

Social stigma associated with TB and HIV/AIDS among Kudumbashree members: A cross-sectional study

Leyanna Susan George¹, Rakesh P S¹, Vijayakumar K¹, Akhilesh Kunoor², Anil Kumar³

¹Department of Community Medicine, ²Pulmonary and ³Microbiology, Amrita Institute of Medical Sciences, Amrita Vishwa Vidyapeetham, Kochi, Kerala, India

ABSTRACT

Introduction: TB and HIV/AIDS are the two major public health problems. Stigma and discrimination has an enormous impact on the sufferers. The impact is felt at home, in workplace, and at the institutions. The objective of the current study was to measure the stigma and discrimination associated with TB and HIV/AIDS and to determine the underlying factors related to it among women self-help group members in Kochi city Kerala. **Methods:** A cross-sectional study was carried out among the women self-help group members in Kochi city. A total of 135 participants were included in the study. The study tool was a pretested self-administered questionnaire which captured information regarding the sociodemographic profile and stigma towards TB and HIV/AIDS. **Result:** All the respondents were women with mean age group 47.1(SD- 10.7). Majority (60%) belonged to APL category and were Hindus (52.1%). All the members have heard about HIV/AIDS and TB. The respondents reported that they would not send their children for playing with infected people (TB-49.3%; HIV-37.1%), would stay away from infected people (TB-84.3%; HIV-67.1%), and had discomfort while approaching those are infected (TB-62.1%; HIV-59.3%). Stigma toward TB and HIV was found not to have any association with any of the socio demographic factors. Correlation was observed between stigma scores of TB and HIV/AIDS ($r = 0.853$; $P = <0.001$). **Conclusion:** Stigma toward TB and HIV still exists as a major issue even among women self-help group members in Kochi. It was observed that those who had stigma toward TB also had stigma toward HIV/AIDS. Therefore is need to create holistic awareness about these diseases among women self-help groups.

Keywords: HIV/AIDS, Kudumbashree, stigma, TB

Introduction

Tuberculosis and HIV are two infectious diseases that cause a major burden to developing countries. Caring for patients suffering from both diseases are a major public health challenge.^[1] India accounts for one-fifth of the TB cases in the world with 1.8 million new cases occurring annually in India.^[2] While 2.1 million people are living with

HIV/AIDS making India the third largest country to be affected with HIV/AIDS epidemic.^[3] Individuals with HIV and/or tuberculosis often fall prey to various forms of stigma and this affects their quality of life.^[4] It has been over 50 years since the influential work on stigma by Goffman has been published. More recently, Weiss and Ramakrishna (2006) defined health-related stigma as “a social process or related personal experience characterized by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person or group identified with a particular health problem.”^[5]

Stigma plays a huge role as a barrier in the prevention and control of HIV/AIDS and TB. As it can prevent people from utilizing the

Address for correspondence: Dr. Leyanna Susan George, Department of Community Medicine and Public Health, Amrita Institute of Medical Sciences, Ponekkara, Kochi - 682 041, Kerala, India. E-mail: leyanna.george@gmail.com

Received: 21-03-2020

Revised: 25-04-2020

Accepted: 25-06-2020

Published: 25-08-2020

Access this article online

Quick Response Code:



Website:
www.jfmipc.com

DOI:
10.4103/jfmipc.jfmipc_437_20

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: WKHLRPMedknow_reprints@wolterskluwer.com

How to cite this article: George LS, Rakesh PS, Vijayakumar K, Kunoor A, Kumar A. Social stigma associated with TB and HIV/AIDS among Kudumbashree members: A cross-sectional study. J Family Med Prim Care 2020;9:4062-6.

healthcare services for getting tested for HIV and TB, adhering to treatment and its prevention and control. Both the conditions are highly stigmatized with considerable discrimination toward the sufferers.¹⁶ The government aims to mitigate stigma and discrimination toward these diseases in the community using the help of Kudumbashree members.¹⁷ Kudumbashree is a unique initiative of Government of Kerala for empowering women by creating local women self-help groups who run micro enterprises.¹⁸ These community volunteers have been used by the health system in the past for creating health awareness in their respective communities. It was been planned to utilize the services of these Kudumbashree members in the future to spread awareness regarding TB and HIV/AIDS and also for conducting vulnerability mapping.¹⁹ Therefore, it is crucial to understand the level of stigma the Kudumbashree members have towards TB and HIV/AIDS patients before recruiting them as health awareness ambassadors.

Therefore, our study aimed to assess the whether the Kudumbashree members of the Ernakulam district had social stigma towards TB and HIV/AIDS and to find the sociodemographic factors associated with stigma.

Methodology

The cross-sectional study was carried out after obtaining institutional ethical committee clearance. All Kudumbashree members of Ernakulam district were invited for a meeting conducted at the town hall. A total of 250 members were present for the meeting. The purpose of the study was explained to them and informed consent was obtained from the study participants. Ethical committee clearance was obtained from the institutional ethical committee clearance on 21st May 2019.

The sample size was calculated using the formula $4pq/d^2$, where the prevalence (p) was taken to 45% as per a study done by Duko *et al.*¹⁰ $q = 55\%$ (100-p) and the absolute error $d = 20\%$. The minimum sample size calculated was 123. A self-administered Malayalam questionnaire was distributed to a total 250 Kudumbashree members. However, excluding the grossly under filled questionnaire a total of 140 participants were included in the study.

The questionnaire was in Malayalam and it had two parts consisting of questions regarding sociodemographic profile and about stigma regarding TB and HIV/AIDS. Sociodemographic details such as age, religion, education, and socioeconomic status were collected. The stigma toward HIV/AIDS and TB was captured using a questionnaire adapted from Annelis van rie *et al.*¹¹ The results were tabulated by giving all the correct answers a score of 1 and the incorrect answers a score of 0. Data was analyzed using SPSS version 21, Chi-square test was used to compare stigma toward HIV/AIDS and TB.

Results

All the respondents were females and the mean age was 47.1 (SD: 10.7) with majority (77.9%) of them being in the age group

of 31–59 years. Only 37.1% of the Kudumbashree members were found to have an education of more than high school. Most (60%) of them belonged to APL category and were Hindus by (52.1%) religion. The details of sociodemographic profile is given in Table 1.

It was observed that the stigma associated with HIV/AIDS and TB differed in most aspects. Most of them (84.9%) would keep a secret about a TB infected family member more than an HIV/AIDS infected member (68.6%). At the same time, they were more willing to take care of an HIV/AIDS patient (59.3%) at home rather than a TB patient (22.9%).

34.3% of the members were willing to buy things from a known TB infected shopkeeper, while only 28.6% was willing to buy from a known HIV infected shopkeeper. It was observed that of the respondents 37.1% were willing to allow a HIV infected child to attend school while 49.3% were willing to allow a TB infected child. Similarly, 37.9% of the respondents were willing to have a HIV infected teacher to continue teaching while only 30.1% consented to have a teacher who was infected by TB.

It was also observed that stigma was more toward TB rather than HIV/AIDS. Most of them were more afraid (80.7%) of a TB patient rather than HIV/AIDS patient. They felt the need to avoid a TB patient (80.7%) in the community more than an AIDS patient (66.4%). This was probably because 84.3% felt more disgusted while seeing a TB infected person than an AIDS patient (70.7%). Hence, most (84.3%) stated that they would stay away from a TB patient rather than from an AIDS patient (67.1%) and 80% felt that a TB patient was unclean. The details are provided in Table 2.

It was observed that none of the sociodemographic factors were associated with stigma regarding TB and HIV/AIDS [Tables 3 and 4]. However, it was observed that study participants who had stigma toward TB were also found to have stigma towards HIV/AIDS ($r = 0.853$). [Table 5].

Table 1: Distribution of kudumbashree members based on their socio-demographic profile

| Sociodemographic Profile | Numbers | Percentage |
|--------------------------|---------|------------|
| AGE | | |
| <30 YEARS | 7 | 5.0 |
| 31-59 YEARS | 109 | 77.9 |
| MORE THAN 60 YEARS | 24 | 17.1 |
| RELIGION | | |
| Hindu | 73 | 52.1 |
| Christian | 55 | 39.3 |
| Muslim | 10 | 7.1 |
| Others | 2 | 1.4 |
| EDUCATION | | |
| HIGH SCHOOL AND LESS | 88 | 62.9 |
| MORE THAN HIGH SCHOOL | 52 | 37.1 |
| SOCIO ECONOMIC STATUS | | |
| APL | 84 | 60.0 |
| BPL | 56 | 40.0 |

Table 2: Distribution of kudumbashree members based on their stigma towards tb and hiv/aids patients

| Stigma towards TB and HIV/AIDS | TB No. (%) | HIV/AIDS No. (%) |
|----------------------------------------------------------------------------------------------------|------------|------------------|
| | Yes | Yes |
| 1. Willing to buy something from a shopkeeper who is infected with | 48 (34.3) | 40 (28.6) |
| 2. If a family member is infected will you keep it secret | 123 (84.9) | 96 (68.6) |
| 3. If a family member get infected will you take care in your home itself | 32 (22.9) | 83 (59.3) |
| 4. Will you allow an infected teacher to continue teaching | 53 (37.9) | 42 (30.0) |
| 5. An infected person should be treated in the same hospital with uninfected people | 53 (37.9) | 35 (25.0) |
| 6. An infected person should be allowed to work in the same workplace along with uninfected people | 43 (30.7) | 30 (21.4) |
| 7. An infected person should be allowed to have food along with uninfected people | 51 (36.4) | 40 (28.6) |
| 8. Do you feel any discomfort while approaching who is infected with | 87 (62.1) | 83 (59.3) |
| 9. An infected should be avoided from the community | 114 (81.4) | 95 (67.9) |
| 10. Will you hesitate to communicate who is infected with | 35 (25.0) | 36 (25.7) |
| 11. Will you hesitate to touch who is infected with | 48 (34.3) | 47 (33.6) |
| 12. Are you afraid of who is infected with | 113 (80.7) | 93 (66.4) |
| 13. An infected child allowed to attend school with other uninfected children | 69 (49.3) | 52 (37.1) |
| 14. Knew a person who is infected with | 95 (67.9) | 93 (66.4) |
| 15. Do you feel disgusting while seeing who is infected with | 118 (84.3) | 99 (70.7) |
| 16. Do you stay away from who is infected with | 118 (84.3) | 94 (67.1) |
| 17. An infected person is not clean | 112 (80.0) | 90 (64.3) |
| 18. An infected person gets all his/her needs done | 104 (74.3) | 91 (65.0) |

Table 3: Socio demographic variables associated with stigma regarding tuberculosis

| Characters | Category | Low Stigma (%) | High Stigma (%) | Chi-Square | p |
|------------|-----------------------|----------------|-----------------|------------|-------|
| AGE | <30 YRS | 50.0 | 50.0 | 2.754 | 0.252 |
| | 31-59 | 43.8 | 56.2 | | |
| | >60 YRS | 62.5 | 37.5 | | |
| RELIGION | HINDU | 47.9 | 52.1 | 2.463 | 0.482 |
| | CHRISTIAN | 44.2 | 55.8 | | |
| | MUSILM | 50.0 | 50.0 | | |
| EDUCATION | HIGH SCHOOL AND LESS | 47.7 | 52.3 | 0.007 | 0.934 |
| | MORE THAN HIGH SCHOOL | 46.9 | 53.1 | | |
| | SOCIO ECONOMIC STATUS | APL | 43.9 | | |
| | BPL | 52.8 | 47.2 | | |

Table 4: Socio demographic variables associated with stigma regarding hiv/aids

| Characters | Category | Low Stigma (%) | High Stigma (%) | Chi-Square | p |
|------------|-----------------------|----------------|-----------------|------------|-------|
| AGE | <30 YRS | 5 (71.4) | 2 (28.6) | 3.084 | 0.214 |
| | 31-59 | 41 (48.2) | 44 (51.8) | | |
| | >60 YRS | 9 (69.2) | 4 (30.8) | | |
| RELIGION | HINDU | 32 (59.3) | 22 (40.7) | 2.125 | 0.346 |
| | CHRISTIAN | 20 (45.5) | 24 (54.7) | | |
| | MUSILM | 3 (42.9) | 4 (57.1) | | |
| EDUCATION | HIGH SCHOOL AND LESS | 32 (50.8) | 31 (49.2) | 0.159 | 0.690 |
| | MORE THAN HIGH SCHOOL | 23 (54.8) | 19 (45.2) | | |
| | SOCIO ECONOMIC STATUS | APL | 32 (52.5) | | |
| | BPL | 23 (52.3) | 21 (47.7) | | |

Discussion

The aim of our study was to assess whether the Kudumbashree members of the Ernakulam district had social stigma toward TB and HIV/AIDS patients. This information was required since,

the local self-government along with the health system aimed to utilize the services of these women self-help group members for mitigating to stigma regarding TB and HIV/AIDS among the community members.^[12] This activity was planned as a part of community mobilization toward TB elimination. A study done

Table 5: Association Between The Stigma Scores Of Tb And Hiv/Aids

| TB | HIV/AIDS | | P | Chi-Square |
|-------------|------------|-------------|-------|------------|
| | Low Stigma | High Stigma | | |
| Low Stigma | 47 (90.4%) | 5 (9.6%) | 0.000 | 60.782 |
| High Stigma | 6 (12.5%) | 42 (87.5%) | | |

by Thomas B, *et al.* has highlighted that sensitizing SHGs through model TB sensitization program has aided in strengthening the TB prevention and control activities in communities.^[13]

The study was able to highlight the fact that those who had stigma toward TB also had stigma toward HIV. Studies have stated in the past that even though TB and HIV are different bio medically, the origin of stigma and its impact were found to be the same. Factors resulting in stigma against TB and HIV are because both these diseases result in severe morbidities, it can be easily transmissible to others, and also because the general population perceive that these diseases are usually found among people who are different and have a deviant behavior.^[13,14]

Stigma resulting from TB and/or HIV has found to occur in various contexts such as in the society, family, place of work, healthcare system, etc.^[15] Both these diseases have made the patient get isolated from their friends and family members. It has resulted in many of them losing their jobs, getting excluded from their societies and families.^[16-20] The fear of stigma has had a negative impact on the health status of the people since it prevents people from accessing or adhering to the healthcare services.^[15]

Scaling up of advocacy, communication and social mobilization (ACSM) in the community has been identified to be a crucial step for achieving the ultimate goal of TB elimination and also for reversing the trend of HIV/AIDS.^[21] To conclude, this study was able to identify Khudumashree members as the ideal ambassadors for ACSM against TB and HIV in their local communities. Therefore the primary care physicians can utilize the services of these women self-help groups for widening their reach of health promotion and preventive activities in the communities.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

References

- Bruchfeld J, Correia-Neves M, Källenius G. Tuberculosis and HIV coinfection. *Cold Spring Harb Perspect Med* 2015;5:a017871.
- Steinbrook R. Tuberculosis and HIV in India. *N Engl J Med* 2007;356:1198-9.
- Tanwar S, Rewari B, Rao CD, Seguy N. India's HIV programme: Successes and challenges. *J Virus Erad* 2016;2(Suppl 4):15-9.
- Jittimane S, Nateniyom S, Kittikraisak W, Burapat C, Akksilp S, Chumpathat N, *et al.* Social stigma and knowledge of tuberculosis and HIV among patients with both diseases in Thailand. *PLoS One* 2009;4:e6360.
- Ostrach B, Ginzburg SL, Singer M. *Stigma Syndemics: New Directions in Biosocial Health*. Lexington Books; New York City; 2017. p. 243.
- George1 LS, Lalu2 JS, Paul3 N, Leelamoni4 K. KEYWORDS: HIV/AIDS, Tuberculosis, Awareness, Social Stigma, Students. *Aware Soc STIGMA Assoc HIV/AIDS Tuberc Stud Comp STUDY* [Internet]. 2015 Nov 26 [cited 2020 Jul 12];(93732). Available from: <https://jebmh.com/abstract/93732>.
- TB-COMBI Guide 2.pdf [Internet]. [cited 2020 Jul 12]. Available from: <http://www.stoptb.org/assets/documents/countries/acsm/TB-COMBI%20Guide%202.pdf>.
- Kudumbashree | Overview [Internet]. [cited 2020 Mar 21]. Available from: <http://www.kudumbashree.org/pages/7>.
- Kudumbashree | New Initiatives old [Internet]. [cited 2020 Mar 21]. Available from: <http://www.kudumbashree.org/pages/125>.
- Duko B, Bedaso A, Ayano G, Yohannis Z. Perceived stigma and associated factors among patient with tuberculosis, Wolaita Sodo, Ethiopia: Cross-sectional study. *Tuberc Res Treat* 2019;2019:5917537.
- Rie AV, Sengupta S, Pungrassami P, Balhup Q, Choonuan S, Kasetjaroen Y, *et al.* Measuring stigma associated with tuberculosis and HIV/AIDS in Southern Thailand: Exploratory and confirmatory factor analyses of two new scales. *Trop Med Int Health* 2008;13:21-30.
- 08_chapter3.pdf [Internet]. [cited 2020 Apr 26]. Available from: https://shodhganga.inflibnet.ac.in/bitstream/10603/97550/8/08_chapter3.pdf.
- Thomas B, Priscilla Rebecca B, Dhanalakshmi A, Rani S, Deepa Lakshmi A, Watson B, *et al.* Effectiveness of TB sensitization initiatives in improving the involvement of self help group members in rural TB control in south India. *Trans R Soc Trop Med Hyg* 2016;110:714-20.
- George LS. HIV related stigma and discrimination among people living with HIV/AIDS in Ernakulam District: A qualitative study. *Indian J Community Med* 2019;44:34.
- George LS. HIV related stigma and discrimination among people living with HIV/AIDS in Ernakulam District: A qualitative study. *Indian J Community Med* 2019;44(Suppl S1):34-7.
- Khan A, Walley J, Newell J, Imdad N. Tuberculosis in Pakistan: Socio-cultural constraints and opportunities in treatment. *Soc Sci Med* 2000;50:247-54.
- 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.
18. Long NH, Johansson E, Diwan VK, Winkvist A. Fear and social isolation as consequences of tuberculosis in Vietnam: A gender analysis. Health Policy 2001;58:69-81.
 19. Macq J, Solis A, Martinez G. Assessing the stigma of tuberculosis. Psychol Health Med 2006;11:346-52.
 20. Daftary A, Padayatchi N, Padilla M. HIV testing and disclosure: A qualitative analysis of TB patients in South Africa. AIDS Care 2007;19:572-7.
 21. Conceptualizing Community Mobilization for HIV Prevention: Implications for HIV Prevention Programming in the African Context.