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WHO ethics guidance on TB care and migration: challenges to the implementation process

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SUMMARY

We summarise the current ethical guidance on tuberculosis (TB) care and migration, as set out in the WHO *"Ethics Guidance for the Implementation of the End TB Strategy."* Among other aspects, the Ethics Guidance states that there should be firm legal principles in place that ensure the enforcement of migration law on the one hand and the protection of human rights, including the right to health, on the other are separated from one another. As a challenge to the Ethics Guidance and its implementation, we describe two cases, each of which typifies particular problems. Case one describes the experience of a migrant worker in the United Arab Emirates who is deported when mandatory medical exams show evidence of current or prior TB. Case two raises the issue of providing more than TB care, which may also be needed for holistic care. The paper concludes with our suggestions for ways in which we could make progress towards ethically optimal TB care for migrants.

KEY WORDS: tuberculosis; social justice; migrant; LTBI; universal health coverage

APPROXIMATELY 1 BILLION MIGRANTS live in our world, 250 million of whom are international migrants, which are the highest numbers ever recorded.[1,2] The majority are working migrants, who often face exploitative and abusive conditions with little social protection, inequalities in the labour market, and human trafficking.[3,4] The number of forcibly displaced persons is the highest since World War II, largely due to the war in Syria. Migratory movements, armed conflicts and situations of vulnerabilities can influence patterns of communicable diseases. Researchers therefore discuss the complexities and effects of increasing migratory movements also on tuberculosis (TB);[5,6] call for urgent action to prioritise TB care among refugees;[7] develop adjusted frameworks and screening tools;[8,9] and discuss related ethical issues.[10,11]

Recently, WHO revised its *Ethics Guidance for the Implementation of the End TB Strategy*[12] (henceforth, Ethics Guidance). Due to its increasing relevance, a chapter dedicated to the complex dynamics of migration was introduced into the revised version. Here, we summarize the key points of the Ethics Guidance on migration and discuss challenges in the implementation process using two case-based illustrations.

WORLD HEALTH ORGANIZATION ETHICS GUIDANCE: MIGRATION AND TUBERCULOSIS

The WHO Ethics Guidance calls for account to be taken of the special needs of socially vulnerable groups, including migrants, and for the active tailoring of interventions to provide redress. According to the Ethics Guidance, values or principles such as social justice, solidarity, dignity, equity and autonomy should be respected regardless of citizenship or legal status. In practice, however, citizens and non-citizens are often distinguished in health care settings and other practices, highlighting the potential for the Ethics Guidance to challenge existing approaches in relation to migration and TB.

In addressing the question of whether it is ethically acceptable to enforce mandatory TB or latent TB infection (LTBI) screening at borders, the Ethics Guidance points to an important general principle:

> Screening [...] should always be done with the intention to provide appropriate medical care, and never to exclude or preclude entry. (p 17)

The Ethics Guidance reinforces the principle that screening results should not interfere with entry decisions also in the case of *forced* migration (p 31).

Appropriate management of either active TB or LTBI should be provided from diagnosis on, including

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disclosure of results to migrants and opportunities for informed decision-making, and also during transit.[13]

Referring to the universal right to health, the guidelines call for,

> ...firm legal principles [...] that ensure that the enforcement of migration law on the one hand and the protection of human rights, including the right to health on the other, are separated from one another. (p 31)

This is known as the firewall argument.[14] It derives from the insight that it does not make moral sense to formally provide a right under conditions that make it practically impossible to pursue this right.[14] Following this argument, there is an ethical obligation to develop mechanisms to protect basic rights properly.[11,14] According to the Ethics Guidance this separation is also in the public interest, as the health of all, not only of migrants, will benefit. Furthermore, if migration law and the protection of the right to health are not separated from one another, migrants may be induced to

> ...not fully disclose essential information or be driven to alternative irregular migration routes, resulting in the health [*of all*] [...] put at risk. (p 31)

The Ethics Guidance points to the fact that a separation of both spheres is also beneficial for the appropriate fulfilment of healthcare workers' duties, as they might otherwise be caught in conflicting loyalties towards individual patient care on the one hand, and towards government migration policies on the other.

Once a migrant has entered a country, access to quality TB prevention, diagnosis, care and treatment should be equal to what the host country's citizens receive (p 32). The guidelines hold on to this principle even if it means health systems have to develop specific programs to fulfil it. This could be, for example,

> ...training staff [...] in cultural competency and ensuring that language resources are adequate to overcome potential cultural and linguistic barriers. (p 32)

Lack of coverage of costs should not be used as arguments to withhold TB care. This would not only disrespect the guiding values in TB care for migrants, but also be against the public's interest of infection control. Altogether, withholding treatment is against the WHO's general

> ...goal of universal health coverage, in that no one should suffer from financial hardship or impoverishment paying for needed health services. (p 32)

The Ethics Guidance also addresses deportation and/or repatriation, which we will not address in this paper for reasons of scope and length.

TWO CASE STORIES

In this section, two cases from current TB management in migrants are presented. This serves the purpose of contrasting the status quo of real-world practice with some values and principles in the Ethics Guidance. This will help to shape our argument for the future implementation of the Ethics Guidance; namely that an active engagement with real world situations and on-going, ethical reasoning and advocacy by the stakeholders involved is necessary for ensuring that principles are translated into practice.

Case 1: Forced deportation of labour migrants in the United Arab Emirates

Arjun is a financial services professional who moved from India to Abu Dhabi in the United Arab Emirates (UAE) to work for a large bank in 2016. He left his wife and two children in India, hoping to send money home with the higher salary of his new job. Two months after arriving in Abu Dhabi, the bank's human resource office (HRO) instructed Arjun to visit a local health centre for a medical examination, which included a chest X-ray. Two weeks later, Arjun was asked to return for a TB skin test and then again to have it read. The following week, the HRO informed Arjun there were doubts about his medical fitness and that he would need to provide a sputum sample on 3 consecutive days. A week later, the HRO told Arjun that he had been deemed medically unfit based on a diagnosis of TB and that he could not remain in the UAE. Arjun did not receive a copy of his medical records and was deported back to India at his own expense.

Commentary

Arjun's story is based on testimony collected from migrant workers to the UAE by Treatment Action Group (TAG) and submitted to the Human Rights Council as part of the UAE's Universal Periodic Review, a process in which the human rights record of each UN member state is reviewed every 5 years.[15] TAG conducted in-depth interviews with migrant workers who had been deported from the UAE for evidence of TB after mandatory examinations. These experiences, encapsulated in the figure of Arjun, highlight several issues in the ethical management of TB among migrant labourers. Over 90% of the UAE's workforce is composed of migrant workers, most of whom come from high TB burden countries.[16,17] In countries that are heavily reliant on migrant labour, migrant health policy is in fact public health policy and ethical shortcomings can set back TB elimination efforts.

The laws and regulations governing TB screening of migrant workers in the UAE have evolved over the past three years but remain inconsistent with the

Ethics Guidance and international human rights standards, including rights within the Arab Charter to which the UAE is party. In 2008, Cabinet Decree No. 7 established that migrants seeking employment must undergo mandatory medical examinations to detect infectious diseases, including HIV, TB, and viral hepatitis. Application of the law meant that migrants found to have any lung scars on chest X-rays consistent with TB were declared medical unfit, forcibly deported, and issued with a lifetime ban on re-entering the UAE.[15]

In January 2016, Decree No. 5/2016 amended the existing regulations. First-time applicants considered medically unfit due to a communicable disease are still subject to deportation. However, migrants seeking to renew their work permits—done annually—must also undergo medical exams and, if found to have TB, can be treated inside the UAE and issued with a temporary visa contingent on treatment completion.[18] First-time migrants belonging to special categories (e.g. university students; leading investors; members of the diplomatic corps) can also be treated inside the UAE.[19]

One of the central ethical shortcomings of the amended regulations is that, as applied, they do not distinguish between different forms of TB—e.g., LTBI (which by definition is non-transmissible); the appearance of lung scars on chest X-ray (which could indicate previous, successfully treated TB or lung infections other than TB);[20] and active TB disease (which is rendered non-infectious quickly after starting effective therapy). This makes it difficult to connect people to appropriate interventions following diagnosis. In addition, the amended regulations establish differential treatment of first-time migrants versus renewal applicants and preferred classes of migrants, which could be seen as violating the principle of ensuring non-discrimination in health care access.

Another ethical challenge is that migrant workers are often unable to access their medical exam results as these are provided to the HRO directly.[15] This can undermine migrants' right to information about their own health and deny them the opportunity to make informed health decisions. Many of those deported return home without test results and are unsure whether they have TB, and if so what form.[15] Such policies could also discourage individuals from coming forward for testing if they fear that personal information will be shared with third parties without consent or be used against them in immigration proceedings. In effect, this situation is the opposite of what the Ethics Guidance calls for in terms of the 'firewall argument'. The amendment made to the law indicates that the UAE is willing to revisit its policies, although the revised policy still falls short of the required ethical standards.

What would an ethically grounded, rights-based approach to TB and migration be like? Establishing a firewall between the enforcement of immigration law and health protection and promotion, based on the recognized importance of health, irrespective of a person's legal status, would mean eliminating distinctions between first-time migrants and renewal applicants in terms of TB testing and treatment. Anyone tested for TB should be offered counselling and the option of initiating treatment in the UAE according to the same standards of care offered to UAE citizens. The screening procedure must also distinguish between different forms of TB so that individual responsibilities following diagnosis are set in proportion to varying levels of risk to the person with TB and the community. For example, the Ethics Guidance is clear that treatment of LTBI should never be compulsory because LTBI is by definition non-transmissible and only poses a future theoretical risk. The WHO *Guidelines on the Management of Latent Tuberculosis Infection* state that 'positive test results or status of treatment for LTBI should not affect a person's immigration status or delay the ability to immigrate' (p 13).[21]

In situations where a migrant is found to have active TB, treatment should be offered inside the UAE with limited periods of hospitalization and/or isolation. If active TB is found pre-departure, it may be reasonable to postpone travel until a person is demonstrated to be non-infectious following initiation of effective therapy. Regardless of the type of TB, positive test results should be used as an opportunity to connect a person to counselling and appropriate care, not used as a justification for deportation or to compel involuntary treatment against a person's consent. Migrants should always have the right to access their test results and seek redress should the outcome of a medical exam jeopardize their employment or immigration status.

Case 2: Lack of holistic care for undocumented migrants

Tuah is a 34-year-old who has migrated from Malaysia to Australia, seeking to pursue work. His visa expired 2 years ago, and he has continued to work in seasonal fruit picking and other casual agricultural employment. After a lengthy respiratory illness, he has attended a medical clinic through a public hospital and been diagnosed with TB. At the clinic, he is also diagnosed with diabetes, and told that he should start medication for this also. He is told that treatment for TB is free, regardless of his visa status. However, he will need to attend the clinic, based in a metropolitan area, three times a week to receive medication. He is also informed that—as an undocumented migrant—treatment for diabetes is not covered by the TB programme. As he is ineligible for government-funded programs he will need to obtain necessary medications commercially. He is

concerned, as he will not be able to continue with his work in a rural location, and has no financial support or savings.

Tuah's doctor raises these issues with the TB programme manager. However, she is told that there are no provisions for financial support for non-citizens. The programme manager states that the programme is fulfilling its obligation by providing free TB treatment 'like the WHO says'.

Commentary

This case highlights some of the complexities in provision of 'free treatment for TB' irrespective of visa or residence status. The Ethics Guidance recognises that lack of access to a full range of citizen rights and privileges can result in treatment interruptions or complications and emphasises the need to provide all migrants 'equal access to quality TB prevention, diagnosis, care and treatment as their host country's citizens.' (p 32)

However, the provision of medical services other than for TB is not explicitly addressed. One could argue that provision of treatment for diabetes is a part of provision of TB services, given that treatment outcomes for TB are well-documented to be worse when diabetes is not appropriately managed. However, this approach simply bypasses the broader ethical issue here, which is that health care services, including TB care are to be provided to all as a matter of 'social justice and equity.'

Domestic policies as illustrated in this case have positive elements, as in some countries there is clearly an established understanding that provision of TB care should be free and equitable. However, while this is laudable and consistent with the Ethics Guidance, it fails to recognise that TB is a complex medical and social condition. While dispensing TB medication without cost to the patient is an essential component of health programs for migrants, the aim should be to provide migrants with complete access to the range of services necessary. This includes working to remove barriers to access, whether based on geographic, financial, linguistic or social factors.

When developing and articulating policy on ensuring access to healthcare, there are a number of ethical justifications that can be explicitly elaborated. In addition to the central principle that healthcare is a human right, and a full range of access is a matter of social justice and equity, it is recognised that TB treatment outcomes may be suboptimal if health care access is incomplete. For example, as in the case raised here, if diabetes is not treated in conjunction with TB, affected individuals are more likely to fail treatment, relapse or die. This has critical implications for individuals such as Tuah, but also provides additional reasons for healthcare systems to ensure appropriate access to all necessary services. These reasons are both pragmatic and ethical, as they provide additional justification for expanded access through ensuring improved stewardship of resources for healthcare, and social engagement more broadly. While treatment of comorbidities is a key component of this, this case also illustrates that facilitating access to employment or other means of financial security are critical for holistic patient care.

DISCUSSION

Arjun's and Tuah's cases serve as examples. We use them as paradigmatic cases that could happen in many places in the world with variations. In addition to their specific aspects as discussed above, they help to reveal general challenges in the implementation of the Ethics Guidance. Both cases can help to reflect on the potential and limitations of specific ethics guidelines in general.

First, history has shown that the formulation of principles and guidelines alone does not guarantee ethical conduct. Especially in relation to Arjun's case one fundamental question is thus: What value do ethics guidelines have given the difficult compatibility with some real-world settings?

In response to this we are convinced that a potentially difficult compatibility with real world politics is not a problem of the Ethics Guidance itself. In our view, there is no justifiable reason to adjust its underlying universal principles and values to a less cosmopolitan reality, as they are ultimately based upon human rights and the respect for each individual. These are widely agreed principles, which require active work of implementation rather than compromise on the level of rights and principles.[22–24]

Hence, while we do not recommend changing the universal principles in the guidance itself, sensitivity for real-world settings and appropriate ethical reasoning and if necessary, adaptation in each given situation is required in order to define steps forward. To some extent we hereby follow an approach that was developed in the context of research ethics guidance. Despite their addressing a different type of problem (i.e., research and the role of ethics review), the core message can be applied here: Instead of overly relying on the power of general principles in guidelines, some call for a 'culture of ethical integrity' (p 5)[25] and ask for a 'critical reflection and discussion' (p 2) and a 'constructive learning process' (p 2)[26] in the process of implementation and practice.

We thus urge interested parties to think beyond rather general principles and values set forth in guidelines, but – in our case of TB and migration – to focus also on the given socio-political contexts. Taking each context and situation into account, it is necessary to foster a culture of ethical reflection and integrity in the process of implementation of guidelines. This is often not a simple process. It can require the development of complex and long-term interven-

tions, advocacy and outreach strategies that, together with political will and education, will nurture and secure progress. Even if some caution in relation to the power of guidelines might be appropriate, past development and implementation of ethics guidelines serve to remind us that progress continues to be made.[22] Quantitative and qualitative research can be useful to show where implementation of guidelines might be compromised, but also where positive examples can be found. Publishing and disseminating these positive examples can be helpful to secure progress.

The cases can help to illustrate a second general challenge of specific guidelines. Tuah's case especially highlights the potential of too narrow an interpretation of the Ethics Guidance. This can happen with many other guidelines too that are focussed on one special disease or condition. Here we would like to point to the fact that the guidelines themselves are situated within the overall WHO framework (such as universal health coverage, health equity, social justice). Therefore, it is important that disease-specific WHO guidelines also always convey a general call for holistic care and universal coverage. For an appropriate implementation process it is important to reinforce this message of overall contextual embedding of specific guidelines into a broader ethical framework. Again, quantitative and qualitative research can help to uncover which guidelines might be interpreted too narrowly and to help understand how the overall, holistic WHO agenda can be implemented better.

Furthermore, both cases show that it is important to consider how the current Ethics Guidance stands in relation to internal migration and global migration patterns that continue to evolve. This might come together with the need for flexible engagement with new ethical challenges relating to TB. In the past, policy has largely been based on permanent migrants, usually from high to low TB incidence settings. But more frequent relocation, forced migration, internal migration, and temporary working migration (including situations of exploitation and abuse) raise new potential conflicts, and new opportunities to ensure that health systems are designed to serve those most in need. The Ethics Guidance could, and given constantly changing patterns of migration, should be seen as a dynamic document which is open to include more and other situations. This reinforces our call for on-going critical reflection in the light of changing socio-political contexts, strategies and interventions towards a culture of ethical integrity, and the framing of policy development and implementation as a learning process.

CONCLUSION

The WHO Ethics Guidance is useful for advancing the agenda of providing good and ethical care for TB in the context of migration as it is firmly based upon and defends universal human rights. It is in line with and supported by general theories and frameworks of public health ethics.[27–31]

The successful implementation of the ethical values and principles will depend on the opportunities and the will to translate them into domestic policy and practice. As the cases presented in this paper demonstrate, a critical and on-going reflection of the implementation process is required in addition to the formulation of values and principles. We argue that the way forward should not only include the dynamic further development of guidelines, but also a critical reflection of diverse socio-political contexts, as well as active engagement and advocacy promoting a culture of ethical integrity. Just as migration itself contributes to a robust exchange of new ideas, so continued discussion between global settings will assist in refining our ethical approaches.

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