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Tuberculosis contact tracing: confidentiality, stigma, and collective protection

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Abstract

Tuberculosis remains a major public health challenge, particularly among vulnerable populations. Contact tracing and preventive treatment are essential to interrupt transmission, yet they also raise ethical dilemmas regarding confidentiality and stigma. This study reviewed and discussed these from a bioethical perspective. A narrative literature review was conducted in PubMed, SciELO, LILACS, and Google Scholar, including publications from 2015 to 2024 that examined ethical aspects of tuberculosis contact tracing. Nine studies met the inclusion criteria and indicated that, despite its relevance for disease control, contact tracing may expose individuals and reinforce stigmatization. Fear of discrimination contributed to withholding information and poor adherence to preventive treatment. Mitigation strategies include health education, empathetic communication, informed consent, privacy protection, and ethical training for health professionals. Ethical tuberculosis control requires balancing collective protection with respect for autonomy and human dignity.

Keywords: Latent tuberculosis. Contact tracing. Ethics, clinical. Confidentiality. Social stigma.

Resumo

Rastreamento de contatos da tuberculose: confidencialidade, estigma e proteção coletiva

A tuberculose continua sendo um grande desafio de saúde pública, particularmente entre populações vulneráveis. O rastreamento de contatos e o tratamento preventivo são essenciais para interromper a transmissão, mas também levantam dilemas éticos relacionados à confidencialidade e ao estigma. Este estudo revisou e discutiu essas questões sob a ótica dos princípios bioéticos. Uma revisão narrativa da literatura foi conduzida nas bases PubMed, SciELO, LILACS e Google Scholar, incluindo publicações de 2015 a 2024 que examinaram aspectos éticos do rastreamento de contatos da tuberculose. Nove estudos atenderam aos critérios de inclusão e indicaram que, apesar de sua relevância para o controle da doença, o rastreamento de contatos pode expor indivíduos e reforçar a estigmatização. O medo de discriminação contribuiu para a omissão de informações e baixa adesão ao tratamento preventivo. As estratégias de mitigação incluem educação em saúde, comunicação empática, consentimento informado, proteção da privacidade e formação ética dos profissionais de saúde. O controle ético da tuberculose requer equilibrar a proteção coletiva com o respeito à autonomia e à dignidade humana.

Palavras-chave: Infecção por M. tuberculosis. Busca de comunicante. Ética clínica. Confidencialidade. Estigma social.

Resumen

Rastreo de contactos de la tuberculosis: confidencialidad, estigma y protección colectiva

La tuberculosis es un gran desafío de salud pública, particularmente entre las poblaciones vulnerables. La búsqueda de contactos y el tratamiento preventivo son esenciales para interrumpir la transmisión y plantean dilemas éticos relacionados con la confidencialidad y el estigma. Este estudio revisó y discutió estos temas a partir de los principios bioéticos. Se realizó una revisión narrativa de la literatura en PubMed, SciELO, LILACS y Google Scholar, incluyendo publicaciones de 2015 a 2024 sobre aspectos éticos de la búsqueda de contactos de tuberculosis. Nueve estudios cumplieron los criterios de inclusión e indicaron que, aunque es relevante para controlar la enfermedad, la búsqueda de contactos puede exponer a las personas y reforzar la estigmatización. El miedo a la discriminación contribuyó a retener información y a una baja adherencia al tratamiento preventivo. Las estrategias de mitigación incluyen educación en salud, comunicación empática, consentimiento informado, protección de la privacidad y formación ética del personal sanitario. El control ético de la tuberculosis requiere equilibrar la protección colectiva con el respeto a la autonomía y a la dignidad humana.

Palabras clave: Infección por M. tuberculosis. Trazado de contacto. Ética clínica. Confidencialidad. Estigma social.

The authors declare no conflict of interest.

Research

Tuberculosis (TB) remains one of the major public health challenges worldwide, imposing a substantial burden of morbidity and mortality, particularly in contexts of socioeconomic vulnerability. In 2023, an estimated 10.8 million individuals were diagnosed with tuberculosis globally, and the disease once again became the leading cause of death from a single infectious agent, surpassing COVID-19. In the same year, approximately 1.25 million individuals died from tuberculosis, highlighting the magnitude of the problem and the need for effective prevention and control strategies [1].

The World Health Organization (WHO) highlights contact tracing as a key intervention, as it enables both early detection of active cases and identification of individuals infected with *Mycobacterium tuberculosis*. In such cases, preventive treatment can reduce the risk of progression to active disease and, consequently, help interrupt the chain of transmission [1-4].

Although contact tracing is essential for TB control, it can raise ethical concerns, particularly regarding the protection of confidentiality during the active identification of contacts. This risk may contribute to stigmatization, as the disease has historically been associated with social and economic vulnerability, HIV coinfection, and incarceration [5-7].

Stigma associated with tuberculosis has been linked to delayed diagnosis and treatment initiation, social isolation, and emotional distress, ultimately compromising treatment adherence and quality of life, while also creating barriers to contact tracing [5-7]. From this perspective, ending tuberculosis will not be achieved with biomedical advances alone; it also requires addressing stigma and human rights violations as integral components of health policies, thereby ensuring dignity, equity, and social participation for affected individuals [8].

In this context, although contact tracing contributes to collective protection, it may also pose risks to individuals, particularly regarding confidentiality and stigma. This situation highlights a bioethical conflict involving the principles of beneficence, non-maleficence, autonomy, and justice. Thus, this study aimed to review, synthesize, and discuss bioethical dilemmas related to the risk of breaches of confidentiality and stigmatization in tuberculosis contact tracing, as well as to identify recommendations for stigma mitigation strategies.

Method

This narrative review aimed to review, synthesize, and discuss bioethical dilemmas related to the risk of breaches of confidentiality and stigmatization in tuberculosis contact tracing. The guiding question was: How can tuberculosis contact tracing compromise the confidentiality of index cases and contribute to stigmatization from a bioethical perspective?

The literature search was conducted in October 2025 on PubMed (via MEDLINE), SciELO, and LILACS (via VHL Regional), and complemented by Google Scholar to identify gray literature and relevant institutional documents. The search strategy was developed based on the main concepts of the research question. Controlled vocabularies from MeSH (Medical Subject Headings) and DeCS (Health Sciences Descriptors) were selected in Portuguese, English, and Spanish. The search strategies were structured using the Boolean operators AND and OR (Appendix I) [9].

Original articles, narrative and systematic reviews, and official documents published by national and international health institutions, such as the World Health Organization and the Brazilian Ministry of Health, were included, provided that they addressed ethical, bioethical, or confidentiality-related aspects of tuberculosis contact tracing. Publications from the previous 10 years were prioritized, using the WHO's 2015 Global Tuberculosis Report as a temporal reference. This report marked the transition from the Stop TB Strategy to the End TB Strategy and established global targets for reducing TB incidence and mortality by 2035. No language restrictions were applied.

Duplicates, works not available in full text, and publications that did not directly address ethical aspects of tuberculosis contact tracing were excluded. Editorials, letters, and publications unrelated to tuberculosis contact tracing or that did not address bioethical issues were also excluded.

The initial screening was based on titles and abstracts. Potentially eligible articles were then read in full, and those meeting the inclusion

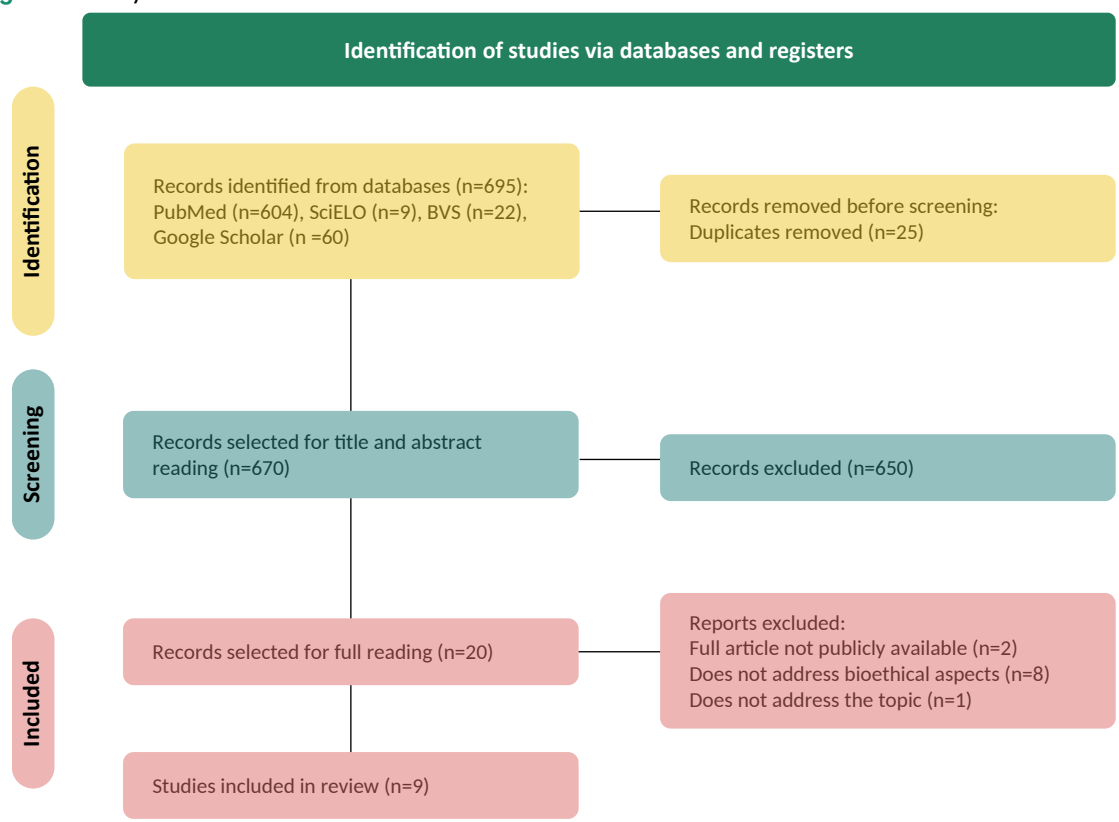
criteria comprised the final analytical sample. The content of the selected documents was qualitatively and interpretively analyzed using thematic analysis, focusing on thematic axes related to the principles of bioethics: autonomy, beneficence, non-maleficence, and social justice, with an emphasis on ethical dilemmas concerning confidentiality and stigma in public health.

In addition to the narrative synthesis, a word cloud was generated as a complementary visual resource to represent the most common terms in the discussion of the included articles. The image was generated using the online tool WordClouds, considering the absolute frequency of each word after removing prepositions and other terms considered to have no analytical significance.

Results

A total of 695 records were identified across PubMed, SciELO, LILACS, and Google Scholar. After removing 25 duplicates, 670 records remained for title and abstract screening. Of these, 650 publications were excluded because they did not address ethical aspects or focused on diseases other than tuberculosis. Twenty full-text articles were assessed for eligibility, of which nine met the inclusion criteria and were included in the final review (Figure 1).

Figure 1. Study selection flowchart



The publications, dated between 2015 and 2024, covered diverse epidemiological, social, and cultural contexts, including high-tuberculosis-burden countries and low-incidence settings [10-18]. Chart 1 summarizes the main characteristics of the included studies.

Chart 1. Characteristics of the studies included in this narrative review

Author; year	Title	Country	Study type	Ethical issue	Main conclusion
Rebeiro and collaborators; 2020 [10]	Knowledge and stigma of latent tuberculosis infection in Brazil: implications for tuberculosis prevention strategies	Brazil	Survey	Stigma	Knowledge linked to stigma
Basu and collaborators; 2020 [11]	Ethical issues in expanding latent TB management in high burden countries	High-burden TB countries	Commentary	Autonomy, justice, resource allocation	Balance principles
Nagarajan; 2023 [12]	Tuberculosis disease disclosure patterns and associated factors: findings from a prospective observational study	India	Observational	Disclosure, stigma, social impact	Fear of stigma influences disclosure and social support
Szkwarko and collaborators; 2017 [13]	Child contact management in high tuberculosis burden countries: a mixed-methods systematic review	High-burden TB countries	Systematic review	Barriers, stigma, access, health system	Gaps in care cascade
Holzschuh and collaborators; 2017 [14]	Use of video directly observed therapy for treatment of latent tuberculosis infection — Johnson County, Kansas, 2015	USA	Case report	Confidentiality	Privacy is required in digital care
Faccini and collaborators; 2015 [15]	Tuberculosis-related stigma leading to an incomplete contact investigation in a low-incidence country	Italy	Case report	Confidentiality, stigma	Stigma affected tracing
Spruijt and collaborators; 2020 [16]	Knowledge, attitudes, beliefs, and stigma related to latent tuberculosis infection: a qualitative study among Eritreans in the Netherlands	Netherlands	Qualitative	Stigma	Fear of LTBI associated with stigma
Denholm and collaborators; 2020 [17]	Latent tuberculosis infection and the End TB Strategy: ethical tensions and imperatives	Multinational	Review	Autonomy, justice	Need balance individual versus collective
Oo and Borry; 2024 [18]	Contact investigation in multidrug-resistant tuberculosis: ethical challenges	Belgium	Conceptual	Confidentiality, public interest	Conflict individual versus collective

The studies employed various designs, including qualitative and observational studies, systematic reviews, and theoretical bioethical analyses, reflecting an ethical debate around confidentiality, stigma, autonomy, and social justice in contact tracing and the diagnosis and treatment of tuberculosis infection.

Studies explored the perceptions and attitudes of individuals with tuberculosis, their contacts, and that of health professionals toward evaluation and preventive treatment [10,12,16]. Systematic reviews, case reports, and experience reports revealed structural and cultural barriers to adherence and gaps in the care cascade [13,14]. Theoretical reflections discussed individual rights and collective responsibilities in public health strategies [11,17,18].

Figure 2 shows the most frequent words in the articles included in the review, highlighting *Tuberculosis*, with 15 occurrences, followed by *stigma*, with 12, and *public health*, with 10.

A growing interest in the ethical dimensions of tuberculosis infection and contact tracing was observed, coinciding with WHO's End TB Strategy implementation [1]. The reviewed publications (2020–2024) highlight advances in patient-centered approaches, stigma reduction, and confidentiality protection, signaling a shift toward an integrated, ethical, and human rights-based approach [10-11,15-17].

Differences were also evident between high- and low-burden settings. In the former, ethical challenges were mainly associated with health system limitations and patients' socioeconomic vulnerability [10-12], raising concerns about justice and equity in access to care. In the latter, issues such as stigma, fear of disclosure, confidentiality breaches, and loss of trust in health services were predominant [13-16].

Figure 2. Word cloud of the most frequent terms in the reviewed articles



Across all studies, there was consensus that tuberculosis contact tracing is essential for disease control but may involve significant ethical risks, particularly regarding breaches of confidentiality and stigmatization of individuals diagnosed with TB [10,12,18].

Confidentiality emerged as one of the most vulnerable ethical values. A study conducted in Italy reported that fear of disclosure led a worker to conceal her professional contacts, resulting in an incomplete investigation and continued transmission [15]. A similar situation was observed in India, where disclosure patterns were strongly influenced by fear of discrimination [12].

Stigma also emerged as a major ethical dilemma. Qualitative studies and systematic reviews revealed that stigma associated with tuberculosis and infection influences both contact tracing and adherence to preventive treatment, hindering effective control measures. Fear of disclosure led some families to avoid health services and, in some cases, to discontinue follow-up of child contacts [13]. Among Eritrean immigrants, cultural beliefs, misinformation, and fear of rejection fueled stigma and reinforced avoidance of and mistrust toward health professionals [16]. Beyond its social implications, stigma represents an ethical challenge in public health, as it undermines trust, compromises adherence, and conflicts with fundamental principles of dignity, justice, and non-maleficence [19,20].

The studies propose multiple strategies to mitigate these challenges. Health education and empathetic communication are considered essential to reduce fear and misinformation. Culturally sensitive interventions and community participation can promote better adherence and reduce stigma [10,16].

Additionally, ethical counseling and informed consent are identified as key practices to strengthen autonomy and prevent social harm [11,17]. At the institutional level, ensuring privacy and ethical training for healthcare teams are crucial [17]. Finally, from a public policy perspective, the authors emphasize the importance of strategies guided by the principles of justice, equity, and reciprocity [17,18].

Discussion

This literature review reveals that ethical dilemmas surrounding tuberculosis contact tracing are mainly related to stigma, confidentiality, tensions between individual autonomy and collective protection, and barriers affecting the care cascade.

From a bioethical perspective, the four principles of autonomy, beneficence, non-maleficence, and justice intersect in tuberculosis contact tracing, highlighting tensions between collective protection and respect for individual rights, especially when public health measures require information sharing or actions without an individual's full consent [19]. The principle of autonomy may be compromised when individuals feel pressured to undergo testing or preventive treatment or to disclose their diagnosis without consent [7,8]. Beneficence and non-maleficence may come into conflict when efforts to protect the collective result in moral or social harm, such as fear, shame, or discrimination [8]. The principle of justice is also affected when vulnerable populations face greater exposure and reduced protection, raising ethical concerns about equity and fairness in public health measures [19].

Beyond principlism, these dilemmas can also be interpreted within the framework of public health bioethics, which offers a broader approach to analyze ethical issues in interventions aimed at protecting public health. From this perspective, ethical evaluation encompasses not only respect for individual autonomy, but also proportionality of public health measures, minimization of harm, social justice, protection of vulnerable populations, and ethical legitimacy of state actions.

These principles are consistent with the Universal Declaration on Bioethics and Human Rights, which establishes that health interventions must respect human dignity, confidentiality, and non-discrimination and protect vulnerable individuals, while also recognizing the social responsibility of governments to promote health and equity [20].

Interventions that may limit privacy or individual freedom must be justified by a clear public health objective, based on scientific evidence, implemented using the least restrictive means, and conducted in a fair and non-discriminatory manner. These considerations are particularly relevant to tuberculosis contact tracing, in which measures intended to prevent transmission may generate stigma, discomfort, or fear, especially in socially vulnerable contexts [19,21].

Ethical and educational measures are necessary to reconcile respect for individual privacy with the public health need to ensure collective protection, since contact tracing often requires balancing the right to confidentiality with the duty to prevent transmission to others.

Although contact tracing is justified by the principle of beneficence, its implementation must respect autonomy, informed consent, and limits on disclosure [10-14]. Reducing stigma depends on continuous educational actions that promote empathy, community participation, and clear communication about differences between infection and active disease. Accessible communication campaigns using appropriate language can help reduce fear and isolation while strengthening the relationship between patients and health services [10,13,16].

Beyond the individual and community levels, institutional support and public policies guided

by justice and equity are essential, particularly because individuals may face personal and social challenges when contributing to public health efforts. Ethical protection in contact tracing requires safe environments and psychosocial support to ensure the dignity and respect of all those involved [11,17,18].

Individuals who engage with public health surveillance in the interest of collective welfare should be provided with psychosocial support, protection of their dignity, and equitable access to care, as recommended by international bioethical frameworks that emphasize social responsibility and the protection of vulnerable populations [20,22,23]. From this perspective, ethical contact tracing is not merely a moral requirement but also a practical condition for the success of public health policies.

Thus, applying bioethical reflection to contact tracing deepens the understanding of tuberculosis control, reaffirming that disease elimination depends not only on the effectiveness of interventions but also on respect, dignity, and the protection of those involved, especially in situations where the interests of the individual and the collective may conflict.

The findings of this review demonstrate that contact tracing, diagnosis, and treatment of tuberculosis infection, although essential for disease elimination, must be conducted in an ethically sustainable manner that reconciles collective protection with individual autonomy and dignity. As highlighted in the literature, overcoming stigma is essential to achieving these goals and depends on preparing health professionals to recognize and avoid discriminatory attitudes, thereby strengthening patient trust and support. Incorporating topics such as empathetic communication and confidentiality into professional training and daily practice can contribute to more ethical and humanized care [5,8,16].

This review has limitations inherent to its narrative design. Although a broad search was conducted across multiple databases, the comprehensiveness of the literature cannot be guaranteed, as relevant studies may not have been identified due to limitations in the search descriptors or a lack of indexing in electronic databases. Another limitation is the heterogeneity of the included studies, which varied in methodology, context, and scope, making direct comparisons difficult.

Despite these limitations, this review provides an integrated and updated synthesis of the main bioethical dilemmas related to confidentiality and stigma in contact tracing, diagnosis, and treatment of tuberculosis infection, contributing to ethical reflection and the development of more humane practices within tuberculosis control programs.

Future studies should further examine the ethical dilemmas experienced by health professionals, patients, and managers in contact-tracing actions, exploring how principles such as autonomy, justice, and confidentiality are applied in practice. Qualitative and comparative studies conducted in high- and low-burden settings may help identify effective strategies for mitigating stigma and building trust within health services. Additionally, integrating ethical evaluations into public health policies is recommended to promote more humanized practices in tuberculosis control.

Final considerations

Contact tracing and the diagnosis and treatment of tuberculosis infection are fundamental strategies for disease control but involve ethical challenges that require careful consideration. This review showed that confidentiality and stigma remain major dilemmas, particularly in socially vulnerable contexts, where the duty to protect the collective may conflict with individual rights. Incorporating the bioethical principles of autonomy, beneficence, non-maleficence, and justice into care and surveillance practices is essential to balance epidemiological effectiveness with respect for human dignity. Achieving tuberculosis elimination goals therefore depends not only on biomedical advances but also on an ethical, people-centered approach.

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Dinah Carvalho Cordeiro: conceptualization; data curation; formal analysis; methodology; project administration; writing – original draft; writing – review & editing.
Tamiris Moraes Siqueira: conceptualization; data curation; formal analysis; methodology; writing – review & editing.
Jonas Byk: conceptualization; methodology; validation; supervision; writing – review & editing.
Anete Trajman: conceptualization; methodology; validation; supervision; writing – review & editing.

Data availability: All data used or generated in this study are described and presented in full in the body of the article.

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Research

Appendix I

Search equation in the consulted databases

Search equation:
"Tuberculose Latente" OR "Infecção Tuberculosa Latente" OR
"Tuberculosis Latente" OR "infección tuberculosa latente" OR
"Latent Tuberculosis" OR "Latent Tuberculosis Infections"
AND
"Busca de Comunicante" OR "Investigação de Contato" OR "Avaliação de Contato" OR
"Trazado de Contacto" OR "rastreo de contactos" OR "investigación de contactos" OR
"Contact Tracing" OR "Infectious Disease Contact Tracing"
AND
"Ética Clínica" OR "Ética" OR
"Ética Clínica" OR "Ética" OR
"Ethics" OR "Ethical Issues"
AND
"Confidencialidade" OR "Informação Confidencial" OR "Privacidade dos Dados do Paciente" OR "Sigilo" OR
"confidencialidad" OR "privacidad de los datos del paciente" OR
"Confidentiality" OR "Privacy of Patient Data"
AND
"Estigma Social" OR "Estigmas Sociais" OR
"Estigma Social" OR "Estigmas Sociales" OR
"Social Stigma" OR "Social Stigmas"