View Point

Neonatal Tetanus among Nomadic Populations in India: An Insight into Socio-political Roadblocks and Pitfalls in Healthcare

Running Title: Neonatal Tetanus among Nomadic Population

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Abstract

India achieved neonatal tetanus elimination status in 2015. Immunization coverage still continues to be low among its nomadic populations and there is a large lacuna in data related to them. In this case study, the death of a nomadic neonate due to neonatal tetanus case in South India in December 2018, was investigated to examine the five major inter-linked pathways which could lead to the neonatal tetanus case in this community. Social determinants of health as well as health care access form major factors influencing health seeking behavior. When seen in the light of Maslow's hierarchy of needs, the lack of basic facilities, social isolation and economic vulnerability makes it impossible to focus on progress to a higher state of well-being. Filling the gaps in the health of indigenous populations will be central to the achievement of global initiatives like Universal Health Coverage and Health for All.

Key words: Delivery of Healthcare, Health Services Accessibility, Social Determinants of Health, Tetanus, Transients and Migrants

Introduction

Tetanus was identified as a disease of global public health importance in the 1980s when its elimination was put forth as an important goal in the 42nd World Health Assembly in 1989 and the World Summit for Children in 1990 [1,2]. At the time, tetanus was the cause of 6.7 neonatal deaths out of 1000 live births worldwide [1,2]. Subsequently, sustained efforts were taken up by countries around the world with a focus on maternal and neonatal immunization, and an elimination target of less than one case of neonatal tetanus per

1000 live births in every district or similar administrative unit in every country per year [3]. As of December 2020, only 12 countries are yet to achieve the elimination status [3]. India achieved the same in 2015 [2].

The Neglected Group

The term indigenous population is conventionally used vaguely to describe the large groups of people across the world with a wide range of social, cultural and political characteristics, making a common definition difficult [4]. *Lancet*, in a series of articles on the health of these populations, drew up a panel of criteria as a common point of identification including, among others – historical continuity, distinct culture and strong links to natural resources [5]. Immunization coverage continues to be lower among indigenous populations in first world countries as well as in India, proving to be potential hidden pockets for various vaccine preventable diseases including tetanus [6,7]. Yet, the population remains largely hidden from the mainstream and there is a large lacuna in data related to them.

Indian Scenario

Similar to the many indigenous groups worldwide is the nomadic population of India, which stood at an estimated one million in 1982 [8]. They continue to be a neglected population with limited access to education, mainstream opportunities and healthcare due to various factors [4]. Of these, the social determinants encompassing a wide range of inter-linked factors such as social and economic status, education and literacy, social support networks, social capital, cultural practices, and the level of access to health services form the cornerstone of neonatal deaths in these communities.

A neonatal tetanus (NT) death case was reported in a tertiary care hospital of Puducherry, South India in December 2018. The baby hailed from a nomadic community of rural Tamil Nadu, a neighboring state. The baby was delivered at home and subjected to traditional norms surrounding childbirth including withholding of breastfeed and poor umbilical cord hygiene. There were multiple delays in seeking healthcare as well. The detailed clinical aspects of the case are described elsewhere [9]. An investigation was undertaken and we found failures at multiple levels which contributed to the occurrence of tetanus. These include poor healthcare access, inadequate antenatal and post-natal care, exposure to unhygienic environments and living conditions, difficulty in tracking of the community, and a lack of ownership from the healthcare system. In this perspective, we examined the five major inter-linked pathways which could lead to the development of tetanus in nomadic neonates. **(Figure 1)**

Roadblocks and Pitfalls

1. **The Socio-Cultural Pathway**

The social status of an individual or a community is the standing or importance it has with respect to others in the society [10]. It is quite often linked with occupation and income levels. Higher income and higher social status are linked to better health [11]. In the case of nomadic populations, their social status is ascribed at birth to be very low in the social ladder. The lack of opportunities for economic progress makes this standing static. The centuries-old legacy of low socio-economic status paves way for social exclusion and isolation from the larger fabric of society around them. This in turn limits the reach and strength of social support networks they are able to form, which reduces the exposure of individuals to health-related information from the mainstream society. However, indigenous societies are also seen to have

a strong kinship relationship [4]. When networking is limited, social capital is largely drawn from bonding among the members of the community rather than bridging, leading to re-enforcement and strengthening of existing cultural and social norms within their own community and resisting external opportunities for change. Culture acts as an overarching factor that shapes food choices, health values and patterns of healthcare behavior to a large extend which may be altered to varying degrees by individual experiences and preferences [4]. Personal behavior remains influenced by norms to a large extent, including health-related behavior. Thereby, culturally accepted methods of delivery and child-care thus continue to prevail even in the face of evidence-based medicine.

2. The Politico-Social Pathway

De-notified, nomadic and semi nomadic communities are considered to be the most deprived sections of Indian society who are subjected to social stigma and atrocity [12]. The long history of exclusion from the mainstream communities and misuse of legal procedures against them has made the people wary of approaching social services. A total of 237 castes and tribes were given the criminal-by-birth tag under the ambit of the Criminal Tribes Act, 1871 by the British Government [13]. After Independence, the Indian government replaced this Act with the Habitual Offenders Act of 1952, which took out the clause involving tribes, but which informally continues to be misused today [14]. The United Nations Committee on the Elimination of Racial Discrimination called attention to the same in 2007 [15]. These communities are hard to reach and less visible as they are constantly moving from one place to another in search of livelihood, leading to frequently being left out from government schemes and services.

The first National Commission for De-notified, Nomadic and Semi-nomadic Tribes (NCDNT) was constituted in 2003, reconstituted in 2005 (Renke Commission), which submitted its report in 2008 [16]. With none of them being able to come up with concrete lists of the communities for which they were set up nor with tangible and achievable targets through recommendations based on surveys, the last NCDNT, chaired by Bhiku Ramji Idate was constituted with the aim of studying their various problems and recommend measures to solve the issues more comprehensively. In 2018, Idate report recommended constitutional amendment so that all these communities can be added as a third category after Scheduled Castes (SC) and Scheduled Tribes (ST) [17-18]. It also advocated release of 2011 caste census, which is yet to be made public, on these 150 million Indians, so that policies can be made specifically for them [19]. In the current scenario however, social exclusion continues to be a major determinant of access to healthcare, for this population.

3. The Economic-Environmental Pathway

A poor economic status translates to poor environmental conditions as well. The physical environment has two components, the one at home and at the workplace. The families are deprived of necessary provisions such as safe water and sanitation due to the lack of permanent habitation and inadequate public infrastructure, especially in rural areas. This leads to poor personal hygiene. The work environment is also often hazardous, with long working hours and intense physical labor. Manual labor in unorganized settings usually is accompanied by lack of provisions for personal protection or liabilities in case of accident. Many women resume work in the immediate post-natal period and bring the child along to the workplace.

Exposure to unsafe environments, both in the home and work environment, in the immediate post-natal period exposes both the mother and child to tetanus.

4. The Health Literacy Pathway

Literacy is an important determinant of health as it directly influences the person's exposure to and ability to understand and apply health information. Illiteracy directly leads to poor health knowledge which translates to unhealthy personal behaviors and poor health seeking behavior. Poor health seeking behavior becomes a component of decreased access to healthcare.

5. The Healthcare Pitfall Pathway

There are two major pitfalls in the current healthcare delivery system which leads to inadequate health care access for the nomadic population. One is the inability of the system to cope up with the unique needs of the nomadic population in terms of follow up across erratic timings and locations. The long working hours which extend beyond the scope of that of the field level health workers form an important basis for the drop in the number of follow up visits. The frequent change of habitat also poses a risk to the viability of follow up. The second pitfall is the stigma and lack of ownership expressed by the health personnel towards the nomadic community. The existent pattern of social exclusion strengthens this negative attitude.

Conclusion

All the different pathways are in no way distinct and lead towards reinforcing the deprivation that the nomadic tribes are subjected to. All of them stem from a paucity of security in terms of basic social and economic needs. When seen in the light of Maslow's hierarchy of needs, this lack of basic facilities, social isolation and economic vulnerability makes it impossible to focus on progress to a higher state of well-being. Therefore, social security needs to be addressed first. It is possible to integrate indigenous populations with the mainstream society in terms of economic capabilities, job opportunities and health access, even while retaining their cultural distinctiveness, as observed in many societies around the world. However, the most important aspect would be concerted efforts for relevant data generation with respect to these communities which can influence policies and political will. Filling the gaps in the health of indigenous populations will be central to the achievement of global initiatives like Universal Health Coverage and Health for All.

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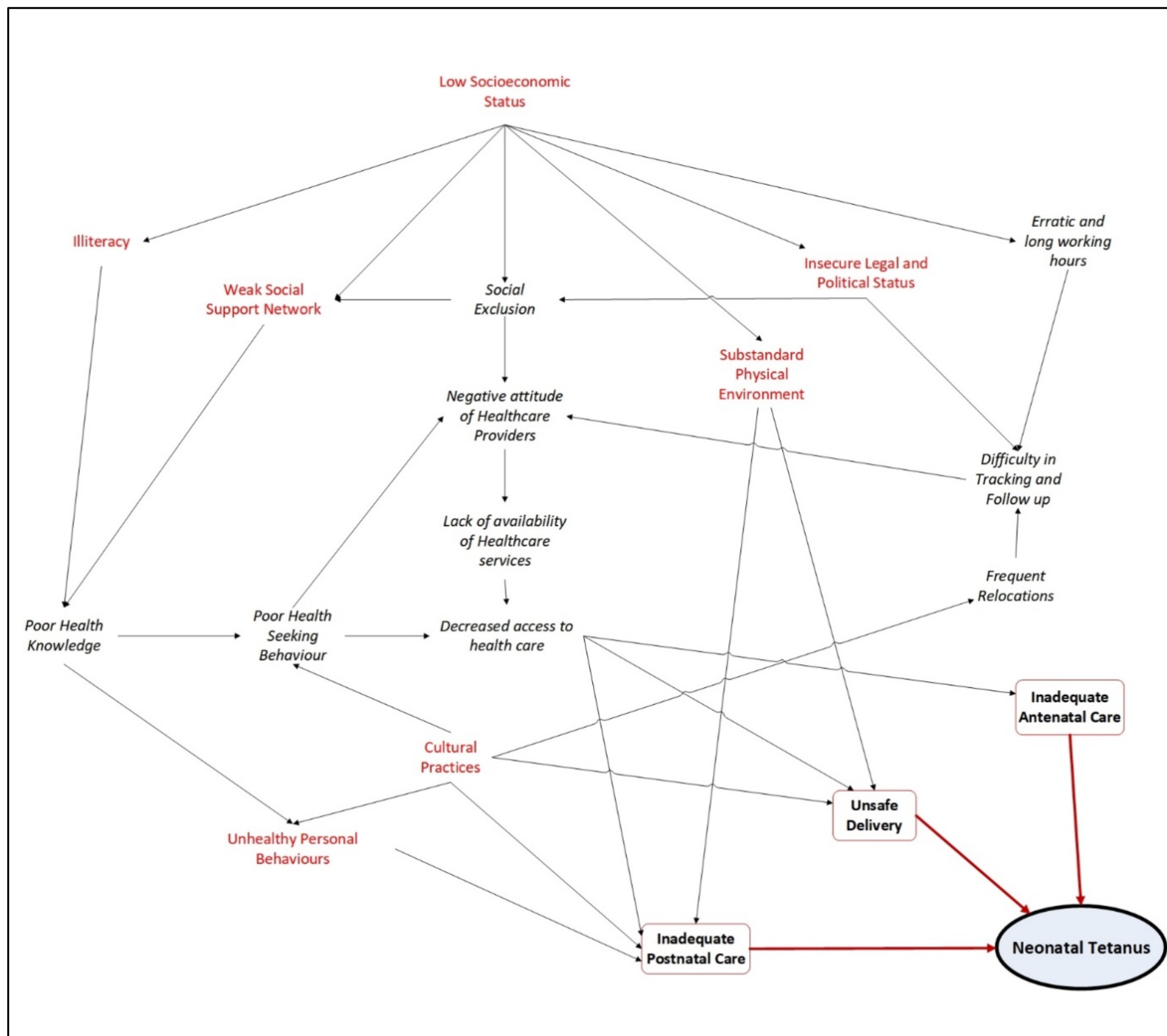
Figure: 1 Web of Causation for Neonatal Tetanus among Indian nomads



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