Review Article

Socio-psychological factors related to tuberculosis diagnostic test seeking behavior in Pakistan

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Authors' Contribution

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Abstract

Although, social and psychological factors have scientifically well documented role in determining the health seeking behavior of tuberculosis (TB) patients globally, however, the need to understand why these factors affect the health seeking behavior of TB patients in the light of behavioral theories in still unmet. This study evaluates the role of social and psychological factors affecting TB diagnostic test seeking behavior of patients in low socioeconomic country like Pakistan in relation to "Health Belief Model", a best-fit health behavior theory. Literature was searched systematically to find the studies addressing psychosocial factors affecting the diagnostic test seeking behaviors of TB patients in Google scholar, Medline and PubMed. The related articles had been reviewed for the period of 1998 to 2013. Emphasis was laid to review all studies conducted in Pakistan however where needed reference from other countries with similar socio-demographic characteristics was also included. The four key components of Health Belief Models; perceived susceptibility and severity and perceived benefits and barriers explain the relation between the socio-psychological factors and low treatment seeking behavior of TB patients. Inadequate knowledge and misconceptions about susceptibility and severity of TB disease is contributing towards low health seeking behavior. Further, false beliefs and distrust in treatment are the perceived barriers, which decrease motivation for benefits and superimpose the condition.

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INTRODUCTION

uberculosis, though a curable disease kills 1.8 million people annually, on average, killing one person every 15 seconds (WHO, 2016). TB burden is not evenly distributed across the globe; rather it is concentrated heavily in resource deprived countries which share around 80% of this global disease burden (Onyango *et al.*, 2011). Pakistan, a developing nation despite of providing free of cost diagnostic and treatment facilities to TB patients, is still facing daunting challenge in controlling epidemic of this disease. One of the key factors behind this rising trend of TB is low health seeking behavior of TB patients, which is reflected by Case Notification Rate (CNR); proportion of TB patients in a community being diagnosed and reported as TB patients by National TB Control Program. In Pakistan, the CNR for tuberculosis is very low in Pakistan, around 63% (WHO, 2016).There is a need to understand the reasons for this variation in health seeking behavior between different countries and most importantly for low diagnostic health seeking behavior in Pakistan. For the cause, this study evaluates the health

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seeking behaviors in context with established health behavior theories. Behavioral theories explain the reasons behind an explicit behavior. Many theories like Health Belief Model, social cognitive theory, diffusion of innovation model, trans-theoretical model and theory of reasoned action/planned behavior describe personal and collective health seeking behavior for the selected response (Glanz *et al.*, 2008).

From social and behavioral studies, it can be concluded that personal perception about the susceptibility and severity of tuberculosis and perceived benefits, barriers and personal ability to control the behavior are critical determinants of explicit behavior of participation in screening test for the diagnosis of tuberculosis. All these factors are the basic concepts of Health belief Model. This Model provide the required information about the importance of these factors in determining the behavior of TB patients in terms of seeking health care. Social cognitive theory adds some further details that the effects of punishment/reward, personal goal setting and societal goal seeking are attributed factors for the behavioral response of community (Munro et al., 2007). However, in this scenario these factors explained by social cognitive theory may not be very appropriate. Therefore, for this specific topic this paper would explain the psychosocial factors influencing health-seeking behavior in relation to Health Belief Model. Health Belief Model and health seeking behavior of TB patients

Health Belief Model describes certain basic elements that determine the probability that a specific behavior would be prevalent or not in a particular psycho-social set up. The key concepts of Health Belief Model are perceived susceptibility, perceived severity, perceived barriers and benefits, cues to action and selfefficacy. Perceived susceptibility and severity are jointly considered as the perceived threat from tuberculosis. From patient's point of view, the advantages of participation in diagnostic testing for tuberculosis are the perceived benefits and the disadvantage of showing the same behavior are the perceived barriers. Efficacy to action is the patient's perception about the effectiveness of proposed act (participation in screening for tuberculosis) in reducing the possible threat from the health outcome. Health Belief Model suggests that in face of threat from tuberculosis, belief elements produce variant degree of psychological willingness towards participation in tuberculosis

screening programs. If perceived threats and perceived benefits are more than perceived barriers, the motivation would be towards positive behavioral response that is for participation in screening program for diagnosis of tuberculosis. Similarly, if perceived barriers are more than perceived benefit and perceived threat it would lead to decrease willingness to action (Carpenter *et al.*, 2010).

In Pakistan, people having signs and symptoms of tuberculosis usually do not go directly to public health facilities supported by National TB Control Program (NTP). After visiting general physician in their neighborhood. they are referred to NTP (Khan et al., 2000). The refusal or delay in participation for diagnostic test is mainly contributed in this interval of being referred from physician to NTP (Sagib et al., 2011). In 7 country study, it was found out that delay from appearance of sign and symptoms to first health seeking behavior (Non TB units) was only 9.9 days in Pakistan as compared to 69 days in Somalia. Whereas diagnostic delay (from first health seeking behavior at general diagnosis physician to at tuberculosis specialized Unit of NTP) is maximum in Pakistan (96.3 days) while in Iraq it is only 43 days (Bassili et al., 2008).

Perceived susceptibility

For diagnostic seeking behavior, perceived susceptibility means that the perception of people about the probability of being infected with tuberculosis. Inadequate knowledge about cause, risk and mode of transmission of disease leads to altered perceived susceptibility of tuberculosis among patients having sign and symptoms of chest disease (Faisal *et al.*, 2014).

Perceived susceptibility to tuberculosis is different in various regions of world. A study in Kenya has shown that people who are smoker, alcohol drinker or have been exposed to extreme weather are only considered to be susceptible of disease. The study also states that many participants believed that TB is a hereditary disease (Liefooghe *et al.*, 1997).

In a study conducted in Ethiopia, It was found that 81.5% (n=703) people believe that those who get exposed to cold wind would be susceptible of developing the disease (Gelaw *et al.*, 2011). A study in Karachi Pakistan found that 47.6% of TB patients believed eating contaminated food was the cause of disease, further 57% responded that separating utensils with TB patients was an important preventing factors while 57% believed that stress and trauma was also the cause of TB (Khan *et al.,* 2006). NTP Pakistan mentioned in 2010 that people in all 4 provinces of Pakistan have

variety of different concepts about the spread of disease which in turns determines their likelihood of getting the diseases.



Figure 1: Health Belief Model for TB diagnostic health seeking behavior of TB patients in Pakistan

Like in Baluchistan, most of the people believe that tension, not having breakfast and wearing TB patient slippers are modes of transmission. In Sindh, sharing food and utensils along with sleeping on bed with TB patients are the sources of transmission. In Punjab, sharing of utensils and spitting freely are considered as the source of spread. Lastly in NWFP, sitting with Tuberculosis patient and polluted (dirty) environment are considered to be responsible for getting infection.

A qualitative study conducted in seven districts of Malaysia determined the perception about cause and consequences of tuberculosis and it was found out that 96% respondents did not know the actual cause of the disease. Many of them believed that it was due to tear in the body or due to hard work (Rundi, 2010). From the literature review, it can be concluded that in developing countries like Pakistan it is believed that people having breakfast daily, not working hard, not exposed to pollution and not sharing things with tuberculosis patients would not be

susceptible of disease (Onyango et al., 2011). Studies have also showed that this distorted perception about susceptible being of tuberculosis is more in uneducated, females, children, and villagers as compared to other beings. In addition to these misconceptions about the modes of transmission of tuberculosis, inadequate knowledge about the disease itself causes decrease in perceived susceptibility for tuberculosis. The inadequate knowledge about TB disease predominant in rural area as compared to urban settings (Warsi et al., 2016). In a study carried out by Agboatwalla et al. (2003) in Karachi and its suburbs, it was found out that 86% of the patients had never heard about tuberculosis before being diagnosed. Among all the patients who have heard about tuberculosis it was found out that in 44.6% the source of information was family and friends.

Perceived severity

Perceived severity involves the concept that if remained undiagnosed, what would be the

adverse financial and health outcome. This psychosocial belief is primarily attributed by knowledge about the adverse physical and social outcomes of the disease and this knowledge varies with sex, educational level, community awareness and other environmental influences. In rural/suburban areas of Pakistan, tuberculosis is perceived to be very dangerous. incurable and infectious disease that leads to lona term morbidity and mortality. In 7countriesstudy conducted in Karachi 171 patients were interview about the severity and consequences of tuberculosis, 23% of the participants linked infertility as a consequence of

tuberculosis(Bassili *et al.*, 2008). Although TB is perceived to be dangerous for both male and female patients but female are considered to face more social consequences than males. For male patients, tuberculosis leads to job loss and reduced income while in females it is related to social consequences like breakups, difficulty in taking care of the children and other disturbances in family life (Atre *et al.*, 2004). Physical, financial and social consequences of tuberculosis are perceived threat that enhances the likelihood of participation in tuberculosis screening programs.



Figure 2: Factors related to TB diagnostic health seeking behavior of TB patients in Pakistan

Perceived benefits

Perceived benefits are the motivational factors for health seeking behavior of people. In a study carried out in Pakistan, tuberculosis patients registered in tuberculosis management facility were being interviewed to determine their perception about the adverse outcome of the disease if remain unmanaged and perception about positive health outcomes with early diagnosis of tuberculosis. 85%participants responded that if, tuberculosis remained undiagnosed or unmanaged it results in serious adverse health outcomes. Additionally 75% of patients believed that if TB patient remained unmanaged it would lead to spread of infection in family (Khadim *et al.*, 2003).

Perceived barriers

Global literature research suggest that lack of trust in public services, stigma attached with the disease, cultural believes and perceptions regarding treatment options like home remedies, self care and seeking care from local non medical folks are perceived barriers in diagnostic test seeking behavior among patients having chest symptoms. Additionally gender disparity affecting women health, low education level of head of family and financial burden associated with treatment at private sector also limit health seeking behavior of tuberculosis infected patients. Certain religious believes in some places also put a barrier in health seeking behavior. A study in Punjab Pakistan, 50% (n=1080) of respondents believed that community rejects those who get TB (Mushtaq et al., 2011). The 1020 household were interviewed in South Africa for their perception about tuberculosis, 95% people declared tuberculosis a stigma. People show delay in health seeking behavior because they believe that once they would be diagnosed as case of tuberculosis, their family life as well as social life would get affected (Cramm et al., 2010)

In seven country study, it was seen that about 85% of the tuberculosis patients feel ashamed of being diagnosed as tuberculosis positive and 90% of patients believed that their family and social life was affected with the diagnosis. Additionally 96% of the females believed that girls did not show diagnosis seeking behavior for tuberculosis because it future prospect affects the of their marriage(Agboatwalla et al., 2003). In Pakistan, social consequences include divorce, social outcast of patient and his/her family, diminished marriage prospect of the affected especially the female as it is believed that pregnancy relapses the disease (Liefooghe et al., 1997).

Cost of healthcare is a major factor that affects the health seeking behavior in developing countries like Pakistan. The cost of formal health care is considered very high that's why people are found to treat their illness to traditional healers and other informal sector (Qureshi and Shaikh, 2006). Though NTP (Government) units in Pakistan provide free diagnosis and treatment for tuberculosis, nearly 56% of patients seek medical advice from four to five private health care providers before they are referred to specialized chest treatment unit for the diagnosis of their treatment. These visits to private physicians cost huge financial burden on patient even before they get finally diagnosed. This unnecessary financial load creates perception in community that tuberculosis puts heavy financial burden on diseased. Additionally the concept that this disease is related to the hours lost from work put additional barrier in health seeking behavior of patients having sign and symptoms of Tuberculosis. Females in Pakistan are financially dependent on males so delay in health seeking behavior of female patients is also contributed by financial constrains. An additional perceived barrier to health seeking behavior is the concept that the illness would be cured by itself (60.5%) (Qureshi et al., 2008).

TB is considered as incurable disease in a study conducted in Sialkot, Pakistan. Stigmatization, fear of isolation and fear of being divorced are considered major factors that hinder treatment seeking behavior of TB patients (Liefooghe *et al.*, 1995). A study conducted by Amir Khan evaluated cultural influence on health seeking behavior in healthcare settings of Pakistan showed that as Tuberculosis is social stigma, people try to hide the diagnosis and they usually do not trust on healthcare provider that he/she would maintain confidentiality of their diagnosis (Khan *et al.*, 2000).

In addition, the communication barrier exists between patient and doctor which also,

contribute in delay in health seeking behavior. This study showed that people usually do not believe that they would get appropriate and sufficient knowledge about their disease status from their public healthcare provider (Khan *et al.*, 2000).

Typical feature of the described health seeking behavior of men was that they neglect symptoms until the disease reached a serious stage, by which time they tend to go directly to public health services without first visiting private health practitioners. Women, on the other hand, were described as having a tendency to seek out private services and practice self-medication before seeking care at public services (Shaikh and Hatcher, 2005).

Cross sectional study conducted in Pakistan determined the likelihood of choices people make in certain illnesses like tuberculosis. A qualitative analysis using EDM (Ethnographic Decision Model) explained why people show health seeking behavior and prefers to choose one method of treatment over the other. The objective of this study was to explore the factors influencing health seeking behavior and also the decision about participation in diagnosis and treatment for tuberculosis in Pakistan.

All sputum smear positive individual registered during January and February 2002 at Rawalpindi tuberculosis center were included in this study. Patients were selected by systematic sample selection method and mean age was 34.2 years. About 91% of them belonged to economically productive age group (15-59), while 60% of the participants were illiterate living in 1-2 bedroom houses. 100% of the patients showed diagnostic test seeking behavior due to symptoms suggestive of tuberculosis like cough. fever, chest pain and general ill-health. In 62% of cases cue to action (diagnostic test seeking) was severity of symptoms. In 85% of cases family advice was also motivation factor for health seeking behavior while in 75% of such patients seeking healthcare was facilitated by people living with patients under the same roof. In 94% of the patients family support was an important factor in their decision of participation in diagnostic testing for tuberculosis. The facilitative role of family members in decision of seeking care for tuberculosis is also observed in a study conducted in India. Availability of free diagnostic test as well as free drugs at specialized tuberculosis center were also motivational factors for seeking healthcare (Khadim et al., 2003). In Pakistan, perceived

susceptibility of tuberculosis is low mainly due to inadequate knowledge about the cause, risk and mode of transmission of the disease. People who have heard about tuberculosisbelieve that this disease leads to adverse health outcomes if remained unmanaged. Most of the patients believe that disease is curable if diagnosed early but still the perceived financial and social consequences of the diagnosis limit diagnosis seeking behavior of tuberculosis patients. For male patients, participation in screening program and diagnosis of tuberculosis leads to Job loss and reduced income while in females it is related to social consequences including disturbances in family life.

CONCLUSION

In conclusion, the low rate of case detection is believed to be caused by social barriers like stigma, lack of social support and trust in public health facilities, gender disparity women health and inadequate affecting knowledge about disease process. Public health interventions to detect the missed TB cases in community must consider constrains in health seeking behavior of TB patients. These factors are critical to halt the disease and reverse its incidence in line with the sustainable development goals.

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