

Nature and Causes of Locomotor Disabilities in India

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Abstract

A large proportion of disability around the world is preventable. Levels of disability in many poor countries can be reduced by achieving the international development targets for economic, social and human development. In this paper, the author studied the different contributory and causative factors of locomotor disability, disease states and the significance of poverty in relation to disability in Eastern part of India. Final data were collected from 200 people with locomotor disability by personally visiting each individual and their family at their home or institutes on the basis of personal interviews, discussions with them, their parents and teachers. Data were collected by situational sampling technique and tools used for the study were General information schedule (GIS) and Semi-structured interview schedule. The study revealed that various diseases which resulted in locomotor disability in some way were related to poverty. The nature and causative factors for various diseases which resulted in locomotor disability are malnutrition, unhygienic condition in the pre-natal and postnatal period of the mother as well as carelessness of the medical practitioners. Among the other associated significant indirect causes has been found to be illiteracy, ignorance of the parents, and various socio-cultural issues. However, general improvements in living conditions will not be enough but an integrated and specific steps are required for prevention of disability, ensuring that people with disabilities are able to fully participate in the developmental process and claim their rights as well as obtain a fair share of the benefits as full and equal members of society.

Nature and Causes of Locomotor Disabilities in India

There is no accurate data on the global number of people with disabilities in the world, but it is estimated that over 650 million people are disabled, out of which 520 million live in developing countries, 300 million are women and one person in 20 has a disability (United Nations Development Programme, 2010). The motor disability counts the second highest percentage of disability, it is perhaps the most neglected as it is often felt that this group does not need any special care or attention like the other categories (viz. visual, mental, hearing impaired) and thus characterized as an underrepresented group in the disability movement. In developing countries, 80 to 90 percent of persons with disabilities of working age are unemployed, compared to 50-70 percent in industrialized countries. Disability in the developing countries has a different cause structure from disability in the developed world. Although it is not a rocket science to determine

the contributory and causative factors, it is clear that in developing countries the proportion of disability caused by poverty is much higher than it is in developed countries. India with 17.5% of the world's population is the second most populous country in the world with population over 1.21 billion people (Census of India, 2011). India may have come across tremendous development in every sphere in the last 5-7 years which has attracted a lot of international gaze and envy but unfortunately about 22% of our population still remains below poverty line. In the prime areas there exists drastic disparity in rural and urban India in the family structure across the population on socio cultural parameters, household income and their educational status. It wouldn't be surprising if research on disability in rural and urban India might put forth the same prevalent observation that we often see between a developed and developing nations.

Poverty and Disability

From the socio-economic status it is found that most of the people with disability belong to below poverty line and rural areas. Although most countries acknowledge that disability has been associated with poverty (Yeo and Moore, 2003; Hoogeveen, 2005; Elwan, 1999) but few have the data and a relatively nascent methodology to investigate it. Research in rural India found that a higher proportion of households with self reported disabled members were below the poverty line, had lower total assets, smaller land holdings, and greater debt than households without disabled members (Harriss-White, 1996 and 2003). "The combination of poverty and disability is a fearsome one. Either one may cause the other, or their presence in combination has a tremendous capacity to destroy the lives of people with impairments and to impose on their families burdens that are too crushing to bear" (Acton, 1983). Poverty can cause disability with its associated malnutrition, poor health services and sanitation, unsafe living and working conditions. Conversely, the presence of a disability can trap people in a life of poverty because of the barriers disabled people face to taking part in education, employment, occupational mobility, social activities, and indeed all aspects of life (Mont, 2007). The ability to work is an important aspect of psychosocial functioning, which reflects social status, self-esteem and the opportunity to socialize (Yelin 2004; Panopali 2007). Together, poverty and disability create a vicious circle one leading to another and vice-versa and it seems there is no short pathway to come out of this vicious cycle. Down the years this has been a burning issue for researchers from various discipline be it health science, nutrition experts, educationists, sociologists, economists and many more.

Lwanga-Ntale (2003) reported that the current disabled population is more likely to be poor and their poverty is not only limited to their generation but passed on to their children. The infant mortality rate in India as document is 30.15 deaths/1000 live births (CIA, 2009), which is over six times that in the U.K. 4.85 deaths/1,000 live births. The prominent reasons so far has been found to be diseases of various kinds, malnutrition, unhygienic condition/ environment in the pre-natal and postnatal period of the mother as well as carelessness of the medical practitioners. Among the other associated significant indirect causes has been found to be illiteracy, ignorance of the parents, and various socio-cultural issues.

Women's nutrition aspect and disability

Rural parents are not familiar with the nutrition aspects or maternal care and thus, sick mothers gives birth to sicker child. Micronutrient deficiencies in mothers place their infants at risk, since the fetus receives essential nutrients from the mother raising the infant's risk of low birth weight

(defined as a birth weight of less than 2,500 grams) and early death (Ransom and Elder, 2003). Even mild maternal malnutrition can impair fetal development. Low birth weight is the strongest determinant of a child's survival, which account for the majority of infant deaths in the first week of life. A variety of nutritional deficits, including iron deficiency and insufficient caloric intake, can increase a woman's chances of having a low birth-weight infant (Ransom and Elder, 2003). In developing countries every year a staggering figure of approximately 200 million children under the age of five suffer from stunted growth as a result of chronic maternal and childhood under nutrition (UNICEF Report, 2009). Those infants who survive tend to suffer with a higher burden of disease, which not only damages their ability to work during adulthood but also their cognitive impairment, developmental problems, and a greater susceptibility to illness. Infants born to mothers with anemia are at greater risk of low birth weight, premature birth, and impaired cognitive development (Nokes, et al., 1998; Rush, 2000).

Mothers who do not consume enough iodine are more likely to miscarry or have a stillborn child. The physical growth and mental development of the children who do survive is often severely impaired, and children may suffer irreversible mental retardation (United Nations, 2000). Folate deficiency at the time of conception can cause neural tube defects in infants, and maternal zinc deficiency is associated with preterm delivery, low birth weight, and increased infant mortality. Other B vitamins, including B6 and B12, are important for ensuring children's healthy neurological development (Ransom and Elder, 2003). In Indian context malnutrition is an extremely complex, inter-generational phenomenon with multiple causes, such as micronutrient deficit, infection and disease; early marriage of girls, frequent pregnancies, ignorance regarding proper maternal and child care, inadequate health services for women and children, low access to safe drinking water and hygienic sanitation. All these factors points towards one prominent sole cause of malnutrition, which is poverty.

A large proportion of disability around the world is preventable. Levels of disability in many poor countries can be reduced by achieving the international development targets for economic, social and human development. However, general improvements in living conditions will not be enough. Integrated and specific steps are required for prevention of disability, ensuring that people with disabilities are able to fully participate in the developmental process and claim their rights as well as obtain a fair share of the benefits as full and equal members of society. This paper assesses the different contributory and causative factors of disability, disease states and the significance of poverty in relation to disability.

Objectives of the Study

To study the nature and causes of locomotor disabilities in Eastern part of India

Methodology

Sample

The sample was restricted to locomotor disabilities mainly. Data were collected by situational sampling technique from different sources namely educational institutes, vocational institutes, vocational rehabilitation centers, government and non government NGO's, employment exchanges, hospitals etc. The Eastern part of India (West Bengal) was used for the study due to

its significance as the most crowded state and because it has been reported as having a high number of people with locomotor disabilities (Census of India, 2001). The study is the result of a project involving 200 (100 male and 100 female) with locomotor disabilities. The age range of the subjects was 18 years to 20 years. The nature of disability includes amputee, burn, polio, or bone anomalies, and locomotor disabilities due to various diseases etc with 45% to 90% disability as certified by the government hospitals in India. Figure 1 shows the nature of disability in the study.

The final break of the samples is as follows:

Persons with Locomotor disability	Sample Size
Male	100
Female	100
Total	200

Tools

- **General information schedule (GIS):** The *first* section comprised of demographic characteristics of the subjects such as age, gender, habitat etc.
- **Semi-structured interview schedule:** This comprised of information about their nature, cause and severity of disability.

Data Collection and Statistical Treatment

At initial stage tracking these locomotor disabilities was really a cumbersome affair, which was done by taking help from various special institutes and special employment exchanges spread over different parts. After collecting the addresses the survey packets were made containing an informal cover letter and self-addressed, stamped envelope and mailed to 1000 randomly selected potential respondents. Instructions were provided for those needing help and they were directed to consult the author for assistance. Only 250-300 locomotor disabilities responded via phone or letters. Final data were collected from 200 locomotor disabilities by personally visiting each individual and their family at their home or institutes on the basis of personal interviews, discussions with parents, teachers and the disabilities person concerned. Some of the institutes also arranged for some interviews to be taken at the spot. Quantitative and qualitative analyses were done for the study.

Findings and Discussion

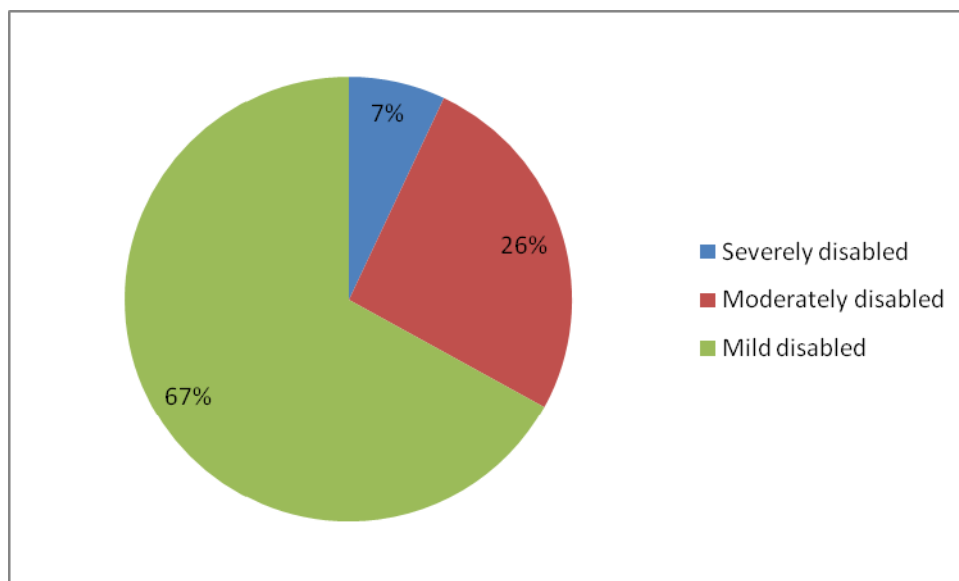
Informants were asked questions on the type of locomotor disability they experienced.

Severity of Disability

The samples in the study comprised of having 45% to 90% disability as certified by the medical practioners. During the interview with the people with physical disability and their parents it was found that percentage of disability as assigned by the medicational practioners, board of doctors in the government and non government hospitals were not without flaws and raised much dissatisfactions and incongruence in many cases. According to some parents the percentage given to their ward after medical examinations was not a very good way to justify their ward's

disability. They also had to go from time to time for a re-evaluation of the severity of disability as assigned.

Figure 1. Severity of Disability



For data analyses a relative comparison was made by dividing them on three categories on the basis of the percentages assigned by the doctors viz as mild disabled- below 55% disability, moderately disabled- 56% to 69% disability and severely disabled- above 70% disability. In the study 67% of the people with disability belonged to mild disabled category, 26% were moderately disabled and about 7% were found to be severely disabled as depicted in figure 1. In India this certificates indicating their severity is very significant as the facilities and provisions like travel grant, financial assistance for the one accompanying are provided on the basis of the severity of disability or in other words the category or percentage assigned to them so parents and also the person concerned had their own grievance in regard to this.

Location of Disability

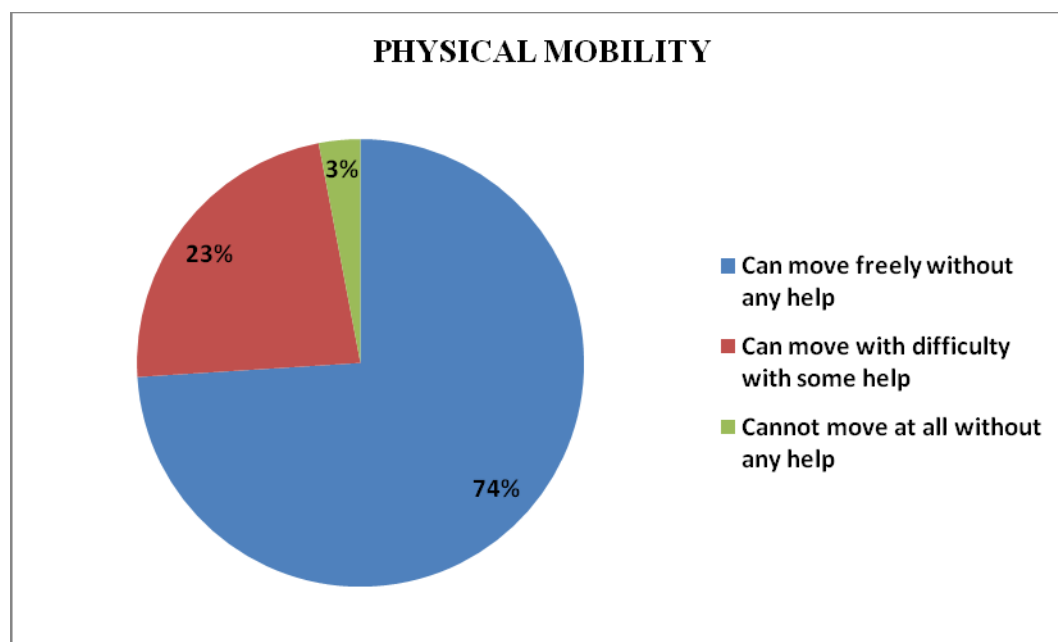
In the study it was found that about 75% of the disabilities were located in the lower limbs (either one or both) and about 17% were affected in both upper and lower limbs. Only about 6% of the cases were found to be related with upper limbs (either one or both) and just 2 % were spinal cord related impairment.

Physical Mobility Status

With the help of assistive devices/aids (like wheel chair, crutches, calipers), about 74% of the people with physical disability (Figure 2) reported that they can move without any physical companion. About 23% of the people with physical disability need both assistive devices/aids and somebody to physically assist for their mobility. There are 3% of the people with locomotor disabilities who cannot move or perform any activity without a constant companion. This means these 3% of the people with physical disability are totally dependent on others for their daily

activities and survival. Inability to perform self-care tasks or activity of daily living (ADL) without help is widely used in social surveys as a measure of physical dependency.

Figure 2. Physical mobility



The analysis of the data for various contributory and causative factors of disability revealed that strikingly 46% (Figure 3) of the people with locomotor disabilities to be polio victim, 10% did not know much about their own specific nature of disability although they had locomotor problem. Congenital amputee and lack of growth in the limbs (one/ two/ both) after birth accounted for 4% each; where as another 4% cases resulted from incidences of burn during some accident. In spite of so many initiatives taken up by the government polio still remains the single largest cause of locomotor disability. It gives us the indication that we need to look into the other issues which are acting as a stumbling block and preventing the government initiatives to funnel down to the local masses. Although a comparative analysis between 2002 and 2010 gives an indication that the number of people being given the polio vaccination has increased from 32% to 54% which is of course a positive indication (Halder, 2008, 2009).

Socio-economic Characteristics

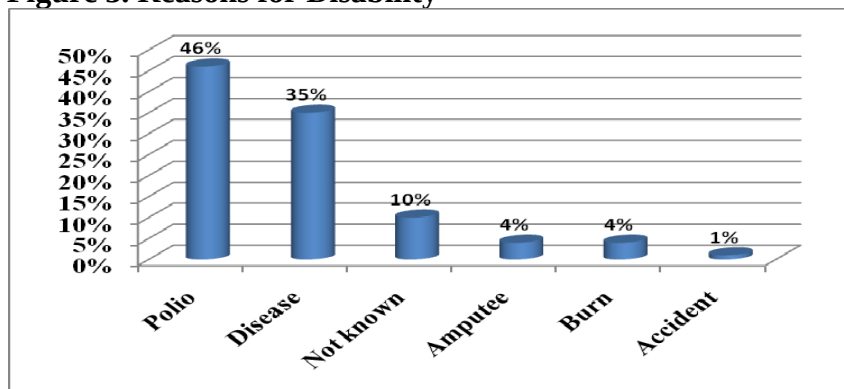
Our data revealed that about 78% of the people with disabilities belong to the moderate-lower income group. Large percentage of population lives in rural or semi urban areas were daily wage earners. About 53% of the challenged people belong to the lower income group. Large percentage of this population lives in rural areas. Poverty is the greatest cause and effect of disability. Malnutrition resulting from poverty is the greatest single cause of disability. Girls in rural areas are married at a very early age and thus they are not in a healthy state for multiple deliveries. Our data indicates that women who have greater control over household resources tend to be healthier and better nourished as do their families because they tend to spend more on the nutrition, health, and well-being of their households. In some areas, especially in South Asia, due to cultural norms pregnant women's are discouraged from eating nutrient-rich foods that are

thought to be harmful or taboo. To avoid the difficult labor women may be encouraged to consume less food during pregnancy so that they will have smaller babies, believing that smaller babies will pass easily through the mother's pelvis (Brems and Berg, 2000).

The analysis of the educational status of the parents of the locomotor disabled person revealed that mostly they belong to low education category with many even illiterate, thus orthodoxy, superstition engulfed their mind which made an impact on every aspect of their life. The lack of medical care in the initial phases of pregnancy was also a reason for this cause. A burning example of the orthodoxy, superstition and unawareness of the parents may be Mira Das, severely challenged with 90% disability in both the upper and lower limbs. She hails from very poor socioeconomic condition. She was not given any vaccination. When she was detected with polio the doctors advised for medicine but her mother did not know anything about polio and its consequences. Being unsatisfied she called local quack of her village who poured hot oil on the young baby in order to cure her. Immediately she developed blisters all over her body which was sufficient enough to take a toll of the child's condition. Her illiterate parents later on realized their fault and provided all sort of support but it was too late. It appears that poverty and low education was the root cause of disability in most cases.

Disability due to Diseases

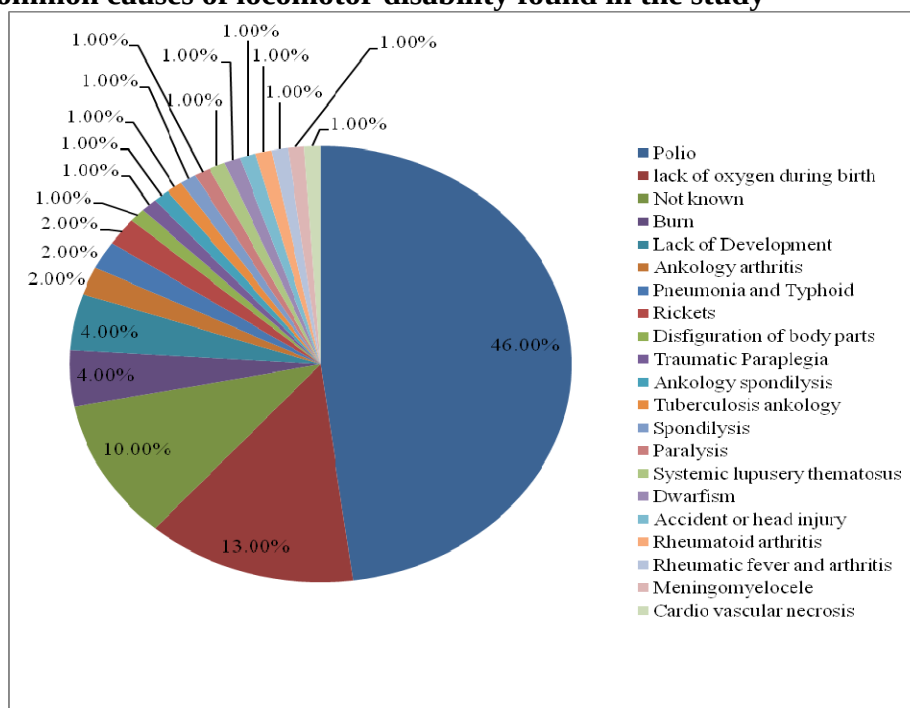
Figure 3. Reasons for Disability



Strikingly 35% of the people with locomotor disabilities was due to congenital and various other diseases (Figure 3). During our study, we dig deeper into the nature and causative factors of these diseases which resulted in locomotor disability and found that in some way these diseases are related to poverty. The likelihood that these disabled people will experience poverty is greater than the able-bodied population. The obvious reasons which can be attributed are exclusion and discrimination; unequal access to food, health care and education; and reduced capabilities for work. It is quite shocking to note that 13% of locomotor disabilities in the study were due to lack of oxygen supply during delivery of the child. Rickets caused 2% of locomotor disability in the initial stages of development and another 2% were due to Ankylosing spondylitis. Among the other reasons were 1% each due to dwarfism, accidents, paralyzes, systemic lupus erythematosus, ankylosing spondylitis, traumatic paraplegia, disfiguration of body parts from birth, cardiovascular necrosis, meningomyelocele, rheumatic fever and arthritis.

The NSSO Survey on Disability (2002) reported about 45% of the locomotor disability were attributed to deformity of limb, more than 20% to dysfunction of joints of limb, another 15% to paralysis, 10% to any other deformity of body and 8% to loss of limbs. Deformity of limb was more prevalent in the rural sector whereas a higher percentage of persons were locomotor disabled due to dysfunction of joints of limb. The present study reveals that there should be more options in order to explore the wide range of type and causes of locomotor disability prevalent in society, the complexity of which seems to be increasing with years.

Figure 4. Common causes of locomotor disability found in the study



The ability to work is an important aspect of psychosocial functioning, which reflects social status, marital status, self-esteem and the opportunity to socialize. The cost of work-related disability is large since it affects their quality of life and ability to work, resulting in substantial direct and indirect costs to the individual and society. Although most of the diseases in our study accounts for only 1-2%, but they are significant if we correlated our sample size 200 with the current 1.21 billion population of India. The diseases that we found in our study (Figure 4) which resulted in locomotor/physical disability have been categorized in the subsequent section for ease of understanding.

Disability due to autoimmune diseases and abnormality in bones and joints

The indirect costs related to disability greatly exceed the direct cost of medical care. Rheumatoid arthritis (RA) is a chronic, systemic, inflammatory, progressive disease occurring in about 0.75% of the adult population in India (Malaviya, 1993). In our study all these factors accounted for 2% in total (Figure 4). Arthritis or rheumatism is a group of conditions involving damage to the bones, joints, muscles, tendons. Arthritis is gender biased; with 60% of the people with arthritis are women. A study designed to assess the health-related quality of life of patients with RA in India affirm the need of awareness among the population regarding improvement in the quality

of life with early intervention needs to be emphasized (Mathew, 2009). According to a study conducted in 2010 (Sokka, 2010) among 32 countries, 16 with high gross domestic product (GDP) (>24K US dollars (USD) per capita) and 16 low-GDP countries (<11K USD), was analyzed for work and disability status at onset and over the course of rheumatoid arthritis (RA) and their clinical status. It was concluded that work disability remains a major problem and high among people with (RA) during this millennium. In low-GDP countries, people remain working with high levels of disability and disease activity with poor clinical status than patients who had stopped working in high-GDP countries. Cultural and economic differences between societies affect work disability as an outcome measure for RA. There are different forms of arthritis such as osteoarthritis/spondylitis, rheumatoid arthritis, fibromyalgia and related autoimmune diseases.

Our study depicted 1% of the people with locomotor disabilities were suffering from Ankylosing spondylitis (AS), which is a long-term disease that causes inflammation of the joints between the spinal bones, and the joints between the spine and pelvis, which may limit work ability or restrict vocational options and affect interpersonal relationships. A research on US population (Ward, 2008) indicates that AS has important influences on family life as well as on work ability. The risk of never marrying was similar among those with longstanding and earlier AS and among men and women, indicating that having the diagnosis alone may be an important mediator of this outcome. Patients with AS often have concerns about having their children who might also be affected by AS. The study found that pregnancy and childcare concerns are likely more important factors influencing the decision to have children than concerns about passing AS to future generations.

Traumatic paraplegia results from fracture dislocation of the spine and has significant worldwide health and social impact. We found 1% of the people with locomotor disabilities were suffering from Traumatic paraplegia. Spinal cord injury has an incidence between 10.4 and 59 individuals per million inhabitants per year (Wyndaele and Wyndaele, 2006). The injury damages the spinal cord, and consequently always affects both sides of the body. While some people can walk to a degree, many are dependent on wheelchairs or other supportive measures. Currently, only limited treatments to enhance spinal cord function are available in the clinical setting (Hawryluk et al., 2008). A hospital-based study from India (Agarwal, 2007) about the overview of the characteristics of patients with spinal injuries in this hospital revealed that the ratio of men to women who sustained spinal injuries was 3.6:1, with maximum number of patients was in the age range of 20-39 years.

In autoimmune diseases such as systemic lupus erythematosus, our own the immune system attacks the body's cells and tissue, resulting in inflammation of joints and tissue damage. The disease occurs nine times more often in women than in men, especially in women in child-bearing years ages 15 to 35 (Wallace, 1997). A study from south India depicted that patients often experience long-term morbidity that can adversely affect quality of life and ability to work, resulting in significant burden on the individuals and their family members (Robert, 2006). According to the American Autoimmune Related Diseases Association, Inc. (AARDA), autoimmune disease is now the third major category of illness in the United States and many industrialized countries, following heart disease and cancer, and it is the fourth leading cause of disability among women in the United States.

Dwarfism itself is not a disease. A dwarf is a person of short stature with arms and legs short in comparison to your head and trunk. According to a recent study by Dr. Rauch (2011) their mental development is usually borderline or within the low normal range but cerebrovascular events that are common in childhood can result in significant cognitive impairment and cerebral palsy. We found 1% of the people with locomotor disabilities were suffering from Dwarfism. Achondroplasia is a genetic condition that causes about 70 percent of all dwarfism.

Diseases that can be related to malnutrition, unhygienic condition/environment or illiteracy

The nature and causative factors of the diseases which resulted in locomotor disability due to malnutrition, unhygienic condition/environment or illiteracy in some way are related to poverty. Polio is a highly infectious disease caused by a virus, which invades the nervous system, and can cause irreversible paralysis (usually in the legs). There is no cure for polio; it can only be prevented by giving Polio vaccine. Since the Global Polio Eradication Initiative was launched, the number of cases has fallen by over 99% from an estimated 350 000 cases in more than 125 endemic countries in 1988 to 1288 reported cases in 2010 (WHO, 2010). The analysis of our data revealed that staggering 46% (Figure 3 and 4) of the people with locomotor disabilities to be polio victim.

We found 1% of the people with locomotor disabilities were suffering from Myelomeningocele, which is a birth defect in which the backbone and spinal canal do not close before birth. Some defects can be repaired surgically, but brain or spinal cord damage is usually permanent. As the life expectancy of these individuals' increases, Dr. Dicianno et al. (2008) reviewed the last 20 yrs of literature pertinent to the rehabilitative care of this, summarizing current evidence-based practice, key areas in which scientific evidence is lacking and future direction of research. Low levels of folic acid in a woman's body before and during early pregnancy are thought to play a part in this type of birth defect. The vitamin folic acid (or folate) is important for brain and spinal cord development.

Rickets is a disorder caused by a lack of vitamin D, calcium, or phosphate. It leads to softening, weakening and deformity of the bones. Vitamin D is absorbed from food or produced by the skin when exposed to sunlight. Not getting enough calcium and phosphorous in your diet or malnutrition can lead to rickets. A study by Balasubramanian et al. (2003) showed that in India, perhaps due to cultural habits limiting exposure to sunshine pubertal girls are most at risk of vitamin D-deficiency rickets. For calcium-deficiency rickets, in India, there is evidence that young children need more calcium and 1000 mg of calcium as a daily treatment was found to be adequate. In our study 3% of the people with locomotor disabilities were due to Rickets and other disfiguration of body part. Rickets is among the most frequent childhood diseases in many developing countries.

Rheumatic fever (RF) is an inflammatory disease that may develop after an infection with *Streptococcus* bacteria. Although it has become much less common in developed country but it is still a large problem in many developing countries. The disease can affect the heart, joints, skin, and brain. The impact of the disease through disability, premature deaths and economical losses is substantial at the national level. There are plethora of literature in Indian medical journals describing an undeniable relationship between the incidence of RF and living standards. The parts of the country with the highest prevalence today are also those regions with the poorest

healthcare infrastructure (Routary, 2003; Stollerman, 2001; Tandon, 2004). Rheumatic fever mainly affects children ages 6-15. Rheumatic fever used to be a leading cause of death and disability in children. Our data revealed that 1% of the locomotor disabilities were due to Rheumatic fever.

Conclusion

The United Nation has established Millennium Development Goals in 2000 to improve women's and adolescent girls' nutrition (Ransom and Elder, 2003). The objective is to challenge nations to create effective interventions not only improves the health of girls and women, but far-reaching intergenerational effects that can help countries develop. Public health systems should encourage households to meet the dietary needs of women and adolescent girls throughout their lives, and ensure their access to high-quality health services, clean water, and adequate sanitation. Adequate nutrition is important for women not only because it helps them be productive members of society but also because of the direct effect maternal nutrition has on the health and development of the next generation. There is also increasing concern about the possibility that maternal malnutrition may contribute to the growing burden of cardiovascular and other non communicable diseases of adults in less developed countries.

Preventing malnutrition requires a political commitment. Policymakers should ensure that girls have access to education. Our education curriculum should focus on increasing women's knowledge about nutrition and their decision making power. Such policy measures can help increase women's age at first pregnancy, an important determinant of maternal health and child survival, and can encourage women to space their births. The government should record the prevalence of birth weight, the number of children who are underweight and how many of them are girls, anemia prevalence among adolescent girls and women of reproductive age from time to time. Nutrition is affected by a complex set of factors, governments and programs are most likely to succeed in addressing malnutrition if they approach the problem from a variety of angles.

Women who have greater control over household resources tend to be healthier as do their families because they tend to spend more on the nutrition, health, and well-being of their households. Microfinance programs provide women with small loans for their businesses, are another way to raise women's status and improve their ability to provide for themselves and for their families. In Ghana, for example, an innovative health program combined health education with access to microfinance. Women received village banking services, including access to loans, as well as education about breastfeeding, child nutrition, diarrhea treatment and prevention, immunization, and family planning practices. An assessment conducted three years after the program began found that participants' 1-year-old children were healthier and better nourished than those of nonparticipants (World Bank, 2002).

Apart from diseases that can be related to malnutrition, unhygienic condition or illiteracy; there are other diseases that can be lead to disability such as autoimmune diseases; and abnormality in bones and joints. These problems may limit work ability or restrict vocational options for the patients. The economic costs associated with work disability in patients can be substantial, and indirect costs due to lost wages are greater than direct medical costs. The ability to work is an important aspect of psychosocial functioning, which reflects social status, marital status, self-

esteem and the opportunity to socialize. The presence of a disability can trap people in a life of poverty because of the barriers disabled people face to taking part in education, employment, occupational mobility, low family income, living in rural unhygienic conditions, social activities, and indeed affect all aspects of life. In India the awareness among the population regarding improvement in the quality of life with early intervention needs to be emphasized. The physical damage caused by the illness can well be followed-up and curtailed. However, the psychological and social morbidities very easily evade the eyes of the clinician. Thus, improved work disability outcomes will require attention to social, economic, and political issues and wider physician and public education in addition to improved medical management of the disease. An integrated approach is required, linking prevention and rehabilitation with empowerment strategies and changes in attitudes.

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