "number of work hours" and "nature of work i.e. hard or easy in terms of physical effort required" and "level of earning" as indicators of patient ability to earn. The indicators for an opportunity to earn were "job offer" and "degree of socialization".

Disease related costs

The disease related costs included the direct out of pocket expenses as well as an opportunity costs. The direct cost associated with treatment process includes mainly travel cost, service charges and miscellaneous incidental expenses incurred during visit to the health facility. In an economic analysis (Khan, 2002), conducted with more than 300 treated TB patients in three districts of Pakistan, it was found that an average distance between patient home and TB care facility was around 15 km, and a visit to health facility took patient around 2 hours and a quarter of travel time. The average facility visit cost a TB patient about 20 rupees. It was also noted that patent incidental expenses during the facility visit was also equivalent or more than average travel expense. Each TB patient was required to visit health facility every month to get clinically examined and collect drugs for the next month. Here this is worth mentioning that the government of Pakistan, through TB Control Programme, has arranged for the free-of-charge laboratory testing and anti-TB drugs for each TB patient reporting to the network of health facilities.

However, to access the free-of-charge diagnosis and treatment services, TB patient is required to spend some money from his/her own pocket. In the same study, it was found that an average opportunity cost for the TB patient to visit the health facility was around 60 rupees, which is additional to the out of pocket expenses mentioned. It was further noted that daily-wagers males were more vulnerable to the opportunity cost issue, because they were generally less able to visit the facility without losing the whole day work.

APPENDIX B

Individual/ family mechanisms

The individual/ family coping mechanisms are those arrangements where economic consequences of TB diagnosis and treatment are managed mainly through the efforts and/ or resources of individual TB patients and their families. Some obvious options are as follows:

Household members' participation in labor force: This is where one or more family member, generally a female or a youth, who was not previously engaged in any earning responsibility enters the labor force to earn for the family. These jobs, when available, generally vary in skill and time requirements as well as the emoluments. The decision for the family member to enter the labor force is generally a "necessity" rather than "choice".

Change in lifestyle: The life style in the study refers mainly to housing, food and leisure. This is where patient and his/her family change any one or more of these three to cope with economic consequences of TB diagnosis and treatment. The changes may include: a) the housing i.e. going for smaller or cheaper premises, b) the food i.e. reducing the intake and/or substituting with low-cost items, and c) leisure i.e. minimizing expenses on leisure activities such as holidays, sports, social events etc.

Deferred investment – financial investment and child education: In the study, this refers to postponement of family investments in physical assets and/or human capital. The physical assets may include land, house, bank accounts, stocks, motorcycle/ car etc. The investment in human capital includes mainly education of family members. The deferred investments include both the disinvesting (from past investments) and postponing of further (planned) investments.

Loans from formal or informal sources: Loan, in this study, refers to any monetary loan taken by the patient and/or family to cope with economic consequences of TB diagnosis and treatment. The formal sources of loan may include banks or employee's organization, whereas the informal sources mainly include relatives and friends.

Selling the family assets: Family asset, in this study, refers to any living or non-living commodity that can be sold for money. The living commodity includes cows, sheep, horse, dog etc., whereas the nonliving entities include land, house, ornaments, household hardware etc. Any selling of asset(s), by patient and/or family, to cope with economic consequences of TB diagnosis and treatment will be included in the study.

Beggary: Beggary, in the study, refers to situation where patient or family member gets involved in any form of beggary just to cope with economic consequences of TB diagnosis and treatment.

Insurance i.e. risk reduction measure before getting the disease: Insurance, in this study, refers to situations where patient and his family members were able to cope with economic consequences of TB diagnosis and treatment just because they were covered with health insurance policy.

Societal mechanisms

The institutional or societal coping mechanisms are those where an institution or society in general plays important role in patients' dealing with economic consequences to them and their families.

Government-run support networks: The Zakat and Bait-ul-Mal are two public-run mechanisms to channel the social support to those in need. Each of these two has defined procedures for selecting and supporting eligible individuals. In this study, we refer to situations where patient and his family members were able to cope with economic consequences of TB diagnosis and treatment because of their access to either Zakat or Bait-ul-Mal process.

Individual philanthropist: In this study, the philanthropist refers to an individual or an organization that provides social support to eligible individuals. The support from an individual philanthropist is generally in the form of cash

to supplement the household expenses and/or meet the out-of-pocket disease related expenses. In other situations, in-kind support may also be offered to patient family such as pulses, wheat, rice, edible oil etc.

Social rehabilitation: In this study, social rehabilitation refers to any capacity building measure meant to enhance patient and his/her family capacity to cope with economic consequences. This may include providing inputs such as vocational training, micro-enterprise development training and support, and hardware e.g. sewing machine, cycle.

Food supplementation: In this study, food supplementation refers to any activity resulting in provision of food item(s) to patient and his/her family. The two main approaches include: a) onsite provision of supplement meal, juice, milk etc. during patient visit to the health facility, and b) provision of food items for the patient to take home for his family consumption. The examples are pulses, wheat, rice, edible oil etc.