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Leprosy Narratives and Disability Studies: Rights Perspective

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Abstract[1]

Despite its disabling experience (limitation in daily living activities, exclusion and discrimination), it can be argued that leprosy has hardly been considered as disability in modern days and consequently its analysis was limited within disability studies. This may be due to a number of reasons such as the limited knowledge on the nature of leprosy, misconception about the 'disease' and scarce recognition of leprosy issues by the first wave of disability scholars.

This paper will look into recent scholarship in disability studies that deals with leprosy issues, namely in health care and Community Based Rehabilitation (CBR) discourses where the bulk of literature is available.

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[1] Résumé

Malgré ses conséquences graves (limitation d'activités quotidiennes, exclusion et discrimination), la lèpre de nos jours est rarement considérée comme une 'incapacité' et par la suite son analyse fut limitée dans l'étude sur le handicap. Cela pourrait être attribuable à la savoir limitée sur la nature de la lèpre, la compréhension erronée de la maladie et la pénurie des études sur le sujet par la première génération de chercheures dans le domaine du handicap.

Ce compte rendu examen la recherche et l'érudition contemporaine sur la lèpre, en particulier l'évidence disponible dans le domaine de la santé et de la réadaptation à base communautaire (RBC) où se trouve un tas de connaissance sur le sujet. Par conséquent, l'analyse fera la lumière sur la réponse mondiale envers la lèpre incluant les pratiques pour combattre la lèpre au Canada. En faisant cela, la discussion soulignera les pratiques de mise à l'écart sociale et son rôle dans la ségrégation et l'exclusion de personnes affectées par la lèpre de la société.

Étant donné que la lèpre est une condition liée souvent à la pauvreté, il y a eu du succès dans la lutte contre la lèpre à travers la stratégie de RBC qui est centrée sur la mise au point de conditions préalables au développement socio-économique local. Pour contrer le stigma, l'exclusion sociale et le rejet de droit humain, l'autonomisation des personnes affectées par la lèpre est fondamentale et cela va avec la consolidation de l'économie familiale. De même, il est important d'appuyer les efforts pour la prévention du handicap et créer les opportunités pour l'éducation et renforcement de compétence pour une meilleure inclusion. Cet article explore ces questions de perspective droite sur le handicap en se basant sur le CDPH.

Mots clés : lèpre, stigma, participation sociale, autonomisation, CDPH, étude sur le handicap

As such it will highlight recent responses to leprosy issues, namely those in Canada. In particular, the paper will look into segregation practices and how this contributed to the exclusion of people affected by leprosy from society.

Given that leprosy is often associated with poverty, recent response has seen notable success through CBR approach to affected people focusing on fighting the roots cause of poverty. To overcome stigma, social exclusion and denial of human rights, empowerment of people with leprosy is important together with strengthening family economy and providing program of prevention of disability as well as equal opportunities for education, skills development and overall inclusion. This account discusses these issues from disability rights perspective of the Convention on the Rights of Persons with Disabilities (CRPD).

Keywords: leprosy, stigma, social participation, empowerment, CRPD, disability studies.

Introduction

Over the past three decades, heated debate has taken place around the concept of disability, its construct and approaches to dealing with it. Different models of explaining and dealing with disability have emerged such as the medical model, the social model or the human rights model all of which provide varying perspectives towards disability and indeed can complement one another. However, the social model of disability has particularly flourished and its views were widely endorsed as it explains disability within the boundaries of society without ignoring the limitation of the individual. Disability from this perspective is socially constructed and culturally produced form of oppression and the solution lies in removing discriminatory disabling barriers (Barnes and Sheldon, 2010).

The social model is often considered as synonymous to human rights perspective on disability as it has played an instrumental role in promoting disability rights worldwide leading to the historical international treaty on disability (UN-CRPD, 2006). This marked a new era and resulted in the harmonization of national policy and program of many countries to align them with the Convention on the Rights of Persons with Disabilities (CRPD) and has also led to the introduction of a number of international declarations in favour of persons with disabilities such as that on leprosy (UN, 2015a). Yet, it can be argued that leprosy issues remain poorly addressed within the disability debate, in part because of historic barriers and epistemological frameworks that disassociate leprosy from disability. What little scholarship does exist focuses on international human rights policies around leprosy and efforts to facilitate community inclusion such as ‘Community Based Rehabilitation’ (CBR) programs. It can be concluded that further research is necessary to keep advancing efforts for persons with leprosy.

In this account, a critical analysis is presented throughout the text based on theoretical review of available literature. The analysis highlighted a number of preconditions necessary for the inclusion of people with leprosy such as access to protection services including socio-sanitary services, Community Based Rehabilitation and enhancement of the advocacy capacity of the disability sector in general. This account is divided into three sections and conclusion. The first section looks at leprosy from rights perspective and provides a global portrait of people affected by the disease. The second section proposes practical solution for reaching out to people affected by leprosy through Community Based Rehabilitation. The third section looks at leprosy in Canada and in Canadian disability studies. A set of steps forward concludes this account.

For advancing towards an inclusion agenda, it's necessary to enhance social participation and devise mechanisms to protect the right to education, health and community life in general. Participatory mechanisms for the harmonization of national laws and policies in line with CRPD can be advantageous and can help empower people with leprosy (individually and collectively) and strengthen their voice and advocacy. Together this may help improve inclusion outcomes related to equity and non-discrimination, fulfill CRPD rights and achieve Sustainable Development Goals (SDGs) (Turmusani, 2019).

A Rights Perspective to Leprosy

In 1948, the UN declared that human rights are universal and include everyone in the human family, regardless of gender, race, or disability. By nature, human rights are integral and interdependent; one depends on the fulfilment of another. Disability rights are also interconnected but have prerequisites necessary for daily living such as rehabilitation, accessibility and accommodation. The latest universal human rights instrument came into force in 2006 and centred on disability - known as Convention on the Rights of Persons with Disabilities (CRPD[2]). Although CRPD is not leprosy centred convention, this instrument has taken note of the particular

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[2] The purpose of UNCRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity. The Convention requires the signing countries to ensure that they take measures to ensure fulfillment of the objectives stated in the UNCRPD treaty. The Convention on the Rights of Persons with Disabilities and its Optional Protocol was adopted on 13 December 2006 at the United Nations and entered into force on 3 May 2008. The Convention follows decades of work by the international community to change attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as 'objects' of charity and medical treatment towards viewing persons with disabilities as 'holders' of rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. The Convention is intended as a human rights instrument with an explicit, social development dimension.

needs of all persons with disabilities and that includes by definition people with leprosy. The principal theme in the convention remained on protection and promotion of rights inspired by the system of international human rights.

Guided by CRPD, there has been notable progress on the rights of people with leprosy manifested by international declarations and statements introduced recently to promote and protect the rights of people affected by leprosy. This includes London Declaration on Neglected Tropical Diseases (NTD) and UN guidelines to promote the rights of persons affected by leprosy. To combat NTD including leprosy, London Declaration on Neglected Tropical Diseases highlighted the timely call to commit resources across the sector to remove risks causing NTD, namely poverty and ensuring access to WASH, improve living conditions and health education (Molyneux, 2016). Taking this a step forward, the United Nations in its resolution on the elimination of discrimination against persons affected by leprosy and their families, has elaborated guidelines and principles to promote and protect the full rights of persons affected by leprosy in line with universal conventions and treaties, namely CRPD and this includes the active participation of persons affected by leprosy in the decision-making process (UN, 2015a). Similarly, in developing vision 2030 of leaving no one behind, the world community has specifically included the eradication of NTD including leprosy in its Sustainable Development Goals (SDGs), namely Goal 3, target 3.3 (UN, 2015b).

Nonetheless, despite the notable progress on the status of persons with disabilities in present-day culture, attitudes towards this population remain somehow ambivalent and may underpin erroneous beliefs and perceptions. Indeed, attitudes towards persons with leprosy may remain ambivalent in some contexts (and for some stakeholders). For example, the way that an old man from Cambodia thinks about leprosy may differ from

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It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced (UN-CRPD, 2006).

The CRPD has 50 articles. 30 of these articles provide specific rights for persons with disabilities, including living independently; being part of the community; getting access to education; accommodations; and accessible voting; getting accessible information, and many other rights and freedoms (Arch Disability Law Centre, 2020).

The CRPD has been the most swiftly ratified international treaty. It has been well received by the international community. As of 11 May 2016, 164 States and the EU ratified the Convention, representing the majority of member States in the United Nations (UN Enable, 2016). Mechanisms have been set up for supervising the implementation of CRPD, namely under the Committee on the Rights of Persons with Disabilities (UN, 2010).

a young woman in South Korea. The misunderstanding of the needs of people with disabilities to equal opportunities, the lack of reasonable accommodation and unequal rights have all perpetuated negative views on the ability of persons with disabilities to succeed and become contributing members in society. Addressing attitudinal barriers is therefore a key issue to effective inclusion of people with leprosy and in line with social model ideals and disability rights.

To enhance the right to inclusive services for people affected by leprosy in a given country, monitoring the compliance of disability rights as a whole would be necessary. This means the enactment and harmonization of national laws in line with CRPD and that involves setting up mechanisms for monitoring its implementation according to article 33 of CRPD (UN, 2010). As such, a central body at national level (a focal point, i.e. disability commission) to monitor the compliance of CRPD through national laws as well as development plans and programs would be needed. Towards that end, it requires a reporting mechanism on progress made and this is to be submitted to the Committee on the Rights of Persons with Disabilities at UN-OHCHR. A notable provision made by CRPD in this regard is that concerning ‘Access to Justice’ (A2J) for persons with disabilities including people affected by leprosy. Given that systems of protection in many developing countries may be limited mainly to prevention against violation of rights, there is a need to move beyond concepts of ‘prevention’ and ‘promotion’ of rights into activities of ‘reclamation’ of rights by legal means, when necessary.

Towards that end, it’s important to highlight the situation of people affected by leprosy in global perspective and the way in which they have been perceived and treated in different cultures of the day.

Leprosy in Global Context

The root cause of leprosy was contested until the late 19th century when Hansen discovered the Mycrobacterium leprae responsible for the disease. Until then, views ranged mainly between contagionism (i.e. infectious causes) and anti-contagionism (i.e. causes due to hereditary, sanitary and or dietary lifestyle) (Menke et al., 2011). In some societies such as in Suriname, for example, people with leprosy have been perceived as a risk to the health and social order in society by colonial powers in the 18th century (Snelders, et al. 2021). Consequently, they were excluded from families and isolated in their own protective communities. The possibility of infection has often generated attitudes of fear or hatred toward those affected and pushed them further into isolation - that was a typical response to plague. In some countries, people affected by leprosy were segregated and had to wear bells so that people know that they were nearby (Milson and Johnson 1985, Milot, 2008).

In late antiquity (about AD 250 to 750[3]) of the Middle East for example, leprosy was known as the

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[3] This period saw the re-establishment of the Roman Empire, its conversion to Christianity and its replacement in the West by Germanic kingdoms, the continuing Roman Empire in the Eastern Mediterranean, the Persian Sassanian

plague ‘Black Death’. Responses to plague in cultures of the day (including in Islam, Christianity and Judaism[4]) was ambivalent and included avoidance of disease and the risk of contagion as well as communal responsibility towards affected individuals. Leprosy was considered as God’s will and at worst as a divine punishment to sins - for those who forebear it, it was considered as a reward. Prayers and supplication were common reaction to the disease. Healing included purification of homes by different scents and burning the belonging of victims as measure of spiritual cleansing. Although quarantine measures were often taken to fight the plague, there was no persecution to affected communities. The segregation of an individual or community, however, resulted in disruption of their economic life, affected social participation and caused stigma and discrimination. Recovery and healing was also possible, but associated stigma continued for a lifetime. That said, social reintegration was not without obstacles due the strong stigma attached to leprosy and fear of infection. Stigmatic exclusionary measures included for example, authorizing the unfavourable option of divorce in Islam when the spouse contracts leprosy (Long, 2011) or removing the ‘infected’ clergy from office and banning them from entering Catholic Church (Parlopiano, 2015).

In extreme cases as in the Middle Ages Europe (about 5th to 15th century[5]), people affected by leprosy were severely persecuted and cruelly tortured to the point of death (Zamparoni, 2016). Such response to plague may be seen throughout history. However, a systematic institutional support was also created to cater for those affected by plague including leprosy. In Medieval Islam for example, combating the disease included a wide range of interventions such as prevention, treatment and rehabilitation. Hygienic practices including clean water and sanitation is believed to have played an important role in preventing the plague in Muslim culture (Osborn, 2017). Equally, mobile clinics/hospitals (Bimaristan) were also common rehabilitation interventions and were deployed at time of plague (Miller, 2006). In recent history, church missionaries established institutional care for those affected by leprosy throughout the world, notably in developing countries. It may be argued in line with Turmusani (2003) however, that despite the usefulness of these models of care, they may also have contributed to segregating people with leprosy and somehow, reinforced their stigma.

Yet, the contemporary response to leprosy continues to be characterized by neglect and indifference. Despite the advancement in human rights system, present-day views towards people affected by leprosy continue

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Empire, and the rise of Islam (Nicholson, 2018).

[4] Response to leprosy in Judaeo-Christian theology is multifaceted – for example, in 2 Kings 5 in the Old Testament as well as in Luke 5:12-14 in the New Testament (Louis Segond, 2009). Equally in Islam, the Qur’an (Surah 3:49; Surah 5:110; Surah 20:22; Surah 27:12) (Ali, 1987) and Hadith (Volume 7, Book 71, Number 608) refer to leprosy affected people in a number of occasions (Khan, 2009).

[5] This period covers all key aspects of European history, society, and culture from 500 to 1500 (Bjork, 2010).

to be similar to wider views on disability and persons with visible disabilities. It can be argued therefore that although society has a better understanding of leprosy and its treatment (due to advancement in medicine and technology of rehabilitation), negative attitudes towards affected people continue to prevail (Subramaniam, 2003; Sermrittirong et al., 2015). Exclusion and discrimination are also omnipresent at all levels in family, local communities as well as in accessing services including education and employment. This is mainly due to the long-lasting stigma attached to this group.

Stigma attached to visible disabilities is typically linked to discrimination and begins by acts of negative labelling or stereotyping certain individual or community such as those affected by leprosy. This is often followed by injurious responses to affected people including sanctions and acts of discrimination (World Bank, 2007; Luka, 2010; Cross et al., 2011; Singh et al., 2012). It's a complex process that takes place within a social setting and overt ime becomes part of cultural norms and values. Given its social construct, measures put forward to dealing with leprosy attached stigma can be effective when they are socially grounded and culturally sensitive while being deeply rooted in the local community and the environment in which the interplay between these forces takes place. For example, local communities can devise culturally appropriate measures to deal with people affected by leprosy, but this depends on the severity of their impairment. Therefore, it can be argued that an individual with visible lesions of leprosy is more likely to experience discrimination and stigma compared with a person without symptoms of the disease (Sermrittirong, & Van Brakel, 2014).

To deal with the devastating consequences of stigma, awareness and advocacy can be reinforced by effective policies and decentralized practices to make good governance happen, especially in the developing world. For example, to increase universal access to services and social participation of people with leprosy, proper public policies need to be in place in line with CRPD. This can be coupled with strengthened linkages with stakeholders (i.e. government agencies, NGOs...) on issues such as diagnosis, referral and early intervention including multi-drug treatment and rehabilitation. This could be facilitated when effective policies exist for the integration of leprosy treatment into public health care services.

Among organizations that promote inclusion for this population is The Leprosy Mission (TLM) and its worldwide network including The Leprosy Mission Canada (TLMC). In their recent report entitled 'unfinished business' The Leprosy Mission has highlighted their progressive approach towards leprosy by presenting a comprehensive framework that includes three axes of intervention in line with Global Leprosy Strategy - Accelerating Towards a Leprosy-Free World (WHO, 2016). This includes: stopping the transmission of leprosy; preventing disability and promoting inclusion with special focus on reducing stigma, providing inclusive employment and enhancing inner well-being (i.e. mental health services). Recognizing the close relation between leprosy and poverty (Patil, 2013) as a cause and as a consequence, TLM has aligned its strategic plan with various SDGs, particularly concerning the fulfilment of SDG1. However, the focus of TLM remained on SDG3, target 3.3 for good health and well-being, namely the total eradication of Neglected Tropical Disease (NTD) (TLM, 2017). At the global level, The Leprosy Mission (TLM) also engages in research and innovation and currently runs an active research program internationally to promote social acceptance, inclusion and dignity of people affected by leprosy (TLM, 2015).

Moreover, TLM is actively involved in CBR practices across the world. For example, they run an active CBR program in Nigeria. Interventions supported by TLM included case detection and treatment with multidrug therapy (MDT); prevention of disabilities; and socio-economic rehabilitation (Ebenso, et al. 2010). In Bangladesh, in 2006 TLM started a CBR project targeting those with leprosy-related disabilities. The project worked primarily in livelihood development, empowerment, and disability management, although assistance for children's education, vocational training in the community, and building sanitary latrines were also available (Bowers, 2018). The following section discusses CBR in relation to social participation.

Community Based Rehabilitation (CBR) and Social Participation

Given the 'relatively' segregated or semi-segregated communities in which people with leprosy live in, CBR may offer a practical solution for reaching such isolated communities and provide them with quality mainstream services within their localities, especially in remote settings. This structure has the potential of providing inclusive complementary services such as home care without creating unnecessary parallel system. CBR is a strategy for community development focusing on rehabilitation, equal opportunities and inclusion of persons with disabilities. It can be considered as a comprehensive approach in supporting the inclusion of people affected by leprosy. Within CBR, both the community and individuals are considered as equal partners in the rehabilitation process. The needs, priorities and resources of the local community and that of persons with disabilities are defined locally. The key issues in CBR are: awareness raising to overcome attitudinal barriers and capacity building of the local community as well as participation and referral services, all of which, aims at inclusive development (Turmusani, Vreede et Wirz, 2002; Hartley, 2006).

According to CBR Matrix (CBR Guidelines - WHO, 2010), there are five components that work together under this strategy. These are: inclusive education, livelihood, health, social and empowerment. Examples of interplay between components may include: how the empowerment component helps in raising awareness and advocacy on rights of people with leprosy to inclusive living. The empowerment component of CBR can be very useful in overcoming attitudinal barriers in the local community and for policy influence. Another example is how the health component, namely the availability of assistive devices can contribute to the rehabilitation and preparedness of persons with leprosy to receive effective education. Indeed, a prosthesis can greatly improve the movement and autonomy of an individual with amputated leg and help in their everyday integration in school.

In the context of disability, the lack of opportunity to perform habitual activities leads to the exclusion from norm-stream life and significantly limits the social participation (Fougeyrollas, et al., 1998; Heeren, et al., 2014). The environmental barriers in place add yet another obstacle to the disabling experience of persons with disabilities (Barnes and Sheldon, 2010; WHO, 2011). Hence, the right to social participation is fundamental to integration, inclusion and development which ultimately help in the protection of rights. The increased participation of people with leprosy in various life activities are in themselves acts of advocacy for equal opportunities in inclusive living. To advocate = to participate. To illustrate the link between CBR and social participation, one could look at how CBR plays a role in overcoming attitudinal barriers related to social activities, for example.

A higher level of participation of people with leprosy, however, is that of their representation on disability DPOs as well as representation in local and all levels of governance. This allows them the opportunity to take part in the decision-making process and at the same time empower them to acquire life skills including leadership qualities. Genuine participation, however, is that which fulfils life habits related to survival needs as well as to the role and responsibilities such as that of education, health care and employment.

The social participation is among the models that are well developed in Canada, namely in Quebec. The conceptual framework of social participation can be useful in understanding the dynamics pertaining to the stigma and social exclusion for people affected by leprosy in Canada and can be used also in measuring and researching inclusion and empowerment issues. Below is a brief portrait of leprosy in Canada.

Leprosy in Canada

Leprosy has a recent history in Canada dating back to 19th century. First cases are believed to have appeared in the town of Tracadie and then Newcastle in New Brunswick. Persons with leprosy were sent to Sheldrake Island the majority of whom influenced by Father Gauvreau teachings and some were made to go by the police. The living conditions were very harsh at the Lazaretto of Sheldrake and Tracadie. Many residents perceived it as a prison causing some to escape and eventually, they burned it down. New facilities were built with improved conditions - a doctor was assigned to lazaretto ‘hospital’ and in 1868, nurses ‘Sisters of Charity of Hotel Dieu in Montreal) joined in to provide care services (Milson and Johnston, 1985). Concurrently, there were also cases of leprosy on the other coast of Canada among the Chinese immigrant community in Victoria, BC at the end of the 19th century. Affected people were isolated to poorly serviced D’Arcy Island and later to Bentinck Island with little improved services. Both D’Arcy/Bentinck and Tracadie operated until mid of the 20th century and closed down at the passing of their last resident (Milot, 2008; Kula and Robinson, 2013). These ‘colonies’ Boggild et al. (2004) and Milot (2008) provided early models of segregated care in Canada and is considered in this analysis as an influencer in the institutionalization of persons with disabilities including for example, eugenics policy and practices.

The situation has changed over the years and systematic support to providing care and rehabilitation for people affected by leprosy was also put in place, often by civil society organizations. One leading organization is The Leprosy Mission Canada (TLMC) who started its work in 1892 when Mr. & Mrs. Watt of Guelph, ON, opened their home for the mission. The Mission inspires strong Canadians support. Over the years and during much of last century, TLMC (2011) became a significant source of support to people with leprosy providing holistic intervention focusing on both medical aspects and inclusive well-being. This included, for example, solutions for breaking out of extreme poverty, low-cost housing, business loans and skills development including vocational training and rehabilitation interventions. In 2014, TLMC was renamed ‘effect: hope’ to reflect the true nature and mission of the organization (TLMC, 2014). Effect Hope operates at home and abroad and has a successful action research focusing on transforming the lives of people with leprosy by equipping families living in extreme poverty in Bangladesh, for example, with tools they need to thrive. This includes curing and caring for people with leprosy (i.e. life skills such as hygiene and sanitation practices) as well as skills for income-generating activities and advocacy training. The onus is placed on fighting stigma attached to leprosy and creating opportunities for inclusion (Effect Hope, 2016).

As for diagnostic care and prevention, endemic leprosy does not exist in Canada for more than half a century with the closing down of the last leprosarium in 1965. However, individual cases of leprosy exist and being estimated at approximately 500 people in 2011, according to TLMC. These cases (mainly linked to immigrant communities) however, don’t pose a risk and being treated properly (TLMC, 2011). Provincial data shows, for example, that between 2008 and 2012, an average of 3 cases of leprosy was reported in Ontario, annually (QPO, 2014) whereas in Manitoba, the incidence remains stable with most cases been already diagnosed, previously. There have been two new cases reported since 1991 (Manitoba Health, 2001).

Yet, the global eradication of leprosy, remains a challenge. Despite the effectiveness of Multi-Drug Treatment (MDT), there are a number of factors contributing to the ongoing incidence of leprosy such as difficulties in detection, limited success of awareness and public education programs and limited success of prevention efforts, especially transmission within the household (Boggild, et al., 2004).

Despite poor documentation of leprosy (Manitoba Health 2001/2015; QPO, 2014), records show that first cases appeared among the immigrant community. In fact, since its first apparition in Canada (in NB and then BC during the 19th century), leprosy has been and continues to be linked to immigration as it often manifests among immigrants’ population (Milot, 2008; Kula and Robinson, 2013). This is why communicable disease issues (i.e. leprosy) continue to receive heated debate in immigration circles and increasingly being challenged as grounds for discrimination against the admissibility of immigrants and newcomers to Canada. This debate is taken further when discussing leprosy in disability studies in the next section.

Leprosy and Disability Studies

Internationally, there are dozens of open access studies on leprosy issues. In addition to detection, prevention and treatment of leprosy, studies also cover a wide range of themes concerning the lifecycle of people affected by leprosy. Given the strong stigma attached to leprosy leading to the exclusion, a number of studies have addressed stigma issues (WHO, 2006; Luka, 2010; Cross et al., 2011; Singh et al., 2012; Sermrittirong, S & Van Brakel, 2014; Dadun, et al., 2016). Recent studies also looked at the role of CBR in the inclusion of people with leprosy under disability rights perspective (Van Brakel, 2007; Cornielje, et al., 2008; Van Brakel et al., 2010; Velema, and Cornielje, 2016; Deepak, et al. 2013).

Despite the disabling consequences of leprosy (limitations in daily activities, exclusion and discrimination), leprosy profile remains low and somehow relatively infrequent in disability studies in Canada (Boodman, et al. (2021). This may be due to reasons mentioned earlier related to misunderstanding of rapport between leprosy and disability, on the one hand, and the distinctive outcomes of scholarship carried out by medical professionals as opposed to social model advocates, on the other. In the early years of disability movement, social model scholars often overlooked the medical aspects of impairment (i.e. disease and ailments) and focused more on the disabling barriers in order to establish disability as a human rights issue. The situation has changed now under the influence of CRPD and the firm foundation of disability studies as part of social science and humanities in many countries of the world. Indeed, the CRPD is one of many catalysts to influence the disability sector. In fact, the current scholarship has become more collaborative and interdisciplinary in nature and this is considered as positive development that could go further in its scope of inclusiveness. Recognizing the relatively young history of disability studies in Canada, namely in Quebec (Boucher, 2003; Fougeyrollas, 2010; Prince, 2016; Parent, 2017; and many other writers), no wonder the paucity of leprosy issues within the field. In reviewing the history of disability studies in Canada, Reaume presents an account of studies covering the field since the period of confederation including early studies focusing on disability and exclusion among immigrants noting some generic analysis that could also apply to leprosy issues (Reaume, 2012).

Overall, there is limited scholarship in this area within Canadian disability studies[6]. Among recent

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[6] In conclusion to this section, it should be pointed that these mentioned studies are among few sources available on leprosy in Canada and further study on leprosy is necessary to facilitate the social participation of people affected by leprosy and ensuring their rights.

published research (open access) that somehow addressed the question of social exclusion of persons with disabilities in Canada is Capurri analysis of the inadmissibility to immigration on the grounds of disability or communicable diseases which typically includes TB and leprosy (Capurri, 2012). Another analysis is that of Kaul and Robinson (2013) on mistreatment of immigrants with leprosy in 19th century Canada.

Yet, the limited studies on the subject focus mainly on the medical aspects of leprosy (Johnston, 1995; Boggild, 2004, Milot, 2008). Another study linking the past with the present is that of Parlopiano on the concept of disability in Canon Law (Parlopiano, 2015). Its implication on the spiritual inclusion of people affected by leprosy has a global dimension deeply rooted in the work of the Catholic Church which has been active in providing care to people affected by leprosy throughout the world including in Canada.

Steps Forward

There are changing perspectives towards people affected by leprosy in knowledge production practices. Scholarship in disability studies has successfully moved the debate from care and rehabilitation into inclusion and empowerment of persons with disabilities. Such scholarship has also influenced global policy towards people affected by leprosy and resulted in specific declarations in their favour (i.e. London Declaration on Neglected Tropical Diseases; UN Resolution on Leprosy). Recent waves of human rights, namely CRPD has also played a central role in raising awareness and influencing policies of equal opportunities for persons with disabilities including people with leprosy. The Sustainable Development Goals of leaving no-one behind have likewise raised the profile of marginalized groups and emphasized their needs for protection and promotion of their rights for inclusive living. To improve the profile of people affected by leprosy in debate, policy or practice, innovative research practices (i.e. measuring social participation, impact of leprosy on family, advocacy research, evaluation studies, etc.) are required for enhancing evidence-based knowledge on leprosy issues.

Meanwhile, to keep momentum with the advancements in the field and contribute to the achievement of WHO roadmap of 2020 and SDGs vision 2030 of eradicating NTD (i.e. leprosy), policy debate and scholarship need to align in the same direction in order to influence approaches dealing with leprosy on the grounds. An effective approach for reaching those with leprosy who remains out of the public service system involves the adoption of CBR, namely for providing comprehensive package of care, treatment and rehabilitation for inclusive living as well as for fighting poverty and creating opportunities for socio-economic empowerment while reinforcing protection system and removing various disabling barriers, notably attitudinal barriers. Scholarship under a disability rights perspective on the above issues are paramount and can greatly influence research agenda, policy debate and strategic actions for developing models of good practices. This modest

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contribution not only invites further exploration, but builds upon existing knowledge.

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