AWARENESS MODULE ON DISABILITY

ignou
THE PEOPLE'S UNIVERSITY

National Centre for Disability Studies
Indira Gandhi National Open University
Maidan Garhi, New Delhi-110068

Awareness Module
on
Disability

National Centre for Disability Studies
Indira Gandhi National Open University
Maidan Garhi, New Delhi – 110068

Designed and Developed by	Content Editing
Dr. Hemlata	Dr. Hemlata
Dr. Sanjay Kant Prasad	Dr. Sanjay Kant Prasad

PRODUCTION

Mr. Promila Sony
Assistant Registrar, MPDD, IGNOU, New Delhi

November, 2021

ISBN-

Further information about the School of Performing and visual Arts and the Indira Gandhi National Open University courses may be obtained from the University's office at Maidan Garhi, New Delhi-110068 or website: www.ignou.ac.in

Printed and published on behalf of the Indira Gandhi National Open University, New Delhi by Registrar, MPDD, IGNOU, Maidan Garhi, New Delhi.

Laser Composed by Tessa Media & Computers, C-206, Shaheen Bagh

Contents

Foreword

Preface

Rights of Persons with Disabilities Act 2016 - at a Glance

Unit – 1	Locomotor Disability	15
Unit – 2	Leprosy Cured	25
Unit – 3	CEREBRAL PALSY	31
Unit – 4	DWARFISM	37
Unit – 5	Muscular Dystrophy	41
Unit – 6	Acid attack	44
Unit – 7	Visual Impairment	50
Unit – 8	Low Vision	54
Unit – 9	Deafness and Hard of Hearing	58
Unit – 10	Speech and Language Disability	63
Unit – 11	Intellectual Disability	68
Unit – 12	Specific Learning Disabilities	73
Unit – 13	Autism	79
Unit – 14	Mental Illness	83
Unit – 15	Chronic Neurological ConditionMultiple Sclerosis	89
Unit – 16	Parkinson	93
Unit – 17	Disability Due to Blood DisorderHaemophilia	96
Unit – 18	Blood DisorderThalassemia	101
Unit – 19	Disability Due to Blood DisorderSickle Cell Disease	105
Unit – 20	Multiple Disabilities	109

FOREWORD

IGNOU is a Central University established by an act of Parliament, with the objective of providing higher education to all, who aspire for it including the disadvantaged and unreached section of our great nation. The University is committed to excellence in teaching, training, capacity building, research, scholarship and public service. IGNOU values the appropriate and judicious use of information and communication technologies and the satellite media to support quality teaching and learning.

The University functions through its large number of study centres spread across the country, coordinated by Regional Centres located in all the states. The Academic leadership is provided by the 21 schools and various centres of the University for designing, development and delivery of various programmes ranging from certificate to doctoral level.

The Awareness module on Disability prepared by National Centre for Disability Studies of Indira Gandhi National Open University is a step towards creating awareness about the rights of persons with disabilities (Divyangjan) as per Rights of Persons with Disabilities Act 2016. Under this act, the number of disability is 21. This module covers all the 21 specified disabilities. This module is unique effort towards sensitizing all the learners in general and IGNOU learners in particular. This module provides the information about the concept and definition, common identification criteria about assessment by medical board for the issue of disability certificate to persons with disabilities (Divyangjan).

I take the opportunity to congratulate Director, NCDS and his colleague for bringing out such an informative awareness module on disability.

I hope this will prove to be helpful for all the readers, learners as well as all those NGOs and academicians who are associated with persons with disabilities.

With Best Compliments.

(Prof. Sumitra Kukreti)
Pro-Vice Chancellor, IGNOU
New Delhi

Dated:- 08.11.2021

PREFACE

Disability is a human diversity. This human diversity is disadvantage as well as challenge for the larger society in any part of the world. A society can not declare itself modern and equitable, unless it makes sincere efforts to achieve equality in extending opportunities to all its less privileged citizens including persons with disabilities.

The 2011 census shows that there are 2.68 crore persons (2.21% of the total population) in the country having one or other form of disability. Under these circumstances, Government of India has enacted "Rights of Persons with Disabilities Act 2016", which ensure to safeguard the Rights of Persons with Disabilities (Divyangjan).

IGNOU being an apex organization in the Indian Higher Education System in Open and Distance Learning has established the National Centre for Disability Studies (NCDS) with broad objective to work for the care and cause of Persons with Disabilities, creating awareness about the need and potentials of persons with disabilities, conduct researches on various aspects of disabilities, sensitization, orientation and training to wide range of service providers, policy makers and implementing authorities.

This awareness module on Disability has been developed by NCDS to create awareness about the 21 types of disabilities scheduled under RPwD Act 2016. This module comprising of 20 units alongwith one brief write up on provisions, terminology and salient features of RPwD Act 2016. We expect that this module will serve the purpose to sensitize people about the concept and identification through sign and symptom and also help in assessment need of issuing of disability certificate.

I am sure that the awareness module will help the learner in developing their knowledge about various disabilities covered under Rights of Persons with Disabilities Act, 2016.

I wish to compliment my colleague Dr. Hemlata and all staff of NCDS for their contribution and effort in timely and successful completion of this module.

(Dr. Sanjay Kant Prasad)
Director, NCDS

Dated:- 08.11.2021

Rights of Persons with Disabilities Act 2016 - at a Glance

By -Dr. Sanjay Kant Prasad

Background – The Rights of Persons with Disabilities Act 2016 was enacted by Parliament and implemented in December, 2016. This is an act to give effect to the UNCRPD and its principles for empowerment of persons with disabilities. RPwD Act, 2016 was enacted as a part of the larger harmonization process undertaken by the Govt. of India in fulfilment of its commitment and international obligation arising out of India becoming a state party to the UNCRPD.The principles lays down by the convention includes,

a) Respect for inherent dignity, individual autonomy including freedom to make one's choices, and independence of persons;

b) Non- discrimination:

c) Full and effective participation and inclusion in society:

d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

e) Equality of 0pp0rtunity;

f) Accessibility;

g) Gender equality; and

h) Respect for evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities;

Salient Inclusive Features -

The RPwD Act, 2016 is more compatible with the UNCRPD. The following salient features bring out some fundamental points of concern of this new legislation, which seems having more inclusive in nature.

- Explicitly envisages civil and political rights of persons with disabilities in addition to emphasizing the economic, social, and cultural rights. For example, it talks about equality and non-discrimination, protection from cruelty and inhuman treatment, accessibility in voting, etc.

- Adopts a social and human rights-based approach to disability and recognizes that persons with disabilities have equal human rights and fundamental freedom as with others in the society.

- Explicitly recognizes all persons with disabilities as any other person before the law and enjoins it upon the appropriate Govt. to ensure that they are able to enjoy their legal capacity equally with others.

- Adopts a twin-track approach in respect of the matter with the result that in addition to making dedicated and specific provisions for women and children with disabilities, also mentions them in other appropriate places as well.

- Expands the categorization of persons with disabilities so as to cover 21 conditions or diversity. The scope of entitlements also stands enhanced and expanded in the RPwD Act, for example, the quota of reservation in Govt. jobs from 3% to 4%, in admission to institutions of higher education from 3% to 5%, in poverty alleviation schemes has been increased from 3% to 5%, etc.

- Strengthens the regulatory, monitoring, and grievance redressal mechanisms in terms of their functions and composition. It also stipulates designation of Special Courts at the district level for fast track disposal of the cases of persons with disabilities under the Act. The Act prescribes penal provisions, (chapter 16) inter alia, for contravention of provisions of the Act, or of rules and regulations framed thereunder; and, also for fraudulently availing of benefit by any person under the Act, etc.

- Provides for representation of persons with disabilities including representation of women with disabilities in the various bodies to be created under this new legislation. Thus the value and indispensability of experiential expertise also stands recognized.

- Provides for time-limit for compliance with some of its substantive provisions which includes provisions in respect of compliance with accessibility norms, which is an important component for inclusion of Persons with Disabilities(Divyangjan).

- Provides for enabling persons with disabilities to access justice. Provisions for persons with disabilities in the event of situations of risk, natural disaster and humanitarian emergencies have also been made in the act. It also provides for creation of National and State Fund for the benefit of persons with disabilities.

- Explicitly stipulates that no person with disability shall be discriminated on the ground of disability unless it is shown that the impugned act or omission is to achieve a legitimate aim. This Act also provides that certificate of disability issued under Section 58 of the Act shall be valid across the country. This will save persons with disability from the hassle of obtaining fresh disability certificate when and if they move from one state to another.

- The RPwD act has listed and recognized 21 conditions as specified disabilities. These 21 conditions have been broadly categorized and distributed under physical disability, intellectual disability, and mental behaviour, disability caused due to (a) neurological condition, and (b) blood disorders, and multiple disabilities. Persons with specified disabilities have further been subdivided into two categories, namely, persons with benchmark disabilities; and persons with disabilities having high support needs.

The Act says 'person with disability having high support needs' means a person with benchmark disability certified under clause [a] of sub-section 2 of section 58 who needs high support. Section 2 [l] stipulates that "high support" means an intensive support, physical, psychological and otherwise, which may be required by a person with benchmark disability for daily activities, to take independent and informed decision to access facilities and participating in all areas of life including education, employment, family and community life and treatment and therapy. Thus all persons having high support needs are necessarily also persons with benchmark disability; but all persons with benchmark disabilities are not necessarily persons having high support needs.

Definition and Concepts -

Keeping in view the need of inclusion in true sense, the Act defines all the important concepts in a very comprehensive manner, such as;

Persons with Benchmark Disabilities means a person with not less than forty percent (40%) of a specified disability certified by the certifying authority.

Discrimination in relation to disability, means any distinction, exclusion, restriction on the basis of disability which is the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field and includes all forms of discrimination and denial of reasonable accommodation.

Barrier means any factor including communication, cultural, economic, environmental, institutional, political, social, attitudinal or structural factors which hamper the full and effective participation of persons with disabilities in society.

Communication includes means and formats of communication, languages, display of text, Braille, tactile communication, signs, large print, accessible multimedia, written, audio, video, visual displays, sign language, plain-language, human-reader, augmentative and alternative modes and accessible information and communication technology.

Establishment includes a Government establishment and private establishment.

Public building means a Government or private building, used or accessed by the public at large, including a building used for educational or vocational purposes, workplace, commercial activities, public utilities, religious, cultural, leisure or recreational activities, medical or health services, law enforcement agencies, reformatories or judicial forum, railway stations or platforms, roadways bus stands or terminus, airports or waterways.

Information and communication technology includes all services and innovations relating to information and communication, including telecom services; web based services, electronic and prints services, digital and virtual services.

Public facilities and services includes all forms of delivery of services to the public at large, including housing, educational and vocational trainings, employment and career advancement, shopping or marketing, religious, cultural, leisure or recreational, medical, health and rehabilitation, banking, finance and insurance, communication, postal and information, access to justice, public utilities, transportation.

Reasonable accommodation means necessary and appropriate modification and adjustments, without imposing a disproportionate or undue burden in a particular case, to ensure to persons with disabilities the enjoyment or exercise of rights equally with others. **Transportation systems** includes road transport, rail transport, air transport, water transport, para transit systems for the last mile connectivity, road and street infrastructure, etc.

Universal design means the design of products, environments, programmes and services to be usable by all people to the greatest extent possible, without the need for adaptation or specialised design and shall apply to assistive devices including advanced technologies for particular group of persons with disabilities.

Important Provisions for Education and Empowerment

Education - The RPwD Act, 2016 clearly states that the appropriate government and local authorities shall endeavour that all educational institutions funded and recognised by them provide inclusive education to the children with disabilities(Section 16).The act stipulates that every child with a benchmark disability between the ages of six to eighteen years shall have the right to free education in a neighbourhood school or in a special school of his/her choice (Section 31).It further enjoins it upon the appropriate government and local authorities to ensure that every child with a benchmark disability has access to free education in an appropriate environment till s/he attains the age of eighteen years. Also provides for reservation of not less than five per cent seats for students with disabilities in government higher education institutions and in other higher education institutions receiving aid from the government (Section 32).

The act emphasize upon inclusive education as appropriate authorities needs to develop and provide facilities to create an inclusive environment and inclusive nature of education so that all children with disabilities could get education irrespective of the nature and type of disabilities in the same school with other students. It is the role of school to identify the educational need of each child with disability and provide the required facilities to fulfil the need. However, curriculum modifications, teacher capacity building, need identification as well as evaluation pattern are to be decided by appropriate authorities .Such inclusive nature of education not only provide opportunity to children with disabilities for better learning rather gives a strong base for their overall development, life skill and positive attitude towards self and society.

Employment - The act provides for reservation of not less than four per cent jobs in government establishment against total number of vacancies in the cadre strength in each group of posts meant to be filled by persons with benchmark disabilities (Section 33). Besides, increasing the percentage of reservation in government job, the act emphasize upon skill training and development of persons with disabilities, which ultimately widen the scope of self-employment and more participation in national growth and development.

Allotment of Land and Housing- The provision for five per cent reservation in allotment of agricultural land and housing in all relevant schemes and development programmes, with appropriate priority to women with benchmark disability.It further provides for five per cent reservation in all poverty alleviation and various developmental schemes with priority to women with benchmark disability. There is also provision for five per cent reservation in allotment of land on concessional rate, where such land is to be used for the purposes of promoting housing, shelter, setting up of occupation, business, enterprise, recreation centres, and production centres. The increase in percentage of reservation provides greater chance for persons with disabilities to be included in the scheme and established and mainstreamed them in the society.

Accessibility – The accessibility has been given high priority in this act to ensure inclusion of persons with disabilities and provide them a barrier free environment. The Act inter alia, prescribes time-limit for mandatory observance of accessibility rules. The act clearly mention from section 41to 46 that appropriate government shall take suitable measures to provide, (a) facilities for persons with disabilities at bus stops, railway stations and airports conforming to the accessibility standards

relating to parking spaces, toilets, ticketing counters and ticketing machines;(b) access to all modes of transport that conform the design standards, including retrofitting old modes of transport, wherever technically feasible and safe for persons with disabilities, economically viable and without entailing major structural changes in design;(c) accessible roads to address mobility necessary for persons with disabilities.

The appropriate Government shall develop schemes, programmes to promote the personal mobility of persons with disabilities at affordable cost to provide for, — (a) incentives and concessions ;(b) retrofitting of vehicles; and(c) personal mobility assistance.

The appropriate Government shall take measures to ensure that (i) all contents available in audio, print and electronic media are in accessible format;(ii) persons with disabilities have access to electronic media by providing audio description, sign language interpretation and close captioning;(iii) electronic goods and equipment which are meant for everyday use are available in universal design. The other provisions provides under the act, which directs the appropriate government to take measures to promote development, production and distribution of universally designed consumer products and accessories for general use for persons with disabilities, all existing public buildings shall be made accessible in accordance with the rules formulated by the Central Government within a period not exceeding five years from the date of notification of such rules.

The provisions for accessibility have to be implemented in a time bound manner. If all resources, facilities, information, communication and infrastructure are equally accessible by persons with disabilities, their dependency on society will decrease and dependency on self will increase. It is ultimately the right of persons with disabilities to have equal opportunity and access to all resources, facilities, information, communication and infrastructure of the society. All such provisions of the act have great meaning for making society inclusive for persons with disabilities and achieve the goal of inclusion and spirit of UNCRPD.

Special Provision for Persons with Disabilities with High Support Needs -

The RPwD Act, 2016 states that any person with a benchmark disability, who considers herself/ himself in need of high support, or any other person or organization on his or her behalf may apply to an authority to be notified by the appropriate government requesting for high support. The said authority will then refer the case to an Assessment board to be constituted for the purpose. The assessment board shall examine the case and submit a report to that authority certifying that the person does need high support. The authority on being satisfied about the genuineness of the case shall take steps to provide high support to that person in accordance with government norms.

Conclusion and recommendation -

All the above provisions as well as other provisions covered under this act are meant to protect the rights of persons with disabilities (Divyangjan) and provide them equal opportunity and to ensure a non-discriminate and accessible environment and resources to achieve the goal of inclusion and full participation.

UNIT 1 LOCOMOTOR DISABILITY

By - Dr. Hemlata

Introduction

In this unit we will be discussing about locomotor disability that has been added in Rights of Persons with Disabilities Act, 2016 as one the disability. We will also discuss about characteristics and causes, assessment and intervention strategies for locomotor disabilities.

We often see people having difficulty in moving from one place to other or holding things with hands. In simple words this condition is called locomotor disability or some people may say it physical challenge. The correct term is Locomotor Disability.

Renu is not able to walk like her friends after her accident and she feels that how the simple walking has become difficult for her. Similarly there are other persons having locomotor disability who find difficult in gripping up or picking up things. All these conditions are called locomotor disability. In this unit we will discuss about locomotor disability in detail.

Objectives

After reading this unit, you will be able to:

- Define locomotor disability
- Explain characteristics and causes of locomotor disability
- Discuss the assessment and interventions strategies for locomotor disabilities.

Concept and Meaning

The concept of locomotor disability focus on the disability related to bone, joints and muscles due to which a person is not able to execute the day to day tasks.

Locomotor disability is defined as a person's inability to execute distinctive activities associated with moving both herself /himself and objects from place to place and such inability resulting from affection of bones, joints, muscles or nerves (RCI Act 1992).

The term Locomoter is derived from the Latin words Loco that means – " from a place" and motivus that means – "causing motion". Therefore Locomotor means movement from one place to another. Thus Locomotor disability means hampered movement from one place to another place.

Rights of Persons with Disabilities Act, 2016 defines locomotor disability as – a person's inability to execute distinctive activities associated with movement of self and objects resulting from affliction of musculoskeletal or nervous system or both, including Leprosy Cured, Cerebral Palsy, Dwarfism, Muscular dystrophy and acid attack victims.

Characteristics

Persons having locomotor disability may have following common characteristics

1. Difficulty in body movement control
2. Difficulty in movement of upper or lower limbs
3. Stiffness or tension in muscles
4. Absence of Legs/Leg/Hand/Hands/foot/feet or deformity in these parts
5. Difficulty in holding or picking objects
6. Difficulty in walking, standing or sitting.
7. Weakness in muscles or imbalance in muscles.
8. Problems in bladder or bowel problems.
9. There may be sensory loss.
10. The person may not be able to walk on linear path.
11. Deformity in body parts
12. Delayed milestones

Causes

Locomotor disability may be caused because of the following reasons:

1. Polio
2. Clubfoot
3. Congenital absence of limb
4. congenital dislocation of hip
5. Accidents
6. Trauma
7. Fall from height
8. High fever in early childhood
9. Stroke
10. Bone tumors
11. Spinal tumors
12. Lack of supply of oxygen to brain
13. Brain damage
14. Metabolic disease
15. Degenerative disease
16. Muscular dystrophy
17. Rhetumatoids

Assessment

Assessment of locomotor disability can be done at home but for specific needs the opinion of expert must be taken. At early age identification of disability will be beneficial for giving suitable intervention. At home the child can be asked to do the following:

- lift the arm overhead
- stand upright on both legs
- stand upright on each leg separately
- walk on straight path
- pick up an object from the floor
- run a short distance

If the child is not able to do one or more activities then locomotor disability may be identified and opinion of expert may be taken.

Guidelines for Evaluation of Permanent Physical Impairment (PPI) of Upper Extremities

a) The estimation and measurement shall be made when the clinical condition has reached the stage of maximum improvement from the medical treatment. Normally the time period is to be decided by the medical doctor who is evaluating the case for issuing the PPI Certificate as per standard format of the certificate.

b) The upper extremity is divided into two component parts; the arm component and the hand component.

c) Measurement of the loss of function of arm component consists of measuring the loss of range of motion, muscle strength and co-ordinated activities

d) Measurement of loss of function of hand component consists of determining the prehension, sensation and strength. For estimation of prehension opposition, lateral pinch, cylindrical grasp, spherical grasp and hook grasp have to be assessed.

e) The impairment of the entire extremity depends on the combination of the impairments of both components.

f) Total disability % will not exceed 100%.

g) Disability is to be certified as whole number and not as a fraction.

h) Disability is to be certified in relation to that upper extremity.

ARM (UPPER EXTREMITY) COMPONENT

Total value of the arm component is 90%

Principles of evaluation of range of motion (ROM) of joints

a) The value of maximum ROM in the arm component is 90%

b) Each of three joints i.e. shoulder, elbow and wrist component was earlier weighed equally - 30%. However, functional evaluation in clinical practice indicates greater limitations imposed if hand is involved. So, appropriate weightage is given to involvement of different joints as mentioned below;

Shoulder = up to 20%, Elbow = up to 20%, Wrist = up to 10%, & Hands = up to 40%, dependent upon extent of involvement (mild – less than 1/3, moderate – up to 2/3, or severe – almost total). If more than one joint of the upper extremity is involved, the loss of percentage in each joint is calculated separately as above and then added together.

Principles of evaluation of strength of muscles:

a) Strength of muscles can be tested by manual method and graded from 0-5 as advocated by Medical ResearchCouncil (MRC), London, UK depending upon the strength of the muscles **(Appendix -I).**

b) Loss of muscle power can be given percentages as follows:

   i) The mean percentage of loss of muscle strength around a joint is multiplied by 0.30.

   ii) If loss of muscle strength involves more than one joint the mean loss of percentage in each joint is calculated separately and then added together as has been described for loss of motion.

Principles of evaluation of coordinated activities:

a) The total value for coordinated activities is 90%

b) Ten different coordinated activities should be tested as given in the **Form A. (Appendix II – assessment proforma for upper extremity)**

c) Each activity has a value of 9%

d) Average normal range of different joints for reference is at **Appendix III**,

Combining values for the Arm Component:

The total value of loss of function of arm component is obtained by combining the value of loss of ROM, muscle strength and coordinated activities, using the combining formula.

$$a + \frac{b\,(90-a)}{90}$$

where a = higher value and b = lower value

HAND COMPONENT

a) Total value of hand component is 90%

b) The functional impairment of hand is expressed as loss of prehension, loss of sensation and loss of strength.

Principles of evaluation of prehension:

Total value of prehension is 30%

It includes:

a) Opposition - 8%

Tested against
- Index finger - 2%
- Middle finger - 2%
- Ring finger - 2%
- Little finger - 2%

b) Lateral pinch - 5% - Tested by asking the patient to hold a key between the thumb and lateral side of index finger.

c) Cylindrical grasp - 6% Tested for

   i) Large object of approx. 4 inches size - 3%

   ii) Small object of 1-2 inch size - 3%

d) Spherical grasp - 6% Tested for

   i) Large object of approx. 4 inches size - 3%

   ii) Small object of 1-2 inch size - 3%

e) Hook grasp - 5% -Tested by asking the patient to lift a bag

Principles of Evaluation of sensation:

a) Total value of sensation in hand is 30%.

b) It shall be assessed according to the distribution given below:

   i) Complete loss of sensation

      Thumb ray 9%

      Index finger 6%

      Middle finger 5%

      Ring finger 5%

      Little finger 5%

   ii) Partial loss of sensation: Assessment should be made according to percentage of loss of sensation in thumb/finger(s).

Principles of Evaluation of strength

a) Total value of strength is 30%.

b) It includes:

   i) Grip strength 20%

   ii) Pinch strength 10%

Strength of hand should be tested with hand dynamo-meter or by clinical method (grip method). 10% weightage to be given to persons with involvement of dominant upper extremity (mostly right upper extremity) due to acquired conditions (diseases/ injuries etc.).

For shortening of upper extremity, addition weightage is as follows:

First 1" - No additional weightage

For each 1" beyond first 1" - 2% additional weightage.

Additional weightage - A total of upto 10% additional weightage can be given to following accompanying factors if they are continuous and persistent despite treatment.

i) Deformity

In functional position	3%
In non-functional position	6%

ii) Pain

Severe (grossly interfering with function)	9%
Moderate (interfering with function)	6%
Mild (slightly interfering with function)	3%

iii) Loss of sensation

Complete Loss	9%
Partial Loss	6%

iv) Complications

Superficial complications	3%
Deep complications	6%

Total % of PPI will not exceed 100% in any case.

Disability % is to be certified in relation to that extremity.

Disability % is to be mentioned as whole number, and not as a fraction.

Combining values of hand component:

The final value of loss of function of hand component is obtained by summing up values of loss of prehension, sensation and strength.

Combining values for the Extremity

Values of impairment of arm component and impairment of hand component should be added by using combining formula:

$$a + b\,(90-a)/90$$

where a = higher value and b = lower value.

Guidelines for Evaluation of Permanent Physical Impairment in Lower Extremity

The measurement of loss of function in lower extremity is divided into two components, namely, mobility and stability components.

MOBILITY COMPONENT

Total value of mobility component is 90% which includes range of movement (ROM) and muscle strength.

Principles of Evaluation of Range of Movement:

a) The value of maximum range of movement in mobility component is 90%

b) Each of three joints i.e. hip, knee and foot-ankle component was earlier weighed equally - 30%, but functional evaluation in clinical practice indicates greater limitations imposed if major proximal or middle joints are involved and, therefore, the appropriate weightage is given to involvement of proximal and middle joints, as follows:

Hip= up to 35%, Knee= up to 35%, Ankle= up to 20%, dependent upon extent of involvement (mild – less than 1/3, moderate – up to 2/3, or severe – almost total).

If more than one joint of the limb is involved the mean loss of ROM in percentage should be calculated in relation to individual joint separately and then added together to calculate the loss of mobility component in relation to that particular limb.

Principle of Evaluation of Muscle Strength:

a) The value for maximum muscle strength in the extremity is 90%.

b) Strength of muscles can be tested by Manual Method and graded 0-5 depending upon the residual strength in the muscle group.

c) Manual muscle strength grading can be given percentage as below:

Numerical Score of Muscle Power	Qualitative Score	Loss of Strength in %
0	Zero	100
1	Trace activity	80
2	Poor	60
3	Fair	40
4	Good	20
5	Normal	0

d) Mean percentage of muscle strength loss around a joint is multiplied by 0.30 to calculate loss in relation to limb.

e) If there has been a loss muscle strength involving more than one joint the values are added as has been described for loss of ROM.

Combining values for mobility component:

The values of loss of ROM and loss of muscle strength should be combined with the help of combining formula: a+b (90-a)/ 90 where a = higher value, b = lower value.

Stability Component

a) Total value of the stability component is 90%

b) It shall be tested by clinical method as given in **Form B** (Assessment Proforma for lower extremity) in **Appendix II**. There are nine activities, which need to be tested, and each activity has a value of ten per cent(10%). The percentage valued in relation to each activity depends upon the percentage of loss stability in relation to each activity.

Extra Points

Extra points (% of impairment) are given for deformities, pain, contractures, loss of sensations and shortening etc.

For Shortening (true shortening and not apparent shortening)

First 1/2"	Nil
Every 1/2" beyond first 1/2"	4%

Maximum extra points for associated problems such as deformity, pain, contractures etc. to be added are 10% (excluding shortening).

a) Deformity

In functional position	3%
In non-functional position	6%

b) Pain

Severe (grossly interfering with function)	9%
Moderate (interfering with function)	6%
Mild (slightly interfering with function)	3%

c) Loss of sensation

Complete Loss	9%
Partial Loss	6%

d) Complications

Superficial complications	3%
Deep complications	6%

Guidelines for Evaluation of Permanent Physical Impairment of the Spine

Basic guidelines:

Permanent physical impairment caused by spinal injuries or deformity may change over the years, the certificate issued in relation to spine may have to be reviewed as per the standard guidelines for disability certification**.**

Permanent physical impairment should be awarded in relation to the Spine.

TRAUMATIC LESIONS

Cervical Spine Injuries:

No.	Cervical Spine Injuries	Percentage of PPI in relation to the Spine
i.	25% or more compression of one or two adjacent vertebral bodies with No involvement of posterior elements, No nerve root involvement, moderate Neck rigidity and persistent Soreness.	**20%**
ii.	Posterior element damage with radiological evidence of moderate dislocation/subluxation including whiplash injury:	
	A) With fusion healed, No permanent motor or sensory changes	**10%**
	B) Persistent pain with radiologically demonstrable instability.	**25%**
iii.	Severe Dislocation:	
	a) Fair to good reduction with or without fusion with no residual motor or sensory involvement	**10%**
	b) Inadequate reduction with fusion and persistent radicular pain	**15%**

Cervical Intervertebral Disc Lesions:

No.	Cervical Intervertebral Disc Lesions	Percentage of PPI in relation to Spine
i.	Treated case of disc lesion with persistent pain but no neurological deficit	10%
ii.	Treated case of disc lesion with pain and instability	15%

Thoracic and Thoracolumbar Spine Injuries:

No.	Thoracic and Thoracolumbar Spine Injuries	Percentage of PPI in relation to Spine
i.	Compression of less than 50% involving one vertebral body with no neurological manifestation	10%
ii.	Compression of more than 50% involving single vertebra or more with involvement of posterior elements, healed, no neurological manifestations persistent pain, fusion indicated	20%
iii.	Same as (ii) with fusion, pain only on heavy use of back	15%
iv.	Radiologically demonstrable instability with fracture or fracture dislocation with persistent pain	30%

Intervention

Person with locomotor disability may have difficulty in moving or lifting objects and they may be having restrictions in performing their daily living activities. It is very important to provide appropriate intervention to them. As soon as any sign of locomotor disability is noticed the child may be taken to hospital so that the doctor can diagnose the problem and its causes if there is a scope for treatment that may be given immediately or in some case there may be a scope of corrective surgery. The decision may be taken as per the condition. With timely intervention impact of disability can be minimized. In case the disability can not be cured appropriate intervention can reduce the impact of impairment and lessen the effects of disability. Team of rehabilitation professionals that include physiotherapist, occupational therapist, prosthetics and orthotics, psychotherapist, vocational counselors and social counselors etc. need to work collaboratively for providing appropriate intervention to the individual.

Appropriate and combined use of medical, social, educational and vocational intervention for training the individual will help them in gaining highest level of functional ability to perform various activities. The purpose of invervention is to enable the persons with disabilities to actively participate in various activities in different spheres of life. Medical rehabilitation will help in restoration of various functions of body parts affected due to disability. Vocational rehabilitation will provide opportunities and build capacity of the individual to earn livelihood and live a satisfactory life. It is very important to provide them psychogical support so that they feel confident and can live a dignified life.

Conclusion

Locomotor disability can hamper the ability of an individual to live a life. Therefore it is very important to indentify the disability at the earliest and provide appropriate intervention so that they can live independently. There is a need to provide accessible environment to them so that they can move freely at par with other individuals and engage in vocational activities. With appropriate rehabilitation they can earn their livelihood and live independent life and contribute effectively for the society.

References:

1) RPwD Act, 2016 (The Gazette of India).

2) Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 2 LEPROSY CURED

By -Dr. Sanjay Kant Prasad

Introduction

This unit is focusing on the concepts, meaning and common characristics, causes, treatment and rehabilitation aspects related to leprosy and leprosy cured Persons with Disabilities.. Leprosy Cured is one of the specified disability among the 21 disabilities scheduled in the RPwD Act 2016. The most important aspect related to leprosy is effect of leprosy in the form of disability on the persons suffering from leprosy. The RPwD Act 2016 considered disability as a social issue rather than medical issue. Therefore, the effect of leprosy is more a Social problems rather than Medical Problem.

The term *leprosy* originates from ancient Greek which denotes, "A disease which makes the skin scaly", in turn a nominal derivation of the verb, "to peel, scale off". The word entered into the English language via Latin and Old French. The first attested English use is in the *Ancrene Wisse,* a 13th-century manual for nuns ("Moyseses hond..bisemde o þe spitel uuel & þuhte lepruse." *The Middle English Dictionary,* s.v., "leprous"). A roughly contemporaneous use is attested in the Anglo-Norman *Dialogues of Saint Gregory,* "Esmondez i sont li lieprous" (*Anglo-Norman Dictionary,* s.v., "leprus"). This disease leprosy is also called Hansen's disease named after physician Gerhard Armauer Hansen.

Objectives

After reading this unit, learner will be able to:

- Describe the concept and definition of leprosy
- Identify the various causes of leprosy
- Explain the idenfication as per RPwD assessment guideline.
- Explain the various rehabilitation aspects of leprosy

Concept and Definition

Leprosy is a progressive bacterial infection that affects the skin, peripheral nerves in the hands and feet, and mucous membranes of the nose, throat and eyes. It destroys nerves, which can lead to a loss of sensation in affected areas. This loss of sensation means that small cuts can go unnoticed and become extensively infected the person may not notice the cut until the infection is severe enough to be visually obvious. This can result in the loss of fingers or toes or in other visible deformities from optimistic infections.

In brief, it may be defined as chronic, potentially disability disease, mainly affecting the nerves, skin and eyes caused by a bacillus mycobacterium leprae, which microscopically resembles the organism of tuberculosis. The more clear understanding of this complex disease could be understood by:

i) Long incubation period (usually 2-5 years)

ii) The remarkable diversity with reference to the level of immunity of different individuals

iii) Increased frequency of adverse immunological reactions based on either cell mediated or antigen mechanisms.

iv) Its propensity to produce disability and deformity which may be severe in some cases affecting eyes, face or limbs,

v) Social and Psychological consequences of leprosy for the patient, family and community, in some cases it leads to outright stigmatization and rejection.

The world map shows the prevalence of leprosy in somewhat tropical, but in the past leprosy has been quite widespread in Europe, Scandinavia, China, Korea, and Japan. The likelihood contributions in development and spread are mainly poverty, poor socio economic condition, malnutrition, lack of clean water and inadequate basic resources.

Leprosy cured Persons with Disabilities means a person who has been cured of leprosy but is suffering from i) loss of sensation in hand or feet as well as loss of sensation and paresis in the eye and eye- lid but with no manifest deformity. ii) Manifest deformity and paresis but having sufficient mobility in their hands and feet to enable them to engage in normal economic activity. iii) Extreme physical deformity as well as advanced age which prevents him/her from undertaking any gainful occupation.

Classification

There are several different approaches for classifying leprosy, however, parallels exist.

- The World Health Organization system distinguishes “paucibacillary” and “multibacillary” based upon the proliferation of bacteria (“pauci-” refers to a low quantity.)
- The SHAY scale provides five gradations.
- The ICD-10, though developed by the WHO, uses Ridley-Jopling and not the WHO system. It also adds an indeterminate (“I”) entry.
- In MeSH, three groupings are used.

Tuberculoid: It is characterized by one or more hypopigmented skin macules and anaesthetic patches, where skin sensations are lost because of damaged peripheral nerves that have been attacked by the human host’s immune cells.

Borderline: Borderline leprosy is of intermediate severity and is the most common form. Skin lesions resemble tuberculoid leprosy but are more numerous and irregular; large patches may affect a whole limb, and peripheral nerve involvement with weakness and loss of sensation is common.

Lepromatous: It is associated with symmetric skin lesions, nodules, plaques, thickened dermis, and frequent involvement of the nasal mucosa resulting in nasal congestion and epistaxis (nose bleeds) but typically detectable nerve damage is late. There is a clearcut difference in immune response to the tuberculoid and lepromatous form.

Signs and symptoms

Skin lesions are the primary external sign. Left untreated, leprosy can be progressive, causing permanent damage to the skin, nerves, limbs and eyes.

Contrary to folklore, leprosy does not cause body parts to fall off, although they can become numb and/or diseased as a result of the disease.

The most common symptoms of leprosy are:

- skin lesions that have decreased sensation to touch, heat, or pain and are are lighter than your normal skin color
- skin lesions that do not heal after several weeks to months
- numbness or absent sensation in the hands and arms, or feet and legs
- muscle weakness

Leprosy can eventually cause cosmetic disfigurement, nerve damage in the extremities, and sensory loss in the skin and muscle weakness. People with long-term leprosy may lose the use of their hands or feet due to repeated injury resulting from lack of sensation.

Causes

Leprosy is caused by the organism Mycobacteriumleprae. *Mycobacterium leprae*, one of the causative agents of leprosy. As acid-fast bacteria, *M. leprae* appear red when a Ziehl-Neelsen stain is used. Main article: Mycobacterium leprae

Mycobacterium leprae and *Mycobacterium lepromatosis* are the causative agents of leprosy. *M. lepromatosis* is a relatively newly identified mycobacterium which was isolated from a fatal case of diffuse lepromatous leprosy in 2008.

An intracellular, acid-fast bacterium, *M. leprae* is aerobic and rod-shaped, and is surrounded by the waxy cell membrane coating characteristic of *Mycobacterium* species.

Due to extensive loss of genes necessary for independent growth, *M. leprae* and *M. lepromatosis* are unculturable in the laboratory, a factor which leads to difficulty in definitively identifying the organism under a strict interpretation of Koch's postulates. The use of non-culture-based techniques such as molecular genetics has allowed for alternative establishment of causation.

While the causative organisms have to date been impossible to culture *in vitro* it has been possible to grow them in animals. Charles Shepard, chairman of the United States Leprosy Panel, successfully grew the organisms in the footpads of mice in 1960. This method was improved with the use of congenitally athymic mice ('nude mice') in 1970 by Joseph Colson and Richard Hilson at St George's Hospital, London.Eleanor Storrs at the Gulf South Research Institute discovered that wild armadillos in Louisiana were naturally infected with leprosy. Naturally occurring infection also has been reported in non-human primates including the African chimpanzee, sooty mangabey, and cynomolgus macaque.

Assessment as per DEPwD Guidelines.

WHO grading of disability in Leprosy:

Highest grade for each eye or hand or foot =2. Maximum EHF sum score = 12 (E= Eyes, H=Hands, F=Feet)

Grade	Eyes	Hands	Feet
0	No eye problem due to leprosy; no evidence of visual loss	No anaesthesia, no visible deformity or damage	No anaesthesia, no visible deformity or damage
1	Eye problem due to leprosy present, but vision not severely affected as a result of these vision: 6/60 or better; can count fingers at 6 metres).	Anaesthesia present, but no visible deformity or damage	Anaesthesia present, but no visible deformity or damage
2	Severe visual impairment (vision worse than 6/60, inability to count fingers at 6 metres). Also includes lagophthalmos, iridocyclitis and corncal opacities	Visible deformity or damage present (such as cracks/wounds, claw fingers, wrist drop, contractures, amputation etc.)	Visible deformity or damage present (such as cracks/wounds, claw toes, foot drop, contractures, amputation etc.)

For sensory testing of hands and feet, light touch (just enough to indent the skin very slightly) of the tip of ball point pen is recommended.

For testing loss of corneal sensation, light touch of the clean cotton wisp from the lateral side is recommended. It is also to be noted whether blinking of the eyes is normal or not.

Muscle power is tested clinically by Voluntary Muscle testing of commonly examined peripheral nerves and graded as per the Medical Research council, London Scale.

EHF (Eyes, Hands, Feet) Grade Score is calculated

Higher the Score, greater the Disability. Maximum EHF Score possible is 12.

EHF Score is 0-1, then % of Disability is up to 20%

EHF Score is 2-3, then % of Disability is 20% to 40%

EHF Score is 4-5 then % of Disability is 41% to 60%

EHF Score is 6-7 then % of Disability is 61% to 70%

EHF Score is 8-9 then % of Disability is 71% to 80%

EHF Score is 10-11 then % of Disability is 81% to 90%

EHF Score is 12 then % of Disability is 91 to 100%

Intervention

All the patients must be bought under the network of the centre for the treatment, Adequate specific and regular treatment should be ensured. Maintenance of treatment records is obligatory as it helps in follow up and tracing the defaulters.

Side by side, the patient should be explained the advantages of the treatment of leprosy and its effect on control and progress of the disease. Furthermore, it is important to create facilities for indoor, treatment of acute complications of the disease. In addition facilities for dressing of deformities should be made available. Similarly referral centre may be created for specialized treatment where complications and deformities can also be effectively managed. Treatment through

medicinal intervention is also having great importance in the treatment of leprosy. All the medicinal interventions include chemotherapy.

Chemotherapy

Treatments are aimed to eliminate the microorganism that causes leprosy and to reduce the symptoms. Common treatments include**:Dapsone, Rifampin, Clofazimine, Ethionamide, Aspirin,Prednisone and Thalidomide**

Earlier, treatment of leprosy was restricted to Dapsone mono therapy. It predisposed to the emergence of secondary and subsequent primary Dapsone resistant bacilli. In order to check the spread of drug resistant mutants, WHO recommended the multi drug therapy with the objective i) to cure the patient ii) to interrupt the transmission of the infection in the community iii) to stall the emergence of drug resistant mutants and iv) to prevent the deformities.

Short course chemotherapy for 6 months is recommended for pause-bacillary patieats and it is administered to all freshly diagnosed cases of pauci bacillary and also to that dapsone treated pauci-bacillary patients, who have relapsed. The treatment is stopped after 6 months.

The proposed chemotherapeutic regimen for multi bacillary (MB) leprosy is recommended for i)Freshly diagnosed MB cases ii) Patient, who have responded satisfaction by to previous dap some muno therapy iii) Patients, who have not responded satisfaction to previous dap some mono therapy iv) Patient, who have relapsed after cessation of dap some mono therapy. The treatment is recommended for minimum 2 years.

Many newer anti-leprosy drugs have been introduced such as Fluroguinotones, Mynocycline Macrolides and Phenazine, which are effectively treating and diagnosing the leprosy patients.

Rehabilitation

The rehabilitation of the person should start from the day of diagnosis. Physiological rehabilitation of the patient is very important, along with the sympathetic attitude and understanding of the patient is of considerable assistance. It helps in gaining the confidence of the patient and changing has attitude towards leprosy. The leprosy workers should help in finding suitable jobs for the patients so that they become self sufficient and useful for the society. Financial assistance through welfare agencies would also be helpful for their rehabilitation.

Conclusion

Leprosy is common in many countries in the world, and in temperate, tropical, and subtropical climates. Approximately 100 cases per year are diagnosed in the U.S. Most cases are limited to the South, California, Hawaii, and U.S. island possessions. In India, around 120,000 leprosy patients existed in 1881. The central government passed the Lepers Act of 1898, which provided legal provision for forcible confinement of leprosy sufferers in India. In MeSH, three groupings are used.

Tuberculoid: It is characterized by one or more hypopigmented skin macules and anaesthetic patches, where skin sensations are lost because of damaged peripheral nerves that have been attacked by the human host's immune cells.

Borderline: Borderline leprosy is of intermediate severity and is the most common form. Skin lesions resemble tuberculoid leprosy **Lepromatous:** It is associated with symmetric skin lesions, nodules, plaques, thickened dermis.

Treatments are aimed to eliminate the microorganism that causes leprosy and to reduce the symptoms. Common treatments include**, Dapsone, Rifampin, Clofazimine, Ethionamide, Aspirin, Prednisone, Thalidomide**

The transition of leprosy rehabilitation from medical to psycho social, and from institutional to community-based processes, in line with the move towards promoting rights and inclusion, would need to be accompanied by certain changes. The major change in strategy in rehabilitation for people with disabilities over the past 25 years has been the expansion of services into the community.

References

1. Nelson K.E (1998) "Leprosy" in Maxcy resource – Last public Health and Preventive Medicine, 14th edition. Ed.RB Wallace Stanford CT: Application & Large.
2. Action Programme for the elimination of leprosy, Status report 1996. WHO/ LEP/96.5 World Health organization Geneva, Switzerland.
3. RPwD Act, 2016 (The Gazette of India).
4. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 3 CEREBRAL PALSY

By - Dr. Hemlata

Introduction

In this unit we will discuss about cerebral palsy that is covered under Rights of Persons with Disabilities Act, 2016 as one of the disability under the broad category of "Locomotor Disability". The characteristics, causes, types of cerebral palsy, assessment and intervention will be discussed in brief.

When a child has cerebral palsy it means that a group of non-progressive conditions are present and that can be characterized by abnormal motor control, posture difficulty. This may be present because of brain injuries or neurological reasons. Basically cerebral palsy is an umbrella terms that covers a group of non progressive, non contagious motor conditions that causes physical disability.

Meenu is a three years old girl, she is always active and energetic but she has difficulty in gripping things and movement. Initially her family thought that in due course she will be all right but later on they realized that there is some difficulty with her and they took her to a doctor who informed them that menu has cerebral palsy and advised them to go to centres where she could be given therapies and interventions. Her mother took her to one such organization where she was provided regular intervention and therapies, as a result menu has started showing improvement. Now she attends a regular school where the teachers provide her support in her studies and the aya in the school takes her to toilet and drops her outside the school gate from where her parents take her home.

There are many children who have this type of condition or other associated difficulties. In this unit we will discuss about cerebral palsy in detail.

Objective

After undergoing this unit you will be able to understand cerebral palsy and become familiar with: -

- Concept and meaning of cerebral palsy
- Various type of cerebral palsy
- Characteristics and causes of cerebral palsy
- Assessment and Intervention of cerebral palsy

Concept and Meaning

The word Cerebral Palsy is made of two words – Cerebral that means concerning the brain and palsy that means paralysis or inability to move. Basically due to damage to the brain cerebral palsy occurs. It is a disorder of control of muscles that causes difficulty in coordination, movement and positioning of the body. This happens because of the damage in the part of brain that controls the body movement. The damage caused to the brain is non-progressive but it cannot recover or cured. If proper intervention is given to the child having cerebral palsy the problems of coordination, movement and posture can be reduced and the functioning of the child can be improved, whereas if poor positioning is there and no proper intervention is given the problems of the child can be worsen.

Rights of Persons with Disabilities Act, 2016 defines cerebral palsy as "Group of non-progressive neurological condition affecting body movements and muscle coordination, caused by damage to one or more specific areas of the brain, usually occurring before, during or shortly after birth".

The effect of cerebral palsy is different in each individual and it depends on the part of brain that is damaged. Some children are affected mildly whereas others may be affected severely and may have difficulty in holding, sitting, walking etc.

Characteristics

The children affected with cerebral palsy may have the following characteristics:

1. Stiff muscles
2. Spasticity
3. Lack of muscle coordination
4. Involuntary movement of muscle or tremors
5. Delay in fine motor and gross motor skills
6. Difficulty in walking and abnormal gait.
7. Wrong body posture
8. Breathing difficulties
9. Excessive drooling
10. Difficulty in swallowing
11. Difficulty in gross motor skills such as walking or running
12. Difficulty in fine motor skills such as writing and holding micro objects
13. Perceptual difficulties
14. Difficulty in toileting, feeding, combing and other self grooming activities
15. Problem in vision
16. Problems in hearing and speaking
17. Difficulty in social and emotional situations

Types of cerebral palsy

Cerebral palsy can be of various types depending on the severity, type of movement or by the number of limbs affected, let us try to understand it in brief.

Types of cerebral palsy according to the degree of severity:

1. Mild: In this motor and posture related problem with minimum disability are present, the child will be independent with proper intervention, therapy and education.
2. Moderate: In this condition the child will be affected more but with the help of adapted devices he or she will be able to function and complete daily living activities.
3. Severe: In this type of condition the child will be dependent on others to meet his/her basic needs.

Type of cerebral palsy according to limb involvement:

1. Monoplegia: In this condition any one limb of the body usually an arm is affected.
2. Hemiplegia: In this condition one side of the body is affected and usually arm is more involved than the leg.
3. Paraplegia: In this condition both the lower limbs are affected.
4. Diplegia: In this condition all the four limbs are affected, usually both legs are more severally affected than the arms.
5. Quadriplegia: In this condition all the four limbs are affected.

Types of cerebral palsy according to movement disorder:

1. Spastic cerebral palsy: This is most common type of cerebral palsy and it is caused by damage to motor cortex. In this the muscles are tight and stiff, because of that the movement is limited. Spasticity may affect only a few movements or in very severe cases the whole body is affected.
2. Choreo-Athetoid cerebral palsy: It results because of damage to the cerebellum. Cerebellum is part of the brain that helps in coordination and fine tune movements and balance, because of the damage there is difficulty in controlling and coordinating body movements.
3. Mixed type cerebral palsy: In this condition various areas of brain are affected and because of that both muscle tone and voluntary movements are affected. Usually spasticity is more and as the child grows the involuntary movement increases.

Causes

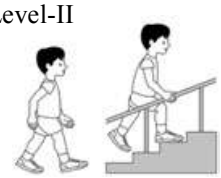
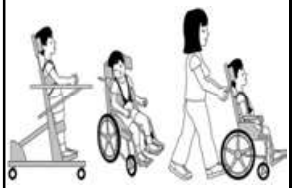
There are various factors responsible for cerebral palsy, which are as following:

1. Infections in the mother during pregnancy
2. Rh incompatibility
3. Toxaemia
4. Poor maternal nutrition
5. Bleeding during pregnancy
6. Intake of alcohol
7. Smoking
8. Metabolic disorder during pregnancy
9. Multiple pregnancies
10. Complications during the birth process
11. Lack of oxygen to the brain during the birth
12. Injuries to the brain at the time of birth
13. Premature birth
14. Low birth weight
15. Infection of the brain and spine
16. Brain tumors
17. Accidents leading to head injury

Assessment

The assessment of cerebral palsy should be done as per the guidelines issued by Dept. of Empowerment of Persons with Disabilities, Govt. of India for assessment of cerebral palsy.

The Gross Motor Function Classification System (GMFCS) should be used for evaluating cerebral palsy affected individuals. It is based on self-initiated movement, with emphasis on sitting, transfers, and mobility.

GMFCS Level	Description of Mobility status	% of permanent impairment in relation to whole body
Level-I 	• Can walk indoors and outdoors and climb stairs without using hands for support • Can perform usual activities such as running and jumping • Has decreased speed, balance and Coordination	Less than 40%
Level-II 	• Can climb stairs with a railing • Has difficulty with uneven surfaces, inclines or in crowds • Has only minimal ability to run or Jump	40 to 50%
Level-III 	• Walks with assistive mobility devices indoors and outdoors on level surfaces • May be able to climb stairs using a railing • May propel a manual wheelchair and need assistance for long distances or uneven surfaces	51 to 60%
Level-IV 	• Walking ability severely limited even with assistive devices • Uses wheelchairs most of the time and may propel own power wheelchair • Standing transfers, with or without assistance	61 to 79%
Level-V 	• Has physical impairments that restrict voluntary control of movement • Ability to maintain head and neck position against gravity restricted • Impaired in all areas of motor function • Cannot sit or stand independently, even with adaptive equipment • Cannot independently walk but may be able to use powered mobility	80% or more

Note:

i) In a person with cerebral palsy, other than problems of movement or posture, there may be other limitations such as visual impairment, hearing impairment, speech impairment, epilepsy, mental sub-normality (low IQ) etc. These are assessed separately as per the guidelines and the final disability % calculated using the combining formula: a+b (90- a)/ 90 (a = higher value, b = lower value).

ii) Total permanent physical impairment/disability % will not exceed 100%.

iii) Disability is to be certified in relation to the whole body.

This is a five-level classification system, and the primary criterion is that the distinctions between levels must be meaningful in daily life. Distinctions are based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement. At present, expanded and revised version of GMFCS is available (GMFCS- E&R).

Manual Ability Classification System (MACS)

The Manual Ability Classification System (MACS) describes how children with cerebral palsy (CP) use their hands to handle objects in daily activities. MACS describes five levels. The levels are based on the children's self-initiated ability to handle objects and their need for assistance or adaptation to perform manual activities in everyday life.

MACS can be used for children aged 4–18 years. MACS spans the entire spectrum of functional limitations found among children with cerebral palsy and covers all sub-diagnoses.

Level I includes children with minor limitations, while children with severe functional limitations will usually be found at levels IV and V. MACS levels are stable over time.

The certifying medical authority needs to know the following to use MACS:

The child's ability to handle objects in important daily activities, for example during play and leisure, eating and dressing, is to be considered as per the following scale:-

Level I. Handles objects easily and successfully. At most, limitations in the ease of performing manual asks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.

Level II. Handles most objects but with somewhat reduced quality and/or speed of achievement. Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.

Level III. Handles objects with difficulty; needs help to prepare and/or modify activities. The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.

Level IV. Handles a limited selection of easily managed objects in adapted situations. Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.

Level V. Does not handle objects and has severely limited ability to perform even simple actions. Requires total assistance.

MACS Level	Feature	% of permanent Impairment
Level I.	Handles objects easily and successfully.	20%
Level II.	Handles most objects but with somewhat reduced quality and/or speed of achievement.	30%
Level III.	Handles objects with difficulty; needs help to prepare and/or modify activities.	40%
Level IV.	Handles a limited selection of easily managed objects in adapted situations.	55%
Level V.	Does not handle objects and has severely limited ability to perform even simple actions.	70%

Intervention

If a new born child has low birth weight or any unusual symptom is there, immediately take doctor's advice, if the child has fits, immediately gets medical attention. The infant must receive attention of the mother and in case there is any difficulty, early intervention should be provided. The diet should be nourishing and nutritious, breastfeeding is best for six months however, supplementary foods may also be given from fourth months onwards.

Early diagnosis of Cerebral palsy is most important and in case of any difficulty proper intervention should be given. If the child shows atypical behavior then the parents should immediately take advice from the expert.

Early identification is the most important aspect for intervention of any disability. As soon as the child is born and it is establish that cerebral palsy is there early intervention programme should be initiated. Providing intervention to the child will include stimulating environment where with the help of mother or therapist the child has opportunity to explore, learn concepts and practice skills.

Usually the developmental milestones at every stage are based on the average situations, many times children achieve a particular milestones earlier than other children, whereas in certain milestones may lack behind. Missing one or two milestones in developmental stages should not cause worry to parents. In case there is a certain pattern in the missing of milestone or there are several milestones that are missed then they need to be cautious and consult a doctor or therapist.

Conclusion

Cerebral palsy is a developmental disability that occurs due to damage in a part of brain that is concerned with movement and because of this damage there is a difficulty in movement, coordination and posture. This damage can happen before, during or after birth. Depending on the kind of damage the severity of disability and type of difficulty is defined. It is very important to provided early intervention to the children affected with cerebral palsy, this intervention should be focused on developing the residual capacity of affected child and building on the skills with the help of appropriate therapy. The children affected with cerebral palsy may be provided education and vocational training as per the need.

References:

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 4 DWARFISM

By - Dr. Hemlata

Introduction

In this unit we will discuss about dwarfism that has been added as a disability under the broad category of "Locomotor Disability" in Rights of Persons with Disabilities Act, 2016. The characteristics, causes , assessment and intervention strategies will be discussed in brief.

You might have seen some people having very short height and because of that others make fun of them and do not treat them well. In every walk of life they face difficulty there are very few people who treat them as a person otherwise they are either part of pity by others, or sometimes ridiculed. We have to give respect to them as a human being and empathize with them. Government has realized the situation of such persons and added dwarfism in the RPwD Act 2016 as one of the disability.

Madhav is 15 years old but his height is only 4 feet and his head is bigger than the children of his age and in proportion to his body. His school children and neighbors made fun of him. His self esteem was low because of this and one day he broke down in school. The counselor had a discussion with him and advised to take few sessions with her. After few sessions his self esteem was not low and he was feeling happy and devoted more time in his studies and hobby. He acted very well in the annual function of school and even won the award of best actor. Now his classmates and children of other classes understand him and become friendly with him. Timely intervention of school counselor helped him a lot.

In this unit we will discuss about dwarfism in detail.

Objectives

After undergoing this unit you will be able to -

- Discuss concept and meaning of dwarfism
- Describe characteristics and causes of dwarfism
- Explain assessment and intervention strategies for dwarfism

Concept and Meaning

When a person is short in stature because of genetic or medical reasons it is called dwarfism.

As per RPwD Act 201 - "Dwarfism means a medical or genetic condition resulting in an adult height of 4 feet 10 inch (147 cms) or less."

The dwarfism can be categorized into two categories – disproportionate and proportionate. In disproportionate dwarfism the proportion of body parts is not equal either hand will be bigger or average and arms and legs will be shorter or trunk will be short with longer limbs. In proportionate dwarfism the body parts are in proportion to the height of body of the individual.

Common Characteristics

When a person is unusually short in height then this condition is called dwarfism. Dwarfism is not a diseases, and there is no single medical condition responsible for dwarfism however there might be various causes for this.

1. Very short arms and legs that may cause difficulty in daily living.
2. Large forehead
3. Sometimes difficulty in breathing
4. Narrowing in the spine
5. The size of torso is usually normal in some cases
6. Poorly developed rib cage
7. In some cases arms, legs and torso is short
8. The size of hands, feet and head is normal in some cases
9. There may be spine and hip related problem
10. Foot deformities may be present
11. Cleft palate may be present
12. Facial bones may look flat
13. Joint pain and mobility issues
14. Scoliosis, clubfoot or moving difficulty may be present
15. Limited elbow mobility
16. Head is disproportionately large
17. Prominent forehead
18. Neck bones may be unstable
19. Twisted feet
20. Bowed legs
21. Slower growth rate
22. Delayed or no sexual development during teenage
23. Short fingers often a vide separation is there between middle and ring fingers

Causes

There are various types of dwarfism, the common causes are as following:

1. Metabolic disorders
2. Hormonal disorders
3. Random genetic mutation
4. Abnormal bone growth
5. Hereditary
6. Kidney diseases
7. A rare disorder called spondylo epiphyseal dysplasia congenital (SEDC)
8. Growth hormone deficiency
9. Poor nutrition or deficiency in other hormones

Assessment

The evaluation of a short statured person shall be considered irrespective of whether it is of proportionate variety or disproportionate variety and is accompanied by an underlying pathological conditions,

Every 1" vertical height reduction shall be valued as 4% permanent physical Impairment in relation to whole body. Associated skeletal deformities such as contractures or deformities shall be evaluated, separately and total percentage of both shall be added by combining formula.

Height of the adult	% of permanent impairment
4 feet 10 inches	Nil
4 feet 9 inches	4%
4 feet 8 inches	8%
4 feet 7 inches	12%
4 feet 6 inches	16%
4 feet 5 inches	20%
4 feet 4 inches	24%
4 feet 3 inches	28%
4 feet 2 inches	32%
4 feet 1 inches	36%
4 feet	40%
3 feet 11 inches	44%
3 feet 10 inches	48%
3 feet 9 inches	52%
3 feet 8 inches	56%
3 feet 7 inches	60%
3 feet 6 inches	64%
3 feet 5 inches	68%
3 feet 4 inches	72%
3 feet 3 inches	76%
3 feet 2 inches	80%
3 feet 1 inches	84%
3 feet	88%
2 feet 11 inches	92%
2 feet 10 inches	96%
2 feet 9 inches	100%

Intervention

Symptoms of dwarfism may be seen at birth or early stages of infancy if the growth of child is deviant from normal milestones or the overall development of the child is lacking you need to consult the doctor. The person affected with dwarfism may face complications in delayed development of motor skills or they may have frequent ear infections that can result in hearing lose at later stage. They may face back pain problems in breathing and bowing of legs etc.

During pregnancy women with disproportionate dwarfism may develop respite problems therefore they may go for cesarean delivery. The persons with dwarfism should not be labeled by a condition the misconceptions about them need to be dealt carefully. The portrayal of person with dwarfism should not be in comic sense or negative misconceptions because it can impact on their self esteem and that would result in their disempowerment. As a society we need to provide them appropriate opportunities and reasonable accommodation during school education and later on at higher education. There is need to spread awareness about their condition and sensitizing their classmates, family members, community members and society at large so that they don't feel isolated and vulnerable in the society. With appropriate intervention they can become a productive member of society and contribute for its development.

Conclusion

Most of the infrastructure and facilities in our country are planned on the basis of average height of individuals. A dwarf person has short stature and may have proportionate or disproportionate body parts due to that they have difficulty in performing various activities i.e. if they go to office they will not be able to use the furniture provided to other employees, similarly at home they will not be able to use the door closures or will not able to open the windows. These are some general difficulties apart from that they may be having other pathological conditions and health issues. We need to understand their situation and provide appropriate intervention so that they can live a independent life and contribute effectively in nation building.

References

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 5 MUSCULAR DYSTROPHY

By -Dr. Sanjay Kant Prasad

Introduction

This unit deals with the specified disability covered under RPwD Act.2016, namely muscular dystrophy. The overall unit consists of the concept and meaning, types, causes of muscular dystrophy. Further unit also have in brief about the assessment of muscular dystrophy as per guidelines issued by D/o EPwD, Govt. of India along with about intervention in brief. The unit is based on the following objectives.

Objectives

After reading this unit, the learner will be able to:

- Describe about the concept and meaning
- Discuss about the types and causes
- Explain about the assessment criteria for certification of disability.
- Discuss about the intervention strategy used for management of the disability.

Concept and Meaning

Muscular Dystrophy is a hereditary genetic muscle disease that weakens the muscles that move the human body. The person with muscular dystrophy has incorrect and missing information in their genes, which prevents them from making the proteins, needed for healthy muscles. It is characterized by progressive skeletal muscle weakness, defects in muscle proteins and the death of muscle cells and tissue. Due to weak muscle, the ability to walk and perform even daily activities like brushing the teeth etc. becomes affected. The disorder can also affect heart and lungs in few of the cases. There are some forms of muscular dystrophy, which are apparent at birth or develop during childhood.

It often runs in families, because of its heredity and genetic characteristics. A child having parent with muscular dystrophy, may inherit a mutated gene that causes muscular dystrophy. On the other hand some people have the mutated gene but do not have muscular dystrophy. But this healthy person can pass the mutated gene to their child.

Types

It is believed that there are more than 30 different types of muscular dystrophy. However some of the common types are discussed below:

— Becker muscular dystrophy (BHD): - This is common muscular dystrophy. Symptom may appear anytime between 5 years of age to 60 years, but mostly appear during teenage years. Male are more likely to be affected by BHD. This affects the hip, thigh, and shoulder muscles, and eventually the heart.

— Duchinne Muscular Dystrophy (DMD): - these types of muscular dystrophy affect mostly boys between the age of 2 to 5 years. However girls can also get it. This is most common form of muscular dystrophy. The child faces difficulty in walking, running or jumping.

— Facioseapulohumeral Muscular Dystrophy: - this type of muscular dystrophy affects muscles in the face, shoulder blades and upper arms. Symptoms tend to be appearing before the age of 20.

— Congenital muscular dystrophy (CMD): - this condition present at birth. An infant may have week muscles, a curved spine and joints that are too stiff or loose. The children, who have CMD, may develop learning disabilities, seizures and vision problems.

— Myotonic Dystrophy: - People with myotonia usually have difficulty in relaxing their muscles. This also affect the hearth and lungs.

— Oculopharyngeal Muscular Dystrophy: - This is rare from. This type of MD weakens muscles in the eyelid and throat.

Causes

Most of the person inherits genetic mutation or changes, which causes muscular dystrophy. Apart from this, no other cause is known for developing muscular dystrophy.

Symptoms

The person with muscular dystrophy consists of many of the following symptom:

— Enlarged calf muscles

— Difficulty in running and walking

— Trouble in swallowing

— Learning disabilities

— Stiff or of loose joints

— Muscle pain

— Curved spine

— Heart problems, such as arrhythmia and heart failure (cardio sympathy)

— Breathing problems.

Assessment of Muscular Dystrophy as per Guidelines issued by D/o EPwD

After detailed clinical examination of the features namely, weakness, contractures, scoliosis cardiac or pulmonary, disability is computed based on the criteria for each of these and added to the locomotor disability component, using the combining formula a+b(90-a)/90. Here (a=higher value, b=lower value). Disability is to be expressed in relation to the whole body.

Intervention

The following intervention may help in management of muscular dystrophy.

— Physio and occupational therapy – These therapy strengthen and stretch muscles. Also help in maintaining function and range of motion.

— Speech therapy – For those, who are having problem in swallowing.

— Surgery – It relieves tension in contracted muscles and corrects spine curvature.

— Medical device such as walkers and wheel chairs, improve mobility and prevent falls.

Apart from this, corticosteroids and heart assistive devices are also useful in management of muscular dystrophy.

Conclusion

Muscular Dystrophy is a hereditary genetic muscle disease that weakens the muscles that move the human body. It often runs in families, because of its heredity and genetic characteristics. There are more than 30 different types of muscular dystrophy. However some of the common types are Becker muscular dystrophy (BHD), Duchinne Muscular Dystrophy (DMD), congenital muscular dystrophy (CMD), Oculopharyngeal Muscular Dystrophy and Myotonic Dystrophy etc. Most of the person inherits genetic mutation or changes, which causes muscular dystrophy. The intervention strategy includes physio-occupational therapy, speech therapy, surgery etc.

Reference

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 6 ACID ATTACK

By - Dr. Hemlata

Introduction

In this unit we will discuss about acid attack, that has been added as a disability in Rights of Persons with Disabilities Act, 2016. The common characteristics, causes of acid attack , assessment and intervention will be discussed in this unit.

You might have heard about the case of four sisters who were attacked by throwing acid, this was done by two men for taking revenge. Similarly another case was in news for quite some time where a young girl was attacked by throwing acid on her face she fought the case and united many other such victims. In 2013 the Supreme Court put a ban on the sale of acid. The order said that the retailers should keep the data of the buyers of the acid so that the misuse can be prevented. Despite that in India acid attacks are increasing. The acid is thrown on a person with an intention to torture or disfigure them, usually the victims of acid attack are females. The intention of attack is quite often to humiliate the person. It occurs as a revenge taking action against the victim and it is establish that 80% of acid attacks are on females. Many times due to fear the cases are unreported. In 2016 acid attack victim have been included in the categories of Disability covered under RPwD Act, 2016. They will also get the benefit of Govt. of India and State Governments provided from time to time to persons with disabilities.

Objectives

After undergoing this unit you will be able to:

- Understand the concept and meaning of Acid Attack
- Enumerate the common characteristics of acid attacks victims
- Discuss the causes of acid attack
- Elaborate on assessment and intervention for acid attack victims

Concept and meaning

Acid attack means throwing acid or any other substance on the body of other person with the intention of taking revenge or disfigure them. Usually acid is thrown on the face or upper part of the body. As per RPwD Act, 2016 “acid attack victims means a person disfigured due to violent assaults by throwing of acid or similar corrosive substance”.

Common Characteristics

The common characteristics of acid attack are as following-

1. Deformity in skull and loss of hair
2. Damage in ear cartilage
3. Deafness may occur
4. Damage and deformity in eyes that can lead to blindness
5. Nose can be deformed

6. Deformity in hands
7. Scars in the body
8. Limitation of movement of the body
9. Shrinking of chin and neck area
10. Respiratory problems may occur
11. Nostrils may be damaged
12. Possibility of other associated health problems due to damage in the various organs
13. Mental health issues may occur
14. Anxiety and depression may be seen
15. Lower self-esteem
16. Poor self consciousness
17. Acid attack may lead to physical disability

Causes

There are various reasons responsible for acid attack such as following -

1. Enmity
2. Intention of humiliation of the victim
3. Issues related to gang war and rivalry
4. Minority or caste based discrimination
5. Conflict because of land or property
6. Motive of taking revenge because of refusal of sexual advances
7. Demand of dowry

Assessment

The assessment should be done as per the guidelines issued by Dept. of Empowerment of Persons with Disabilities, Govt. of India for assessment of acid attack victims.

Definition "**acid attack victims**" means a person disfigured due to violent assaults by throwing of acid or similar corrosive substance.

Acid attacks cause chemical burns. Acids cause coagulation necrosis with precipitation of proteins. They can cause lifelong bodily disfigurement. The medical effects of acid attacks are generally extensive. Acids used in acid attacks may be acetic acid, carbolic acid, chromic acid, formic acid, sulphuric acid, nitric acid, hydrochloric acid, hydrofluoric acid, oxalic acid, phosphoric acid etc. The severity of the damage depends on the concentration of the acid and the time before the acid is thoroughly washed off with water or neutralized with a neutralizing agent. The acid can rapidly eat away skin, the layer of fat beneath the skin, and in some cases even the underlying bone.

Impairments resulting from acid burns are not restricted to the skin. Often, more than one system is involved, such as skin, musculoskeletal, respiratory, vision etc. Scarring represents a special type of disfigurement. Scars affect sweat glands,

hair growth, and nail growth, and cause pigment changes or contractures and may affect loss of performance and cause impairment. The lymphatic system can be affected in the lower or upper extremity, causing chronic swelling of the leg and feet, or the arm and hand respectively.

Since majority of acid attacks are aimed at the face, eyelids and lips may be completely destroyed, the nose and ears severely damaged. Acid can quickly destroy the eyes, blinding the victim. The eyelids may no longer close, the mouth may no longer open, and the chin may become welded to the chest.

Given below are the frequently noted physical consequences of acid attacks:

Skull : May be partly destroyed or deformed. Hair is often lost.

Forehead : Skin may shrink, as though stretched tightly, and be scarred.

Ears : Shriveled up and deformed. Deafness may occur immediately or later.

Cartilage in the ear is usually partly or totally destroyed, exposing the victim to future infection and hearing loss.

Eyes : Direct acid contact or acid vapors can damage eyes, causing blindness. Even if the eyes survive the acid attack, they remain vulnerable to other threats which can cause blindness during the victim's recovery. Eyelids may have been burned off, or may be deformed by scarring, leaving the eyes to dry up and go blind. This is very difficult to prevent.

Nose : Shrunken and deformed. Nostrils may close completely because the cartilage is destroyed.

Cheeks : Scarred and deformed.

Mouth : Shrunken and narrowed, and may lose its shape. Lips may be partly or totally destroyed. Lips may be permanently flared, exposing the teeth. Movement of the lips, mouth and face may be impaired. Eating can be difficult.

Chin : Scarred and deformed. The scars may run downward, welding the chin to the neck or chest.

Neck : Often badly damaged. It may have a thick cord of scarred flesh running down from the chin to the upper chest, or a wide, heavily-scarred area on one side of the neck. Victim may be unable to extend the neck, or the head may constantly lean to one side.

Chest : Often badly scarred. The chest may have narrow lines of scars or wide patches of scars from acid splashes or drips. In girls and young women, the development of their breasts may be stopped, or their breasts may be destroyed completely.

Shoulder : May be badly scarred, especially around the underarm, which may limit the victim's arm movement. In some cases, one or both of the victim's upper arms may be stuck like glue to the sides of their body.

Disability in acid attack victims is to be estimated by taking into consideration extent of damage in terms of area and depth, as is in cases of thermal injuries (burns). Good colour photography with multiple views of the area of involvement enhances the description. Every acid burn, regardless of the depth of injury, heals

with some element of contracture. Contractures frequently require a series of staged surgical procedures before optimal function and cosmesis are achieved. Scar tissue is less tolerant of the everyday stress imposed on it than normal skin. An extremity can be considered impaired even if it has a full range of motion because of a poor quality of skin after the chemical burn- skin that is thin and fragile, likely to ulcerate easily even with minor injuries. Even people who have received skin grafts can have intolerance to sunshine, heat, cold or sensation.

Restriction of normal movement by contracture is not limited to the extremities. Scars around the trunk also can become tight and stiff. When a scar occurs over the trunk or anterior chest, severe and chronic postural changes can result which may cause secondary spinal deformity or altered respiratory function. A badly scarred perineum or buttocks may make sitting in one position for prolonged period painful and difficult.

The guideline for assessment shall be as follows:

Part of body affected	**Deficit**	**% of permanent impairment**
Scalp and vault including forehead	Disfigurement alone Deformity or full thickness loss	5 10
Eye brows (Right & Left)	Loss of part of one or both Total loss of one or both	3% each 5% each
Eye lids- Upper Lower	Skin disfigurement alone Deformity or full thickness loss Skin disfigurement alone Deformity or full thickness loss	3% each 5% each 2% each 3% each
Ear (Pinna)	Skin disfigurement alone Deformity due to full thickness involvement of skin and cartilage without obliteration of meatus Deformity due to full thicknessinvolvement of skin and cartilage withobliteration of meatus	2% each 3% each 5% each
Nose	Skin cover disfigurement alone Deformity due to full thickness involvement with both nares (nostrils) patent Full thickness deformity with one nares obliterated Full thickness deformity with both nares obliterated	3% 5% 10% 20%
Lips	Skin cover disfigurement one lip alone Deformity or full thickness loss of one lip alone Deformity due to involvement of both lips leading to contracture	3% 5% 10%
Cheek and lateral area of face	Skin disfigurement Deformity or full thickness loss	5% each side 10% each side

Neck	Skin cover disfigurement Deformity due to involvement of skin, muscle or deeper tissue	5% 10%
Breast (Female)	Only skin cover disfigurement Deformity resulting in loss of functiondue to involvement of i) skin, areola & nipple ii) Skin, areola, nipple &parenchyma	5% each 10% each 15% each
Front of trunk & abdomen excluding breast	Only skin cover disfigurement Deformity or full thickness loss	5% 10%
Total back	Only skin cover disfigurement Deformity or full thickness loss	5% 10%
Groins	Only skin cover disfigurement Deformity or full thickness loss	2% each 5% each
Buttocks	Only skin cover disfigurement Deformity or full thickness loss	3% each 5% each
Genitalia	Skin loss resulting in mild deformity Severe contracture of orifices or sloughing of urethra or severe deformity of penis	7% 20%
Thigh	Only skin cover disfigurement Deformity or full thickness loss	3% each 5% each
Lower leg	Only skin cover disfigurement Deformity or full thickness loss	3% each 5% each
Foot	Only skin cover disfigurement Deformity or full thickness loss	3% each 5% each
Upper arm	Only skin cover disfigurement Deformity or full thickness loss	3% each 5% each
Forearm	Only skin cover disfigurement Deformity or full thickness loss	3% each 5% each
Hand	Only skin cover disfigurement Deformity or full thickness loss	5% each 10% each

Mouth: Sometimes, the lips may be partly or totally destroyed, exposing the teeth. Eating and speaking can become difficult. Up to 20%

Esophagus: Inhalation of acid vapors creating upper digestive tract problems Up to 20%

Respiratory involvement: Acid vapors creating upper respiratory problems Up to 20%

In addition, significant respiratory function impairment is to be assessed based on the guidelines as given in respective section and weightage added depending on severity of involvement.

Miscellaneous: An additional weightage of up to 10% shall be given based on gender, age, occupation, and any other physical impairment not mentioned above.

The total % of permanent impairment/disability will not exceed 100%.

Intervention

Urgent response and intervention is needed for acid attack, as soon as the skin come in contact with acid it should be washed with water immediately. Some of the part of the body like eye may be damaged badly and immediate medical intervention is required. Home remedies should be avoided and local hospital may contacted. There is an urgent need for awareness on this issue and action may be taken to minimize such incidence. The sale of concentrated acid was also banned because of this reason.

Several acid attack survivors have joined together and started helping the acid attack victims, one such organization is PALASH Foundation that is helping the survivors for their psycho social rehabilitation. These organizations work as advocates for the empowerment of victims of acid attack. They provide research and other opportunities to the survivors and work for economic independence of acid attack survivors. Some acid attack survivors have come together and started a cafe in Agra and Lucknow. With proper support from the community they were able to initiate this cafe. The role of family and community is very important for rehabilitation of such survivors.

Conclusion

Acid attack can cause disfigurement in the body that can not be corrected and it has a long lasting impact on the individual. The severity of the damage occurred due to acid attack depends on the quick intervention provided at the time of attack. It is very important that the acid may be neutralized by washing thoroughly with water or any other neutralizing agent. Due to acid attack the layer of skin is badly damaged that result in disfigurement and impairment. The acid attack survivors needs to be provided medical intervention as well as psychological and counseling support.

References:

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 7 VISUAL IMPAIRMENT

By - Dr. Hemlata

Introduction

This unit deals with visual impairment that is one of the disabilities covered under Rights of Persons with Disabilities Act, 2016. The unit will provide you an overview on the concept and meaning , common characteristics , causes , assessment and intervention of visual impairment.

Visual Impairment means lack of vision. The persons having visual impairment is not able to see the objects or might have a perception of light that means she or he may be able to differentiate between light and dark. The legal definition of blindness depends on the measurement of visual acuity that means the ability to see clearly from a certain distance. You might have seen that visual acuity is tested at the eye clinic for distant vision and near vision and based on the ability to read a certain letter visual acuity is measured. For example if a person has 10/100 visual acuity it means the object, s/he can see at 10 feet distance can be seen by a person having normal vision at 100 feet.

Objectives

After undergoing this unit you will be able to:

- Explain the concept and meaning visual impairment
- Elaborate on the common characteristics of visual impairment
- Enumerate the causes of visual impairment
- Discuss the assessment and intervention strategies for visual impairment

Concept and meaning

A person may be considered having visual impairment if the field of vision is totally restricted. As per the RPwD Act, 2016 visual impairment includes blindness and low vision. We will be discussing both in separate units.

As per Rights of Persons with Disability Act, 2016 "blindness" means a condition where a person has any of the following conditions after best correction (i) total absence of sight (ii) visual acuity less than 3/60 or less than 10/200 (snellen) in the better eye with best possible correction (iii) limitation of the field of vision subtending an angle of less than 10 degree.

For educational purpose blind individuals are those who are severely impaired and must be taught to read through computers, Braille or other methods. They need to be taught plus curriculum to that they can learn the subjects of their choice.

Characteristics

The common characteristics of visual impairment are as following -

1. Excessive rubbing of eyes
2. Poor eye hand coordination

3. Difficulty in tracking
4. Difficulty in moving things
5. Squinting or blinking of eyes when looking an object
6. Difficulty in concentrating and comprehending reading material
7. Blurred vision may be there
8. Double vision may be there
9. Feel dizziness, nausea, fatigues and headache after reading books
10. Tilting of head, closing or blocking one eye while reading
11. Skipping lines during reading
12. The pupils may be hazy
13. Watering eyes
14. Redness in eyes

Causes

There are various reasons responsible for visual impairment such as following -

1. History of visual impairment in the family
2. Vitamin A deficiency during early childhood that can cause xerophthlmia or dry eyes
3. Marriage between close relatives (Congenital marriage)
4. Cataract
5. Glaucoma
6. Rh incompatibility between parents
7. Infections in mother during pregnancy like cyphilis, rubella during first three months of pregnancy.
8. Malnutrition in the pregnant mother
9. Excessive x-rays during pregnancy
10. Intake of drugs
11. Premature birth
12. Low birth weight
13. Lack of oxygen to the infant during delivery
14. Damage during birth
15. Injury to eye or head
16. Poor eye hygiene

Assessment

The assessment of visual impairment should be done as per the guidelines issued by Dept. of Empowerment of Persons with Disabilities, Govt. of India for assessment of disabilities.

Nature of Certificate: The medical authority will decide whether disability certificate should be temporary or permanent. The disability shall be permanent to be certified. The certificate can be temporary if condition is likely to worsen and also for specific purposes such as for pursuing education. The need of reassessment, if required, should be clearly mentioned in the certificate with time frame. In certain cases such as keratoconus, developmental defects, operated congenital cataract with corneal decompensation, operated congenital glaucoma with hazy cornea etc., the patient especially can be issued a temporary certificate.

Assessment of Visual Impairment for Certification and Gradation

Vision assessment should be done after best possible correction (medical, surgical or usual/conventional spectacles). The Ophthalmologist shall circle the vision Status and the Percentage Impairment and mark the Disability category accordingly as under:-

Better eye Best Corrected	**Worse eye Best Corrected**	**Per cent Impairment**	**Disability category**
Less than 3/60 to 1/ 60 Or Visual field less than 10 degree around centre of fixation	Less than 3/60 to No Light Perception	90%	IV a (Blindness)
Only HMCF Only Light Perception, No Light Perception	Only HMC FOnly Light Perception,No Light Perception	100%	IV b (Blindness)

For Visual acuity the line should be read completely, in case of partial line read, one line below that line should be taken for visual acuity.

Intervention

Persons with visual impairment should be provided appropriate intervention so that they can learn at par with other children. They can go to special schools or inclusive schools where the teachers can provide them education. These children may be provided multisensory training and exposure to plus curriculum that is not extra but compensatory, it helps them to learn better, the areas of plus curriculum may be as following:

1. Braille reading and writings skills
2. Training for use of equipments like tailor frame, abacus, brailler etc.
3. Training for use of computers including various softwares
4. Training in use of mobile phones and other electronic devices
5. Orientation and mobility training

The aim of intervention is to provide them proper rehabilitation facilities to live so that they are able to live as normal life as possible. Govt. of India has taken several initiatives for providing vocational rehabilitation to persons with visual impairment with proper training they can work in any field of their choice in government and non-government organizations. They can even start their own

business with the help of National Handicapped Finance and Development Corporation or any other agency.

Conclusion

Person with visual impairment needs to be provided adequate support and training so that they can live an independent life. It is the responsibility of family to identify the visual impairment at early stages and take them for assessment and provide intervention based on the condition of child. Early identification is very important and beneficial for overall development of persons with disabilities. They need to be provided adequate educational and vocational facilities so that they can live independent life and contribute for the society also.

References:

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 8 LOW VISION

By - Dr. Hemlata

Introduction

In this unit we will discuss about low vision as one of the disabilities covered under Rights of Persons with Disabilities Act, 2016. We will also discuss the concept and meaning of low vision, it's common characteristics and describe the causes of low vision along with some intervention strategies.

A person with low vision has difficulty in seeing the objects and despite using the glasses they are not able to see properly. With corrective glasses and magnifier they are able to carryout their daily living activities. There are various types of assistive devices and technologies available for them to accomplish their daily living activities, educational, vocational and recreation activities. In this unit we will talk about various assessment and intervention strategies for persons with low vision.

Objectives

After undergoing this unit you will be able to:

- Understand the concept and meaning of low vision
- Discuss the common characteristics of low vision
- Describe the causes of low vision
- Innumerate the assessment and intervention strategies for low vision

Concept and meaning

When we talk about a person with low vision it means a person having impairment of visual functioning that is there even after treatment or standard refractive correction but who can completing a task with the help of appropriate assistive device.

From the educational point of view person with low vision are those who can learn to read large print or regular print with the help of magnifier. As per Right of Persons with Disabilities Act, 2016 "low vision means a condition where a person has any of the following conditions, namely: -

i) Visual acuity not exceeding 6/18 or less than 20/60 upto 3/60 or upto 10/200 (snellen) in the better eye with best possible corrections; or

ii) Limitation of the field of vision subtending an angle of less than 40 degree up to 10 degree"

Common Characteristics

The common characteristics of low vision are as following -

1. Difficulty in seeing
2. Difficulty in walking at unknown places
3. Delay in concept development
4. Problem in language development

5. Difficulty in self help skills i.e. eating, dressing, grooming, toileting
6. Lack of eye contact
7. Unable to see things clearly from a little distance
8. Difficulty in indentifying the finger form a little distance
9. Difficulty in estimating the distance
10. Dependent on other senses
11. May be slow in group activities

Causes

The causes of low vision may be as following -

1. Blood incompatibility
2. Infections
3. High fever during early childhood
4. Macular degeneration
5. Diabetes
6. Glaucoma
7. Cancer of the eye
8. Brain injury
9. Albinism
10. Hereditary disorder of eye including retinitis pigmentosa,
11. Cataract

Assessment

The assessment of low vision should be done as per the guidelines issued by Dept. of Empowerment of Persons with Disabilities, Govt. of India for assessment of disabilities.

Assessment of low vision for Certification and Gradation

Vision assessment should be done after best possible correction (medical, surgical or usual/conventional spectacles). The Ophthalmologist shall circle the vision Status and the Percentage Impairment and mark the Disability category accordingly as under:-

Better eye Best Corrected	**Worse eye Best Corrected**	**Per cent Impairment**	**Disability category**
6/6 to 6/18	6/6 to 6/18	0%	0
	6/24 to 6/60	10%	0
	Less than 6/60 to 3/60	20%	I
	Less than 3/60 No Light Perception	30%	II (One eyed person)
6/24 to 6/60Or Visual field less than 40 up	6/24 to 6/60	40%	III a (low vision)

to 20 degree around centre of fixation or hemianopia involving macula	Less than 6/60 to 3/60	50%	III b (low vision)
	Less than 3/60 to No Light Perception	60%	III c (low vision)
Less than 6/60 to 3/60OrVisual field less than 20 up to 10 degree around centre of fixation	Less than 6/60 to 3/60	70%	III d (low vision)
	Less than 3/60 to No Light Perception	80%	III e (low vision)

- For Visual acuity the line should be read completely, in case of partial line read, one line below that line should be taken for visual acuity.

Matrix Table

Left Eye Vision [Best Corrected Visual Acuity (BCVA)])

		6/6 to 6/18	6/24	6/36	6/60	3/60	2/60	1/60	HMCF TO PL-
Right Eye Vision [Best Corrected Visual Acuity (BCVA)]	6/6 to 6/18	0%	10%	10%	10%	20%	30%	30%	30%
	6/24	10%	40%	40%	40%	50%	60%	60%	60%
	6/36	10%	40%	40%	40%	50%	60%	60%	60%
	6/60	10%	40%	40%	40%	50%	60%	60%	60%
	3/60	20%	50%	50%	50%	70%	80%	80%	80%
	2/60	30%	60%	60%	60%	80%	90%	90%	90%
	1/60	30%	60%	60%	60%	80%	90%	90%	90%
	HMCF TO PL-	30%	60%	60%	60%	80%	90%	90%	100%

- Yellow- Right eye is Better eye Brown- Left eye is better eye
- Percent disability is marked inside the box corresponding to the visual acuity for both eyes

Field of Vision around centre of fixation

Left Eye

Right Eye		<40° to 20°	<20° to 10°	<10°
	<40° to 20°	40%	50%	60%
	<20° to 10°	50%	70%	80%
	<10°	60%	80%	100%

- Yellow- Right eye is Better eye Brown- Left eye is better eye (only better eye Fields to be taken in to account for determining the %)

Intervention

Appropriate intervention can help children with low vision to achieve mastery in social skills, self help skills and educational skills. Appropriate educational facilities should be provided to these children wherein multisensory approach is used to teach them various skills. Use of assistive devices can enhance their

learning. They also need to be provided training of orientation and mobility. The role of parents and teachers is vital for the learning of children with low vision, they need to involve children in various activities at home and school. There are certain points that needs to be kept in mind while interacting with children with low vision are as following:

1. Addressed the child by his or her name while interacting with them.
2. If the child is not attentive touch his or her shoulder to make sure that he or she is listening and involve them in the discussions.
3. Facial expressions should be avoided and verbal statements should be used while discussing with them.
4. The listening skills of children with low vision may be improved so that they can follow directions and the receptive language is improved.
5. Give attention to such children.
6. Encourage them to interact with family members, neighbour and others in the community or market place etc.
7. Include them in various activities at schools with other children and provide appropriate support wherever required.
8. Avoid isolation for children with low vision

Technology can help them to perform various activities, with training and help of assistive devices they can work in almost all the fields. Some of the technologies useful for children with low vision are large print computers that can enlarge the text on the screen, close circuit TV can enlarge printed material on a TV screen and the background can be changed as per the need. Optical aids and magnifiers help hem to read and perform various other activities. These devices are available as handheld devices or the same can be mounted or installed on their study table.

Conclusion

The children with low vision has limitation in vision therefore we need to provide them explanation and interpretation in verbal language and provide more learning experiences where they can learn by doing and use their other senses. It is important to provide them appropriate intervention and learning environment so that they can learn and become independent. Various types of vocational skills can also be provided to them as per their interest. The family and teachers need to realise the importance of vocational education and economic empowerment of persons with low vision so that they can become productive member of the society.

References:

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 9 DEAFNESS AND HARD OF HEARING

By - Dr. Sanjay Kant Prasad

Introduction

This unit deals with the hearing impairment, such as deafness and Hard of hearing. The unit provides you a broader concept and overview of deafness as well as hard of hearing, degree of hearing loss which constitute deafness and hard of hearing, causes, identification through common characteristics, assessment for identification as well obtaining of certificate of disability. The hearing mechanism is also included in brief for the sensitization and general awareness.

Objective

After reading this unit the learner will be able to

- Describe about the deafness and hard of hearing.
- Discuss about the causes and types of hearing impairment.
- Explain about the assessment criteria for identification and obtaining the disability certificate.
- Understand about the intervention strategy for management of deafness and hard of hearing.

Concept and Definition

'Deaf' refers to hearing loss of 70 DB or more in speech frequencies in both ears.

'Hard of Hearing' means person having 60 db or 70db hearing loss in speech frequencies in both ears.

Hearing is an important sensory channel that allows the detention, discrimination, recognition and comprehension of auditory stimulus. Hearing helps to detect and localize even soft environmental sound and to acquire speech and language for communication or exchange of feelings, thoughts and ideas.

Hearing Disability or Deafness is an auditory problem experienced and complained by the individual. It reduces the functional potential and restricts the performance level.

The definition of hearing according to WHO based on the quantitative threshold is given below.

According to WHO, "A hearing threshold level of 26-40 dB or the ability to hear and repeat words spoken is a normal voice at a distance of one meter is called mild decrease in hearing".

A hearing threshold level of 41-60 dB or ability to hear and repeat works using a raised voice at distance of one meter is called "moderate decrease in hearing".

A hearing threshold of 61-80 dB or the ability to hear some words, when shouted into the ear is called severe decrease in hearing.

A hearing threshold level of 81 dB or greater or inability to understand even a shouted voice is referred to as profound decrease in hearing.

Deafness is usually the result of inner ear or nerve damage. It may be caused by a congenital defect, injury, disease, certain medication exposure to loud noise or age related wear and tear.

Types of hearing impairment or Deafness

Broadly hearing impairment is classified medically as conductive, sensore-neural and central deafness.

1. **Conductive Hearing Loss**:- The function of outer and middle ear is to carry the sound to the inner ear as a conducting apparatus. Any damage to this part restricts the sound either wholly or partly for reaching to the inner ear resulting into conductive hearing loss. Usually such type of hearing loss responds to medical treatment.
2. **Sensory-neural Hearing Loss**: - The inner ear is the perceiving apparatus. Damage to this apparatus which carries sound signal to the brain creates 'deafness' which is termed as 'perceptive deafness or sensory neural deafness or hearing loss. Sometimes child might have both perceptive and conductive deafness. In this case, the treatment of conductive part of deafness can only be done.
3. **Central hearing loss: -** 'Central hearing loss' is an abnormality in the central nervous system due to brain damage or psychogenic disorders or disease. Perceptive and central deafness can not be cured by medicine or surgery but can be improved only through training.

The above classification of deafness is for medical purpose. However for social and behavioral purposes another type of classification is relevant based on degree of hearing loss. The chronology or age of onset of deafness is of great importance for education.

Deafness from birth or pre acquisition of language creates many difficulties in the acquisition of linguistic communication skills. Such child or persons are termed as prelingually deaf. Based on degree the deafness or hearing loss is classified as mild, moderate, severe and profound.

Mild	-	25-50 db loss
Moderate	-	51 to 70 db loss
Severe	-	71 to 90 db loss
Profound	-	91 db and above

Deaf people usually have profound hearing loss, which implies very little or no hearing. Whereas persons with hard of hearing may be mild to severe.

Causes of Deafness and Hard of Hearing

Broadly there are two causes, which contribute to the development of deafness.

1) Endogenous causes – It is the result of biological process such as heredity syndromes, metabolic and endocrine disorders and blood incompatibilities e.g. Rh incompatibilities.
2) Exogenous causes – It is the result of some accident or of some foreign objects or agent either blocking or destroying some aspect of the auditory bacterial infections e.g. viral infections, meningitis mumps, rubella and measles etc.

Study was conducted on 928 deaf children to identify the causes of deafness and the following results were revealed.

Cause	Percentage
Heredity	24%
H/o Rubella	8.5%
Meningitis	5.3%
Anoxia	2.9%
Neo-natal jaundice	2.8%
Medication during pregnancy	1.1%
Medication during infancy	2.5%
Idiopathic	23.9%
Rubella Eye Signs	29.0%

Common Causes

The common causes of hearing impairment or deafness have been divided into pre-natal, peri-natal and post-natal.

The Pre-natal causes consist of family history of childhood deafness, consanguineous marriage, poor health condition of mother, excessive alcohol or nicotine intake by expectant mother, excessive exposure of X-ray etc.

The Peri-natal causes consist of premature delivery, lack of oxygen during birth, absent or delayed birth cry, birth weight less than 1200 gms.

The Post-natal causes consist of deformities of ear, nose, face and throat, infectious diseases, injury to head or ear, neglected ear discharge high blood pressure, diabetes etc.

The Assessment identification of deafness and hard of hearing

The assessment of hearing loss is done by audiologist. The assessment is done by using various audiological equipments. Some of these are as under.

1. Pure tone audiometer
2. Speech audiometer
3. Play audiometer
4. Sound field audiometer
5. Impedance audiometer
6. BERA

The Assessment of deafness and hard of hearing as per DEPwD guidelines

Measurement of Air Conduction Threshold (ACT)

a) ACT can be measured by using standard pure tone audiometry for right and left ear separately.

b) In case of non-reliable ACT additional tests are recommended such as immitance speech audiometry or audiometry Brainstem response tesing.

c) Measurement of ACT may be difficult in children aged 3.5 years. In such

cases, conditioned pure tone audiometry/visual reinforcement audiometry (VRA) shall be conducted.

Computation of percentage of disability

Calculation of Pure tone average of ACT for 500H_3, 1000 H_3, 2000 H_3 and 4000 H_3 for right and left ear separately. If there is no response at any frequency ACT is considered as 95 dB.

Monaural percentage of disability by PTA may be calculated by using ready reckaner given in the guidelines of assessment of disabilities published by DEPwD dt. 4th Jan. 2018.

Intervention

The most important form of support service required by a hearing impaired person is speech and language training by a speech therapist. The language of the child needs to be stimulated both by parents and the teacher. Besides, a hearing impaired child might also require the following:

- Acceptance of the disability by others.
- Right type of hearing aid.
- Proper use and maintenance of hearing aid.
- Right ear mould fitting.
- Speech training.
- Language development.
- Congenital and language stimulating environment.
- Positive attitude.

Methods of Communication

- Oral/ auditory- oral method: - In this method, the child is taught to make maximum use of his/her hearing through amplification. It also stresses the use of speech reading to aid the child's communication. Use of any form of manual communication is not encouraged although natural gestures may be used.
- Auditory – verbal uni- sensory method: - This method emphasizes maximum use of auditory skills. The child is taught to use listening skills. No manual communication is used and the child is discouraged from relying on visual cues. This method is very useful with children with cochlear implant.
- Sign Language: - This is a manual language, which is distinct from spoken language for communication one uses signs/ gestures/actions.
- Total Communication: - I this method, the child is exposed to a formal sign language system, finger spelling, natural gestures, speech reading, body language, oral speech and use of amplification.

While communicating with the hearing impaired child, the following rules should be followed.

- Sentence should be simple and short.
- More visual clues should be used.

- The child should get first hand experience.
- Use of proper hearing aid is very important.
- Speech reading should be clearly visible.

Conclusion

Hearing Disability or Deafness and hard of hearing is an auditory problem experienced and complained by the individual. It reduces the functional potential and restricts the performance level. The type of hearing disability includes conductive hearing loss, sensory neural hearing loss and central hearing loss. The common causes of hearing disabilities are pre- natal, peri natal and post natal. The assessment is done by using various audiological equipments. The most important form of support service required by a hearing impaired person is speech and language training given by a speech therapist.

References

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 10 SPEECH AND LANGUAGE DISABILITY

By -Dr. Sanjay Kant Prasad

Introduction

This unit deals with the concept and meaning of speech and language disability. Speech and language disability is one of the specified disabilities under RPwD Act, 2016. Apart from concept find the types, causes and various interventions to overcome the speech and language disability. The content of the topic has been included with the following objectives.

Objectives

After reading this unit, the learner will be able to

- Describe about the meaning of speech and language disability.
- Discuss about the various types and general causes of speech and language disability.
- Explain about the various intervention method of speech and language disability

Concept and Meaning

Speech and Language are the tools that are used by the human being to share thoughts, ideas and emotions. Language is the set of rules shared by the individuals who are communicating with each other. Language allows the individuals to exchange thoughts, ideas and emotions on the other side speech is a expression of language. Though language is also expressed through writing, signing or even gesture by those people who have neurological disorders.

Speech and Language disability is a form of communication disability. Therefore delay in development of speech and language milestones is an indication of communication disability. Broadly speaking individual with speech and language disability are those who are unable to communicate effectively through spoken mode.

However as per RPwD act 2016, the speech and language disability means a permanent disability arising out of conditions such as laryngectomy or aphasia affecting one or more component of speech and language due to organic or neurological causes.

Types of Speech and Language Disability

Speech disability consists of those which are characterized by errors in voice, articulation and fluency. These are termed as voice disorders, articulations disorders and fluency disorders. The language disability consists of delayed language and deviant language.

Voice disability or disorder

The different types of voice disorders include pitch disorders, Loudness disorders and quality disorders which an individual is having voice disorders, it may sound to be rough, noisy, high pitched or low pitched.

Articulation disability or disorder

Articulation is a component of speech. It is considered as disorder, when a person is unable to produce the sound of his or her language the articulation disorder consists of the error of substitutions, omissions, distortions and additions.

Fluency Disorders

It is described as easy smooth, flowing and effortless speech. Fluent speech impress the listener with rhythmic flow as well as feel easy to produce and require less effort, struggle and muscular tension to the speaker. Stuttering is main disorder of fluency characterized by excessive amount of dysfluencies or excessive amount of speech sound excessive muscular effort in speaking, hand and feet movement etc. The dysfluencies in stuttering are characterized by repetitions, prolongations, interjections, silent pauses and broken words.

Cluttering

It is a complex fluency disorder with impaired fluency, rapid but disordered articulations, usually combine with disorganized thought and language production.

Delayed Language: - It follows the pattern of a normal development but considered delayed if compared to the other child of the same age group.

Deviant Language: - It does not follow the pattern of normal development. It includes the grammatical structure of sentence and words, the meaning of words, vocabulary and effective use of language in social or everyday life.

Causes

The common causes of voice disorder is vocal abuse and misuse resulting from chronic behaviors like smoking, drinking, shouting, throat clearing, coughing and using pitch and loudness of voice inappropriately.

The causes of language disorders are many; some of the prominent causes are given below.

- **Hearing loss**: - Hearing loss is developmental age may lead to profound speech delay. The hearing loss is of two types conductive and sensor neural. The children having conductive hearing loss associated with middle ear fluid during the first few years of life are at risk of developing delayed speech. Sensor neural hearing loss is a result of intrauterine infection, Kernictevous drugs, hypoxia, intracranial hemorrhage, bacterial meningitis, few syndrome like pendred syndrome, warden burg syndrome etc. and chromosomal abnormalities.
- **Intellectual disabilities: -** The child with intellectual disability has both language delay as well as delayed auditory comprehension and delayed use of gestures.
- **Developmental disorder: -** Autism is characterized by delayed and deviant language development failure to develop the ability to relate to others and ritualistic and compulsive behaviors including repeated motor activities.
- **Expressive language disorder: -** Children with expressive language disorder fail to develop the use of speech at the usual age. These children have no other issue except the primary deficit of brain dysfunction that results in an inability to translate ideas into speech. Generally gesture is used by such children to supplement their verbal expression.

- **Psychosocial deprivation: -** Inadequate language stimulation parental absenteeism, emotional stress and child neglect results into an adverse effect on speech and language development.
- **Cerebral Palsy: -** The children with cerebral palsy usually show delay in speech. The factors such as hearing loss, spasticity of muscles and defect in the cerebral cortex are the contributing factors in delay of speech in cerebral palsy.

Signs and Symptoms

Following are some of the common characteristics of children with speech and language disability.

- Problems in language comprehension
- Inappropriate responses.
- Failure to understand instruction.
- Limited language expression
- Problem in learning speech
- Linguistic non-fluency
- Revision of utterances
- Problem in articulation
- Short span of attention.
- Limited social interaction.
- Lack of functional writing skills.
- Problems in learning words.

Assessment to obtain certificate of Disability

These are the conditions for which the speech and language disability certificate is issued.

- Laryngectomy
- Glossectomy
- Bilateral vocal cord paralysis
- Dysarthia
- Mexillofacial anomalies
- Apraxia of speech

Following scales are used to assess the speech and language disability.

i) Speech intelligibility test

ii) Voice test

iii) Language test.

The verbal output of person should be evaluated using perceptual speech intelligibility scale developed by AYJNISHD 2003) or perceptual rating scale affected SIA to be measured as per the score given below

Score	Percentage of speech intelligibility affected
1	0 - 15
2	16 - 30
3	31 - 39
4	40 - 55
5	56 - 75
6	76 - 89

Voice Test

The measurement of overall voice clarity affected is done by using 'Consensus Auditory Perceptual Evaluation of Voice (CAPE-V) or Dysphonia Severity Index (DSI). Average score to be given weitage for the percentage of OVCA.

Score	Percentage of OVCA
1	0 - 15
2	16 - 30
3	31 - 39
4	40 - 55
5	56 - 75
6	76 - 89
7	90 - 100

Calculation

$$\frac{2 \times \text{upper \% of SIA} + \text{upper \% of OVCA}}{3}$$

Language test – Western Aphasia Battery (WAB) in Indian languages is to be administered post six month of the onset of the stroke and aphasia. Aphasia quotient is to be calculated as per standard procedure by a speech language pathologist

Intervention

The different intervention strategies are used to manage speech and language disorder/disability. Some of the important interventions are as follows: -

- Language intervention by speech & language therapist
- Behavioral intervention through behavior modification technique
- Speech therapy
- Parent – Mediated intervention

- Peer- mediated intervention
- Pragmatic/social communication
- Sensory Based intervention
- Relationship Based intervention

(All interventions must be executed by expert therapist)

Conclusion

Speech and Language disability is a form of communication disability. Therefore delay in development of speech and language milestones is an indication of communication disability. Broadly speaking individual with speech and language disability are those who are unable to communicate effectively through spoken mode.

However as per RPwD act 2016, the speech and language disability means a permanent disability arising out of conditions such as laryngectomy or aphasia affecting one or more component of speech and language due to organic or neurological causes.

Speech disability consists of those which are characterized by errors in voice, articulation and fluency. These are termed as voice disorders, articulations disorders and fluency disorders. The language disability consists of delayed language and deviant language.

The common causes of voice disorder is vocal abuse and misuse resulting from chronic behaviors like smoking, drinking, shouting, throat clearing, coughing and using pitch and loudness of voice inappropriately and vocal cord surgery.. The causes of language disorders are many, such as hearing loss. Cerebral palsy and psycho-social deprivation etc.

Reference

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 11 INTELLECTUAL DISABILITY

By - Dr. Hemlata

Introduction

In this unit we will be discussing about intellectual disability that is one of the disability covered under Rights of Persons with Disabilities Act, 2016. The common characteristics, causes, assessment and intervention strategies will be elaborated in this unit.

Intellectual Disability means a person having below average intelligence some time we see person with disability who are not able to understand the instructions given by family or friends and they are not able to adapt the behavior appropriately. You might have heard people saying around you that so and so has low IQ or s/he does not understand the things that are told to them. Basically in intellectual disability the person has limited mental functioning, understanding, following instructions, recall of memory, communications skills and social skills because of these issues the person may be less capable of self care or require the help of others for their living skills. They may learn the skills but require continuous practice and may forget if they are not practicing it. The family members need to keep these children engaged with various activities that give them the chance to practice their daily living skills. In this unit we will talk in detail about intellectual disability, its causes and characteristics etc.

Objectives

After undergoing the information given in this unit you will be able to:

- Explain the concept and meaning of intellectual disability.
- Describe the common characteristics of intellectual disability
- Discuss the causes of intellectual disability
- Elaborate the assessment and intervention strategies for intellectual disability

Concept and meaning

As per Rights of Persons with Disabilities Act, 2016 intellectual disability is define as – "a condition characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and adaptive behavior which covers a range of everyday, social and practical skills"

In persons with intellectual disability significant limitations is seen in intellectual functioning as well as in adaptive behaviours. They are not able to generalize the things that are told to them in one situation. Therefore they have problems in conceptual, social and practical skills in adapting things. They need to be told things in simple and clear words that need to be repeated again and again. Intellectual disability can be classified on the basis of need for support, psychological classification and educational classification, of the basis of IQ level of the individual and educational support required for them.

Psychological classification

The Psychological classification of intellectual disability is based on the IQ level of the person with intellectual disability. The IQ level can be assessed with the help of following formula:

$$IQ = \frac{MA}{CA} \times 100$$

IQ = Intelligence Quotient

MA= Mental Age

CA = Chronological Age

On the basis of IQ level Intellectual Disability can the classified in four categories:

Level	**IQ**
Mild Intellectual Disability	52-69
Moderate Intellectual Disability	36-51
Severe Intellectual Disability	20-35
Profound Intellectual Disability	Below 20

Educational classification

Based on the level of functioning educational classification of intellectual disabilities can be decided and the type of education to be given to a child will be based on this classification. The child is assessed for functional level and based on that an individual education programme (IEP) for teaching can be prepared.

1. Educable (IQ approximately 50-70) – The children in this group can learn simple reading, writing and arithmetic. They possess social communication skills and can be trained to work in open employment as they are able to travel independently and perform semi skilled jobs etc.
2. Trainable (IQ approximately 20-49) – The children in this category have limited social competency, they can learn simple functional academics and by proper training they can perform unskilled work and employed in sheltered workshops.
3. Custodian (IQ below 20) – The children in this group are dependent on others and they need constant support for their living skills, for them acquiring even functional literacy is difficult.

Recent educational classification – is based on the chronological age of children that is as following:

1. Preprimary – 3 to 6 years
2. Primary – 7 to 10 years
3. Secondary – 11 to 14 years
4. Pre vocational – 15 to 18 years
5. Vocational – above 18 years

Characteristics

Children with intellectual disability may have following characteristics -

1. Poor intellectual functioning
2. Difficulty in adaptive behavior
3. Difficulty in learning concepts
4. Difficulty in social skills
5. Difficulty in communication
6. Difficulty in self care and home living
7. Social and interpersonal skills
8. Poor memory
9. Delay in developmental milestones
10. Difficulty in grasping social rules
11. Limitation in cognitive functions like understanding the reason of a particular problem
12. Difficulty in logical thinking
13. Low attention span
14. Difficulty in grooming skills
15. Difficulty in personal care skills
16. Self concept is poor
17. Lack of social emotional skills
18. Lack of motivation
19. Lack of attention
20. Maladaptive behavior
21. Poor gross motor and fine motor skills
22. Difficulty in recognizing common shapes like square, rounds, straight line etc.
23. Slow in physical and mental activities
24. Unable to attend group activities
25. Like the company of children of younger age
26. Feeling shy in group activities

Causes

There are various causes responsible for intellectual disability some of them are as following -

1. Genetic factor i.e. down syndrome, trisomy 21, fragile X syndrome, PKU etc.
2. Prenatal causes i.e. German measals, syphilis, influenza, encephalitis, smoking, drugs, radiation, and oxygen deficiency to the fetus etc.
3. Perinatal i.e. lack of oxygen during birth, neo natal jaundice, brain damage during birth, premature birth etc.
4. Post natal i.e. encephalitis, measals, cardiac arrest, malnutrition, disorder of lipid metabolism during early infancy etc.
5. Other causes i.e. head injury, stroke, iodine deficiency, malnutrition, poor sanitation and low birth weight etc.

Assessment

Assessment of children with intellectual disability is very crucial for proper intervention. As per the Dept. of Persons with Disabilities, Govt. of India guidelines the assessment of children with intellectual disabilities should be done as following -

Screening: Many of these children are on follow-up with pediatricians as developmental delay. Hence, they can be assessed by pediatricians and screened for associated co-morbidities, viz. hearing/ vision/ locomotor impairments/ epilepsy. Then these children are referred for detailed assessment.

Diagnosis: The screened children will be referred to child/clinical psychologists for Adaptive functioning and IQ testing. The tools that can be used for the same include:

i) Adaptive functioning: VSMS

ii) IQ testing: BKT/ MISIC

Based on the above, the diagnosis of ID will be confirmed. Based on adaptive functioning assessment, severity scoring will be done and disability for ID charted.

Disability calculation: The disability calculation will be done based on VSMS score. The following will be used for disability calculation:

i) VSMS score 0-20: Profound Disability-100%

ii) VSMS score 21-35: Severe Disability-90%

iii) VSMS score 36-54: Moderate Disability-75%

iv) VSMS score 55-69: Mild Disability-50%

v) VSMS score 70-84: Borderline Disability-25%

Age for certification: The minimum age for certification will be one (01) completed year. Children above one year and up to the age of 5 years shall be given a diagnosis as Global Developmental Delay (GDD). Children above the age of 5 years shall be given a diagnosis and certificate as Intellectual Disability.

Validity of Certificate:

i) Temporary certificate for children less than 5 years: The certificate will be valid for maximum 3 years/ 5 years age (whichever is earlier).

ii) For children more than 5 years: The certificate will mention a renewal age. The certificate will have to be renewed at age of 5 years, 10 years and 18 years. The certificate issued at 18 years age will be valid lifelong.

Intervention

The role of family and society is very important in providing proper intervention to children with intellectual disability. With proper intervention they can learn social adjustment and few academic skills that can help in vocational training. The intervention should be provided based on the needs of the child in least restricted environment so that they can learn basic skills and able to live as independently as possible. The family members and teachers need to find out the strength of the children and accordingly plan for providing intervention to them.

They should be provided individualized education based on their abilities. The teaching learning process for these children should be concrete that means that they should be taught using the real life examples i.e. flash cards, pictures, hands on materials, models, actual life situations etc. Task analysis should be used that means breaking the larger task into smaller steps and teaching each step carefully to them. Several repetitions would be required for teaching one simple task to these children. Life skills such as grooming skills, daily living skills and social skills may be taught to them through various activities. Involvement of parents and siblings is important therefore they may be made a part of teaching learning process for these children.

Teamwork is important in implementing the individualized education programme for children with intellectual disability where special educators, sport teachers, family members, siblings and other professionals need to work together for progress of the student in a particular skill.

The ground rule should be to have patience, trust the child and encourage independence of the child. With collaborative efforts a lot of improvement can be achieved in the learning of children with intellectual disability.

Conclusion

Persons with intellectual disabilities can be indentifying by the common characteristics mentioned in this unit. Precautions during pregnancy may avoid the birth of child with intellectual disability. There are several intervention strategies that can be provided by the special educators, family members and other professionals that can help these children in learning various skills for their rehabilitation.

References:

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 12 SPECIFIC LEARNING DISABILITIES

By -Dr. Sanjay Kant Prasad

Introduction

This unit deals with the concept and definition of learning disabilities, types, causes, common feature for identification, formal assessment as well as assessment for obtaining disability certificate. The intervention strategy to overcome the learning disabilities and include in a mainstream group is also described in this unit.

Objectives

After reading this unit, the learner will be able to

- Describe the definition and concept of learning disabilities.
- Describe the different types of learning disabilities.
- Discuss and identify children with learning disabilities.
- Discuss the common features and formal assessment.
- Explain the causes of learning disabilities.

Concept and Definition

Learning disability (LD) is a disorder that affects the child ability during development period either to interpret what they perceive or to link information from different parts of the brain.

Learning disability is a hidden disability, as it does not leave visible signs that would make others sympathetic or offer support. In comparison to other disabling condition, learning disabilities are the most vague and mystifying. It affects individuals differently at different stages of life such as early childhood, elementary school years, adolescence and adulthood. The students with learning disabilities may also have attention, emotional and social problems.

Usually learning disabilities is defined as a neurological condition, which manifest as the "inability" to listen, speak, read, spell, write and do mathematical calculation.

According to National Joint Committee for Learning Disabilities – "It is a general term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning and mathematical abilities. These disorders are intrinsic to the individual presumed to be due to central nervous system dysfunction and may occur across the life span.

After analyzing this definition, the natures of learning disabilities are as follows.

Heterogeneous disorder: - Heterogeneity in this definition acknowledges that learning disabilities are composed of dissimilar conditions that can be manifested in several ways.

Underachievement: - This definition indicates that individual with learning disabilities are underachievers. Underachievement is verified by documenting intra individual differences across abilities e.g. A person is good reader but relatively poor in mathematics.

Central Nervous System Dysfunction: - Many researches have shown the relationship of learning disabilities with traumatic brain injury. The scan of a dyslexic brain was compared to that of a non dyslexic brain and it was seen that different areas of the brain were functional during identical stimulation.

Psychological Processing Disorders: - This psychological process could be attention, memory, thinking, reasoning or anything related to a mental action.

Types of learning disabilities

Broadly Learning Disabilities is classified in four major types. These are :

1) **Dyslexia**:- It is a specific learning disability which is characterized by difficulties with accurate or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often not at par with the other cognitive abilities. Other difficulties may be observed like problems in reading, comprehension, reduced reading experience etc.

2) **Dysgraphia**:- It is also a specific learning disability characterized by difficulties in writing spelling and content. Very poor handwriting, irregular letter formation and inconsistent spellings are the main complaints arise out of dysgraphia.

3) **Dyscalculia**:- It is defined as disorder of calculation or mathematical disorders. It can be grouped as

   - **Verbal dyscalculia** – It means verbal use of mathematical terms and symbols.
   - **Lexical dyscalculia** – It means difficulty in reading digits, symbols or multi-digit numbers.
   - **Practognistic dyscalculia** – It means difficulty in making comparisons of objects.
   - **Graphical dyscalculia** – It means difficulty in writing dictated number or copying symbols.
   - **Operational dyscalculia** – It refers to difficulties in addition, substraction, multiplication and division.
   - **Ideognostical dyscalculia** – It refers to difficulty in comprehending ideas and making mental calculations.

4) **Dyspraxia**:- It is also a category of specific learning disabilities which refers to dysfunction in ability to plan and to execute movement pattern of a non habitual skill, such as :-

   - Difficulty in performing such skill which is not done previously as well as where motor planning is required.
   - Difficulty in sensory processing often in the tactile systems.

- Low emotional stability easily frustrated and not willing to change.

Cause

The causes or etiological factors contributing to development of learning disabilities are not very much confirmed. However, these factors usually fall into five categories i.e. perceptual, neurological, genetic, biological and environmental. The detailed description of these factors is given below.

1. **Perceptual**: - The perceptual factors include the deficit in visual, auditory, tactile, kinesthetic and proprioceptive perception as well as combination of all these factors causing learning disabilities. These factors are

    - **Perceptual modality**: - It refers to the deficit in visual auditory, kinesthetic, tactile and proprioceptive input. The strength of learning of most of the students depends on their preferred and non-preferred modalities.

    - **Perceptual overloading**: - It is very difficult for some of the students to integrate input received through several modalities. In such case the perceptual system may overload and the child becomes confused.

    - **Perceptual Style**:- Any stimulus perceives either in whole or part. This depends on the person who perceives the stimulus. Those who perceive the object in whole, they note the object in its entire structure at a time whereas those who perceive the object in part focus on details of the object. This ability of perceiving the things in part and whole is very much essential in academic performance.

2. **Neurological**: - Neurological damage is considered as one of the factors contributing to the development of learning disability. It may occur due to brain injury, infections or any complexity during prenatal, natal and postnatal periods. However, it is very difficult to establish the extent and nature of neurological damage. Delay in maturation and neurological immaturity are also found in children with learning disabilities.

3. **Genetic**:- Though, the relationship between genetic factors and learning disabilities is remain to be established but the tendency towards learning disabilities have been observed within a family. The evidence have been seen more in identical twins rather fraternal twins.

4. **Biological**:- The major biological imbalance is found due to absence or excessive amounts of biochemical substances. Poor or lack of nutrition may also lead to poor bio chemical function in the brain. Poor diet and malnutrition can damage the child's ability to learn by damaging inter-sensory abilities.

5. **Environmental**:- Factors like accident or any type of trauma to the brain, nutritional deficit, emotional instability and consuming substances like mercury may cause brain damage, which ultimately lead to learning disabilities.

Common Characteristics – Instead of different form of specific learning disabilities, children with learning disabilities shows few common symptom or characteristics. These are

- Disorders of attention
- Perceptual impairment
- Deficit in motor coordination
- Disorder of memory and thinking
- Disorder of language
- Disorder of listening
- Social and interpersonal characteristics

Symptom

The symptom and common sign differs in terms of classification and category of learning disabilities. Keeping in view the common characteristics, category wise description is given below.

Dyslexia:- A child with dyslexia shows some specific characteristics and error pattern, such as refuse to read, cry and often try to distract the teacher, lateral head movement, omission of word, substituting one word for another, very slow, erratic rate of reading due to repetition of words, mispronouncing of word, reading words sentences in wrong order, difficulty in quick recognition of words difficulty in answering questions about a passage, unable to answer specific questions about a passage, difficulty in combining sound into words, very poor memory, therefore difficulty in remembering words or letter, difficulty in appropriate grouping of words etc.

Dysgraphia: - A child with dysgraphia has very poor writing, which is characterized by straight writing, too heavy writing, too irregular writing, and too wide spacing between two words. The details symptoms includes absence of prewriting skills and pre-requisite skills for fine motor control, poor visual memory and poor visual translation, poor attention span confusion in direction, not able to begin the letter and continue and complete in a conventional manner, loss of fluency in writing, lack of uniformity in writing.

Dyscalculia: - Most of the characteristics attributed to children with learning disability are related to dyscalculia such as difficulty in memory, reasoning, perception, language and motor functioning etc.

The common errors that child with dyscalculia shows are as follows.

- Difficulties in grasping the difference between up and down, high and low and far and near.
- Difficulties in understanding size or quantity relationship
- Difficulties in discriminating between left and right.
- Problem in understanding number sequence.
- General difficulty with learning math symbols.
- Inability to count on fingers.
- Problems with subtraction and division
- Confusion regarding place value
- Problem in sequencing.
- Poor memory.

Dyspraxia - Individuals have difficulty in planning and executing tasks involving fine motor skills.

Assessment of obtaining Disability Certificate

Screening

The teacher of the Public and Private school shall carry out the screening in class III or of eight years of age by applying a screening test. If the test shows test three or more answers are in 'frequently' column then the child should be referred for further assessment.

Every school shall have a screening committee headed by the principal of the school. After screening test if an anomaly is detected then the teacher should bring it to the notice of principal and screening committee of the school. The teacher shall interview the parents to assess their involvement and motivation regarding their child's education. If the parents are motivated and screening questionnaire suggests SLD then the child should be referred for further assessment to the pediatrician. Further the assessment will be done by following three steps.

1. The pediatrician will do the initial assessment. This will involve a detailed examination including vision and hearing assessment.
2. Child/clinical psychologist will do the I Q assessment using MISIC or WISC 111. If the I.Q is determined to be > 85 (less than 85) then step 3 will be applied.
3. This would involve application of specific psychometric tests for diagnosis of SLD determining its severity scale.

Intervention

The intervention to support the child with learning disabilities includes the following:

- **Occupational therapy**: - This represents the concept of pursuit, participation or being engaged in an activity. This therapy enhance the sensory process, sensory-perceptual motor skills, perceptual motor process and learning like sensory stimulation, motor planning, sensory integration training and perceptual motor training.
- **Speech and Language therapy**: - It is a remedial intervention to improve the communication behaviour and facilitate learning of new communication behaviour. It deals with the speech language problem like abnormal speech, problem in expression and comprehension articulation problems, voice problems fluency problems etc.
- **Behaviour Modification therapy: -** Children with learning disabilities are at increased risk of developing behaviour problem such as violent and destructive behavior, temper tantrums, self injuries behaviour, repetitive behaviour etc.

The behaviour modification therapy is done by using techniques like restructuring of environment, Extinction, Time out, Response cost, over correction reprimands,

physical restraints, aversion, differential reinforcement and self management strategies.

Conclusion

Learning disability is a hidden disability, as it does not leave visible signs that would make others sympathetic or offer support. In comparison to other disabling condition, learning disabilities are the most vague and mystifying. It affects individuals differently at different stages of life such as early childhood, elementary school years, adolescence and adulthood. It is one of the disabilities covered under RPwD Act 2016. The students with learning disabilities may also have attention, emotional and social problems. The types of learning disability include dyslexia, dysgraphia, dyscalculia and dyspraxia. There are many causes including perceptual, neurological, biological, genetic and environmental. Assessment for issuing disability certificate is done by using I.Q and other psychometric tests. The intervention consists of occupational therapy, speech and language therapy and behavior modification techniques.

References

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 13 AUTISM

By - Dr. Hemlata

Introduction

In this unit we will discuss about autism that has been added as a disability in Rights of Persons with Disabilities Act, 2016 under the broad category of "Intellectual Disability". We will also discuss about characteristics, causes, assessment and intervention strategies for autism.

Human beings interact with each other through voice or gestures. When is child is born the first contact is with mother and the communication is through eye contact or cry or smile as per the need when the children grow they learn to speak and communicate with mother and family but when a child has autism the communication is not as in other children. The children with autism lack social skills they are not able to make eye contact or maintain interaction. With proper intervention the children with autism are taught appropriate educational skills and the strategies for adjustment in family and society so that they can be independent as far as possible. You might have watched the movie "My Name is Khan" this movie is based on a person having autism, the various activities of daily life of this individual and several incidences in the society are depicted beautifully in this movie.

Objective

After undergoing this unit you will be able to:

- Discuss the concept and meaning of autism
- Elaborate the common characteristics of person with autism
- Enumerate the causes of autism
- Discuss the assessment and intervention strategies for persons with autism

Concept and Meaning

Right of Persons with Disabilities Act, 2016 says that – "Autism Spectrum Disorder means a neuro-developmental condition typically appearing in the first three years of life that significantly affects a person's ability to communicate, understand, relationships and relate to others, and is frequently associated with unusual or stereo typical rituals or behaviors.

Autism Society of America (ASA) define autism as "Autism is a complex developmental disability that typically appears during the first three years of life and is the result of a neurological disorder that affects the normal functioning of the brain, impacting development in the area of social interaction and communication skills. Both children and adults with autism spectrum disorders typically show difficulties in verbal and non verbal communication, social interactions and leisure or play activities".

DSM-IV has given a very elaborate definition. As we said earlier this is a disability which has a lot of variation in it and hence this definition has given a lot of support to the professionals. This will also give you an insight into how details testing is done of a person who is suspected to have any disability, because if

you label a person incorrectly it can have serious repercussions on that person. Hence professional have to be very ethical in their work.

The assessment of Autism Spectrum disorder is based on the major three criteria which are the limitations of the person with ASD. These three have been further elaborated under (1), (2), and (3). Hence in order to be diagnosed as ASD, there must be some components in the person from each of the three areas put under (1), (2) and (3):

1. **Qualitative impairment in social interaction, as manifested by at least two of the following:**
    - Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
    - Failure to develop peer relationships appropriate to developmental level
    - A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
    - Lack of social or emotional reciprocity.
2. **Qualitative impairment in communication as manifested by at least one of the following:**
    - Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
    - In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
    - Stereotyped and repetitive use of language or idiosyncratic language
    - Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
3. **Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:**
    - Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
    - Apparently inflexible adherence to specific, nonfunctional routines or rituals
    - Stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)
    - Persistent preoccupation with parts of objects

Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

1) Social interaction
2) Language as used in social Communication
3) Symbolic or imaginative play.

Characteristics

The common characteristics of persons with autism are discussed are as following

1. Avoid eye contact
2. Unresponsive to people around them
3. Avoid physical contact
4. Difficulty in reading and interpreting social cues from others
5. Poor or very negligible language development
6. Avoid to be hugged or cuddled
7. Avoid playing and interactive with others
8. Do not like company of other children
9. Like self stimulating behaviors such as swaging, rocking etc.
10. May engage in destructive behavior
11. Will speak only to express their needs
12. May also have intellectual disability
13. May show excellent memory
14. Like to follow fix routines
15. Avoid social interaction

Causes

The causes of autism may be as following -

1. Biological causes
2. Abnormal brain development
3. Genetic reasons
4. Environmental factors

Assessment

The assessment of autism is very important for providing proper intervention to the child. The diagnosis is made on the basis of observation of child's behaviour, communication and developmental levels. There are several diagnostic tools available for diagnosis that are as following:

1) Autism Diagnostic Observation Schedule generic (ADOS)
2) Pre Linguistic autism Diagnostic Observation Scale
3) Child observation rating scale (CARS)
4) Autism Diagnostic Interview – Revised
5) DSM -4 criteria
6) Autism diagnostic Interview (ADI) (Le Couteur et al., 1989)

7) Checklist of Autism in Toddlers (CHAT)

8) Checklist of Autism I Toddlers – Modified (M-CHAT)

9) Screening tool for Autism in two year olds (STAT)

10) Social communication Questionnaire (SCQ) for children of 5 years and older

11) Gilliam Autism Rating Scale (GARS)

12) Behavior Rating Instrument for autistic and other atypical Children (BRIAC).

Intervention

Autism cannot be completely cured, however with proper intervention and efforts it can be managed well. Each child is unique and have different needs therefore intervention also needs to be individualized depending on the condition of the child. Early identification and intervention help in providing the better and structured education to the child. There are various approaches and methods available or intervention to children with autism but while planning any intervention the interest of the child needs to be kept on first priority and accordingly therapies should be given. Activities planned in the therapies should be divided into simple steps and may be planned in a way that keep the attention of the child throughout the activity. When a child achieves a milestone or complete a task, that time positive reinforcement should be given.

Involvement of siblings and parents in the intervention programme for child should be the priority and in each setting i.e. home based, centre based or school based, the parents may be involved. The children with autism need to be provided child centered intervention and the interest of the child should be kept in mind while planning the activities. There may be a need to provide life skill training, training in cognitive and language development, auditory integration training and behavioral intervention. With appropriate intervention child with autism can become independent.

Conclusion

Each child has different capabilities particularly children with autism have unique characteristics and their needs should be fulfilled keeping in mind their unique capabilities. They need to be provided multi facetted intervention so that they can learn and grow. The main issue with them is language and communication skills therefore the challenge is to take care of this very specific requirement and provide intervention. The level of motivation among children should be kept in mind while providing the intervention with proper intervention these children can learn and become a productive member of society.

References:

1. RPwD Act, 2016 (The Gazette of India).

2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 14 MENTAL ILLNESS

By -Dr. Sanjay Kant Prasad

Introduction

This unit is concerned to deal with the various aspect of mental behavior/illness which leads to "mental illness". The word 'Health' is part and parcel of human life. When we think about the health, many words draws our attention on related terminology like 'physical', 'mental', social, emotional etc. Health has two important dimensions that are "physical" and 'mental'. In other words, it is physical health and mental health.

The physical health is the easiest dimension of health, which is the indicator of Bio-medical definition. On the other side mental health is ability to respond to various experiences of immediate as well as remote environment. One more dimension of health is considered important, which is "Social dimension" that includes ability to perceive as a member of a larger society. The roof of the social health is "positive material environment" as well as "positive human environment which are largely concern with the social network of the individual.

Objectives

After reading this unit, the learner will be able to :-

- Describe about Concept and Meaning of Mental illness
- Explain briefly about Causes of mental illness.
- Describe about the types and common symptoms of mental illness
- Describe about the assessment and certification as per RPwD Act 2016.

Concept and Definition

Mental Behavior/Health

Mental Behaviors refers to the ability of individual to recognize the environment, understand his or her own role and react as per the need and requirement and express with balance emotion, with logical thinking and action etc. Very recently Park 1995 defined mental behavior or mental health as "A state of Balance between the individual and the surrounding world, a state of harmony between oneself and others, co-existence between the realistic of the self and that of other people and that of the environment".

Mental Illness

It refers to the condition that results in disruption of a person's thinking, feeling, mood and ability to relate to others caused by social, psychological, genetic, biochemical and other factors like trauma, infection etc.

The Psychiatrist and other professionals dealing with mental health attributes mental illness to organic/neuro chemical causes, which can be treated with medication, psychotherapy life style adjustments and other supportive measures. Major mental illness includes clinical depression, bio-polar depression schizophrenia and obsessive compulsive disorder etc.

The term mental illness refers to different type of mental disorder, which includes disorder of thought, mood or behavior that cause distress and result in reduced ability to function, psychologically, socially, occupationally or interpersonally. Those having mental illness might have difficulty in handling daily activities, family responsibilities and relationship, workplace responsibilities etc.

Major Types of Mental Illness

The commonly occur mental illnesses include the following:-

- Anxiety Disorders
- Depressive Disorders
- Bipolar Disorders
- Schizophrenia
- Personality Disorders
- Substance Use Disorders
- Disruptive Behavior Disorders
- Dementia etc.

1. Anxiety Disorders

The anxiety disorders are different from day to day anxiety as being more intense and persistent to a degree, which interferes with person's life. In such situation, concern individual may like to seek professional support in order to overcome the anxiety disorder. In a more clear way it can be said that anxiety disorders are different from day to day anxiety, which involve anxiety that is more intense, persists for longer duration and leads to phobias that interfere with one's like.

The following disorders are very much similar to anxiety disorders, which can be distinguished by using DSM-IV (1994).

- Panic Disorder – It refers to sudden feeling of panic associated with physical systems like : shortness of breath, dizziness, chest pain, feeling faint, dry mouth, pounding heart, tingling fingers or feet, sweating, an urge to fee, difficulty in gathering thoughts, fear of dying or losing control etc.
- Agoraphobia – It refers to the anxiety being in a place, where it is difficult to get help or it is also difficult to get away. The situation of concern include crowded places, open spaces, buses, traveling along and being long away from home.
- Phobia – Phobias are more severe and consistent than the normal fears or anxieties. It refers to repeated irrational fear of a specific object, activity or situation. The intensity of the fear is so high that it drive the person to extremes to avoid the situation
- Obsessive Compulsive Disorder – It refers to persistent unwanted thoughts and being driven to perform a behaviour to a degree, which seems excessive even to self and causes disruption to everyday life.

These are the neurotic disorders which differentiate between anxiety disorder and normal anxiety.

2. Depressive Disorders

Depression is used to describe feeling of sadness and grief. However the common use of word depression and depressive illness, both are different. In depressive illness the mood changes are more severe and persistent than normal negative feeling and may also accompanied by other symptoms.

The diagnosis of depression established by the symptom like:

a) loss of interest in normal daily activities. One lose the interest in or pleasure from activities which he used to enjoy this is termed as 'anhedonia'.

b) one feels sad, helpless or hopeless and may have crying spells.

c) one feels easily tired, exhausted and always has feeling of dullness and debilities.

In addition to these depressive illness also shows the symptoms such as, sleep disturbances, impaired thinking or concentration, significant weight loss or gain, low self esteem, less interest in enjoyment and persistent negative view of self situation and the future leading to thoughts of death, dying or suicide.

The major types of depression include following:

- **Reactive Depression** – The depression in response to the distressing event, e.g. relationship breakdown or loss of a job. The intensity of feeling is very severe and persistent than normal unhappy feeling resulting into sleep problem etc.

- **Major Depression** – Even severe than reactive depression. The symptoms include sleep disturbance, appetite or weight loss, poor concentration, difficulty in making decision guilt and poor self esteem or suicidal thoughts etc.

- **Depression with Psychotic features** – It is more serious form of depression where person loose it is contact with reality and experience symptom of psychosis.The person may stop eating and drinking and have hallucination or delusion such as believing being controlled or threatened by others.

- **Bipolar Depression** – Extreme mood swing with period of depressed mood alternating with period of manic mood. The manic phase denotes with extreme happiness, rapid speech reduced sleep, lack of inhibition, irritation with those who ask question, grandiose plan and belief etc. Some persons may have many episodes of depression before having another manic phase or vice-versa.

- **Dysthymia** – It is less severe but more continuous form of depression. It last atleast for two years and often more than five years. The sign and symptom of this form of depression is not disability.

3. Schizophrenia

It is a mental illness having psychotic symptoms. It affects around one in hundred people. It is characterized by unusual thoughts and emotions that are considered inappropriate by others. This term mainly refers to changes

in the person's mental and social functioning, while their thoughts and perceptions become disordered.

The schizophrenia is caused by contribution of number of factors. It is evident from research that certain substances in the brain are involved in the development of this illness particularly the neurotransmitter dopamine. The environment and life style may also play a role. Stressful incidents will often precede the onset of schizophrenia. However stress and substance abuse do not necessarily cause a psychotic illness.

The symptom of schizophrenia includes both positive and negative symptoms.

Positive symptoms such as Hallucination, Delusion, Disorganized thinking, agitation seen as a result of disorder, normally not seen in healthy people. Hallucinations and illusions are distortions of perception that are common in people suffering from schizophrenia.Delusions are irrational personal false firmly held beliefs. Persons with paranoid type of schizophrenia often have delusion of persecution or irrational belief that they are being cheated harassed poisoned or conspired against.Persons with schizophrenia may not be able to connect thoughts into logical sequences this is called disordered thinking.

Negative symptoms of schizophrenia are lack of drive or initiative, social withdrawal, emotional unresponsiveness etc.

Most individual with schizophrenia are not violent rather they tend to be withdrawn and prefer to be left alone. They have higher rate of suicide. The severity of symptom and long lasting chronic pattern of illness often lead to high level of disability.

The type of schizophrenia includes Paranoid schizophrenia, Disorganized schizophrenia, Catatonia schizophrenia, Residual schizophrenia and undifferentiated schizophrenia.

4. Personality Disorders

It refers to the range of disorder characterized by a pattern of thoughts, feelings and behavior which are markedly different from others peoples in same society, culture or environment. Persons with personality disorders tend to differ from others in a way they view themselves and other people and usually have problems with relationship.

Causes

The causes or etiology of mental illness influence all aspects of human life including intellectual capabilities, basic temperament, primary reaction tendencies, stress tolerance and adaptive resources. Biological conditions such as faulty genes, endocrine imbalances, malnutrition, injuries and other conditions that interfere with normal development and functioning are potential causes of mental illness.

A) Genetic defects are clearly a potential cause of psychopathology. Among these the chromosomal aberration and faulty genes are of major concern which may produce abnormality or make an individual more vulnerable to stress. The Genes can affect behaviour through the influence on the physical and chemical properties of the body.

B) Childhood experiences and home environment are another factor, which contribute to the development of mental illness. The factor includes childhood trauma, parental deprivation, pathogenic parent-child relationship maladaptive family structure and specific frustration conflicts and pressure. All these factors are not independent to each other, rather they function as a primary, pre-disposing precipitating or reinforcing cause in a given condition.

Traumatic experiences in childhood, shelter our feeling of security and adequacy and are important in influencing our environment. Traumas are opt to leave sears that never heal completely. The after effect of early traumatic experiences depends heavily on the support and reassurance given to the child by parent or other significant members of the family.

Parental deprivation such as separation from the parent(s) and placement in an institution, lack of adequate nurturing at home etc.

Pathogenic parent child relationship which a two way relationship and behaviour of each person affect the behaviour of other person.

Some of the factors, which are important and considered under parent-child relationship and are contributing to mental behaviour or mental illness. These are:-

i) **Parental Rejection**:- It is manifested in many ways as physical neglect denial of love and affection, lack of interest in child's activities and achievements, failure to spend time with child and lack of respect for child's feeling.

ii) **Unrealistic demands**:- Many parents place excessive pressures on their children to live up to realistically high standards. Such expectations become a matter of what parents value matter than what the child need.

iii) **Over Permissiveness and indulgence**:- Overly indulged children are characteristically spoiled, selfish, inconsiderate and demanding. On the other hand high permissiveness and low punishment have high positive correlation with antisocial, aggressive behaviour during later childhood.

iv) **Inadequate and irrational communication**:- Many parents oftenly discourage the child for asking question and fail to foster the information exchange. Resulting these parents usually fail to provide required support and assistance during crisis periods.

Besides the above, pathogenic family structures which includes inadequate families, antisocial families, discordant and disturbed families and disrupted families are the contributing factor in developing pathogenic mental behaviour.

C) **Psycho-social factors**:- The interpersonal factors play significant role in maladaptive behaviour and mental illness. The devaluating frustration such as failure, losses personal limitation, lack of resources, guilt and loneliness and leading factors.

Assessment of Mental illness for issuing disability certificate

The assessment of Mental illness with reference to the benchmark disability required to have clinical assessment may be by administering IDEAS scale, I.Q. test and other suitable psychometric and projective tests.

In case of application of I.Q. test the percent of mental illness may be defined as

Score	Degree of Disability
50-69	Mild Disability
35-49	Moderate Disability
20-34	Severe Disability
Less than 20	Profound Disabiltiy

Based on the score, the assessment board decided the percentage and issues the disability certificate for indicating benchmark disability, traumatic experiences and pathogenic

Intervention

The goal of intervention is to reduce symptoms of emotional disorder, improve personal and social functioning, develop and strengthen coping skills and promote behavior for making persons life better and comfortable.

Most of the intervention method for mental disorder or illness can be categorized as either somatic or psychotherapeutic. Somatic treatment includes drug therapy, whereas psychotherapeutic treatment includes individual, group, or family and marital psychotherapy, behavior therapy, and hypnotherapy.

The Drug therapy can be prescribed by registered licensed psychiatrist other mental heal care professions such as clinical psychologist counselor primarily practice psychotherapy.

Conclusion

Mental Behaviors refers to the ability of individual to recognize the environment, understand his or her own role and react as per the need and requirement and express with balance emotion, with logical thinking and action etc. The term mental illness refers to different type of mental disorder, which includes disorder of thought, mood or behavior that cause distress and result in reduced ability to function, psychologically, socially, occupationally or interpersonally. The types of mental disorders includes anxiety disorders, depressive disorders, bipolar disorders, personality disorders, substance use disorders, disruptive behavior disorders and dementia etc. The causes consists of genetic, childhood experiences and pathogenic parent child relationship etc.

References

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 15 CHRONIC NEUROLOGICAL CONDITION MULTIPLE SCLEROSIS

By -Dr. Sanjay Kant Prasad

Introduction

This unit deals with the description about the Multiple Sclerosis which is a benchmark disability in RPwD Act 2016 under the broad category of "Disability Due to Chronic neurological conditions." Here in this unit the learner will find the concept and meaning of multiple sclerosis, its different type, causes common sign and symptom and in brief about the intervention required to manage this disability. The main thirst of this unit is providing clear information to learner as how this disability is assessed as per guidelines issued by the D/o EPwD, to issue disability certificate to person having multiple sclerosis.

Objectives

After reading this unit, the learner will be able to

- Describe about the concept and meaning of multiple sclerosis.
- Explain about the causes and contributing factors of multiple sclerosis
- Discuss about the assessment with reference to obtain disability certificate

Concept and Definition

Multiple Sclerosis (MS) refers to an immune mediated process in which an abnormal response of the body's immune system is directed against the central nervous system (CNS). The Central Nervous System is made up of brain, spinal cord and optic nerves. The immune system causes inflammation within the central nervous system that damages myelin. Myelin is a fatty substance that surrounds and insulates the nerve fiber. When myelin or nerve fibers are damaged or destroyed in Multiple sclerosis, messages within the CNS are altered or stopped completely. Damage to area of the CNS may develop a number of neurological systems that will vary among people with Multiple Sclerosis in type and severity.The damaged areas develop sear tissues which gives the disease its name – multiple areas of searing or multiple sclerosis.

Though the cause of Multiple Sclerosis is not very much known but it is believed to involve genetic susceptibility, abnormalities in the immune system and environmental factors that combine to trigger the disease.

In nutshell, multiple sclerosis is inflammatory nervous system disease in which myelin sheaths around the axons of nerve cells of the brain and spinal cord are damaged which leads to demyelization and affecting the ability of nerve cells in the brain and spinal cord to communicate with each other.

Types of Multiple Sclerosis

The international Advisory Committee on Clinical Trials of MS (2013) has defined

four types of Multiple Sclerosis disease. These are:-

i) Clinically Isolated Syndrome (CIS)

It is a first episode of neurological symptoms caused by inflammation and demyelization in the central nervous system.

When CIS is accompanied by lesions on a brain MRI that is similar to those seen in Multiple Sclerosis, the person has a high likelihood of second episodes of neurologic symptoms and diagnosis of relapsing-remitting multiple sclerosis. When CIS is not accompanied by multiple sclerosis like lesions on a brain MRI, the person has a much lower likelihood of developing multiple sclerosis.

ii) Relapsing – remitting MS (RRMS)

It is most common disease course – characterized by clearly defined attacks of new or increasing neurologic symptoms. These attacks also called relapses or exacerbations and are followed by period of partial or complete recovery. During remissions, all symptoms may disappear or some symptom may continue and become permanent. RRMS further characterized as either active or not active and worsening or not worsening as well.

iii) Secondary Progressive MS (SPMS)

Persons who are diagnosed with RRMS will eventually transition to a secondary progressive course, where in, there is a progressive worsening of neurologic function (accumulation of disability) over time. This type is also further characterized as either active or not active and with progression without progression as well.

iv) Primary Progressive Multiple Sclerosis (PPMS)

It is characterized by worsening neurologic function (accumulation of disability) from the onset of symptoms without early relapses or remissions. PPMS can be further characterized as either active or not active and with progression and without progression as well.

Common Characteristic & Symptoms

The common symptoms of multiple sclerosis are as follows:

- **Muscle Weakness**: - The development of weak muscle is seen in the people having multiple sclerosis, due to less use of muscles or lack of stimulation due to nerve damage.
- **Numbness and tingling**: - One of the earlier symtom of muscular sclerosis is needle type sensation which affects the face, body or arms and legs.
- **Lhermitte's Sign**: - This is a experience of a sensation like an electronic shock when moving the neck.
- **Bladder Problem**: - Loss of bladder control id also an early sign of multiple sclerosis.
- **Bowel Problem**: - Facial impaction due to constipation can lead to bowel incontinence.
- **Fatigue**: - This is most common symptom of multiple sclerosis, which restricts the functional ability of a person at home or at work.

- **Dizziness and Vertigo**: - These two are very common problem which hampers balance and coordination.
- **Spasticity and Muscle Spasms**: - This is also an early sign of multiple sclerosis. Damaged nerve fibers in the spinal cord and brain can cause painful muscle spasms in the legs.
- **Gait and Inability Changes**: - Multiple sclerosis changes the walking style of the people due to muscle weakness and problems with balance and fatigue.
- **Pain**: - Many type of pain occur due to weakness or stiffness of muscles.
- **Learning and Memory Problems**: - The multiple sclerosis can make it difficult for people to plan, learn, prioritize the things and multitask.
- **Emotional Changes and Depression**: - There are many emotional changes due to demyelization and nerve fiber damage in the brain.

The other symptom consists of headache, hearing loss, itching, breathing problems, speech disorders, swallowing problems, seizures etc.

The effect of multiple sclerosis has individual differences e.g. few people starts its symptom with suitable sensation and symptom do not progress even for month or years. For few people the symptoms worsen very rapid within a week or months.

Causes

The etiology or causes which develop multiple sclerosis is not very much evident. However, some risk factors involved are given below:

Age: - This is mostly diagnosed between the age of 20 and 40 years.

Sex: - Multiple sclerosis is like to affect women twice in comparison to men.

Smoking: - Those persons who smoke appear to be more sensitive to develop multiple sclerosis.

Genetic factors: - It is more likely to pass down in the genes. But it is believed that environmental trigger is very much necessary to develop multiple sclerosis.

Infection: - Exposure to any viruses specifically Epstein – Barr Virus or Mononucleosis may increase a persons risk of developing multiple sclerosis.

Vitamin D deficiency: - Those who have very less exposure to bright sunlight like to develop multiple sclerosis as it also affect immune system.

Vitamin B-12 deficiency: - The body uses Vitamin B when it produces myelin. The deficiency of this develops neurological disorder such as multiple sclerosis.

Assessment

The assessment of neurological conditions is not the assessment of disease rather assessment of its effect in form of clinical manifestation.

Generally any neurological assessment for the purpose of has to be done six month of onset of disorder. However exact time period is to be decided by the doctor who is evaluating the case.

In mixed cases the highest score will be taken into consideration. The lower score will be added to it by the help of combining formula:

$$A+b(90-1)/90$$

Additional rating of 10% will be given for involvement of dominant upper extremity.

Additional weightage up to 10% can be given for loss of sensation in each extremity but the total physical impairment should not exceed 100%.

Interventions

The intervention or treatment of multiple sclerosis includes the following.

- Medicine to reduce fatigue – Medicine like Amatadine, Modafinil and methylphenidate may be helpful in reducing multiple sclerosis related fatigue. Some medicine use to manage depression may also be recommended.
- Medicine to increase walking speed – Dalfampridine may help in increase in walking speed in few people (strictly under supervision of registered medical practitioner)
- Other medication may also be prescribed for depression, pain insomnia and bladder and bowel control problems that are associated with multiple sclerosis. Apart from this medicine for relaxing muscle may also be used.
- Physical therapy – Physio and occupational therapist can teach the person for stretching and strong phening exercises and also teach about how to use devices to perform daily routine task use devices to perform daily routine task.

Selecting right intervention procedure depends upon duration and severity of the disease.

Conclusion

Multiple Sclerosis (MS) refers to an immune mediated process in which an abnormal response of the body's immune system is directed against the central nervous system (CNS). The Central Nervous System is made up of brain, spinal cord and optic nerves. Damage to area of the CNS may develop a number of neurological systems that will vary among people with Multiple Sclerosis in type and severity. The types of multiple sclerosis include Clinically Isolated Syndrome (CIS), Relapsing – remitting MS (RRMS), Secondary Progressive MS (SPMS) and Primary Progressive Multiple Sclerosis (PPMS).The symptoms include muscle weakness, numbness and tingling, bowel problem, bladder problem, fatigue, pain learning and memory problem, emotional changes and depression, dizziness and vertigo etc.Major causes include genetic factors, vitamine D deficiency, infections and vitamin B-12 deficiency etc. The assessment for issueing certificate for benchmark disability is done as per guidelines issued by D/o EPwD, Govt. of India. The intervention must be taken under supervision of qualified and registered medical practitioners.

References:

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 16 CHRONIC NEUROLOGICAL CONDITION. PARKINSON

By -Dr. Sanjay Kant Prasad

Introduction

This unit deals with the Parkinson disease as disability. This is one of the disabilities covered under RPwD Act 2016 under the broader title 'Disability due to Neurological disorders' The unit provides you a broader view on concept and definition of parkinson disease, causes and symptoms and in brief about intervention for management of parkinson. The assessment for issue of certificate of disability is also briefly discussed as per guidelines issued for assessment of disabilities by D/o EPwD.

Objective

After reading this unit the learner will be able to

- Describe about concept of parkinson
- Discuss about the causes and symptoms of parkinson.
- Explain about the assessment criteria for identification and obtaining the disability certificate.
- Understand about the intervention for management of parkinson.

Definition and Concept

Parkinson disease or disability is a neurological movement disorder. It is a nervous system affected disorder, which hampers the ability to control movements. If an individual is affected by Parkinson he may shake, have muscle stiffness and feel trouble in walking and maintaining body balances. Gradually the person have trouble in talking, sleeping having mental and memory problems, sometimes experience behavioural changes along with the other symptoms.

Though the occurrence of this disorder is commonly seen in the persons above 60 years and older, but there are incidences of onset of Parkinson disease even at the age of 50 for such cases people believe that heredity also plays role in development of this disorder. However scientist has identified a gene mutation in persons with Parkinson disease whose brain contain lewy bodies, which are alpha-synuclein protein. The researchers are trying to find out the function of this protein and its relationship to genetic mutations. Besides this, many more gene mutations have been found to have role in development of Parkinson disease mutation. In such cases genes cause abnormal cell functioning which affects the ability of nerve cell to release dopamine and cause abnormal cell function which affects the ability of nerve cell to release dopamine and cause nerve cell death. But researchers are yet to understand as how gene mutations influence the Parkinson disease.

Causes

There is an area in brain called substantia nigra. Due to the damage/impairment of the nerve cell in this area, Parkinson disease occur. These nerve cell usually

produce dopamine a chemical, which helps the brain cells to transmits signal message from one area to another area of the brain. When such brain cells die or impaired less dopamine is produced which hampers the operation of another area called basal ganglia. This basal ganglia is responsible for organizing brain command for body movement. The lack or loss of dopamine develops the movements symptoms as seen in the persons with Parkinson disease or disability.

One chemical known as norepinephrine, also works as neurotransmitter, which persons with Parkinson disease lose. This chemical is useful for the proper functioning of the sympathetic nervous system. The nervous system control autonomic functions of the body, such as digestion, heart rate, blood pressure and breathing etc. The loss of chemical like norepinphrine causes few non movement related symptom of Parkinson disease.

Symptoms

The symptom of Parkinson disease varies from person to person. These common symptoms are as follows.

- **Tremor** -: The tremor starts with the hands and arm. It can also affect the jaw and foot. Gradually the tremor become more wide spread and become worst with tension and stress often tremor disappear during movement and during sleep.
- **Rigid Muscles/Stiff Limbs**-: Rigidity of the muscles do not allow the muscles to be relaxed in a normal manner. Rigidity is due to uncontrolled tensing of muscles which do not allow moving freely. Sometimes aches and pains also experienced in the affected muscles, which limit the range of motion.
- **Slowness of Movement** -: Due to brain's slowing down of transmitting the necessary instructions to the different parts of the body movements also got slow. Though, this is very unpredictable behaviour and resulting into disability. This results into one movement the movement is easy but immediately need help for other movements that is why, it is called unpredictable.

Coordination, unsteady walk and balance problem.

It develops a forward lean that makes person more likely to fall while bumped. The person may take short stuffing steps and feel difficulty in starting walk and also difficulty in stopping walk. Some person may feel that feet are stuck to the floor while trying to take steps.

Apart from the above the other symptoms includes, twisting of muscles, spasms or camps, decreased facial expressions, speech may become slurred, changes in handwriting, like it become smaller and very difficult to read, depression and anxiety problems, chewing and swallowing problems urinary problems, difficulties in thought process, halt urinations delusions etc.

Assessment for issuing disability certificate

The disability caused due to chronic neurological conditions is multi dimensional involving manifestations in psycho-social behavior. The neurological conditions which are reversible and without sequel are not certifiable. Only permanent neurological conditions are certifiable. Therefore permanent disability certificate can be issued only in irreversible/progressive cases. If required in certain specific cases are evaluation of disability can be done after a period of one year.

In case where the chronic neurological condition requires only IDEAS then only IDEAS can be administered and degree of disability certified. In case where the chronic neurological condition requires only I.Q. then a standardized IQ test should be used to certify degree of disability.

In some cases, only one test may not estimate disability comprehensively. Such a person may have borderlines score on the test with marked disability score on the other. In such cases both I.Q. and IDEAS shall be used. The score indicating more severe disability shall be degree of disability for the person.

Intervention

For person with Parkinson disease medications are the main treatment. Medication combat Parkinson disease by

- Helping nerve cells in the brain to make dopamine
- Mimicking the effect of dopamine in the brain
- Blocking an enzyme that breaks down dopamine
- Reducing some specific symptoms of Parkinson's disease.

The medication for this problem should be strictly under supervision of a bonafide medical practitioner. Apart from medication physiotherapeutic support and psychological counseling is also helps the person in management of Parkinson disease.

Conclusion

Parkinson disease or disability is a neurological movement disorder. It is a nervous system affected disorder, which hampers the ability to control movements. If an individual is affected by Parkinson he may shake, have muscle stiffness and feel trouble in walking and maintaining body balances. The common symptom includes tremor, rigid muscles and stiff limbs and slowness of movements. Difficulty in coordination, unsteady walks and balance problem are also seen in the person having Parkinson disease. The disability caused due to chronic neurological conditions is multi dimensional involving manifestations in psycho-social behavior. The neurological conditions which are reversible and without sequel are not certifiable. Only permanent neurological conditions are certifiable. Therefore permanent disability certificate can be issued only in irreversible/ progressive cases.

References

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 17 DISABILITY DUE TO BLOOD DISORDER HAEMOPHILIA

By -Dr. Sanjay Kant Prasad

Introduction

This unit deals with the one of the disability mentioned under Rights of Persons with Disabilities act 2016. Haemophilia is a disability due to blood disorders. You will find a description on concept and definition, incidence and challenges, sign and symptom, assessment of haemophilia to determine sevsrity and also to obtain disability certificate etc. The content of the topic has been included with the following objectives.

Objectives

After reading this unit the learner will be able to

- Discuss about the concept and definition of haemophilia.
- Describe about the incidence and challenges of haemophilia.
- Explain about the signs and symptoms of haemophilia.
- Explain about the assessment for obtaining certificate of disability.

Concept and Definition

Haemophilia is a Disorder of Blood Coagulation wherein excessive bleeding occurs with minimum trauma (spontaneous bleed) and sometimes, such bleeding become life threatening. It is categorized as

i) Haemophilia A : (deficiency of clotting factor VIII)

ii) Haemophilia B : (deficiency of clotting factor IX)

In other words it can be said that Haemophilia is an X-linked congenital bleeding disorder caused by a deficiency of coagulation factor VIII or factor IX. This deficiency is the result of mutations of the respective clotting factors genes.

Haemophilia being a genetic disorder, carries in families. The gene of haemophilia is located on the sex chromosome known as 'X' chromosome. In female, both are 'X' chromosome whereas in male there is one X chromosome and the other is smaller 'Y' Chromosome. This implies no escape from clinical haemophilia in man, if sole 'X' chromosome is mutated, where as in women, support from 2nd 'X' chromosome is available, if 'X' chromosome is affected from haemophilia. These are the facts about haemophilia in family, with no history of haemophilia in particular family.

- About one third of the Persons with Haemophilia have no previous family history.
- It may occur in an individual from new genetic mutations.
- Previously affected generations, where any of the daughters was carrying a dormant haemophilia gene.

- Such pattern of gene involvement also provides prediction of risk of haemophilia in the children of a haemophilic. If the father is suffering from haemophilia the son would be normal and would be far away from haemophilia where as all the daughter would carry one mutated gene but without any clinical symptom. In the case of women, if mother has one affected gene, the sons are having 50% chances of clinical haemophilia where in daughters are having 50% chances of a dormant gene in her one 'X' chromosome.

Incidence and Challenges of Haemophilia

The worldwide incidence of haemophilia is 1 in 10,000 births and is almost same throughout globe including India. The bigger challenge is that majority of sufferers are left undiagnosed therefore due to lack of diagnosis majority of haemophilic can not get benefit of the effective treatment. The another big challenge is lack of adequate and reliable laboratory facilities alongwith awareness even among the urban educated population.

The classification of haemophilia is based on the level of severity as mild moderate and severe depending on how much functional clotting factor is available within the body.

Sign and Symptoms

Commonly observed sign and symptom of haemophilia are as follows.

- Bleeding into the joints, this can cause swelling and pain or tightness in the joints. It often affects the knees, elbow and ankles.
- Bleeding into the skin (which is bruising) or muscle and soft tissue causing a built up of blood in the area.
- Bleeding of the mouth and gums and bleeding that is hard to stop after loosing a tooth.
- Bleeding after having shots such as vaccinations.
- Bleeding in the head of the infant after a difficult delivery.
- Blood in the urine or stool.
- Frequent and hard to stop nose bleeds.

Severity of Haemophilia

The severity of haemophilia depends on the individual factor concentration. These are as follows:

Level	% of normal factor in blood	No. of IU per ml	Clinical presentation
Normal Range	50-150 %	0.50 - 1.5 IU	—-
Mild	5-40 %	005 - 0.40 IU	Bleed during a major injury surgery
Moderate	1-5 %	0.01 - 0.05 IU	Bleed less frequently. May bleed for long after surgery. Rare bleed spontaneously
Severe	<1 %	< 0.01 IU	Frequent bleed into muscle/ joints. Frequency of bleeding is high.

According to Dr. Gupta N (2016) "The most common bleeding in haemophilia occurs in muscles and joints. The most affected joint bleeding and most frequent are the knee, ankle and elbow. This bleeding in joints produces immediate pain, swelling, change in colour and temperature and also loss of function.

Assessment of haemophilia as Benchmark Disability

The assessment of haemophilia is important particularly for issuing of disability certificate.

Diagnosis of haemophilia.

The majority of cases with haemophilia have a known family history of the condition. However about one-third of the cases occur in the absence of a known family history. Most of these cases without a family history arise due to a spontaneous mutation in the affected gene. Other cases may be due to the affected gene being passed through a long line of female careers.

If no known family history, then a variety of blood tests can identify as which part of blood clotting mechanisms is defective, if an individual has abnormal bleeding episodes.

Screening Test - The screening test for haemophilia are discussed below:-

Complete Blood Count (CBC)

This common test measures the amount of hemoglobin, the size a number of red blood cells and number of different types of white blood cells and platelets found in blood. The CBC is normal in people with haemophilia. However, if a person with hemophilia has usually heavy bleeding or bleeds for a long time, the hemoglobin and the red blood cell count can be low.

Activated Partial Thromboplastin (APTT) Test

This test measures how long it takes the blood to clot. It measures the clotting ability of factors VIII(8), IX(9), XI(11) and XII(12). If any of these clotting factors are too low, it takes longer than normal for the blood to clot.

The result of this test will show a longer clotting time among people with haemophilia A or B. In this process, the coagulation is stimulated by contact kaolin or collagen or ellagic acid. Normal value 30-32 second.

Prothrombin Time (PT) Test

This test also measures the time; it takes for blood to clot. It measures primarily the clotting ability of factors 1, 2, 5, 7 and 10. If any of these factors are too how, it takes longer than normal for the blood to clot. The results of this test will be normal among most people with hemophilia A & B.

Specific test (factor assay) for the blood clotting factors can then be performed to measure factor VIII or factor IX levels and confirm the diagnosis. Factor assay are required to diagnose and confirm a bleeding disorder. This blood test shows the type of haemophilia and its severity level. It is very important to know the type and severity for planning a best treatment.

Eligibility for Certification- For getting a disability certificate the eligibility are as follows :-

i) History (including family history) especially males being affected and females are spared.

ii) Review of previous medical records.

iii) Physical examination

iv) Baseline Coagulation Profile (Prothrombin time partial thromboplastin time and thrombin time)

v) Factor assay (if available)

Grading for Disability Percentage for Hemophilia

Disability Score	**Percentage of factor activity in blood**	**Clinical Severity**
10 – 20 %	> - 5 %	Asymptomatic but family history is positive and limitation of physical contact sport advised and abnormal a PPT
21 – 39 %	1 – 5 %	Above plus. Occasional spontaneous bleed.
40 – 50 %	< 1 %	Above plus, symptomatic with two bleeds in joints with limitation of full movement. Need to be assessed by orthopedician/psychiatrist
51 to 60 %	< 1 %	Above plus bleeds. Atleast 3 times in last five months and contracture in one joint.
60 to 79 %	< 1 %	Above plus intracranial bleed once/ contracture in two joints.
80 to 85 %	< 1 %	Above plus neurological sequel or with compartmental syndrome with limb weakness.

Intervention

The intervention of haemophilia is very specialized and multi-speciality. A person with haemophilia must visit comprehensive haemophilia care centre for specialized treatment, physiotherapy and psychological support. The centre or hospital will treat the person with AHF infusion followed by other supportive treatment and medicines even prior to assessment. Besides this physiotherapy helps for strengthening muscles and joints. This must be under the guidance of trained and qualified physiotherapist. Further keeping the Persons with haemophilia and family members mentally strong, psychological counseling plays an important role.

Conclusion

Haemophilia is a Disorder of Blood Coagulation wherein excessive bleeding occurs with minimum trauma (spontaneous bleed) and sometimes, such bleeding

become life threatening. It is categorized as haemophilia A and haemophilia B. The classification of haemophilia is based on the level of severity as mild moderate and severe depending on how much functional clotting factor is available within the body. There are many diagnostic test of haemophilia such as CBC, APTT, and PT. Based on the grading for disability percentage, the certificate for disability is issued to persons with haemophilia as bench mark disability.

References

1. Dr. Gupta N(2016) Manual for Haemophilia,Maulana Azad Medical College and Lok Nayak Hospital, New Delhi -2
2. RPwD Act, 2016 (The Gazette of India).
3. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 18 DISABILITY DUE TO BLOOD DISORDER THALASSEMIA

By -Dr. Sanjay Kant Prasad

Introduction

This unit deals with the thalassemia which is a blood disorder. The RPwD Act 2016 has included a group of blood disorder which causes disability. Thalassemia is one of the blood disorders, which can contribute to develop disability. This unit will provide a broader view on the conceptual framework of thalassemia as well as it types, sign and symptom, causes and assessment of thalassemia as per guidelines of RPwD act to get the certificate of bench mark disability.

Objectives

After reading this unit, the learner will be able to

- Describe about the concept and meaning of thalassemia.
- Explain about the causes and contributing factors of thalassemia
- Discuss about the assessment with reference to obtain disability certificate

Concept and Definition

Thalassemia is an inherited blood disorder that causes the body to have lesser quantity of hemoglobin than the normal. This disorder transmits through gene to children from parents. These disorders do not spread either by blood or air or water or sex. This also does not arise out of malnutrition or any other disease.

Inherited disorders are classified in four categories. These are (i) Chromosome related disorder, (ii) Single gene disorder, (iii) multifactorial disorder and (iv) mitochondrial.

Thalassemia is a 'single gene disorder', which transmit from parents to children through one method out of these four methods.

i) Autozomal dominant

ii) Autozomal Recessive

iii) Ex-linked Dominant

iv) Ex-linked Recessive

Thalassemia is transmitted through autozomal recessive pattern.

Types of Thalassemia

There are two main types of thalassemia these are;

i) Alpha thalassemia – This include the hemoglobin H and hydrops fatalis

ii) Beta Thalassemia – This includes the subtype thalassemia H and thalassemia intercedes.

Alpha thalassemia

In this type of thalassemia, there are four genes which are involved in making the alpha hemoglobin chain. One might get two from each of the parents.

- **One mutated gene** – The person has no sign and symptom of thalassemia. But the person is carrier of the disorder and can pass it to their children.
- **Two mutated gene** – One has mild sign and symptom of thalassemia. Such condition is called alpha thalassemia trait.
- **Three mutated genes** – One has moderate to severe sign and symptom.

It is important to note here that from mutated genes is rare and usually results in still birth. The babies born with such condition generally die shortly after birth or require life long transfusion therapy.

Beta thalassemia

In this type of thalassemia, there are two genes which are involved in making the beta hemoglobin chain. One can get one from each of the parents.

- **One mutated gene** – One will have mild sign and symptoms. Such condition is called thalassemia minor.
- **Two mutated gene** – One will have to moderate to severe sign and symptom. Such condition is called thalassemia major

It is important to note here that child born with two defective beta hemoglobin genes usually born healthy but develop sign and symptom within the initial two years of life. The milder form is called thalassemia intermedia which can also result from two mutated genes.

Signs and Symptoms of thalassemia

These are the apparent and manifested sign and symptom of thalassemia

- Fatigue
- Weakness
- Pale or yellowish skin
- Facial bone deformities
- Slow growth
- Abnormal swelling
- Dark urine

In case of severe thalassemia, the following symptoms can also occur and observed.

- **Bone deformities** -: Thalassemia can expand the bone marrow, which causes the bone to widen. This can result in abnormal bone structure especially on face and skull. Such expansion also makes bone thin and brittle and also increasing the chance of broken bones.
- **Enlarged Spleen** -: The spleen helps the body for fighting infection and filter unwanted material like old or damaged blood cells. Thalassemia is generally accompanied by the destruction of a large number of red blood

cells. Enlarged spleen can make anemia worse and it can also reduce the life of transfused red blood cells.

- **Slow growth rates** -: Anemia can slow the growth of the child as well as delay puberty.

- **Heart problems** -: Congestive heart failure and abnormal heart rhythms can be associated with severe thalassemia.

The Assessment of thalassemia as per DPEwD guidelines .

1) Mild anemia refractory to iron supplementation and microcytic, hypochromic with hepatosplenomegaly and confirmed by Hb electrophoresis but asymptomatic and no BT # requirement.

   (Disability Grading - < 40%

2) Thalassemia major with monthly BT # requirement but Haemoglobin maintained at 10 should receive some benefit like time out special leave social security and free treatment transfusion dependent and exertional dyspnoea on walking few yards more than class 2 as per NYHA and AHA.

   (Disability grading – 41-50%)

3) Above plus that major with monthly BT # with sign of bone marrow hyperplasia and osteoporosis decided by bone dexa scan.

   (Disability Grading – 51 to 60%)

4) Above plus iron chelator requirement osteoprosis and serum ferritin less than 1000 ng/ml.

   (Disability Grading 61 to 65%)

5) That major as in level 4 plus with Bimonthly BT # requirement and all the above.

   (Disability Grading 66 to 70%)

6) That major > than bimonthly BT requirement with features of hyperspenism and more than 250 ML packed cell transfusion/kg per year plus feature of level 5.

   (Disability Grading 71 to 75%)

7) That major with splenetomy with infection and plus features as in level 6.

   (Disability Grading 76 to 79%)

8) That major with features as above at level 7 plus haemosiderosis and serum ferritin level > 1000 ng/ml and with multi organ failure decided by echocardiogram, LFT & GTT.

   (Disability grading 80 to 85%)

9) That major with features at level 8 plus with BT associated infections like HBV, CMIV, HIV, HBC etc.

   (Disability grading – 785%)

Intervention

Thalassemia major and thalassemia inter media require life long intervention. The only treatment which can cure thalassemia is Bone Marrow Transplant (BMT). But it is not possible for all persons with thalassemia because of high cost and non-availability of donors.

Thalassemia major is commonly managed by regular blood transfusions and iron cheletion therapy. Availability of Leuko-depleted packed red blood cells and iron cheletors are necessary for appropriate management along with regular monitoring.

Genetic counseling and community awareness programme play a very important role in successful prevention of blood disorders.

Conclusion

Thalassemia is an inherited blood disorder that causes the body to have lesser quantity of hemoglobin than the normal. This disorder transmits through gene to children from parents. These disorders do not spread either by blood or air or water or sex. Thalassemia is a 'single gene disorder', which transmit from parents to children through autozomal recessive pattern. The major types consist of alpha thalessemia and beta thalessemia. Beta thalessemia further divided in to thalessemia minor and thalessemia major based on mutation of gene. The common symptom includes fatigue, weakness, facial bone deformities, slow growth and dark urine etc. The severe symptom such as enlarged spleen, heart problem, bone deformities etc. are also seen in the persons with thalessemia. The assessment of thalessemia as bench mark disability is done as per guidelines issued by D/o DPwD, Govt. of India. The major intervention include blood transfusion and bone marrow transplant.

References:

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 19 DISABILITY DUE TO BLOOD DISORDER SICKLE CELL DISEASE

By -Dr. Sanjay Kant Prasad

Introduction

This unit deals with the description about the sickle cell disease which a benchmark disability in RPwD Act 2016 under the broad category of "Disability Due to Blood Disorder." Here in this unit the learner will find the concept and meaning of sickle cell disease, its different type, causes common sign and symptom and in brief about the intervention required to manage this disorder. The main thirst of this unit is provide a clear information to learner as how this disorder is assessed as per guidelines to issue disability certificate to person having sickle cell disease

Objectives

After reading this unit, the learner will be able to

- Describe about the concept and meaning of sickle cell disease.
- Explain about the causes and contributing factors of sickle cell disease
- Discuss about the assessment with reference to obtain disability certificate

Concept & Meaning

Sickle Cell Disease is a common inherited blood disorder. This disease gets its name "Sickle" as the red blood cells look like a sickle, which is a C shaped form tool. Red Blood cells contain a molecule known as hemoglobin which carries oxygen in the whole body. Hemoglobin is smooth, round and flexible in a healthy body, which allows blood cells to glide easily through blood stream. But when a person has sickle cell disease, the hemoglobin shape is abnormal, which caused red blood cells to become rigid and curved. This odd shaped cells block blood flow. It is very dangerous and cause severe pain, anemia and other symptom.

The clinical syndromes resulting from disorders of hemoglobin synthesis are referred to as hemoglobin opathies. These are grouped in three main categories.

i) Those owing to structural variants of hemoglobin, such as sickle cell disease.

ii) Those owing to failure to synthesize one or more of the globin chan of hemoglobin at normal rate, as in the case of thalassemia.

iii) Those owing to the failure to complete the normal neonatal switch from fetal hemoglobin (HbF) to adult hemoglobin (HbA). This category comprises a group of disorders referred to as hereditary presence of fetal hemoglobin (HPFH).

The Sickle cell disease encompasses both homozygous and the compound heterozygous states, that lead to symptomatic disease as a result of formation of sickle cell due to presence of Hbs.

The homozygous state cause both haemolysirs and also reduced oxygen affinity of Hbs.

The main clinical disability arises from repeated episodes of vaso-occlusive event (painful crisis) organ dysfunction, impairment of vision hearing, anemia, bone disease, pulmonary complications, skin ulcerations, gall bladder stones and psychological problems.

The severity of sickle cell anemia is extremely variable. It is partly due to the modifying factors such as interaction of a thalassemia or synthesis of Hbf and partly to socio-economic conditions and other factors that influence general health.

Types of Sickle Cell Disease

Following are the types of sickle cell disease.

i) **Sickle Cell Anemia (SS)** – when a child inherits one substitution beta globin genes from each parent means, the child has sickle all anemia.

ii) **Sickle Hemoglobin** – C Disease (SC) – In this case, individual have a little different substitution in their beta globin genes that produces both hemoglobin C and Hemoglobin S. This may cause similar symptom like sickle cell anemia, but less anemia due to higher blood count level.

iii) **Sickle beta-Plus Thalassemia** – In this type the disease also contain substitutions in both beta globin genes. The severity of disease varies according to the amount of normal beta globin produced. The symptoms are almost identical to sickle cell anemia. Severe cases needs blood transfusions.

iv) **Sickle Hemoglobin - D Disease** – In this type, the individual has moderately severe anemia and occasional pain episodes. Here the different substitution of the beta globin gene has been found to interact with the sickle hemoglobin gene.

v) **Sickle Hemoglobin - O Disease** – Here, there is another type of substitution in the beta globin gene interact with sickle hemoglobin.

Causes

The Sickle Cell Disease is mainly caused by a problem in the hemoglobin - beta gene found in chromosome 11.

To develop this disease, both the parents need to pass the abnormal hemoglobin gene. In case, both the parents carry the defective gene the chances are 1 out of 4 of inheriting the disease. On the other hand if any child is born with one defective hemoglobin - beta gene, they may become a carrier of the disease. However, carriers do not develop sickle cell disease but carrier can pass the disease on to their children.

People of some ethnicities are more at risk for sickle cell disease than others.

Signs and Symptoms

The symptoms of sickle cell disease vary from person to person and change overtime. The major symptoms includes:-

- **Anemia** -: Sickle cells are more fragile than normal red blood cells and usually die in 10 – 20 days, whereas normal cells live for about 120 days. This creates shortage of red blood cells, which is called anemia. Due to low red blood cells to carry oxygen in the body, it results into fatigue.

- **Pain Crises** -: The pain is a common symptom in all persons with sickle cell disease. It may manifest as dactylitis ("hand-foot syndrome"). The sickle shaped red blood cells block flood flow through tiny blood vessels, cause pain in chest, abdomen, joints and bones. There is variation of intensity and frequency in the pain.
- **Swelling of hand and feet**-: The sickle shaped red blood cells block blood flow to the hands and feet resulting into swelling of hands and feet.
- **Infections**-: Sometimes, sickle shaped red blood cells damage tissues, which leads to ulcers and if spleen is damaged, the person could get infections.
- **Vision problems** -: Sickle shaped cell can get stuck in the blood vessels, which disturb the supply of blood to eyes, resulting into damage to retina and vision problem.
- **Delay Development**-: The children with SCD grow slower than other children.

Assessment of Sickle Cell as per DEPwD Guidelines.

Severity Score	Symptoms and Characteristics	% of Disability
0	Homozygous sickle cell disease but asymptomatic but has got mild pallor (HCT 30) and Spleno hepatomegaly and diagnosis confirmed by HB electrophoresis.	< 40 %
1	Sickle cell anemia such as (HbSS) compound heterozygous (HbS) thalassemia HbSD and HbO anemia that is severe and chronic with persistent hemoerit of 26 % or less and symptomatic requiring blood transfusion to maintain the HbS level < 30 %.	< 40 %
2	Above plus painful crisis due to blood clots in blood vessels at least three times in the past five months.	40-50 %
3	Above plus hospitalization beyond that of emergency care at least three times in the past 12 months.	51 to 60 %
4	Above plus functional impairment caused by sickle cells that meet another disability listing due to arascular necrosis, osteomyelitis and bone infraction of multiple joints, stroke and transient ischemic attack, leg ulcers.	61 to 65 %
5	Above plus permanent loss of spleen function or chronic hypersplenism with recurrent infections more than 3 in last 6 months.	66 to 70 %
6	Above plus complications like impaired neuropsychological function with abnormal cerebral MRI scan sickle nephropathy, sickle cell lung disease, bilateral proliferative retinopathy leading to loss of vision and chronic liver disease.	71 to 75 %
7	Above plus impaired cardiac function due to end organ damage measured by functional ECHO cardiography.	76 to 80 %
8	Above plus sickle cell anemia with BT associated complications due to infection like HBV, CMIV, HBC etc.	81 to 85 %

Intervention

If the severity of the sickle cell disease is accessible, self treatment at home with bed rest, oral analgesia and hydration is suitable.

Blood transfusions are used to treat severe anemia. Iron chelation therapy can be started in patients with SCD receiving regular blood transfusions to reduce excess iron level.

If the retina is damaged by excessive blood vessel growth, laser treatment can prevent further vision loss.

Transfusions are needed in only special indications. If transfusions need, then a pre-transfusion extended red cell typing is required.

The treatment of sickle cell disease must be taken under strict supervision of registered medical practitioner.

Conclusion

Sickle Cell Disease is a common inherited blood disorder. Red Blood cells contain a molecule known as hemoglobin which carries oxygen in the whole body. Hemoglobin is smooth, round and flexible in a healthy body, which allows blood cells to glide easily through blood stream. But when a person has sickle cell disease, the hemoglobin shape is abnormal, which caused red blood cells to become rigid and curved. **Sickle Cell Anemia (SS), Sickle beta-Plus Thalassemia, Sickle Hemoglobin - D Disease** and **Sickle Hemoglobin - O Disease.** The symptoms include anemia, pain crises, infections, and vision problems, swellings of hand and feet and delay development. The assessment for issuing certificate of benchmark disability is as per guidelines issued by D/o EPwD. The treatment of sickle cell disease includes iron chelation therapy, blood transfusion, bed rest ,oral analgesia, and hydration etc are available but must be taken under expert guidance and supervision of registered medical practitioner.

References:

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).

UNIT 20 MULTIPLE DISABILITIES

By - Dr. Hemlata

Introduction

In this unit we will discuss about multiple disabilities, common characteristics of persons having multiple disabilities, causes, assessment and intervention strategies for multiple disabilities. It has been included in the Rights of Persons with Disabilities Act, 2016 as one of the disabilities among 21 disabilities.

Multiple disabilities are a condition where a person has a combination of two or more disabilities at the same time. The person with intellectual disability may have visual impairment or hearing impairment similarly the person with blindness may also have problems in hearing. The most common in multiple disabilities is deaf blindness where the person has difficulty in hearing as well as seeing, because of this condition they are dependent on others or need extensive support for their daily living skills. There may be many difficulties for completing a simple task that can be done easily by others. With appropriate training these individuals can learn daily living skills and communicate effectively with their care givers, perform certain tasks.

Objectives

After undergoing this unit you will be able to -

- Discuss the concept and meaning of multiple disabilities
- Describe the common Characteristics of person having multiple disabilities
- Enumerate the causes of multiples disabilities
- Elaborate the assessment and intervention for multiple disabilities

Concept and Meaning

Multiple disabilities means a combination of two or more disabilities. In simple words the term multiples disabilities means existence of more than one disability at a time. It may be cerebral palsy and hearing impairment or intellectual disability and blindness.

The rights of persons with disabilities act, 2016 defines multiple disabilities as – "multiple disabilities (more than one of the specified disabilities) including deaf blindness which means a condition in which a person may have combination of hearing and visual impairments resulting in severe communication, developmental and educational problems"

Types of multiple disabilities

1. **Deaf blindness**- There may be children who are deaf and blind from birth or become blind at later age. It is very important to provide them training in teaching communication skills. Deaf blind children will not be able to understand the conversation unless someone makes an effort to interpret for them. The deaf blind people understand through finger spelling or one to one sign language is used for them. Some of deaf blind people who are Braille user use a device known as Tell-a-Touch. There are more such devices

that are helpful to persons with deaf blindness in making communication with others. Recently Samsung India has launched a mobile based application named as "Good Vibes" that help in communication with them through a mobile phone.

2. **Pervasive Developmental Disorders:** The pervasive developmental disorders refer to a group of disorders characterized by delays or absence of growth in the basic functions including communication and socialization. Asperger's syndrome and several other disorders in addition to autism may be present at the same time.

3. **Epilepsy and Autism:** The children with autism may also have epilepsy and as a result they may have seizures at certain intervals, the seizures may be a result of motor deficit or intellectual disability. The children with severe motor deficits may have more seizures than other children.

4. **Asperger's Syndrome:** Children with asperger's syndrome are quite often described as 'too bright and articulate to qualify easily for support services and too impaired to function quite well without support'. The children with asperger's syndrome have difficulty in social skills, they have very few interests, problem with non-verbal communication, they may have speech and language peculiarities and motor difficulties.

5. **Visual Impairment and Autism:** Children having visual impairment may also have autism, it is advisable that the screening of all young children having visual impairment should also be done for finding out if the child is having symptoms of autism and appropriate intervention can be provided accordingly. It is very important to provide early intervention as soon as any sign of disability is suspected.

6. **Non Verbal Learning Disorder:** Non verbal learning disorders are characterized by difficulty in integrating information in the non-dominant hemisphere of the brain. This is usually the right hemisphere and the term "Right Hemisphere Disorder" is also used. They have normal verbal language skills, but have difficulty with the following:

    - Non-verbal communication, leading to social difficulties
    - Motor integration, leading to clumsiness, and
    - Visual-spatial orientation, leading to focusing on details rather than "the big picture.

7. **Hyperlexia:** Children with hyperlexia have a fascination with the printed word and an ability to read printed words beyond their ability to understand what they are reading. They may also have significant difficulty in understanding language as shown on the standardized test. Between 18 months and 24 months parents are often amazed by the child's ability to name letter and numbers. By three years, children with hyperlexia see printed words and read them; sometime before they have really learned to talk. The primary and essential cognitive deficit in these children seems to be a disorder in speech and language involving a severe deficit in the ability to comprehend language whether it is spoken or written, as opposed to dyslexia which involves only recognition and or comprehension of written language. Often the best clue to hyperlexia is the child's precocious ability to spell.

8. **Semantic Pragmatic Disorder:** Children with semantic pragmatic disorder have difficulty with communication. They have difficulty in understanding what other people say, and they do not use speech appropriately themselves. The features include:

    - Delayed language development
    - Difficulty in understanding the literal meaning of words and sentences.
    - Difficulty extracting the central idea from instructions.
    - Difficulty following instructions.
    - Learning to talk by memorizing word and phrases, while being unable to use thee same words freely
    - Repeating phrases out of context especially phrases heard on TV.
    - Consfusing pronouns such as 'I' and 'you'.
    - Difficulty understanding questions, especially those beginning with 'how' and 'why'.

    Most children with semantic pragmatic disorder also have some difficulty understanding social situations and expectations, and may be high functioning children with autism.

9. **Rett' Syndrome:** Rett's disorder occurs only in girls, and is characterized by:

    - Normal prenatal and peri-natal development, including a normal sized head at birth
    - Normal development during the first few months of life
    - Slowing of head growth between 5 and 48 months of age
    - Loss of previously acquired purposeful hand movements between 5 and 30 months of age, followed by the development of stereotyped hand movement such as hand washing
    - Poorly coordinated gait or trunk movements
    - Profound mental retardation.

10. **Regulatory Disorder and Multi System Developmental Disorder:** A regulatory disorder is an impairment of the normal ability to process sensations(s), to receive information form the sense and respond (or not respond) to this information while staying calm and attentive infants with regulatory disorders may under react or over react to stimuli such as noises and bright lights. They may show tactile defensiveness; that is, they may stiffen and arch their bodies to avoid the physical handling associated with being dressed or held. They may under react or over – react to pain or they may have difficulty processing several stimuli simultaneously.

Common Characteristics

Person with multiple disabilities may show a vide range of characteristics that may be as following:

1. Difficulty in speech and communication
2. Difficulty in mobility
3. Limited ability to generalizing skills from one situation to another
4. Need support for daily living activities
5. Limited visual ability
6. Delayed language development
7. Limited social skills
8. Difficulty in socialization
9. Difficulty in following the instructions
10. Difficulty in expressing emotions
11. May have anxiety or aggressive behaviour
12. May have self destructive behaviour
13. May have difficulty in motor skills
14. May have difficulty in focusing on certain task
15. Short attention span
16. Poor concentration

Causes

Causes of multiple disabilities may be as following -

1. Viral infection in mother
2. Blood incompatibility
3. Difficulty during delivery or prolonged labour
4. High fever in early childhood
5. Sever jaundice
6. Low oxygen during the birth
7. Infections
8. Polio
9. Premature birth
10. Damage to ear drum during trauma

Assessment

The assessment of multiple disabilities should be done as per the guidelines issued by Dept. of Empowerment of Persons with Disabilities, Govt. of India for assessment of disabilities.

1. The guidelines used for every single disability shall be used for assessment of each disability of a person having multiple disabilities in the first instance.

2. Subsequently, in order to arrive at the total percentage of multiple disabilities, the combining formula:

$$a + \frac{b(90- a)}{90}$$, shall be used where

"a" will be the higher score and

"b" will be the lower score. However, the maximum total percentage of multiple disabilities shall not exceed 100%.

For example, if the percentage of hearing disability is 30% and visual disability is 20%, then by applying the combining formula given above, the total percentage of multiple disabilities will be calculated as follows:-

$$30 + \frac{20(90-30)}{90} = 43\%$$

3 For certifying more than two disabilities, each disability will be evaluated and the degree of disability will be calculated by the notified Specialists in the area. Based on the score received for each disability, they will be graded from the most severe to the least severe. The formula:

$$a + \frac{b\ (90-a)}{90}$$

will be successively applied to subsequent disability till the last disability is covered. This calculation is subject to maximum of 100%.

For example a person may have disabilities 1, 2 and 3, the score for 1 is the highest equal to (a); score for the second is equal to (b) (second highest); and score for 3 is (c) the lowest score. According to the above formula:

$$a + \frac{b\ (90-a)}{90} = x$$

(score of disability 1 and 2 = x)

This (x) will become (a) for the purpose of calculation of disability 3 which is C.

$$x + \frac{c\ (90-x)}{90} = y$$

(score of disabilities 1, 2 and 3 = y)

Such calculation will continue till the last disability is covered subject to a maximum of 100%.

Intervention

As soon as the signs of disability are seeing in the children, early intervention should be provided. After proper assessment and screening intervention should be provided with the help of multi disciplinary team that may include special educators, speech therapist, physiotherapist, occupational therapist, sign language

interpreter/interpreter etc. if the children are going to school the physical arrangement of the classroom should be changed to accommodate the child. Special care and attention should be provided to the children having multiple disabilities as they will need support from others in completing their activities. The other children in the classroom should also be sensitized about the need of children with multiple disabilities. They may be encouraged to assist the children having multiple disabilities in the classroom and school premises. This will not only help the students with disabilities in developing social and communication skills but also be beneficial for other children.

Conclusion

Multiple disabilities is a broad and generic term used as an umbrella term, the persons having multiple disabilities require on extensive regular support in most of their daily living activity, but with proper intervention strategies they may become self reliant and accomplish various tasks related to motor sensory, cognitive, emotional and communication etc. With training and intervention their skills related to mobility self care, daily living skills, communication education and vocational can be improved and they can become productive member of society.

References:

1. RPwD Act, 2016 (The Gazette of India).
2. Guidelines for evaluation and certification of disabilities under RPwD Act, 2016 (The Gazette of India).