

Gender in tuberculosis research

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SUMMARY

Gender studies as an area of research have developed to address the social, cultural and contextual factors that disproportionately affect the ability of women to promote their health and treat disease. The importance of gender in health and disease is now clearly established and increasingly evident in mainstream public health as well as in clinical and social medicine. The inordinate focus on women in the research in this area, however, while justified, has had the effect of almost excluding the experiences of men. More importantly, it continues to limit our

understanding of the dynamic interactive social processes that may provide the key to effective public health interventions for the management and control of communicable diseases. Using tuberculosis as a case study, we outline the contribution of gender studies in the control of disease and highlight the ongoing challenges that need to be addressed to enhance the understanding of the role of gender in public health.

KEY WORDS: gender; tuberculosis; context and social science research

IT IS A MAJOR CHALLENGE to identify research in gender and health that does not focus primarily on women. This is of course not surprising. As an academic discipline, gender studies evolved from second-wave feminism of the mid-1960s. Having addressed women's basic rights as citizens through the suffrage movement in the first wave, second-wave feminism introduced notions of equality and equity as they related to economics, family dynamics, health, well-being and sexuality. Initially, there was an explicit concentration on women's studies and, with the subsequent exploration of relationships and comparative approaches, men's issues were incorporated into the discipline. While there continue to be departments dedicated to women's studies, the broader discipline area has become known as gender studies despite the strong, persistent association with its feminist roots.

The genesis of gender in health and disease control reflects this evolution in ideas. The initial focus on women's health as a special interest topic in health and health care delivery developed in response to the perception of a major bias against women in biomedicine in general and health service delivery in particular.¹ As a body of knowledge, biomedicine was originally based on the male anatomy as the norm, with women as the deviation from this norm. Fluctuations in hormonal levels, pregnancy and breastfeeding precluded the consideration of the female body as 'normal' or 'reliable' for the purposes of producing a constant knowledge base,¹ and women were consequently

also excluded from clinical trials and other medical research that aimed to produce generalisable data.² It was not until 1994, following a policy change by the National Institutes of Health in the United States, for example, that guidelines were provided for the inclusion of women in clinical trials. Until the early 1990s, the symptomatology of most diseases in standard medical texts was compiled from presentations and physiological changes recorded in men,^{3,4} and treatment regimens were based on the average 70 kg man.

Major challenges remain in the study of gender and health, as with other social constructs that reflect the predominant political, economic and ideological characteristics in society.⁵ Research questions that are prioritised and data that are collected provide an indication of power and politics and the commitment to addressing inequalities. This is further reflected in the availability of accurate sex disaggregated data for epidemiological studies.

Social, economic and behavioural research in tropical disease control,⁶ and more recently in human immunodeficiency virus-acquired immune-deficiency syndrome (HIV/AIDS),⁷ has made a major contribution to the recognition of the effects of gender inequalities and discrimination in health, and consequently of the fact that differences in health outcomes were not solely biological.^{8–12} The higher value placed on men's roles and the power differential in relationships also meant that men could command greater access to resources, including those that promote health and prevent and

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treat disease. The inordinate focus on women in gender studies is therefore justified and has been critical in providing the much-needed opportunities to address and redress the inequalities that have resulted from gender discrimination. However, this focus has resulted in the near exclusion of men, limiting the application of significant research and analysis in gender and health. In the control of communicable diseases such as tuberculosis (TB), for example, a critical understanding of the dynamic gender relations that create and sustain vulnerability and poor health outcomes is essential in addition to understanding the experiences of women and men. Using TB as a case study, we outline the contribution of gender studies in the control of disease and highlight the ongoing challenges that need to be addressed to enhance the contribution of gender studies in health.

GENDER IN TB RESEARCH—A BRIEF OVERVIEW

As a disease, TB provides an ideal vehicle for multidisciplinary health research spanning the social, biological and clinical sciences. The cause of TB has been known for over a century and the treatment for at least half a century. The disease persists, however, for largely social reasons that have not been well addressed due to the overmedicalisation of the condition.¹³

TB is a contagious, communicable disease; it is spread through contact with an infected person, making the understanding of human interactions that facilitate contagion absolutely critical to its control. It is a disease of poverty, significantly associated with poor housing, low literacy and nutritional status, and lack of access to health services.¹⁴ There are strong political, cultural and social reasons that contribute to the distribution of poverty and vulnerability to disease and curtail the agency of individuals to make 'healthy choices'. TB is also heavily stigmatised, a significant factor in the disease experience and the dynamics of health care. The social sciences have been critical in understanding these factors, and the importance of multidisciplinary approaches can therefore not be overemphasised. Increases in TB rates in middle- to high-income countries are recorded largely in migrant populations from resource-poor countries.^{15,16} Many of these cases are picked up through immigration screening processes, but poor living conditions among many migrant ethnic minority communities encourage the spread of TB and exacerbate difficulties in case detection and treatment. Increases in TB rates have also been recorded in displaced populations, particularly in refugee camps, areas of conflict and civil disorder.^{17,18} There has also been a significant resurgence in TB rates in prisons.^{19,20}

HIV/AIDS has added a significant level of complexity to previous understanding of TB, reflecting both biological and social challenges. About one third of HIV-positive patients develop TB, through either

new infection or reactivation of latent infection. TB is a major cause of mortality in HIV/AIDS patients.²¹ There are important gender implications for risk, exposure, treatment and outcome.

Diagnosis, risks and treatment

Current prevalence data suggest that TB is 'more a disease of men than of women'.²² This highlights the need for a robust gender analysis to understand the reasons for the differences and to identify effective points of intervention. The epidemiological data highlight the complexities. In broad terms, higher rates in men are consistent across different sources of data, including case detection and notification and prevalence surveys, although most have their limitations. There are variations across geographical regions and age groups. Biological function provides some explanation for the differences; however, there is also an interactive effect with risk and exposure (including lifestyle, such as smoking,²³ and occupation, both from indoor air pollutants associated with cooking and from industrial exposure).²⁴ These activities have significant gender implications.

Other explanations for the differences include differential access to care, health-seeking behaviour and stigmatisation.²⁵ The evidence here is strongest from qualitative studies that point to cultural and health service-related barriers that hinder timely diagnosis in women rather than a reflection of disease occurrence.²⁶ The general reported trend highlights the effect of poverty on access to diagnostic facilities, a factor that disproportionately affects women. Other social barriers to diagnosis include roles such as care of others, which hinders the opportunities to access diagnosis, poor quality of service insensitive to gender-specific needs and greater experiences of stigmatisation and discrimination in women identified as having TB.²⁷

Gender implications of co-infection with HIV involve integrating what is known about the risk factors for both conditions. Risk factors and exposure to HIV are often gender-related, varying from injecting drug use and commercial sex work^{28,29} to the ability to negotiate safe sex relationships. Poverty and the lack of power to make safe and healthy choices also remain important drivers for these underlying dynamics. The HIV pandemic continues to create rapid social and demographic change, perpetuating the poverty-health cycle, again with important gender implications.

Once diagnosed, the non-trivial treatment course for TB poses a significant burden on resources and normal gender roles, and the link between this and adherence to the full treatment regimen has been well established. Adherence to TB treatment is critical because of the potential development of multi-resistant strains with higher case fatality. Implicated in poor adherence are the perennial problems of poverty, acceptability (unpleasantness of side effects) and appropriateness of treatment strategies. Even where treatment

is free, there is no compensation for loss of income, cost of travel or hospitalisation during treatment.³⁰ Recent findings from Weiss et al. highlight the considerable distress caused in men by the loss of income.²⁶ Reports from Ghana indicate that even health workers on the TB ward are stigmatised by their colleagues and other non-TB patients. In addition, the stigma experienced by patients with TB is increased with HIV co-infection.²¹ Although there have been some successes in improving adherence, poor adherence remains a major driver for the development of the DOTS strategy.³¹⁻³³ It remains unclear, however, whether the costs involved in the close monitoring of TB patients by various categories of carers are worth the current level of investment.³⁴ There is some suggestion that the authoritarian approach may further undermine the status of women and present an obstacle to their willingness to seek treatment.³⁵ The stigma of open participation in a DOTS-based programme also presents a major obstacle to the effectiveness of the strategy.

A CRITIQUE OF GENDER ANALYSIS

The above very brief overview of gender and TB demonstrates the importance of the contribution made by gender analysis. Gender analysis allows an exploration of the dynamics of vulnerability and disadvantage and thus provides multiple potential points of intervention for inequalities and disease control at a very basic and fundamental level. A number of methodological frameworks have been developed over the last 25 years that facilitate the analysis of the impact of gender relations on health. While most try to be comprehensive, they necessarily provide a focus on particular aspects of gender relations, and consequently the types of interventions developed to address gender differences in health and health care programmes (see, for example, the Gender Analysis Framework, Harvard Analytical Framework, Moser Framework, Women's Empowerment Framework and People Oriented Planning³⁶). Most of these seek to demonstrate differences in experiences for women, unequal distribution of resources and inequalities in power, capacities and vulnerabilities.³⁷ Interventions that derive from these either focus on those perceived to be more vulnerable, often women, or are at best gender neutral. Others explore the structural factors that create and sustain gender inequalities, providing avenues for structural interventions as well as programmes on a more personal level.³⁷

As a result of the genesis of gender studies, the approach is grounded in the need for advocacy for women. The evidence on gender is generated by researchers with an interest in inequalities, in working with the marginalised and in interventions to compensate for the extreme disadvantages that women have suffered and, in many places, continue to suffer. The evidence base in this area of research is heavily skewed towards

qualitative accounts of victimhood and vulnerability. While the value of these data cannot be underestimated, there are a number of shortcomings with this general advocacy approach that prevent full advantage being taken of the potential of gender analyses.

There has been a tendency to treat women as a homogeneous group; most examples in resource-poor settings pertain to women in marital settings, and mostly those with young children. Although fertility rates are high in many resource-poor countries, they are declining, and the focus on women in child-bearing years may therefore no longer be justified.³⁸ There is a paucity of discussion on issues relevant to older women, a demographic that it has become important to consider due to the increasing prominence of older women in heading households where younger parents have been lost to HIV or, in some cases, conflict.³⁹ Similarly, very little research has explored the differences in experiences across social class, ethnicity, socio-economic status and other factors. DOTS programmes therefore often presume a uniformity of experience and this often affects willingness to participate openly in the programme.⁴⁰ For example, the support for a female factory worker who, for the purpose of earning a living, needs to continue working would require a different programme from a woman responsible for care within the household.

The homogeneity of the descriptions of women's disadvantages also does not account for cultural variations across place and time. Gender relations and hierarchies can vary considerably with context, within countries and between countries. In addition, cultural and social practices and norms evolve over time and the lack of representation of this dynamism creates the impression of static cultures, and precludes the development of culture-based interventions. Gender relations are responsive to political, social and economic events, many of which result in modifications in family structure, roles and social networks.³⁹ There has been very little critical engagement in gender literature, particularly from research in resource-poor settings, with changes in social and economic life, effects of globalisation and urbanisation on gender dynamics and disease transmission.

There is also oversimplification in the treatment of other forms of disadvantage created by socio-economic status, class and caste, ethnicity and geography, which are important factors around which societies are organised. While some gender analyses highlight the complex interrelationships of these factors with gender, there is often a tendency for gender to be given primacy over these factors. There is an underlying assumption that once gender equity and equality are achieved, the effects of other issues will either be reduced or become easier to manage.⁴¹ This is reflected, for example, in descriptions of the cumulative effects of multiple layers of disadvantage.^{11,42,43} However, the complexities arise more from an interactive than

an additive effect, so that, for example, the provision of opportunities (mainly for women) to improve equity as an intervention may not be sufficient to address the interactive effects of gender with any of the other social factors. A focus on integrated social and structural interventions that address general poverty, basic standards of living and accessibility of education within a gender perspective may have a better chance of having far-reaching effects than any one of these in isolation.

A further major critique of gender and health research is the focus on women. With a female bias in gender research, there is a paucity of information related to men's experiences of gender and health and critically the relationships between the experiences of women and men. This lack of information constrains debate and stifles opportunities for broader social interventions. The search for equity has therefore succeeded in mobilising half the population, with little attention paid to the potential contributions that could be made by the other half. Standing characterises this as the 'impact of women' vs. 'gender impact'.⁴⁴ Gender is by definition a comparative construct, and the roles and circumstances of one sex need to be discussed with reference to the other in order to understand and, where necessary, intervene in ways that are meaningful and sustainable for both. This has been particularly evident in interventions that involve community participation.⁸ It is known, for example, that women have less access to resources within the household, but little has been done to study how this balance can be altered, short of creating opportunities for women to increase their earning capacity—at the same time adding a further burden to their workload.⁴⁵ Similarly, men are reported to have greater access to resources, but little is reported about their patterns of expenditure both within and outside their households. The third constraint of current approaches to gender studies is that in the focus on equity, there is a lost opportunity to address gender differences that demonstrate variations that are not necessarily equity-related. For example, adherence to treatment for TB is consistently low in resource-poor settings. While it is acknowledged that women may be disproportionately represented amongst the poor, in a poor community there are qualitatively different reasons for poor adherence between men and women, both of which need to be analysed and addressed.^{14,46} Furthermore, there is a lack of exploration of gender dynamics at the broader institutional level, both at the level of policy development and in direct service provision.¹² While recommendations are often made to train health workers in gender sensitivity,^{26,27} there is often a failure to acknowledge the personal and institutional cultural contexts of health professionals. There is also an assumption that female health staff would necessarily be sensitive to gender issues in working with patients. There is clear evidence that this as-

sumption is wrong; programmes targeted at addressing gender biases in female health workers have shown promising results.^{47–50}

CONCLUSION

The value of gender studies in TB control can be enhanced by 1) the ongoing collection of accurate disaggregated data and 2) a balance in the collection and analysis of gender-based studies to capture not only the experiences of men and women but also the dynamism of the social relationships and interactions of other critical social, cultural and environmental determinants of health. Analytical tools with broad application, including in the analysis of gender, continue to be developed and provide useful guidelines for data collection and analysis.^{25–27}

The renewed focus on optimising the effectiveness of known TB interventions⁵¹ presents an ideal opportunity to develop programmes taking into account the gender dynamics of communities with or at risk of TB. For these to be achieved, multidisciplinary and interdisciplinary approaches are required that do not privilege some forms of knowledge over others. The contribution of gender studies and social sciences research provides valuable input for understanding, accessing and working with populations most at risk.

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RÉSUMÉ

L'étude des sexes est devenue un sujet de recherche afin de répondre aux facteurs socioculturels et contextuels qui affectent de manière disproportionnée la capacité des femmes à promouvoir leur santé et à traiter leurs

maladies. L'importance du sexe dans la santé et la maladie est bien établie aujourd'hui et de plus en plus évidente dans une approche générale de santé publique, tout comme en médecine clinique et sociale. Toutefois,

un intérêt démesuré à l'égard des femmes dans ce secteur de recherche, bien que justifié, a eu pour effet d'exclure quasi totalement l'expérience des hommes. Ce qui est plus important, c'est qu'il continue à limiter notre compréhension des processus sociaux interactifs dynamiques qui peuvent être la clé des interventions de santé publique efficaces pour la prise en charge et la maîtrise des

maladies transmissibles. En prenant la tuberculose comme étude de cas, nous délimitons la contribution des études sur les sexes dans la maîtrise de la maladie et mettons en valeur les défis auxquels il faut répondre actuellement pour renforcer la compréhension du rôle du sexe en santé publique.

RESUMEN

Los estudios de género se han convertido en un campo de investigación cuyo objetivo es analizar los factores de tipo social cultural y contextual que afectan en forma desproporcionada a las mujeres, con el propósito de promover su salud y el tratamiento de sus enfermedades. En la actualidad, la importancia del género en la salud y en la enfermedad se ha determinado en forma clara y cada vez está más presente en las principales consideraciones de salud pública y en la medicina clínica y social. Sin embargo, el interés desmesurado en las mujeres dentro de la investigación en este campo, si bien justificado, ha tenido como consecuencia la exclusión casi total de las experien-

cias de los hombres. Aun más importante, este factor continúa limitando la comprensión de mecanismos sociales interactivos y dinámicos que pueden ser primordiales en la eficacia de las intervenciones de salud pública dirigidas al tratamiento y control de las enfermedades transmisibles. En el presente artículo, escogiendo la tuberculosis como caso de estudio, se esquematiza la contribución de los estudios de género al control de la enfermedad y se destacan las dificultades actuales a las cuales se debe responder a fin de comprender la función del género en la salud pública.
