

Rehabilitation Management of Mentally Retarded amongst Physically Disabled

Methods of Monitoring Progress

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Mental Retardation amongst physically disabled persons, although incurable, is most of the time manageable problem. These children require Special education or training. Outcome of any rehabilitation intervention programme for such children can only be assessed by gain in functional status. The goal of rehabilitation in mild mental retardation is social adjustment with ultimate aim being functional independence. Similarly in moderate, severe and profound retardation aim is to achieve some degree of functional independence, atleast in self-care skills. The progress of rehabilitation intervention can be monitored by using various self care and functional assessment scales. A review of various prevalent methods is presented here.

The effectiveness of any programme of medical intervention is determined by its therapeutic outcome, similarly effectiveness of Medical Rehabilitation is improvement in functional status of the patient. Therefore the progress of patient undergoing medical rehabilitation programme can be monitored by repeated assessment of his functional status. There can be two types of methods which can be used for monitoring progress.

- (1) *Subjective*—Spontaneous observation, no predetermined behaviour or activity performance is recorded. It gives gross idea of improvement.
- (2) *Objective*—Structured, predetermined behaviour, or activity performance is recorded and scoring can be done numerically. Repeated performance can clearly indicate improvement.

Objective Methods—(a) Psychological Assessment
(b) Functional Assessment

(1) Subjective Method

In this method progress can be evaluated by repeated clinical observation at regular intervals. This method will include parental interview, regarding improvement in ADL performance, psychologist's opinion from time to time and feed back on activity performance from OT/PT.

Such method has its limitation in the form of proper recording, and inferences may vary if interviewer is not the same person.

(2) Objective Method

(a) *Psychological Assessment* at regular intervals, specially periodic assessment of adaptive behaviour. The most commonly used scale is Vineland Social Maturity Scale (1). This scale has been adapted for Indian population. In this scale information is elicited by means of semi structured interview with the child/parents guardian. It measures child's adaptive behaviour in following eight areas :

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1. Self help general
2. Self help eating
3. Self direction
4. Self help dressing
5. Socialization
6. Occupation
7. Communication
8. Locomotion

(b) *Functional Assessment*—Functional Assessment (2), (3), (4) is a method for describing abilities and limitations in order to measure an individual's use of the variety of skills included in performing tasks necessary for daily living, leisure activities, vocational pursuits, social interactions and required behaviours. For a comprehensive functional assessment, selected diagnostic descriptors, performance (skill/task) descriptors, and social role descriptors are used to assemble the information desired.

Purposes and uses of Functional Assessment—Problems and areas of need can be identified more accurately and interventions can be developed that are more appropriate for enhancing personal independence and autonomy in fulfilling social roles.

1. Systematically developing a patient problem list that includes limitation in functioning.
2. Determining clinical care changes in patients by comparing functions before and after treatment.
3. Determining the benefits of clinical care in analysing cost benefits and cost effectiveness.
4. Manpower studies as to number and type to levels of severity of disabilities.
5. Prioritization of needs should it become necessary to ration scarce resources.
6. Programme evaluation & quality assurance.
7. Establishing comparability of groups of patients for research studies and for policy planning.

8. Facilitating case management—individualize programme.
9. Documented progress can enhance patients motivation and progress if improvement is feed back to patient.
10. It is possible to compare changes in status over periods of time by assessing functions at appropriate intervals to determine whether rehabilitation programme has been effective.

Desirable Features of a Functional Assessment System—A functional assessment system should meet certain objectives as summarised by Donaldson (5) :—

1. Objective description of functional status at a given point time.
2. Serial repetition allowing detection of changed functional status.
3. Data collected through observation relevant to and useful in monitoring treatment programme.
4. Enhancement of communication among treatment team members and between referral agencies.
5. Comparable clinical observation compatible with research questions.

Ideal System—An ideal functional assessment system should be—

- Simple
- Concrete, permitting consistent & reliable observations
- Comprehensive
- Uniformity of scaling
- Allow convenient manipulation
- Easy analysis

Development of Functional Assessment Instruments—Over the past 30 years many different scales have been developed on these activities performed independently or through assistance. These are used to measure functional independence. According to Donaldson (5) 25 scales met two of three criterias (1) had mechanism of scoring (2) had been used in a survey or research

(3) were applicable to a general rehabilitation population.

Few of these scales are presented here and can be used for assessing the progress of rehabilitation management of mentally retarded amongst physically disabled.

Various Functional Assessment Systems

(1) *Self care Scale (Kenny)* (6), (7) : Since ability to handle functional needs is usually the goal of a physical restoration programme and hence reflects the physical capabilities of the patient as well as his motivation drive and learning ability, it is felt that the numerical selfcare system is a basic tool for measuring improvement, individual patient's progress, as well as progress of an entire disability group which can be depicted numerically.

One such system was developed by grouping the specific self-care activities into larger; more general categories related through a similarity in strength, co-ordination and mobility requirements in six major self-care activities. Bed, transfer, locomotion, dressing, personal hygiene and feeding activities.

These categories are divided into five levels of improvement :

- 0—completely dependent
- 1—require extensive assistance
- 2—moderate assistance
- 3—minimal assistance/supervision
- 4—independent
- Total score of 0—Totally dependent
- Total score of 24—Totally independent

(2) *Pulses Profile* (8)—Developed by Moskowitz and McCann in 1957. The pulses profile is a scale consisting of 6 components, reflecting independence in life functioning the acronym derives from :

- P—Physical condition: basic health/illness status.
- U—Upper limb functions: Self care activities

(drinking, eating, dressing, upper/lower body, donning brace or prosthesis, washing/bathing, perineal care).

L—Lower limb functions : mobility (transferring chair/toilet tub or shower, walking, climbing stairs, propelling wheel chair).

S—Sensory components : sight, communication (verbal/hearing).

E—Excretory functions : control of sphincters (bladder/bowel).

S—Support factors : Psychological/emotional, family/social/financial supports.

Scoring for each component ranges from 1, intact and independent of help from another person to 4, fully dependent, for each function of component area. The subscores for each area are then summed to give an overall measure of functional independence.

Pulse Total—Best score is 6, worst score is 24

—More than 6 & less than 12 :

Mild Disability

—More than 12 & less than 16 :

Moderate Disability

—More than 16 :

Severe Disability

(3) *Barthel Index* (8), (9)—Described in 1965 by Mahoney and Barthel for measuring functional levels of self care and mobility in the physically impaired. These measures of life function have definite implications for assessing and describing medical rehabilitation outcomes and consequently for improving effectiveness of rehabilitation, evaluation and Management.

Barthel Index includes 15 self care, sphincter control and mobility factors; all of which are also included in the pulses profile, Barthel Index however, does not include recognition of physical condition, sensory components, or support factors, areas covered in pulses.

| | Independent | | Dependent | | |
|-----|-------------|---------------|---------------|------------|--|
| | I Intact | II Limited | III Helper | IV Null | |
| | | | | | <i>Self Care Index</i> |
| 1. | 10 | 5 | 1 | 1 | Drink from cup/feed from dish |
| 2. | 5 | 5 | 3 | 0 | Dress upper body |
| 3. | 5 | 5 | 2 | 0 | Dress lower body |
| 4. | 0 | 0 | -2 | 0 | Don brace or prosthesis |
| 5. | 5 | 5 | 0 | 0 | Grooming |
| 6. | 4 | 4 | 0 | 0 | Wash or bathe |
| 7. | 10 | 10 | 5 | 0 | Bladder continence |
| 8. | 10 | 10 | 5 | 0 | Bowel continence |
| 9. | 4 | 4 | 2 | 0 | Care of perineum/clothing at toilet |
| | | | | | <i>Mobility Index</i> |
| 10. | 15 | 15 | 7 | 0 | Transfer, chair |
| 11. | 6 | 5 | 3 | 0 | Transfer, toilet |
| 12. | 1 | 1 | 0 | 0 | Transfer, tub or shower |
| 13. | 15 | 15 | 10 | 0 | Walk on level 50 yards or more |
| 14. | 10 | 10 | 5 | 0 | Up and down stairs from 1 flight or more |
| 15. | 15 | 5 | 0 | 0 | Wheel chair/50 yards only if not walking |

Modified Barthel Index Scoring (8), (9)

The following presents the items or tasks scored in the Barthel index with the corresponding values for independent performance of the tasks :

Scoring—The 15 factors scored in this index are subdivided for scoring as independent (I—Intact, II—limited) and dependent (III—helper, IV—Null).

Total Barthel Score when summed ranges from Zero (Total dependence) to 100 (complete independence)

—A Score of 60 :

Mild to moderate degree dependence.

—A score of less 60 :

Moderate degree dependence.

—A score 40 or less :

Very severe dependence.

—A score of 20 or less :

Almost total dependence in self care and mobility.

(4) *Functional Life Scale*—Developed by Sarno et al. in 1973 (10), recognizes that knowing the actual performance of skills is better measure of degree of disability than knowing the elements that constitute performance. Scale is composed of 44 items designed for application outside of the hospital setting based on interview. It determines functions in 5 areas i.e.

1. Cognition
2. Activities of daily living
3. Home activities
4. Outside activities
5. Social interaction

Normal behaviour is used as the standard for comparison. Items assessed were judged for self initiation, frequency, speed, and overall efficiency and were numerically rated along a continuum from 0-4, yielding a series of sub-scores.

(5) *Long Range Evaluation System (LRES)*—Developed by Grangers and others in 1976 (11). LRES is a functional assessment system designed, tested and used in clinical settings, including medical rehabilitation for in-patients, and out-patients, patients in day-care and home care programmes and residents of long term care facilities. It is a measurement tool for describing areas of service need, severity of handicap, and change in individual over a period of time.

This system provides with a check list with four options and assess in the following area:

1. Active motion of limbs
2. Verbal communication
3. Hearing ability
4. Visual ability
5. Self care ability
6. Mobility
7. Need for physician or nursing services
8. Intellectual and emotional adaptability
9. Adequacy of home setting
10. The level of social interaction or dependence upon home service agency
11. Level of support from the family unit
12. The financial resources
13. Educational level
14. Vocational status

The data collection forms are descriptive checklists prepared for computer entry with

allowance for free text descriptions. Scores are generated as in pulses profile and Barthel Index and are used to represent physical dependence with regard to personal care.

(6) *Escrow Scale* (11)—is intended for persons who are not living in institutions. Rating is from 1 to 4. This scale measures social support. It is a newer scale. It is postulated that the physically disabled persons with a marginal level of independence in personal care are more likely to have potential for independent living if social supports are high as represented by Escrow Scale :

- E—Environment
- S—Social Interaction
- C—Cluster of family members
- R—Resources
- O—Outlook
- W—Work/School/Retirement status

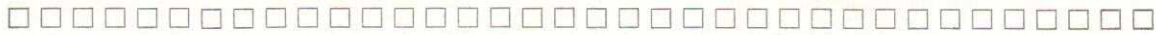
Conclusion

In view of the emphasis on evaluation of benefits derived from rehabilitation programmes, it is important that there be easily replicated measures for demonstrating effectiveness and efficiency of services provided, it is hoped that scales given above and extensively used in west can be used with some modification in our country also for measuring severity of disability and in monitoring rehabilitation progress over a period of time.

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