ORIGINAL ARTICLE

Psychological Distress Among Primary Care Givers of Tuberculous Patients at TB Sanatorium Kotri & Hyderabad

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ABSTRACT

Objective: To study the psychological health of the primary caregivers of TB patients.

Methodology: This is cross-sectional descriptive study done from July 2015 to October 2015 at TB Sanatorium Kotri and TB Sanatorium Hyderabad. A sample of 158 self-professed primary caregivers chosen via convenience sampling after taking informed consent. Caregiver psychological distress was measured using interview based structured questionnaire which included the 42 point DAS scale (Urdu version).

Results: Majority of respondents were male (60.8%), educated (78.5%) and living in joint families (57%). Caregivers mainly belonged to lower (35.4%) and middle (54.5%) economic class. Health worries (both personal and those related to the patient), emotional fatigue due to long and strict treatment regimen, decreased quality of life and uncertainty of positive treatment outcome were the main factors significantly weighing down psychological health of primary caregivers. Moderate mean levels of Depression (16.1), Anxiety (10.4) and Stress (19.1) were noted.

Conclusion: Psychological wellbeing of the primary caregivers should be given adequate attention and psychiatric counselling should be provided to the caregivers so they may be better able to tend to the patients.

Keywords: TB, Primary Caregiver, Psychological Distress, Depression, Anxiety and Stress.

Introduction

Tuberculosis (TB), globally, remains a chief killer. More than 33 percent of the global population is plagued with mycobacterium tuberculosis.[1] In 2009 the estimated TB deaths were 1.3 million worldwide.[2] Similarly here in Pakistan, TB is one of the major public health concerns. Pakistan ranks 5th amongst countries highly burdened with TB worldwide. In the Eastern Mediterranean Region of WHO, it amounts to sixty one percent of the disease burden. An estimated four hundred and twenty thousand fresh TB cases come forth annually and fifty percent of them are positive of sputum smear. Pakistan approximately has the 4th largest patient population of multidrug-resistant TB (MDR-TB) worldwide. The reported TB incidence increased from nearly twenty-one thousand in 2001 to almost twenty seven thousand in 2010. At present, the rate of fresh case detection of smear positive TB cases is 63%.[3]

The myths, no matter how twisted, stem from genuine fear of health. TB is an airborne disease and an index case in a community can transmit infection to more than 10 people over a 1-year period, people exposed to TB cases have a higher risk of acquiring TB infection than the general population. Primary care givers (often families) spend the most amount of time with the patients and fears of infection can seriously unsettle the primary caregivers mentally. Currently, close contacts of TB cases are investigated regularly to rule out TB disease. However, no mental health

surveys on TB contacts are conducted. Thus, whether TB contacts are at risk of psychological distress remains unclear.

The developing world has widespread misconceptions and false beliefs regarding TB and patients as well as their families of feel the brunt of this plague of the mind. These myths have transformed TB into a societal stigma and an important role is played by this stigmatization in reluctant treatment seeking by patient and hesitation on part of the family members to care for the patients.[4] This subject is seldom studied in Pakistan pertaining to awareness of actual dynamics of TB among patients and their families that often serve as the primary caregivers. The reason that cultural and social factors are taken into account is because they play a crucial role in TB patient compliance and family care provision.[5]

The psychological effects of chronic illnesses upon the caregivers and the incumbent emotional fatigue is well proved however, the added effect that is caused by the fear of contracting the illness by the caregivers changes the dynamics of the equation. Thus we aim to study the psychological health of the primary caregivers of TB patients.

Methodology

The cross sectional analysis comprised of a sample of 158 self-professed primary caregivers chosen via convenience sampling from July 2015 to October 2015 at TB Sanatorium Kotri and TB Sanatorium Hyderabad. Participants were selected after taking informed consent. A self-made questionnaire was used to collect the demographic and descriptive data while Caregiver psychological distress was measured using interview based structured questionnaire which included the 42 point DAS scale (Urdu version).

Results

The sample population belonged mainly to different localities of Kotri and Hyderabad representing different gender, ethnic, socio-economic, educational and age groups. Majority of the caregivers visiting the TB sanatoriums were males (60.8%) to females (39.2%). 57% of the respondents were a part of joint family set-up while only 43% belonged to nuclear family set-up. However, a finding defying perceived societal statistical norms is the educational status of the respondents. A vast majority (78.5%) of the respondents were educated while only a meager 21.5% were uneducated.

Care givers of tuberculous patients poured in at the sanatoriums from varied self-defined age group. The decade long groups started from 21 years and went above 51 years. Figure 1 below further explains the age dynamics in detail.

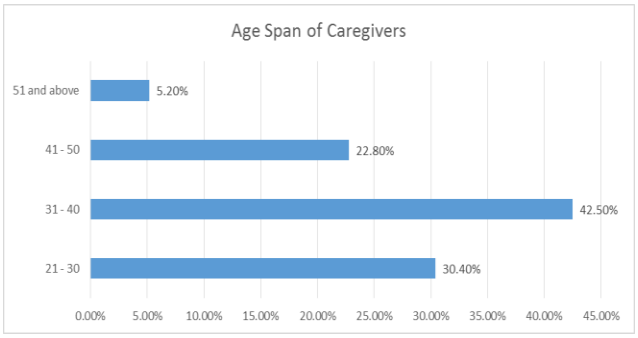

Figure 1. Age Distribution of Caregivers

Depression, Anxiety and Stress were all unearthed in the caregivers. The values are a mean of the values of all respondents. The height of the bars indicates individual levels only and no comparison can be drawn with each other since the standard scales and values differ for each. Depression, Anxiety and Stress too falls within the moderate range (19-25) defined by the DASS scoring manual. Further detail can be derived from Figure 2.

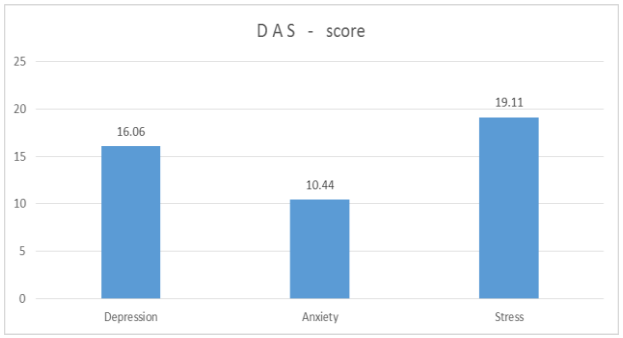

Figure 2. DAS score of Caregivers

Majority of the respondents belonged to the middle socioeconomic class (54.5%). Details are shown in Figure 3.

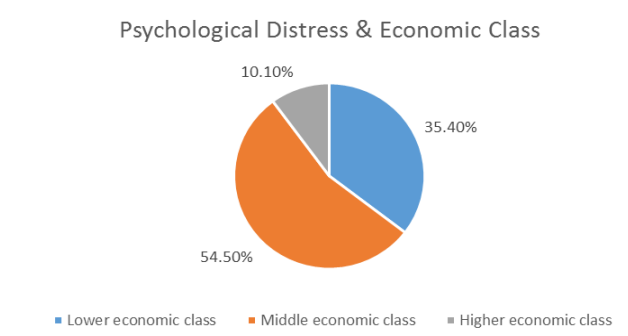

Figure 3. Socio- the economic class of the patients and their primary caregivers

Figure 4 below shows the full spectrum of emotions.

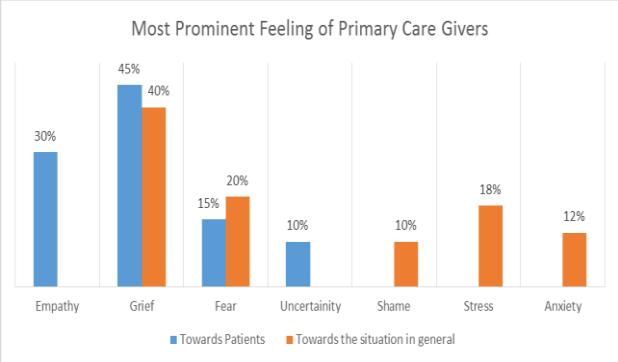

Figure 4: Spectrum of feelings of Caregivers toward patients and in general.

Discussion

This study found the male dominance owing to our conservative societal values and traditions. Another aspect that can be attributed to our societal trends and traditions is the family structure, where more respondents belong to joint family set-up. The origins of depression, anxiety and stress aren't always psychological and emotional in origin. We believe that in our modern society, depression, anxiety and stress are often materialistic and financial in origin. In addition to this, education too nowadays is a materialistic tool that can be bought and sold. Majority of the respondents belonged to the middle socioeconomic class (54.5%), which is synonymous with the national demographics of 2013.

The caregivers experienced a multitude of emotions and feelings towards the patients and towards the situation in general. The exercise of emotions during the long course of treatment leads to emotional fatigue. The fatigue further aggravated the psychological distress. The feelings stemming towards the patient were generally those that benefitted the patient. However, the feelings towards the situation in general were negative and might not seem worrying but are capable of inflicting harm to the psychological health of the primary caregivers.

Pakistan is ranked among countries with highest burden of TB.[6] A person elicits a reaction to TB based on his past knowledge regarding it and a caregiver's response and the quality of care provided by the primary caregivers too is affected by the prior knowledge.[7] Better health-seeking behavior and better care provision is related with better knowledge of TB.[8] Existing literature from India showed 56 to 96% of population were well oriented to knowledge regarding the disease TB.[9-11] One of the reasons why Pakistan shoulders such a high burden of TB is the poor knowledge.[12] Likewise, literature reports almost congruency of the situation in Pakistan, India, and Bangladesh.[10,11,13]

An increase in educational status is linked with increase in knowledge regarding modes of TB spread in a population.[9] Transmission of TB via sharing utensils and saliva is thought of as important in situations like ours[9,12] Most people who knew about the infectious nature of disease linked TB transmission with sharing of utensils and through saliva etc. Rarely did people know about vertical transmission of the disease. Spreading knowledge about this method of spread, in a nation where; fertility is high is important in its prevention.[14] However, false beliefs that spending additional time with or making non-intimate physical contact with the patient were too believed to be causes of spread and not only did it limit the primary caregivers from providing care but it also inflicted fear in their minds and caused psychological distress.

Social discrimination and disease dissemination are common stigmas associated with TB.[16] These stigmas cultivate feelings of shame and fear towards the illness and the patients is tempted to hide it from others rather than seeking adequate treatment unless absolutely necessary. The fears are not dumbfounded since disclosure of the disease gives birth to fear in the family and social contacts of the patient. The moral compulsion of the family to care for the patient often outweighs the fear but the subdued fear and alarm often subdues the psychological health and the transforms into even clinical levels of psychological distress. Ultimate conclusion is poor patient prognosis and greater disease dissemination.

By educating the patients and more importantly the primary caregivers and removing their misconceptions regarding the spread of disease is likely to go away.[17] TB diagnoses were associated with anxiety in the primary caregivers and a sense of stress. Since not only the TB patients but the entire family of the patient are exposed to a great deal of ostracism from the community.[18,19] The families thus have fear of social aversion.[20] Such stigmatization in the society can lead to reluctance of the families to continue to care for the patients in person and increases the chances of the patient being sent to a full time treatment facility if affordable. In this study, nearly 40% of the primary care givers admittedly hid the patient's disease from the society unless it became unavoidably clear.

A majority of relatives feel that the dishes of TB patients should be kept separate from rest of the family members and were under the constant fear that if by chance they happened

to share the dishes by mistake, they would immediately contract the disease despite precaution. These misconceptions were supplemented by the fact that the primary caregivers received inadequate education from their physicians; half of primary caregivers received no information about ways to prevent the spread of disease. A major proportion was unaware that after a few weeks of treatment TB was no longer contagious. Many held the belief that preventive measures should be kept in place for a long or indefinite period of time.

In a similar research conducted in India Singh et al. claimed that only 2.3 percent of the sample was aware that TB was caused by a bacterium.[19] More than half of the primary caregivers in our study were of the opinion that TB may stem from emotional trauma or stress and twenty percent held the belief that after subdual of symptoms the that treatment can be halted. Unavailability of drugs, clinical improvement or financial constraints were allegedly the main reasons leading to defaulting treatment in previous literature.[21,22] While psychological distress and impairment coupled with the loss of will on part of the primary caregivers to care for the patients never figured into discussion in the existing pool of literature anywhere in the world.

Sexual intercourse and evil spirits have been implicated with causing TB in Ethiopia. People there also exhibit a snubbing behaviour towards TB patients.[18] "Cold" has been referred to as a cause of TB in Ethiopia.[21] The prevailing idea that an association between HIV and TB has been hypothesized in Zambia and Ethiopia.[18,23] Estrangement of patients of TB has also been noted in somewhat developed countries like South Africa.[24] In various cultures, diverse societal beliefs such as TB resulting from coitus, after the demise of a member of the family and after a woman has underwent a spontaneous abortion are widespread. People also hold the belief that only traditional healers can treat the disease. A belief also exists that TB of a 'western' type can disseminate from surfers or is due smoking, environmental pollution or alcohol abuse.[25] Research carried out in Bangladesh, which is confronted with similar cultural and social background, have exhibited that mass health education campaigns can improve knowledge level and elicit positive attitudes towards TB.[26] Existing literature talks extensively of removing misconceptions about TB through society based mass awareness strategies as a means of information and education dissemination on TB transmission of TB.[18,19]

Conclusion

Psychological wellbeing of the primary caregivers should be given adequate attention and psychiatric counselling should be provided to the caregivers so they may be better able to tend to the patients. The lack of education regarding the disease is creating a vacuum that is filled with myths and misconceptions. Only mass education and awareness can put an end to the prevalent mindset. Further research need to be conducted to more deeply evaluate the topic and come up with strategies to counteract the current situation.

References

1. WHO Media Center. (2010). Fact Sheet on Tuberculosis; 2010. Available from URL: http://www.who.int/mediacentre/factsheets/fs104/en/.
2. WHO Report. (2010). Global tuberculosis control. Available from URL: http://whqlibdoc.who.int/publications/2010/9789241564069_eng.pdf.
3. WHO. (2010). The global plan to stop TB 2010-2015. Available from URL: http://www.emro.who.int/pak/programmes/stop-tuberculosis.html
4. Ali SS, Rabbani S, Siddiqui UN, Zaidi AH, Sophie A, Virani SJ et al. Tuberculosis: do we know enough? A study of patients and their families in an outpatient hospital setting in Karachi, Pakistan. Int J Tuberc Lung Dis 2003; 7: 1052-8.
5. Khan A, Walley J, Newell J, Imdad N. Tuberculosis in Pakistan. Socio-Cultural Constraints and opportunities in treatment. Soc Sci Med 2000; 25: 389-99.
6. WHO. (2010). Global TB Database. Available from URL: www.who.int/tb/data.
7. Williams G, Alarcon E, Jittimanee S, Walusimbi M, Sebek M, Berga E, Villa TS. Best Practice for the care of patients with Tuberculosis. A Guide for Low income Countries. International Union against Tuberculosis and Lung Disease. Paris, France. 2007.
8. Hoa NP, Thorson AE, Long NH, Diwan VK. Knowledge of tuberculosis and associated health-seeking behaviour among rural Vietnamese adults with a cough for at least three weeks. Scand J Public Health Suppl 2003; 62: 59-65.
9. Sharma N, Malhotra R, Taneja DK, Saha R, Ingle GK. Awareness and perception about tuberculosis in the general population of Delhi. Asia Pac J Public Health 2007; 19: 10-5.
10. Kar M, Logaraj M. Awareness, attitude and treatment seeking behaviour regarding tuberculosis in a rural area of Tamil Nadu. Indian J Tuberc 2010; 57: 226-9.
11. Malhotra R, Taneja DK, Dhingra VK, Rajpal S, Mehra M. Awareness regarding Tuburculosis in a rural population of Delhi. Indian Journal of Community Medicine 2002; 27: 62-8.
12. Ali SS, Rabbani F, Siddiqui UN, Zaidi AH, Sophie A, Virani SJ et al. Tuberculosis: do we know enough? A study of patients and their families in an outpatient hospital setting in Karachi, Pakistan. Int J Tuberc Lung Dis 2003; 7: 1052-8.
13. Mushtaq MU, Shahid U, Abdullah HM, Saeed A, Omer F, Shad MA et al. Urban-rural inequities in knowledge, attitudes and practices regarding tuberculosis in two districts of Pakistan's Punjab province. Int J Equity Health 2011; 10: 8.
14. Croft RP, Croft RA. Knowledge, attitudes and practice regarding leprosy and tuberculosis in Bangladesh. Lepr Rev 1999; 70: 34-42.

15. National Institute of Population Studies (NIPS) [Pakistan], and Macro International Inc. Pakistan Demographic and Health Survey 2006-07. Islamabad, Pakistan: National Institute of Population Studies and Macro International Inc. 2008.
16. Baral SC, Karki DK, Newell JN. Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study. BMC Public Health 2007; 7: 211.
17. Liam CK, Lim KH, Wong CM, Tang BG. Attitudes and knowledge of newly diagnosed tuberculosis patients regarding the disease, and factors affecting treatment compliance. Int J Tuberc Lung Dis 1999; 3: 300-9.
18. Getahun H, Aragaw D. Tuberculosis in rural northwest Ethiopia: community perspective. Ethiop Med J 2001; 39: 283-91.
19. Singh MM, Bano T, Pagare D, Sharma N, Devi R, Mehra M. Knowledge and attitude towards tuberculosis in a slum community of Delhi. J Commun Dis 2002; 34: 203-14.
20. Khan A, Walley J, Newell J, Imdad N. Tuberculosis in Pakistan. Socio-Cultural Constraints and opportunities in treatment. Soc Sci Med 2000; 25: 389-99.
21. Gelaw M, Genebo T, Dejene A, Lemma E, Eyob G. Attitude and social consequences of tuberculosis in Addis Ababa, Ethiopia. East Afr Med J 2001; 78: 382-88.
22. Liefooghe R, Michiels N, Habib S, Moran MB, De Muynck A. Perception and social consequences of tuberculosis: a focus group study of tuberculosis patients in Sialkot, Pakistan. Soc Sci Med 1995; 41: 1685-92.
23. Godfrey-Faussett P, Kaunda H, Kamanga J, van Beers S, van Cleeff M, Kumwenda-Phiri R, et al. Why do patients with a cough delay seeking care at Lusaka urban health centres? A health systems research approach. Int J Tuberc Lung Dis 2002; 6: 796-805.
24. Metcalf CA, Bradshaw D, Stindt WW. Knowledge and beliefs about tuberculosis among non-working women in Ravensmead, Cape Town. S Afr Med J 1990; 21: 408-11.
25. Edginton ME, Sekatane CS, Goldstein SJ. Patients' beliefs: do they affect tuberculosis control? A study in a rural district of South Africa. Int J Tuberc Lung Dis 2002; 6: 1075-82.
26. Croft RP, Croft RA. Knowledge, attitude and practice regarding leprosy and tuberculosis in Bangladesh. Lepr Rev1990; 70: 34-42.