Disability in Saudi Arabia

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ABSTRACT

الإعاقة مصطلح يشير إلى ظاهرة معقدة ومؤثرة متعددة الأبعاد تعيق أنشطة الحياة الرئيسة بشكل جوهري ومقدرة الشخص على التكيف والإندماج في المجتمع. تشير تقارير منظمة الصحة العالمية بأن 15% من سكان العالم يمارسون حياتهم مع أنواع محددة من الإعاقة و 2-4% واجهوا صعوبات جوهرية في العمل. في المملكة العربية السعودية هنالك القليل من الأبحاث عن أسباب حدوث وانتشار الإعاقة والعديد منها موجه إلى الأطفال المعاقين. كما أن هنالك العديد من المعوقات في إجراء أبحاث الإعاقة في السعودية. نستعرض في هذا التقرير الوضع الحالي للإعاقة وأبحاث الإعاقة والتأهيل في المملكة العربية السعودية من الأدبيات المنشورة.

Disability is a complex, influential, dynamic, multidimensional challenge, and it can substantially limit major life activities of human beings and their ability to integrate/reintegrate into society. According to the World Health Organization reports almost 15% of the world's population lives with certain types of disability, of whom 2-4% experience substantial difficulties in functioning. In Saudi Arabia, very limited research has been conducted on the prevalence and incidence of disability, and most of this is on disabled children. There are several difficulties associated with conducting research on disability related issues in Saudi Arabia. Here, we review the current situation of disability, disability research, and rehabilitation in Saudi Arabia from the published literature.

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Disability is a multidimensional and complex concept and it is substantially limits a major life activity of a human. It may affect the persons and his family. This will negatively influence the person, family, and the whole society if the system does not support them.[1] Almost each person will be temporarily or permanently impaired at some point in life, and those who survive will experience many limitations in function and participation in the society. As per the Labor and Workman Law of Saudi Arabia, a "persons with disability" is defined as "any person whose capacity to achieve and continue a suitable job has actually diminished as a result of a physical or mental infirmity." Most extended families have a disabled person, and the non-disabled persons take the responsibility and care for their lives.[1-3] Many countries face the moral and political issue of how best to include and support people with disabilities. This issue will become more acute as the demographics of societies change and more people live in their old age.[4] In developed countries, persons with disabilities have no equal access in the society or even in other services such as health care, education, employment opportunities, and sometimes they were disregarded from everyday life activities. Despite the magnitude of the issue, awareness of and scientific information on disability issues are deficient. In addition, there was no agreement concerning its definitions, internationally comparable information, distribution, and trends of disability. The reasons might be financial, social isolation and/or accessibility. There is a limited number of published literatures addressing the policies and responses concerning people with disabilities.[5]

Persons with disability may require a continuous health care support, regular medical check up, home based support and other supportive services including equipments provision, which make the care programs very costly. Some patients need to be relocated in nursing homes due to their conditions and lack of proper home care. The management of people with disability may needs specialized medical, social, psychological, vocational, and other rehabilitative care.[6-8] The love and support of family plays an important role in taking care

of them. The cost of preventive efforts is significantly lesser than the management of expected complication; thus cost-effectiveness favors the prevention approach.[9] The earlier the medical/rehabilitative care are delivered, the more the chance of reducing its effect of disability and it reduces the chance of expected complication, and the more the quality of life of the person will improve.[5]

Country-reported disability prevalence. Several countries have been collecting prevalence data on disability through consensus and surveys, with many having moved from an "impairment" approach to a "difficulties in functioning" approach. Estimated prevalence rates were vary widely across within countries.[10-12] Most developing countries reported that disability prevalence rates were below those reported in many developed countries, because they collect data on a narrow set of impairments, which yield lower disability prevalence estimates.[5] However, many countries are using International Classification of Functioning, Disability and Health (ICF) framework and related questions in their national disability surveys and consensus.[13-17] In Kingdom of Saudi Arabia (KSA), very limited research has been conducted on the prevalence and incidence of disability, and most of them were on disabled children.

Global estimates of disability prevalence. Several definitions exist worldwide with no consensus on a standard definition being established. According to the World Health Organization (WHO), disabilities are an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a struggle encountered by person in executing a task or action; while a participation restriction is a problem experienced by an individual in the involvement of life situations. Disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he/she lives.[18]

The World Health Survey (2004) conducted by WHO on 59 countries who experienced significant functioning difficulties reported that the average prevalence of disability in adult population was 15.6% (4.2 billion people), ranging from 11.8% in higher income countries to 18% in lower income countries.[5,19] The prevalence level for adults with very significant complications was estimated at 2.2% (92 million people).[5] The analysis of the Global Burden of Disease estimates that 15.3% of the world population (978 million people of the estimated 6.4 billion)[20] had "moderate or severe disability", while 2.9% or approximately 185 million experienced "severe disability".[5]

Disability in Islam. Islam, as a divine religion is against discrimination whether based on any racial, gender, color, or ability.

In the Holy Book of Qur'an, Allah the Almighty has assured us (translation of meanings) in Surah Al-Inshirah that "with every hardship there is relief," (94:5) and in Surah Al-Baqarah that "Allah burdens not a person beyond his scope" (2:286). In Surah Yusuf the Qur'an states, "truly no one despairs of Allah's soothing mercy, except those who disbelieve" (12:87).

Human's life is a full record of hardships, obstacles, struggle and tribulations from birth to death. In this sense, Allah says: "*We create man from a drop of thickened fluid to test him*" (Al-Insaan:2). It is also an important thing that Almighty Allah, when depriving a person of certain ability or gift, compensates him/her for it, by bestowing upon him/her other gifts by which he/she outshines on others. It is confirmed that people who are deprived of sight, have best insight and have very sensitive ears and can hear very low sense of sounds and touch. People with physical disability possess excellent memory capabilities as compensated.

During the pre-Islamic period, the Arab Society has used to disregard the disability of people mainly social isolation and prevention to lead normal lives. They may have a reason of ridicules. Also, people of Madinah used to prevent the limping and blind people from sharing food with them, because they are deemed and repulsive. On this, Allah the Exalted revealed what it means in the holy Quran stated that, no blame is there upon the blind nor any blame upon the limping nor any blame upon the sick nor on yourselves if you eat from your houses, or the houses of your fathers, or the houses of your mothers, or the houses of your brothers, or the houses of your sisters, or the houses of your fathers' brothers, or the houses of your fathers' sisters, or the houses of your mothers' brothers, or the houses of your mothers' sisters, or (from that) whereof you hold the keys, or (from the house) of a friend. No sin shall it be for you whether you eat together or apart. But when you enter houses, salute one another with a greeting from Allah, blessed and sweet. Thus Allah make it clear His revelations for you that happly you may understand"(An-Nur 24:61). There are several companions (Sahaba'a) with special needs for Prophet Mohammed (Peace Be Upon Him)

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who has participated in announcing Islam (Dawa'a) and even joining in battlefield. Their work was very recognized by him and he looked at them same like other Sahaba's.

Disability in KSA. Saudi Arabia is the largest country in the Middle East occupying approximately four-fifth of the Arabian Peninsula and has a population of approximately 28,376,355.[20] Most (65%) of the Saudi population is concentrated in 3 main administrative region namely, Riyadh, Makkah and Eastern Province. In 2011, KSA has a significant increase in the healthcare budget from SAR30 billion in 2008 to SAR68.7 billion in 2011 (**Table 1**).[21]

Disability is one of the most imperative social and economic medical issues in KSA. Compared to the developed countries, the incidence and prevalence of impairment, disability and their socio-demographic properties are unavailable, due to lack of appropriate studies in the specified area.[22] Despite the growing awareness, limited research has been carried out to determine the pattern of disabilities in KSA.[23]

Hurdles in disability research in KSA. Depending upon the definition used, it is estimated that 3.73% of the population has functional disabilities, which limit their independence.[24] But, the countrywide data from demographic survey (door to door national census) indicates that approximately 135,000 or nearly 0.8% of the total Saudi population has disability. These differences are mainly due to definition and under reporting of the burden. The main causes of disabilities are cerebral palsy and developmental delay followed by road traffic accident. The main care gaps are low access to poor families, low service coverage (no long term care, no palliative), and low quality of services in public agencies. In order to address disability related issues, it is imperative to make better use of the existing information on the prevalence of disability. Also, it is essential to address the gaps in current knowledge on the nature of disability.

There are many difficulties associated with conducting research on disability related issues in KSA. Some cultural issues were people feel ashamed of having disable relative and tend to avoid participation in research.[25] Their opinions were based on a simple notion of disability that includes helplessness, continuing dependence, being home-bound, low quality of life, and deficiency of productivity.[24] The important barrier is the lack of epidemiological research on the general population where most disability research were carried out in Saudi Arabia on disabled children.[6,26,27] Another barrier is the limited nature and extent of information about disability, studies were conducted as surveys, and inadequate research on initial identification of disability.[26,28-30] Further, there is no standard outcome measure used to assess or identify the degree of disability.

Table 1 - Population, number of hospitals, and available beds in the Kingdom of Saudi Arabia.[22]

Saudi Arabia	Numbers
Population	28,376,355
Number of hospitals	415
Number of beds	58,696
Hospitals affiliated to MOH	251
Number of beds in hospitals affiliated to MOH	34,450*

MOH - Ministry of Health, *10,948 beds in other governmental sectors

Poor data collection procedures are also the major problem in Saudi disability related research. Nationwide studies reported that the incidence of disability in cities is higher than in rural areas[28,29] and this is in contrast to the fact those medical services and health education programs are well in large cities than in rural areas. Essentially, there is no specialized institute for dealing with or collecting data such as those in the USA where specialized studies offer a good basis for understanding disability statistics.

Leading causes of disability. Road traffic accidents, stroke, cerebral palsy, head and spinal cord injuries, infection and inflammation are the major causes of mortality, hospitalization, and chronic disability in KSA.[20,21] Furthermore, the incidence of consanguineous marriages is too high. A study reported that the overall prevalence of consanguinity was 56%. The first-degree cousin consanguinity was 33.6% being more frequent than all other relations (22.4%). As a result, the risk of disabilities associated with genetic causes is also significant.[31]

Psychological impact of disability. Psychological investigation of the past decades has addressed some of the difficulties encountered by the disabilities in society.[32] Decades ago it was thought that the number of persons with disabilities in KSA was quite low. This is because some families tend to leave them behind closed doors. People with disability were ignored to attend the social gatherings and even relatives can hardly see the disabled people. They may be exposed to society only when sick and during a hospital visit. They are occasionally a stigma for the families. Further, disabled girls were hidden away in home as they could be a reason for his/her sisters not getting married as people will avoid approaching the family. The term disability is not acceptable by the society nowadays and most agencies avoid this term, rather they use the term "people with special needs." Some people avoid this term as a protective strategy for the person and/or family. Denial

could be the whole cause of avoiding this term. It was reported that the anxiety and depression rates were higher in mothers with female disable children.[32] It used to be thought that all types of disabilities is hereditary even if it was acquired during adulthood. The problem started when they are walking and in a wheel chair drooling in public. Adjustment period to acquired disability usually takes time during the sub-acute phase (for the acquired disability) as many are hoping to get rehabilitated, but as soon as a person accept the disability with the tendency of being more strict to religion in both gender. The concept of rehabilitation in most people in KSA is being interpreted in the form of therapeutic "massage" only.

The risk of suicide attempts, and suicide ideation and suicide thought is lesser in acquired physical disability such as spinal cord injury (SCI) in KSA. Person with SCI has committed suicide due to their paraplegia or quadriplegia is rare in KSA. On the other hand, following rehabilitation many persons with paraplegia or quadriplegia completed their higher education in KSA and tend to be more attached to religion than in the pre-morbid status. Extended families is still being practiced and it is part of Islamic tradition. Because of this reason, other patients tend to adjust quickly after the disability. The only disadvantage is the overprotection, which makes the person more dependent on others even after being rehabilitated and achieved self-independence. In fact, patients with difficulty in ambulation wanted the whole therapy to help them walk and will not contribute a lot of attention to self-care training. They would argue that their beloved one would take care for them. Sometimes a recruited caregiver will be vacated to provide the activities of daily living even if the patient is living with the family. Workforce in this regard is not expensive and affordable.

Important existing research on disability in KSA. In KSA, there is a lacunae in research related to prevalence and incidence of disability and most disability research were on disabled children.[28,29] A study from Qaseem reported that the incidence of physical disability (1.7%) was higher in children as compared to mental retardation (1.4%).[30] A national survey was conducted among 60,630 children reported that 3,838 (6.33%) children were reported having a disability. The survey also reported that the highest ratio of handicapped children was in Jazan region (9.9%) and Riyadh had the lowest (4.36%). The most common disability was physical disability (3%) followed by learning disability (1.8%).[29] Further, the highest proportion of disability was found among children of disabled parents, later-in-life pregnancies and mothers had not received medical care and required vaccination during pregnancy.[29] The prevalence of neurological disorders in Saudi children were 45,682. Of them, 313 had chronic neurologic disorder representing a prevalence rate of 68.5 per 10,000 children, which is the highest among all chronic diseases in children. Mental retardation is the most common neurologic disorders with a prevalence rate of 26.3/10,000 and cerebral palsy was 23.4/10,000. It is also found that the major neurologic disorders were the most common pediatric chronic disorders in KSA.[33] A cross-sectional study reported that trauma as an etiology of disability was found to be more common than non-traumatic incidents among males and middle age patients (16-45 years). Traumatic accidents mostly result in quadriplegia (72.8%).[34]

The lack of common measure, definition of disability and the limited epidemiological research in KSA was difficult to assess the burden although it is commonly acknowledged that burden is generally high due to social and environmental factors. According to WHO, the number of those who suffer physical, sensory, intellectual or mental disability to be 15% of the population, although individual countries have given numbers that vary from 4-20%. Based on the findings of WHO, 15% of the disability rate in 2012, it is estimated that 4,070,546 people in KSA require rehabilitation services. If we apply the 3.73% disability rate from KSA surveys, it is estimated that 1,012,209 people suffer some form of disability in KSA.

Policies and practices on disability in KSA. Kingdom of Saudi Arabia is based on the Islamic Sharia, which emphasizes human rights. Persons with disabilities have the right to live with dignity and benefit of welfare.[35] A sound living and the ability to engage into all sectors of society assured through providing rehabilitation and healthcare services for them.[36] On the other hand, there were limited reliable information on disabilities such as numbers, types of disabilities, amputee population, or geographical distribution in annual report of Ministry of Health (MOH). Most of the specialized organizations become more sensitive in reporting the statistics on disabled persons due to security reasons, and it was noticed that the reported data are vastly underestimated, due to poor reporting.[35]

Institutions for persons with disabilities are largely available in urban than rural areas, with an uneven distribution of facilities irrelative to persons with disabilities distribution. Many disabled persons suffer from marginalization due to some reasons such as lack of understanding of the nature of the disability and the fear of dealing with it, being ashamed from the

involvement with their community, poverty, living in remote places, lack of understanding of the ways of dealing with such cases, and ignorance of the role assigned to health facilities.[35]

Medical services and rehabilitation. Health services in KSA are provided mainly by the government through the Ministry of Health (MOH). In 2011, the total number of hospitals in KSA reached up to 415 hospital with 58,696 beds and 5 additional hospitals were added during the year. On this data, 251 were affiliated by the MOH in various regions (34,450 beds including 10,948 beds in other governmental sectors).[37-39] Most of the secondary healthcare services were provided by the general hospitals.[37-39] The require for rehabilitation services is imperative for people who have sustained severe injury often due to trauma, stroke, infection, tumor, surgery, or progressive diseases in order to improve their quality of life. However, the require for rehabilitation crosses all age groups, although the type, level, and goals of rehabilitation differ. People with severe impairments, often elder people, have different goals, require less intensive or active rehabilitation or a longer duration of rehabilitation, and required different types of therapy (passive rehabilitation) than younger people.[39] Also, gender is a significant factor that must be considered in Muslim societies. There are separate rehabilitation facilities for males and females but there are no statistics or data to justify the number or distribution of these facilities. Many vocational rehabilitation trainees are male, while the majority of social rehabilitation intentions on persons with severe disabilities or overlapping are females.

Over the last 2 decades, the MOH has established several rehabilitative services for persons with disabilities and other residents in the country. Most of these programs offer physical, occupational, speech and hearing therapy as well as prosthetic and orthotic services within the existing modern and sophisticated health care service system and infrastructure. Rehabilitation programs and facilities, as an integral part of modern health care delivery services, have received due attention by government authorities, with services being made available to all citizens and residents.[35]

Modern medical rehabilitation in KSA started in the early 1960's following an outbreak of poliomyelitis with many victims, mainly children. This resulted in mainly paralysis or weakness of the lower extremities. Most of the affected people, who survived, were left with some sort of disability largely related to mobility. Because there was no medical rehabilitation department in the few hospitals present at that time, most of the patients were sent abroad by the government for surgical correction of deformity and/or fitting with braces to help in walking. Others received some sort of physiotherapy, but that was limited to patients living in major cities.[39] In early 1970's, the government launched some prosthesis and orthotic centers in some of the MOH hospitals, but that focused only on braces or caliper fitting. In the beginning of the 1980's, the Ministry of Defense and Aviation (MODA) commissioned many medical rehabilitation centers within the Military Hospitals. Some private hospitals also allocated some rehabilitation beds for people who sustained work related disability and were insured by general organization for social insurance. Only in the beginning of the 21st century when real medical rehabilitation centers were opened in few of the MOH hospitals. In addition, there have been some private for non-profit centers, which opened, including Sultan Bin Abdulaziz Humanitarian City.[39] Presently, there are many rehabilitation hospitals/ centers, mainly in large cities, such as Rehabilitation Unit of Prince Sultan Military Medical City of Riyadh (Formerly known as Riyadh Military Hospital), Rehabilitation Unit of King Abdulaziz Medical City, National Guard (Riyadh), Rehabilitation Hospital of King Fahad Medical City (Riyadh), King Saud Medical Complex, Rehabilitation Hospital of Al-Hada Military Hospital (Taif) and Riyadh Care Hospital (Private), and Abdulatif Jameel Rehabilitation Center (Jeddah). Additionally, Disabled Children Association has 7 centers and provides medical, social, and vocational services for children. Moreover, most of MOH hospitals in different regions of KSA have Medical Rehabilitation Department. Their services are mainly physiotherapy for outpatients. There is still a greater necessity for more rehabilitation centers due to the following reasons; growing population, increased road traffic accidents with the consequences of traumatic brain injuries, spinal cord injury, amputation fractures, and others.[39-41] There has been a change in life style and increased incidence of diabetes mellitus, hypertension, ischemic heart disease, and stroke.[5] In addition to that, there are an increased number of children born with cerebral palsy or hereditary diseases because of the consanguinity.[39]

In KSA, medical rehabilitation has to be advanced as 30% of patients who may be admitted to hospitals are in need of some rehabilitation.[39] This would need an immediate referral of the patients in need to the Rehabilitation Medicine services, but as this approach is going to be new, it may get some non-acceptance by some of the colleagues in other medical specialty.

Need of medical rehabilitation hospitals/beds in KSA. As the demographic key indicator of the Saudi census, being a young dominant population, it is

estimated the need of medical rehabilitation services ranges from 10-30% of total admission to the hospitals. If we consider a conservative number, and knowing that in the last cases of MOH, 3,027,575 were admitted to the hospitals within KSA, means that at least 302,757 needed some medical rehabilitation. However, currently, there are approximately 700 beds allocated for medical rehabilitation in KSA. Although some patients may have exposure to rehabilitation services such as physical therapy or speech language therapy, an estimation of no more than 1% of them received the prober active medical rehabilitation programs. The medical rehabilitation program could be carried out in a rehabilitation hospitals/specialized rehabilitation units, outpatients department (visits per service or day care) or as home health care program. Our estimation is also that there is a need of at least 30 rehabilitation beds/100,000 populations which means at least 8000 active rehabilitation beds. It is known that the current numbers of beds are 20.7/10,000 population (207/100,000), which is much below than what the government is aiming for and there is a plan to increase the number by 66,000 beds in the coming 7 years. Rehabilitation should be started as early as possible. This could be acute or sub-acute rehabilitation programs and as inpatients or outpatients. It is estimated that the number of rehabilitation beds needed all over KSA to be approximately 8000 beds based on developed countries benchmark. The future can see a wide range of rehabilitation centers whether by the different government authorities or through public-private partnership (PPP). This of course would need a good deal of fund by the government.

The legislation of disability and disability code. In 1987, the legislation of disability (LD) passed as the first legislation for people with disabilities in KSA. The LD contains important provisions that assurance persons with disabilities rights equal to those of other people in society.[42] In 2000, the disability code was passed by the Saudi government to pledge that people with disabilities have access to free and appropriate medical, psychological, social, educational, and rehabilitation services through public agencies.[43] The above guiding principles support the equal rights of individuals with disabilities in obtaining free and appropriate education and medical facilities. However, these laws were passed a decade ago and not practiced well in KSA. In fact, the lack of the effective implementation has created in a gap between the framework of these laws and the provision of services, resulting in a lack of special education services for persons with disabilities.

Hospital length of stay and quality of life of disabled persons. In KSA, very limited research has been conducted on the hospital length of stay (HLOS) and quality of life (QOL) of disabled persons. Recent research reported that the HLOS of traumatic spinal cord injured patients is 58.8 days and non-traumatic spinal cord injured patients is 46.2 days.[44] The spinal cord injury (SCI) in KSA affects mainly the young male population due to road traffic accident (RTA).[45] The spinal cord injured patient's quality of life (QOL) is significantly affected and/or hampered by factors such as accessibility, financial status, and employment.[46]

Previous research reported that stroke in Saudi population, causes substantial disabilities in an elderly population that is cared for mostly by their families. Apart from its significant impact on the professional and social status of the patients, it creates a major load on their families.[47] A significant percentage of elderly, stroke-related disabilities are expected to afflict tens of thousands in KSA.[47] In terms of cost and resources, the anticipated burden of this group of disability on society and health services is staggering. In addition, the hospital costs and length of stay also increase the burden of the patients' families and the recent study reported that the HLOS of Saudi stroke patient is 45 days.[48] Another recent study reported that the pediatric neurologic disorders such as cerebral palsy are the common neurologic disorders among Saudi children, which considered as an important reason of long-term disability.[33] A study reported that the HLOS of pediatric neurologic disorders in KSA is 32.2 days.[49] The brain injury also causes substantial disabilities in KSA and the HLOS of traumatic brain injured patients is 58.2 days and non-traumatic brain injured patients is 43.5 days.[51]

Special education services. In 1958, the special education services for disabilities was initiated in KSA when few students with blindness received their education in schools known as "scientific institutes".[51] The department of special learning to develop learning and rehabilitation services for 3 important categories of students with disabilities: those with blindness, deafness, and mental retardation were established by the Ministry of Education (MOE) during the year of 1962. Following this, in 1964, 3 institutes were set up in 3 cities: Makah, Aneaza, and Alhofouf for students with blindness.[51]

Currently, the MOE provides educational rehabilitation through educational institutions such as the Noor Institute for the Blind, Amal Institute for the Deaf and the Institute for the Mentally Retarded. Apart from these special schools, government-owned Social

Rehabilitation Centers and other institutes for social welfare provide educational rehabilitation for persons with disabilities in need.[35] Educational programs are also provided for the parents of children with disabilities and the majority of these programs are given by charitable organizations supported by the Ministry of Labor and Social Affairs. However, how effective and helpful these educational programs are in minimizing the impact of disabilities on the family and community and in changing the attitude of the community toward disabled people, are issues that are yet to be answered. Nevertheless, in the last decade, the practice of special education services for students with various disabilities in KSA has improved to support them in obtaining good quality education services in the least restrictive environment. In spite of this effort to improve services, more is needed to improve these services further.

In conclusion, the review reported that there is a lack of published research on disability in KSA. However, these research are greatly needed to plan for appropriate management programs, effective implementation of primary prevention strategies, and proper allocation of health resources in this area.

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