BUILDING PARTNERSHIPS AND REVIEWING APPROACHES FOR EQUITABLE ACCESS TO HEALTH CARE

Bilkis Vissandjée, Professor, Faculty of Nursing, Université de Montréal.

Jaya Singh, Director of Research and Program Development, Save A Mother, India.

Lakshmi Lingan, Professor and Deputy Director, Tata Institute of Social Sciences Research, Mumbai.

BACKGROUND

Building on a diversity of challenges and experiences between health researchers in India and in Canada over the past five years, the goal of this chapter is to demonstrate how a partnership across borders and viewpoints can coalesce around converging preoccupations: the identification and processes of integrating a sex and gender lens into programs and policies addressing tuberculosis (TB) prevention, detection and management in vulnerable contexts. We wish to discuss the values added of multidisciplinary, inter-sectoral collaborative, strengths-based, participatory approaches as essential ingredients for the development, implementation and evaluation of sustainable, ethical and quality interventions and training programs for TB prevention, detection and management in countries such as India.

Using examples from a diversity of case studies, our aim is to demonstrate the importance of gathering or deriving sex and gender sensitive data in order to develop and implement interventions. These are in view of enhancing the health system performance and offer a best quality of care to women, men and families.

The biological concept of "sex" needs to be distinguished from the notion of "gender." Gender is generally defined in the social realm, compared to the biological anchor of the notion of "sex" (Johnson, Greaves and Repta, 2008). The latter is generally constant, while the former is perpetually in flux, socially defined and responding to the social, cultural, economic and political dictates of a given society. Gender can broadly be as how a woman, a man, a boy, or a girl is perceived and expected to behave in the society where he or she "belongs" (Iyer, Sen and Östlin, 2008; Vissandjée and Pai, 2008). Therefore, while the terms "sex" and "gender" may be often used interchangeably, they represent distinct units of analysis.

Accounting for sex and gender in health requires that interventions, programs and policies are examined in order to unravel potential situations of inequality in the distribution of resources, as well as the differing social determinants of access to services for women and men in selected spheres of a society. Accounting for sex and gender in health requires the consideration of differential trajectories and, if and when appropriate, must, like the declaration of human rights, be reinforced by ethical values, namely highlight the level of responsibility of those who are bound to deliver quality health care services for all (Selgelid and Relchman 2011).

INROADS TO EQUITY: ACCOUNTING FOR THE SOCIAL DETERMINANTS OF HEALTH

Tuberculosis (TB), an infectious disease caused by the tuberculin bacillus Mycobacterium tuberculosis, is often associated with high mortality if left untreated; yet, despite being treatable with antibiotics, tuberculosis ranks as the second most fatal infectious disease (WHO, 2011). Because it is contagious, the prevalence of TB is high in densely populated environments where housing is poorly ventilated; such situations are typical in shantytowns of large urban cities in India. In 2011, India had one of the heaviest burdens of TB cases of any country in the world. There is also the additional burden of a form of extra resistant TB (Kamineni *et al.*, 2011). Its estimated 2.0 to 2.5 million cases represented 26% of the global burden in India (WHO, 2011).

While a great deal of progress has been made in global TB control in recent years through the large-scale implementation of DOTS (Directly Observed Treatment with Short course regimen) and the availability of effective diagnostics and antibiotic treatment, the global incidence of TB and MDR-TB (multi-drug resistant TB) remains on

the rise. The global TB targets, namely, detecting 70% of cases, successfully treating 85% of the latter and halving the prevalence and TB associated mortality by 2015 as part of the Millennium Development Goals (MDGs) could likely be met only if current sex and gender sensitive efforts are intensified and targeted to reach the most vulnerable. Efforts, in countries such as India, to provide effective and accessible TB prevention, identification and treatment are fraught with multiple, interrelated challenges such as near-global health-system transitions, challenging coordination between private and public providers, guidelines standardization with the private sector, increasing rural-urban as well as international migration leading to selected co-morbid issues such as HIV/AIDS, diabetes, malnourishment, and alcohol and tobacco use. Against such a backdrop, this paper calls for sex and gender sensitive interventions carried out with a participatory approach to fulfil the Millennium Development Goals while addressing trans-disciplinary and intersectoral challenges associated with TB identification, prevention and management (WHO, 2010).

The literature indicates that sex and gender-related inequalities play a decisive role in the spread and control of TB (Somma *et al.*, 2008). These include the risks of exposure to the bacteria, the types of requests for care, the reactions in healthcare systems, the socio-economic context, and the risk of stigmatisation. These same studies show that women and men with TB are affected by stigma differentially. Such perceptions have been found to affect women more often than men, leading to situations of withdrawal both from the family network and from the health and social-services system. In a comparative analysis of likelihood to disclose TB status in India, men were twice as likely as women to disclose to a confidant (Somma *et al.*, 2008). Although more men generally contract TB, the disease is liable to have serious, even fatal, consequences when women are infected, and it is one of the main causes of death among them (WHO, 2011). However, the cure success rate is higher for women than men, who are more prone to abandon treatment before completion (WHO, 2011).

Introducing a sex and gender lens is essential to enable an improved understanding of the influence of societal norms regarding gender roles on equitable access to health care. Societal norms often impact the social determinants of health in a way that directly disadvantages women and girls. Particularly in low to middle income countries, such as India, women and girls are found to experience lower income, reduced access to and representation within the workforce, a disproportionate care-giving burden, increased exposure to violence and higher degrees of poverty and marginalization compared to men and boys. The negative impacts of these social determinants result in a reduced tendency of women and girls to seek out or access health care services. In addition, women and girls often have fewer services available to them and experience more physical and mental illnesses compared to men and boys (Sen and Ostlin, 2008).

Introducing sex and gender dimensions in the assessment of TB is more than ascertaining which sex has a higher prevalence rate, or a higher fatality rate. It also includes looking at other issues such as differences in risk of exposure to infection, in health-seeking behaviour and health systems response, economic consequences, and stigma associated with being known as a woman or a man with TB. Consequently, though some may contend that, given inconsistent definitions and metrics, a consideration of sex and gender is too complex a task, the reflections presented in this chapter point to the need to shift health care professionals' focus to the ethical consequences of not doing so.

In light of this complexity, negotiations within the research team centred on a number of questions: What are the complex social, political and economic forces that differentially shape the lives of women and men, especially those in difficult health situations—the very people for whom we must develop programs and strategies that take their living environment into account? Would it not be consistent to stress that an intervention geared towards the recognition of strengths should be included in programs when there is a risk of disempowerment? What about the capacity for resilience and collective action, for building on the resources of the network even as the disease heightens the risk of stigmatisation? How does a participatory approach with an equity lens contribute to alleviating vulnerability?

The partnership-based approach rests on an aspiration to tolerance, knowledge and cultural diversity, one which would be rooted in social and economic responsibility. This approach is consistent with findings that involvement in community health initiatives, with or without economic incentives, often incurs benefits in the areas of education, employability, social respect and personal empowerment, resulting in a mutually bene-ficial engagement at the individual and community level, assuming there is alignment of the context-specific expectations of community members, programme managers and policy makers (Glenton *et al.*, 2010).

With such a background, it is expected that sex and gender sensitivity allows better deciphering of the complexity of health experiences that emerge at loci of daily interactions at times at the heart of unequal relations and rights (Sen and Ostlin, 2008). To echo Sen (2009), one needs to be aware that the conditions of vulnerability associated with gender and migration experiences do potentially affect freedom and rights.

INTERDISCIPLINARY AND INTERSECTIONAL PARTNERSHIPS

In terms of ethics, as partnerships are built, terms, approaches, scientific and experiential knowledge of each member need be accounted for. Agreeing on definitions (of sex, gender, migration, social vulnerability, risk, among other concepts); agreeing on results in the search for best practices; and agreeing on how to adapt and implement "best practices" in the field, we were able to create a common and innovative dynamic relation as we evolved in our partnership. Determinants of effective relationships call for "intercultural effectiveness" and stress such skills as acknowledgment of mutual strengths, interpersonal adaptability and a spirit of initiative to develop collaborative strategies makers (Vissandjee *et al.*, 2002; Glenton &. al, 2010; South, Kinsella & Meah, 2012).

The common goal of fostering social transformation and changes in practice requires respect; respect in acknowledging differences, in allowing for specific contributions and varying knowledge-sharing strategies. Our research group was built up through teamwork and cooperation; our emphasis was on sex and gender issues in TB-protection, detection and management programs to ensure they reach those who are most vulnerable.

While what was discussed in this chapter aimed to implement TB prevention and treatment best practices and sensitive processes to social context for countries such as India, the scientific and social implications extend beyond geographical specificity. Assessing international TB programs and literature related to TB prevention and management accounting for sex, gender and migration experience sensitivity is expected to also benefit programs in Canada, given the increasing diversity of migration source countries. In Montreal, Quebec, Canada, about 150 cases per year occurred from 2000 to 2006, 80% of which affected women and men born outside of Canada. In many parts of Canada, India has remained the second most important source country for new immigrants since 1997 (in 2006, 12.2% of new permanent residents in Canada were born in India).

INROADS TO EQUITY: PARTNERSHIP IN ACTION, THE CASE OF *SAVE A MOTHER* (SAM)

Save A Mother (SAM), a non-governmental organization (NGO) founded in 2008, works to design health care solutions for rural communities in India, with a focus on maternal and child health and TB. SAM has had astounding success with a behavior change communication program for maternal health in partnership with low-income women in Uttar Pradesh in India. SAM has achieved a 90% reduction in the maternal mortality ratio over three years, using simple, low-cost, social marketing tools delivered by local health promoters with frequent repetition of key messages (SAM, 2011). This approach is now being implemented along with women and men towards more sensitive TB management strategies in rural UP.

Intersectoral and international partnerships have been integral to the success of SAM's programs. In Uttar Pradesh, SAM partners with Rajiv Gandhi Mahila Vikas Pariyojana (RGMVP) based in Lucknow. RGMVP has helped collectivize over 400,000 women across 200 blocks of UP and are in the midst of scaling up to over one million members. While their primary focus is microcredit and finance, SAM provides the technical expertise for healthcare and leverages RGMVP's platform to reach women and families through organized groups. This partnership has allowed the maternal health program to scale to over 50,000 villages in UP through further partnerships with UNICEF and The Gates Foundation. Likewise, in Karnataka, SAM partners with local organizations in order to amplify the reach of programs.

There is a high burden of TB in the areas where SAM works, almost seven fold higher than previously reported. In addition, there appears to be a gender bias in terms of TB detection and management. In such a scenario, partnership of local NGO's with the government run RNTCP program and DOTS centres is instrumental for TB management programs. Currently, less than 35% of households in rural Uttar Pradesh are aware of the free national public health program for diagnosis and treatment of TB (District Level Household and Facility Survey, 2007-2008). In addition, data from a pilot study of 25 villages in UP indicate that women are less likely than men to get tested for TB; while 60% of men with TB symptoms underwent sputum testing, only 40% of women with symptoms identified through community meetings went for diagnostic tests. Consequently, SAM is working with local and government partners to strengthen sex, gender and migration experience sensitive TB management, prevention and detection in partnership with local women and men in selected target areas.

The qualitative impacts of these programs were demonstrated to transcend health care. Empowering women through health knowledge has increased demand for public health services leading to an improvement in public health delivery as well as other in realms such as attitude towards education of the girl-child. Such results reinforce the importance of integrating a sex and gender approach with the goal of enhanced equity in health service access and reflexive ethical integrity in overall health programs in addition to the ones aimed at TB prevention, detection and management.

AVENUES FOR FURTHER REFLECTION

Global partnerships, incorporating participatory research approaches are needed to address socially relevant responses and practices to global health issues (Vissandjee & Pai, 2007). Community-oriented, gender-sensitive partnerships cannot be overlooked to address both socio-cultural barriers to care as well as resources of those providing treatment. TB programs and services need and should be designed to provide outreach and home-visits for women and men who cannot leave their homes, flexible opening hours at accessible and secure clinic locations as well as health workers trained to identify and respond to challenges associated with social processes and stigma as they affect TB management and control.

We have argued that in order to better understand the significant variations that may enhance women and men's capacities for resilience or conversely expose them to situations of risk, programs such as the ones for TB prevention, detection and management must be adjusted to better deal with and, indeed, highlight the intersecting nature of the social determinants of health. Education and training strategies among a diversity of health care workers – from lay to specialists – must allow for simultaneity in the analysis of the relationship between disease, health care delivery systems, sex and gender and socio-cultural patterns as they are built in the living conditions of women and men going through selected health experiences. Interdisciplinary and inter-sectoral partnerships must reinforce this need for the integration of such an empowerment driven and equity based approach to ethical interventions in public health.

Initiatives to redress persistent gender inequities need to address both the lack of resources and barriers (basic needs approach) as well as the opportunity to attain personal (including health) outcomes (capabilities approach); both are integral components of effective health programs from prevention to treatment taking into account the involvement of communities (Vissandjee *et al.*, 2012). Mainstreaming gender and equity needs to be acknowledged as a critical aspect in the prevention and control of infectious diseases such as tuberculosis.

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LA CRÉATION DE PARTENARIATS ET L'ÉTUDE DES APPROCHES POUR UN ACCÈS ÉQUITABLE AUX SOINS DE SANTÉ

L'intégration des notions de sexe et genre dans l'évaluation de la tuberculose requiert d'aller au-delà de l'identification de qui, homme ou femme, a un taux élevé de prévalence ou de mortalité. Cette appréciation des différences entre les sexes exige de se pencher sur d'autres questions telles que les différences de risque d'exposition à l'infection, aux comportements de santé, aux réponses établies par le système de santé, les conséquences économiques et sociales, incluant une perception de stigmatisation.

Si certains peuvent prétendre que, compte tenu de définitions imprécises, parfois incohérentes, d'outils de mesure limités sinon inexistants de ces déterminants de la santé que sont le sexe, le genre et l'expérience migratoire, l'effort d'inclure ces considérations fait partie des arguments présentés dans ce chapitre. Il est important que les professionnels de la santé se penchent et soient formés pour le faire sur l'éthique inhérente de leur pratique qui se doit d'être sensible à ces trajectoires diversifiées des femmes, des hommes, des filles et des garçons requérant des soins de santé.

C'est dans le cadre d'une telle complexité que le présent chapitre vise à illustrer les diverses négociations que les partenaires (chercheurs et intervenants terrain) ont construites au sein de l'équipe de recherche, en se basant, pour ce faire, sur certaines questions: De quelle façon doit-on, peut-on tenir compte des forces sociales, politiques et économiques qui façonnent la vie différemment des femmes et des hommes, en particulier dans le domaine de la santé, alors que des programmes sont censés être élaborés justement pour les rejoindre ? De quelle façon doit-on doser la nature des implications, de la participation dans les stratégies visant l'*empowerment* afin de ne pas se déresponsabiliser en tant qu'intervenant ou de mettre inutilement des personnes dans des situations à risque ? Qu'en est-il de la capacité de résilience et des ressources dans les actions collectives à considérer alors que c'est souvent le réseau de soutien lui-même qui est à l'origine de certaines perceptions de stigmatisation ? Comment une approche participative avec une perspective d'équité contribue-t-elle à atténuer la vulnérabilité ?

Nous soutenons que dans le but de mieux comprendre les variations importantes qui peuvent améliorer les capacités des femmes et des hommes pour la résilience ou au contraire les exposer à des situations de risque, des programmes tels que ceux de prévention de la tuberculose, de la détection et de la gestion doivent être ajustés afin de mieux traiter et, en effet, souligner le caractère intersectionnel des déterminants sociaux de la santé. Les stratégies d'éducation et de formation à mettre en place auprès d'une diversité de professionnels de la santé doivent ainsi permettre la simultanéité dans l'analyse de la relation entre les systèmes de santé et les défis d'une prestation de soins de qualité dans une perspective éthique et de justice sociale. Des partenariats interdisciplinaires et intersectoriels construits dans le respect et l'éthique devraient permettre de renforcer cette nécessité de l'intégration des déterminants sociaux de la santé vers une responsabilisation basée sur l'équité et l'éthique dans le domaine de la santé.