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DISABILITY AND AWARENESS, A CROSS-SECTIONAL STUDY IN A TERTIARY CARE,PHYSICAL MEDICINE AND REHABILITATION DEPARTMENT OF NORTH INDIA MEDICAL COLLEGE KGMU

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Abstract:
The present study was undertaken to study the awareness of orthopaedically disabled person admitted in department of PMR in King George's Medical University Lucknow Uttar Pradesh.

Aims and Objectives:
To study the biosocial profile of admitted patients and to assess the awareness of disabled persons about the facilities being provided to them by state government of government of india.

Introduction:
It has been felt that differently-abled persons need special arrangements in the environment for their mobility and independent functioning. It is also a fact that many institutes have architectural barriers that disabled persons find difficult for their day-today functioning. The colleges are expected to address accessibility related issues as per the stipulations of the Persons with Disabilities Act 1995, and ensure that all existing structures as well as future construction projects in their campuses are made disabled friendly. The institutes should create special facilities such as ramps, rails and special toilets, and make other necessary changes to suit the special needs of differently-abled persons. The construction plans should clearly address the accessibility issues pertaining to disability. Guidelines on accessibility laid out by the office of the Chief Commissioner of Disabilities.

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Differently-abled persons require special aids and appliances for their daily functioning. These aids are available through various schemes of the Ministry of Social Justice and Empowerment. In addition to the procurement of assistive devices through these schemes, the higher education institute may also need special learning and assessment devices to help differently-abled students enrolled for higher education. In addition, visually challenged students need Readers. Availability of devices such as computers with screen reading software, low-vision aids, scanners, mobility devices, etc., in the institutes would enrich the educational experiences of differently-abled persons. Therefore, colleges are encouraged to procure such devices and provide facility of Readers for visually challenged students.

Disabled Population in India as per census 2011 (2016 updated) – In India out of the 121 Cr population, 2.68 Cr persons are disabled which is 2.21% of the total population. Among the disabled population 56% (1.5 Cr) are males and 44% (1.18 Cr) are females.

Impairment concerns the physical aspects of health; disability is the loss of functional capacity resulting from an impaired organ. Handicap is a measure of the social and cultural consequences of an impairment or disability. The types of disability include loco-motor, paraplegia, cerebral palsy.

People with disabilities are more vulnerable than general population to a range of problem including fatigue, depression, and social isolation and have more limited access to health care. The inability to perform some key activities (e.g. basic mobility, feeding, personal hygiene and safety awareness) due to disability lead to ‘dependency’ – the need for human help (or care) beyond that customarily required by a healthy adult. Such kind of help is given by family members or other ‘informal’ care givers. Overall, a country is greatly affected by the increasing number of dependent people and would need to identify the human and financial resources to support them. This increase will occur more in the context of generally increasing population, and dependency ratios will increase modestly to about 10%. The dependency ratio would increase more in China (14%) and India (12%) than in other areas having more prevalence. The majority of people with disabilities find that their situation affects their chances of going to school, working for a living, enjoying family life, and living normally like other people.. Quality of life is compromised not only for the disabled person, but also for the family. The presence of one person with disability in a family has negative consequences of social stigma which affects the entire household. Social segregation of disabled person is also widespread. The mortality and morbidity among disabled is much greater as compared to people without disability. Although most of the disabilities can be prevented if proper preventive and rehabilitative measures of impairments are undertaken, **it is estimated that only 2% of people with disabilities in developing countries have access to rehabilitation and appropriate basic services**. The public health community has traditionally paid little attention to the health needs of people with disabilities. According to WHO, people with disabilities tend to seek more healthcare than people without disabilities. They also have more unmet needs. Recent surveys by WHO indicate that between 76 to 85% of people with disabilities in developing countries receive no care.

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The persons with Disabilities (equal opportunities protection of Rights and full participation) Act 2015 (PWD Act) is the landmark legislation for the disabled in India. This is possible only if the concerned person is aware of his rights and knows how to go about it. Therefore it is necessary to frequently assess the awareness of this act among the disabled and beneficiaries. No such study has been conducted in central Uttar Pradesh.

The purpose of this study is to understand the disability, awareness and rights of PWD in PMR department of KGMU Lucknow,

There are many measures initiated by Ministry of Social Justice and Empowerment and Ministry of Health and Family Welfare in India.

1. District Rehabilitation Center (DRC) Project started in 1985.
2. Four Regional Rehabilitation Training Centers (RRTC) have been functioning under the DRCs scheme at Mumbai, Chennai, Cuttack, and Lucknow since 1985 for the training of village level functionaries and DRCs professionals, orientation and training of State Government officials, research in service delivery, and low cost aids. Apart from developing training material and manuals for actual field use, RRTCs also produce material for creating community awareness through the medium of folders, posters, audio-visuals, films, and traditional forms.
3. National Information Center on Disability and Rehabilitation
4. National council for Handicapped Welfare
5. National Level Institutes—NIMH, NIHH, NIVH, NIOH, IPH.
6. A new scheme District Disability Rehabilitation Centre for persons with disabilities launched by the Hon'ble Minister of Social Justice and Empowerment, Government of India in Jan/Feb. 2000 is a step towards providing rehabilitation services and implementation of Persons with Disability Act. 1995. The Government has decided to set up District Disability Rehabilitation Centres (DDRCs) in a phased manner. Presently, 199 DDRCs have been sanctioned and 100 new DDRCs are to be set up during the remaining two years of the 11^{th} Plan. The DDRCs were established with the objective of providing comprehensive services to the persons with disabilities at the grass root level. The services include awareness generation, survey, identification and early intervention, counseling, assessment of need for assistive devices, provision/fitment of assistive devices, and their follow up/repair, therapeutic services like Physiotherapy, Occupational Therapy and Speech Therapy, referral and arrangement for surgical correction through Government and Charitable Institutions, facilitation of issue of Disability Certificates and bus passes, sanction of bank loans, and promotion of barrier-free environment.
7. The National Policy for Persons with Disability 2005 is the recent development and welcome step by the Government of India.

More than a billion people in the world today experience disability. These people generally have poorer health, lower education achievements, fewer economic opportunities and higher rates of poverty. This is largely due to the barriers they face in their everyday lives, rather

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than their disability. Disability is not only a public health issue, but also a human rights and development issue. WHO's efforts to support Member States to address disability are guided by the overarching principles and approaches reflected in the *WHO global disability action plan 2014-2021*, the *World report on disability*, and the Convention on the Rights of Persons with Disabilities.

Disability insurance

Disability benefit, or disability pension, is a major kind of disability insurance that is provided by government agencies to people who are temporarily or permanently unable to work due to a disability. In the U.S., disability benefit is provided in the category of Supplemental Security Income. In Canada, it is within the Canada Pension Plan. In other countries, disability benefit may be provided under social security systems.

Costs of disability pensions are steadily growing in Western countries, mainly in Europe and the United States.

It was reported that, in the UK, expenditure on disability pensions accounted for 0.9% of gross domestic product (GDP) in 1980; two decades later it had reached 2.6% of GDP.Several studies have reported a link between increased absence from work due to sickness and elevated risk of future disability pension.

A study by researchers in Denmark suggests that information on self-reported days of absence due to sickness can be used to effectively identify future potential groups for disability pension. These studies may provide useful information for policy makers, case managing authorities, employers, and physicians.

Private, for-profit disability insurance plays a role in providing incomes to disabled people, but the nationalized programs are the safety net that catch most claimants.

The treatment for a medical condition and the services to reduce the disabling effects of that condition may not be readily distinguishable. For this reason and because some persons may have forgotten the source of the services received, under reporting of services may exist. On the other hand, over reporting could occur for persons who received only medical services but listed them as types of rehabilitation services.

AGE AND SEX

Advanced age clearly has a negative effect on prospects for return to work and on the performance of other social activities, apart from the biological association with decrease in function and susceptibility to chronic disease. According to a Survey study, "Social usage and employment practice suggest that chronological age influences capacity evaluation as an independent status attribute.

The young are more likely to hare traumatic injuries or the kind of ailaments that often show significant improvement after rehabilitation services are provided unlike the chronic,

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progressive diseases associated with aging. Younger persons also tend to have fewer multiple conditions and greater residual capacity.
The older disabled persons themselves express lessened interest in services.
Relatively more men than women received services. At the younger ages, the differences were greatest.
Among all the disabled, men and women were about equally interested in obtaining services.

Current and future worldwide dependency ratios.

The greatest burden of dependency currently falls in sub-Saharan Africa, where the "dependency ratio" (ratio of dependent people to the population of working age) is about 10%, compared with 7-8% elsewhere. Large increases in prevalence are predicted in sub-Saharan Africa, the Middle East, Asia and Latin America of up to 5-fold or 6-fold in some cases. These increases will occur in the context of generally increasing populations, and dependency ratios will increase modestly to about 10%. The dependency ratio will increase more in China (14%) and India (12%) than in other areas.. Established market economies, especially Europe and Japan, will experience modest increases in the prevalence of dependency (30%), and in the dependency ratio (up to 10%). Former Socialist economies of Europe will have static .or declining numbers of dependent people, but will have large increases in the dependency ratio (up to 13%).Many countries will be greatly affected by the increasing number of dependent people and will need to identify the human and financial resources to support them. Much improved collection of data on disability and on the needs of caregivers is required. The prevention of disability and provision of support for caregivers needs greater priority.

Material and Methods

A study to assess knowledge and utilisation of services by Person with disability (PWD) in the department of Physical Medicine and Rehabilitation (PMR) KGMU Lucknow.

1.4 STUDY SETTING

The study was conducted in the department of Physical Medicine and Rehabilitation (PMR) King George's Medical University,UP Lucknow.

1.6 STUDY POPULATION

The study population of this study was patients admitted in PMR.

1.7 STUDY DESIGN

Hospital based cross sectional study.

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1.8 SAMPLING:

Sample size : All the patient admitted in the department of PMR,KGMU Lucknow during the study period September 2015 to October 2016 i.e. 102

Inclusion criteria:

Patient who are admitted in PMR department and ready to give consent for the study.

Exclusion criteria:

Uncooperative patients.

A pretested semi-structured interview schedule was used to collect necessary information.

DATA COLLECTION PROCEDURE

The respondents were briefed about the survey in local language. After consent, interview was conducted to fill the schedule form.

ETHICAL CONSIDERATION

Verbal consent was taken from each selected participant to confirm willingness. Honest explanation of the survey purpose, description of the benefits and an offer to answer all Inquires was made to the respondents. Also affirmation that they are free to withdraw consent and to discontinue participation without any form of prejudice was made.

Privacy and confidentiality of collected information was ensured throughout the process, Data was collected in a way that makes it impossible or at least very hard to identify the respondent.

OBSERVATION AND RESULTS

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Table 1. Socio Demographic profile of People With Disability (PWD) (n=102)

Bio-Social Characteristics		**No**	**%**
Age (years)	≤10	28	27.5
	11-30	61	59.8
	31-50	10	9.8
	≥ 51	03	2.9
Gender	Male	72	70.6
	Female	30	29.4
Religion	Hindu	85	83.3
	Muslim	17	16.7
Caste	General	27	26.5
	SC	30	29.4
	ST	1	1.0
	OBC	44	43.1
Type of Family	Joint	94	92.2
	Nuclear	05	4.9
	Single	02	2.0
	Second generation	01	1.0
Education	Illiterate because of disability	42	41.2
	Illiterate because of other reasons	04	3.9
	Primary School	24	23.5
	Middle School	21	20.6
	High School	00	00
	Secondary	10	9.8
	Graduate	00	00
	Post Graduate	1	1
Marital status	Married	24	23.5
	Unmarried	78	76.5

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Maximum PWD were in the age group 11-30 years (59.8%), followed by PWD in the age group less than or equal to 10 years (27.5%).

The proportion of male PWD (70.6%) was more than twice as compared to females (29.4%).

Religion wise proportion of PWD was almost the same as in the general population- Hindu (83.3%) and Muslims (16.7%).

Caste wise distribution shows that maximum PWD belonged to OBC (43.4%) followed by SC (29.4%) and general category, (26.5%) .

Majority of PWD were living in joint families (92.2%) .

Distribution on the basis of Education (41.2%) are illiterate due to disability whereas ,illiterate disable due to other reason (3.9%) ,primary school (23.5%),middle school (20.6%) secondary (9.8%) and post graduate 1%.

23.5% of PWD are married whereas (76.5%) are unmarried.

Table :2 socio-economic status of PWD

Socio economic Status*	Upper class 5357 and above	4	3.9
	Upper middle 2652-5356	10	9.8
	Middle 1570-2651	18	17.6
	Upper lower 812-1569	28	27.5
	Lower <811.	42	41.2

*** B.G.PRASAD SCALE**

On the basis of B.G. prasad socio economic scale, 3.9% belongs to upper class ,9.8% belongs to upper middle ,17.6% belongs to middle, 27.5%belongs to upper lower and 41.2% belongs to lower class

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Table 3 Distribution of PWD on the basis of type and cause of disability (n=102)

Type of disability	**No**	**%**
Orthopaedic	102	100
Others	00	00
Cause of Disability		
Accidental (RTA)	56	54.9
Drug /vaccine related	09	8.8
Physiological	06	5.9
Congenital	20	19.6
Due to other reason	11	10.8

Table 3 shows that all PWD had orthopaedic disability and half of them (54.9%) had acquired it by road traffic accident and about one fifth 19.6% were congenital.

Table 4 Utilisation of Counselling Services by PWD.(n=102)

Assessment	**No**	**%**
Psychological counselling session		
Yes	2	2.0
No	100	98.0

Only 2% PWD underwent psychological training rest (98%) never went for psychological training.

Table 5: Barriers faced by people with disability

Type of barriers faced	**N**	**%**
Transportation related		
Yes	77	75.5
No	25	24.5
Construction and building ramp related		
Yes	62	60.78
No	40	39.2

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People helping attitude towards PWD		
Yes	90	88.2
No	12	11.76
Barrier to entry to parks and malls		
Yes	80	78.4
No	22	21.56

Many barriers are faced by PWD in their day to day life like transportation (75.5%), ,construction and building ramp related(60.78%) people with not helping attitude towards PWD (11.76%) and barrier to entry to parks and malls (78.4%)

Table 6: Awareness among PWD about the facilities available (n=102)

Awareness	**N**	**%**
Physiotherapy		
Yes	86	84.3
No	16	15.7
Prosthesis		
Yes	55	53.9
No	47	46.1
Orthosis		
Yes	50	49.0
No	52	51.0
Surgical intervention on concession		
Yes	50	49.0
No	52	51.0
Free diet to admitted patient		
Yes	94	92.2
No	08	7.8
Vocational training		
Yes	09	8.8
No	93	91.2
Physiotherapy session		
Yes	86	84.3
No	16	15.7

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Counselling session		
Yes	2	2.0
No	100	98.0
Tax relaxation		
Yes	6	5.9
No	96	94.1
Financial assistance		
Yes	7	6.8
No	95	93.1
Pension Scheme to PWD		
Yes	53	52.0
No	49	48.0
Free transportation in bus		
Yes	77	75.5
No	25	24.5
Concession in railways		
Yes	72	70.6
No	30	29.4
3% Reservation in Government job		
Yes	73	71.6
No	29	28.4

Table 5 shows that the order of awareness among PWD regarding facilities available for them is (1) free diet to admitted patients -92.2% (2) physiotherapy -84.3% (3) free transportation in bus-75.5% (4) 3% reservation in government job -71.6% (5) concession in railways 70% (6) prosthesis 53.9% (7) pension scheme to PWD 52% (8) orthothesis 49% (9)surgical intervention on concession 49% (10) vocational Training 8.8% (11) financial assistance 6.8% (12) tax relaxation 5.9% (13) counselling session 2%.

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Table 7: Awareness among PWD regarding facilities for BPL card holders. n=102

Awareness	N	%
Investigation on concession		
Yes	32	31.4
No	70	68.6
Surgery on concession		
Yes	19	18.6
No	83	81.4
Callipers and shoes on concession		
Yes	68	66.7
No	34	33.3

Table 6 reveals that about two third (66.7 %) respondents were aware that facility for callipers and shoes on concession is available for BPL card holders . whereas one third (31.4%) were aware that investigation on concession is also available for BPL card holders. Only (18.6 %) were aware that surgery on concession is also available.

Observation among PWD for awareness of BPL facilities shows that only 31.4 % aware that there is concession on investigation rest 68.6% came to know about this facility after filling of the survey form.
18.6 % of PWD knows that concession on surgery available rest 84.4 percent have no knowledge about the same.

66.7% PWD are aware that there is concession on callipers and shoe.

Conclusion

The present study was conducted at PMR (Physical Medicine and Rehabilitation centre) KGMU, Lucknow .
In this study, 102 people with disability (PWD) who were admitted in PMR department during the period September 2015 to October 2016 were included.
Conclusion drawn from observation are as follows-

- About two third (70.6%) were male, whereas remaining (29.4%) were female.
- Religion wise proportion of PWD was almost same in the general population of Hindu (83.3%) and Muslims (16.7%).
- Majority of PWD living in joint family (92.2%).
- About half (45.1%) were illiterate and belong to lower class.
- All PWD has orthopedic disability and about half (54.9%) of them had acquired it by road traffic accident.
- Only 2% utilize counseling service and had undergone psychological counseling.

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- 92.2%,PWD patients were aware about free diet to admitted patients.

Loss of work is a critical, undesirable situation. .The study data show that the severely disabled tend to be more interested in rehabilitation services than persons with less incapacitating disabilities. A greater proportion of men received services, possibly because of their greater labour force obligations. It is sometimes argued that compensation will act, as a partial disincentive to recovery, but the data show a higher rate of receipt of rehabilitation services and interest in obtaining services among those with income-maintenance payments than among the other disabled. This difference may be partly explained by such factors as the greater severity of the impairments of those receiving earnings-replacement benefits, the routinized referral by social agencies such as social security offices and welfare agencies to vocational rehabilitation agencies, and the inadequacy of benefits to meet the economic needs of the disabled.
Dependent family status, low income, and inadequate education were all related to increased interest in obtaining services.

Our study reaches to conclusion that most of PWD belongs to low socio economic status, illiterate and needy. They expect from government to give them opportunities so that they can live independent life by earning for themselves and for their family.

There are various schemes run by government of which persons with disability are unaware like Pension scheme, and reservation in various government sector.

Even though disabled people constitute a significant 5 to 6 percentage of the population of India, their needs for meaningful employment remain unmet, in spite of the implementation of the `The People with Disabilities' Act 21 years ago, which reserves 3% of all categories of jobs in the government sector for disabled persons (1). Of the approximately 70 million people with disabilities in India, only about 0.1 million have succeeded in getting employment in the industries till now. The industries can however, play a more emphatic role because of their vast employment generating potential and the financial power.

This study was conducted by the National Centre for Promotion of Employment for Disabled People, an organisation working as an interface between the government, industry, non-governmental organisations and international agencies, to promote employment opportunities for people with disabilities in India. The aim of the study was to identify the current practices of Indian industry with regard to the employment of disabled people, 21 years after the `The People with Disabilities' Act was passed. This Act reserves 3% of all categories of jobs in the public sector industries for disabled persons, and incentives for public and private sector companies, that have at least 5% of their workforce comprising of disabled persons

Disability is an important public health problem especially in developing countries like India. The problem will increase in future because of increase in trend of non-communicable diseases and change in age structure with an increase in life expectancy. The issues are different in developed and developing countries, and rehabilitation measures should be

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targeted according the needs of the disabled with community participation. In India, a majority of the disabled resides in rural areas where accessibility, availability, and utilization of rehabilitation services and its cost-effectiveness are the major issues to be considered. Research on disability burden, appropriate intervention strategies and their implementation to the present context in India is a big challenge.

Recent data was collected from department of Physical Medicine and Rehabilitation, PMR KGMU Luck now and various other sources and analyzed. In present study I interview 102 patient admitted in study centre Physical Medicine and rehabilitation, PMR KGMU Lucknow.

During our study we observed that most of patients belong to low socio economic status, below poverty line and illiterate their poverty is so much that they cannot even earn to fulfil their basic needs and demand of life. Some of patients are so much satisfied with PMR department that they wish to stay there as long they are allowed.

Their disability doesn't allow them to stay or to continue any job if they are appointed or wish to be in any suitable job.

All patients of PMR included in my study are orthopedically challenge including amputees, PPRP (Post Polio Residual Paralysis), CTEV (Congenital Talip Equano Varus) and accidental cases for rehabilitation

Suggestions:

1. Advocacy for mainstreaming the systems and services. It requires commitment across all sectors and built into new and existing legislation, standards, policies, strategies, and plans.
2. Invest in specific programs and services for people with disabilities. In addition to mainstream services, some people with disabilities may require access to specific measures, support services, or training. In this process, involvement of persons with disability is of paramount importance as they give insight into their problems and suggest possible solution.
3. Capacity building of health care providers and program managers. Human resource capacity can be improved through effective education, training, and recruitment. A review of the knowledge and competencies of staff in relevant areas can provide a starting point for developing appropriate measures to improve them. Manpower generation by promoting new courses and initiating degree and diploma courses like Physical Medicine and Rehabilitation will address the problem of shortage of manpower in long run.
4. Focus on educating disabled children as close to the main stream as possible.
5. Increase public awareness and understanding of disability. Governments, voluntary organizations, and professional associations should consider running social marketing campaigns that change attitudes on stigmatized issues such as HIV, mental illness, and leprosy. Involving the media is vital to the success of these campaigns and to

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ensuring the dissemination of positive stories about persons with disabilities and their families.

6. Generating representative community-based data will help to plan and execute appropriate measures to address the problems of persons living with disability.
7. Strengthen and support research on disability.
8. To provide counselling to differently - abled students on the types of courses they could study at the higher education institutions.
9. To ensure admission of as many differently-abled students as possible through the open quota and also through the reservation meant for them.
10. To gather orders dealing with fee concessions, examination procedures, reservation, policies, etc., pertaining to differently-abled persons.
11. policies, etc., pertaining to differently-abled persons.
12. To assess the educational needs of differently abled persons enrolled in the higher education institutes to determine the types of assistive devices to be procured.
13. To conduct awareness programmes for teachers of the institute about the approaches to teaching, evaluation procedures, etc, which they should address in the case of differently-abled students.
14. To study the aptitude of differently-abled students and assist them in getting appropriate employment when desired by them after their studies.
15. To celebrate important days pertaining to disability such as the World Disabled Day, White Cane Day, etc., in the institute and also in the neighbourhood in order to create awareness about the capabilities of differently-abled persons.
16. To ensure maintenance of special assistive devices procured by the higher education institute under the HEPSN scheme and encourage differently-abled persons to use them for enriching their learning experiences.

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