Psychology of Rehabilitation

DPSY696

Edited by:
Dr. Vijendra Nath Pathak

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Content

Unit 1: Introduction: Overview of the Profession of Rehabilitation Psychology and Practice, History, Growth and Scope, Role of Psychologist in Rehabilitation

CONTENTS

Objectives

This unit will enable you to:

- Understand the history of rehabilitation psychology
- Elucidate the meaning and definition of rehabilitation psychology
- Evaluate the various goals, scope and methods of rehabilitation psychology
- Discuss the role of rehabilitation psychologists

1.1 Overview and Practice:

Around 2.68 crore population of India is facing the brunt of disability according to the 2011 Census. But they lack support. And the next census (2021) is likely to include all 21 categories of disabilities as per RPWD Act (2016). The number as a result is likely to rise significantly as many new disability conditions have been added since previous PWD Act (1995) which included seven disability conditions.

The demand of trained licensed Rehabilitation Psychologists is quite high and will go on increasing as we get the figure in the next census. But as per the current estimates the number of Rehabilitation Psychologists is very low. Institutions offering courses in Rehabilitation Psychology need to be increased for developing trained manpower for the country. We need to spread awareness on the variety of specialty disability conditions among all stakeholders, namely the general public, affected individuals, their families and the government. Acceptance and action on part the affected individuals and their families complete the process that we as Rehabilitation Psychologists look forward to.

The role of a rehabilitation psychologist is not merely testing, evaluation and intervention but also to focus on the quality of life for a child and his family, where welfare is a significant criterion for treatment goals and rehabilitation to facilitate community integration. If the family needs help, they may look for the following resources and contact-

1. ARPP (India) (Association of Rehabilitation Psychologists & Professionals), India website: www.rehabilitationpsychologistsindia.org
2. Kiran- Mental Health Rehabilitation helpline - 24x7 Toll-free Number 1800 599 0019

For many years, rehabilitation counselling has struggled with development and identity issues that have both excited constructive development and diminished energy and resources that could have better defined its practice. The authors have had the good fortune entering the field, experiencing the practice of rehabilitation counselling, and providing leadership for some of its professionalization efforts during many fascinating and crucial junctures in the last few decades. We have also had the good fortune of both deeply loving the philosophy and practice of rehabilitation counselling and of forming a productive partnership in our work as rehabilitation counsellor, educators at the University of Iowa over the last two decades. The idea of re-structuring of rehabilitation counselling around a clear point of view on its nature and future is necessary. The time worn debate about whether rehabilitation counselling at its core is essentially counselling or case management. It defines an exciting and transcendent view of the potential future for rehabilitation counsellors by firmly focusing on the unique and important partnership its practitioners have with persons with disabilities and yet mindful of the critical grounding we must maintain with the profession of counselling and its standards. Future clients and students seeking to enter the field can derive greater benefit from such clarity of perspective and commitment to one vision that seeks to integrate rehabilitation counselling's practitioners with the strongest potential for excellence in practice and best opportunities in future years.

1.2 Historical Perspectives in Rehabilitation Psychology

Amongst the first charitable organization which contributed to the field of rehabilitation psychology were hospitals. Hospitals were established by the Church during the early Middle Ages, to provide care to the sick and disabled who had no families to care for them. The needs of persons with disability were first addressed by the Red Cross, The National Tuberculosis Foundation, Goodwill Industries and the Easter Seal Society, during the nineteenth and twentieth century. Governmental organizations were set up during the beginning of the nineteenth century for people who had special needs, mental retardation, illness and children.

The definition of disability emphasized the return to work as a goal, from the very beginning. Persons disabled the statute defined as 'any person by reason of a defect or infirmity whether congenital or acquired by accident, injury or disease is, or may be expected to be, totally or partially incapacitated for remunerative occupation.' The primary mission of the agency of each state is to help people with special needs reach their potential for employment or independent living. From a historical perspective, rehabilitation psychology can be seen as a field that is interested in studying and dealing with problems of physical and mental impairments and is committed to deal with these people to enable them to lead a healthy, fuller and a more meaningful life. Both from the inside and outside the profession, psychologists, have been viewed as mental health professionals. As the older mind-body dualism gives way to a more holistic integration of the physical and psychological aspects of life, rehabilitation psychology is gaining increasing interest and relevancy.

Period of growth has been stimulated by war, which has led to growth in rehabilitation psychology as a result of the increased need to care for large numbers of disabled veterans returning from war. Following the Civil War, efforts to care for the American veterans took place. Several agencies, in 1921, were consolidated into the Veterans Bureau, which later became the Veterans Administration and now the Department of Veterans Affairs. This agency played an important role in developing clinical psychology as a profession and in placing psychologists in rehabilitation settings.

Two events that had a great impact on the growth of the field of rehabilitation psychology were a set of domestic programs that were launched by Democratic President Lyndon B. Johnson in 1964-65 and the establishment of the Rehabilitation Act of 1973.

The National Council on the Psychological Aspects of Disability (NCPAD) marked the organizational beginning of Division 22. Psychologists, Jane Shover and Phyllis convened this group, who between 1949 and 1951, called psychologists working with persons with disabilities at several American Psychological Association (APA) annual meetings. During this year, the group formally organized as a special interest group within the APA. By the next year, it had become The

National Council on the Psychological Aspects of Physical Disability (NCPAPD). The change of name reflects the tension between those whose work was primarily with physical disabilities and those who saw rehabilitation in a broader perspective that included mental disabilities. The early role of NCPAD during the annual meetings of the APA was primarily as a focus of activity, but with the course of time there was a greater perceived need for organizational structure to manage the business between annual meetings. The members of NCPAD were ambivalent about making the next step, seeking divisional status within the APA, despite its growth divisional status. It was recommended by the APA board of directors, to grant divisional status to the Council of Representatives, who then voted at the APA annual meeting in August 1958 and thus, Division 22 was officially born.

In a conference held in Princeton, New Jersey, February 3 to 7, 1958 on the role of psychology and psychologists in rehabilitation, the origin of rehabilitation psychology was defined. APA and the US Department of Health, Education and Welfare, were the co-sponsors of the conference. Beatrice Wright (1959) recorded the proceedings of the Princeton Conference and it was published by the APA as 'Psychology and Rehabilitation'. This is an excellent reflection of the thoughts at the time concerning the professionalization of rehabilitation psychology and helps us to understand the goals, viewpoints and methods of this emerging specialty. The scope and nature of rehabilitation were discussed there. The main issue was the degree to which rehabilitation should include mental disorders or remain focused on physical disorders. The tension concerning the name of the National Council reflects this debate.

The multidisciplinary character of rehabilitation resulted in the debate on the scope of rehabilitation. As a medical specialty emerged rehabilitation medicine or psychiatry, at the same time. The role of physical therapists, nurses, and social workers, among others was also important. More than most professional's specialties, rehabilitation psychology involved extensive day to day contact with other professionals from a very wide range of training with very different vantage points on the problems of disability. In the proceeding, an entire chapter was devoted to 'Inter-professional Relations'. It was noted by psychologist, Wright that rehabilitation 'is not the sole province of any one profession. It is rather an expression of a system of values and attitudes toward the person with a disability and his or her place in society.' A key value was a belief that 'purposeful activity' should replace the idleness of mere 'convalescence'.

Vocational focus was another major characteristic of rehabilitation psychology. To provide vocational rehabilitation services to disabled veterans and non-veterans, there were statutory mandates. Vocational counsellors and psychologists were brought into the forefront of rehabilitation by agencies that were created to fulfil these mandates. In the year 1958, the concept of vocational rehabilitation had been broadened to include 'sheltered and homebound employment as well as homemaking.' The discussion also included the roles and functions of psychology in a rehabilitation setting.

At the conference, the training of rehabilitation psychologists was discussed. The doctoral level of training was seen as the most appropriate, followed by the earlier decisions in clinical and counseling psychology. Covering 'soma to psychology', a term which was earlier coined by researchers to describe the study of impact of physique and visible disability on psychological functioning was necessary.

Another conference sponsored by the Office of Vocational Rehabilitation (OVR) was held at Clark University, a year after the Princeton Conference. As starting points, a more formal set of presentations and papers were used. The paper which aimed at guiding the direction of research efforts was considered the most interesting paper and was sponsored by the OVR as the major federal granting agency. Myerson's call for more 'comprehensive theories of illness, disability and rehabilitation' was another salient point. He observed after reviewing the extant theories that an integrated theory would have to integrate facts about the person, the disability, the social setting, the rehabilitation process itself and the 'flexibility or amenability to change of each characteristic'.

The three founding members of Division 22 conducted one of the pioneering studies on the psychological aspects of disability. Psychologists, Dembo, Leviton and Wright sought out veterans and others who had lost limbs in the war or were otherwise visibly different. These veterans were then interviewed and sometimes significant others concerning their adaptation to the changes in physical appearance and function and the reactions of others to their visible disability. Soma to psychology was a term which was coined by Dembo and her colleagues, which refers to the ways in which apparent and obvious physical difference has a psychosocial impact on self and others. Throughout the history of rehabilitation psychology, this social psychological framework has been a major theme.

During this period another important work has summarized the history of literature on psychological adjustment to physical disability. Kurt Lewin, a German-American psychologist played an important role in the psychology and social psychology of disability. The holistic interaction between the individual and the environment was emphasized by his field theory approach to psychology, a concept which was of great relevance to studying how the visible physical differences of amputees led to changed reactions of self and others.

The Lewinian emphasis on the person-environment interaction is reflected in several ways. The individual disability is understood in terms of the impact that the disability has on that individual himself or herself and that individual's opportunity to integrate into the community at large. In this early period, another significant development was the close association between rehabilitation psychologists and Division 17. The distinguishing features of counseling psychology have been its emphasis on working with people who are psychologically normal and who are undergoing significant life-stage transitions. Rehabilitation psychology and counseling psychology share an emphasis on the vocational role and its importance in not only economic but psychological independence. Like counseling psychology, rehabilitation psychology has also been more sensitive to the differences between normalcy and pathology. The field has attempted to identify what factors influence an individual who has a disability to react in an adaptive or maladaptive manner to the circumstances imposed by his or her situation.

Rehabilitation psychology emerged as a distinct specialty within professional psychology, by the 1960's. This year included the intensifying struggle for civil rights and racial justice as well as President Lyndon Johnson's Great Society and the beginning of the Medicare program as a means of providing health care to elderly and disabled individuals.

A disability rights movement gained momentum, in the 1970's, with an emphasis on the psychological issue of normalization and the social challenge against paternalism. This led to the passage of the Rehabilitation Act of 1973. Empowerment is the ethic behind this movement. This movement viewed the people as socially disadvantaged by physical and psychological barriers and changing those environmental features is the major goal.

The Americans with Disabilities Act (ADA) in 1990, was an important development for persons with disabilities. The NCPAD published a newsletter, which kept division members up to date on organizational matters, as well as the Bulletin, which presented more formal scientific and scholarly articles. The first editor of the Bulletin was Lee Myerson. He recognized the need to further improve the quality of the journal and the research contained in it if the division was to truly emerge as an important source of knowledge and assistance to practitioners. The editorship has now been passed to Bruce Caplan, and the American Psychological Association is currently the publisher. Two papers addressed both poverty and the impact of race and ethnicity on rehabilitation and reflecting the growing sensitivity to minority group issues were published during the same time.

The role of self-help groups in the rehabilitation process was provided by Wright (1971). By 1978, the division had matured enough to begin honoring its members who had distinguished themselves through research or service. James Garrett was the first recipient of the Distinguished Service Award for research contribution. He was a key person in arranging sponsorship of the early conferences defining the field of rehabilitation psychology. One of the early handbooks on the psychological aspects of disability was also edited by him. Tamara Dembo and Beatrice Wright, who were part of the early Lewinian tradition in rehabilitation psychology, were the other members to receive this award.

Dembo focused her attention on the importance of practical considerations of actual life problems and advocated actively involving the persons with disability in the rehabilitation process. Wright has contributed to social psychology and has extensively written in the field of rehabilitation psychology.

Psychologist, Wilber Fordyce pioneered behavioral approaches to chronic pain and has contributed more than 20 articles expanding on this theme. Nancy Kerr and Lee Myerson are the two main recipients of the Distinguished Service Award; they collaborated on articles concerning the importance of independence for persons with disability and research methodologies for rehabilitation. Numerous papers on aspects of rehabilitation of persons with mental retardation and sensory disabilities were contributed by Myerson. George Wright was the recipient of the Distinguished Service Award 1988. He wrote extensively on the topic of the competencies of rehabilitation professional and how to train and enhance them.

To honor a senior colleague who had a distinguished career in research in rehabilitation psychology, the Roger Baker Award was initiated in 1988. The first recipient of this award was

Brian Bolton. He has contributed and collaborated on more than 120 articles, books, and chapters in the field of rehabilitation. Recipient of the 1989 Baker Award was William Anthony, who had published nearly 80 articles in the field of psychosocial rehabilitation of mental disabilities.

For his long career interest in attitudes toward disability was received by Bob Yuker in 1991. The Attitudes toward Persons with Disability Scale (ATDP) was developed by him, which has been among the most widely used instruments in assessing such attitudes.

Marcus Fuhrer along with Margaret Nosek, were the recipients of the Barker, who were the 1995 winner of the Garret award, took up the theme of independence for persons with disabilities.

In 1958, American Psychological Association (APA) established the division of rehabilitation psychology as an organization for psychologists concerned with the psychological and social consequences of disability but it got implemented only in August 2015 when, the APA Council of Representatives approved Rehabilitation Psychology as an area of professional psychological practice which had a distinguishing feature of aiding to specified problems in a particular population. Since its genesis, there have been some major developments in the field of rehabilitation psychology. Let us recapitulate it in the following section.

- In 1994 Division 22 of APA (established in 1958) which focused on Rehabilitation psychology along with Professional Issues Committee was given more importance and a leadership role and Division 22 in the same year organized APA Conference on Health Care Reform.
- In 1995, establishment of The American Board of Rehabilitation Psychology (ABRP) occurred.
- In 1996, Division 22 played an important role in developing the APA Interdivisional Health Care Committee whose purpose is to establish a common agenda for promoting the professional, educational, and scientific goals of health care psychology.
- In 2010, establishment of the Foundation for Rehabilitation Psychology occurred.

Over the years, people with physical and mental disabilities have witnessed a wide variety of attitude, some more welcoming and the others less welcoming, in terms of social expectations and participation. Social stigma, lack of knowledge and discrimination has, in the past and to some degree in the present too, left people with disability with few employment opportunities. In order to bring about a shift in the attitude and develop more acceptance towards people with disability, a comprehensive civil rights law called The Americans with Disabilities Act (ADA), was established that prohibits, discrimination on the basis of disability and provides protection in the areas of employment and public services to such people.

The interests of many rehabilitation psychologists became increasingly focused toward the specialty of neuropsychology, with the advent of 'neuropsychological rehabilitation', which is the use of psychological principles and techniques to address the needs of persons with neurological disabilities.

Neuropsychology began primarily as an aid to diagnosis and much work has been done by members of both Division 22 and Division 41 to enhance the use of psychological assessment data to diagnose brain damage. Relationship between the environment and the patient has been one of the themes of neuropsychological rehabilitation. More emphasis was given on the correlation between test performance and the presence or localization of a lesion, by classical neuropsychology.

The founding members of the division were involved in working with children, but in 1987, a special interest group was created for psychologists involved in pediatric rehabilitation. Pediatric rehabilitation has been but one of several special interest groups that have emerged as the field of rehabilitation psychology has grown in complexity and specialization.

In the 1970's and 1980's there was a dramatic growth in rehabilitation and its diversification into subspecialties including but not limited to psycho-social rehabilitation of the chronically mentally ill, neuro rehabilitation of traumatic head injury and stroke survivors. Medicare and Medicaid are some government benefit programs which have begun to encourage beneficiaries to use health maintenance organization (HMO'S) and other types of managed care. Rehabilitation Psychologists felt the impact of private credentials bodies, in addition to managed care, with which all psychologists who are health care providers have to deal with.

The major private credentialing body in this specialty area is the Commission for Accreditation of Rehabilitation Facilities (CARF) and its standard mandating inclusion of psychologists on the inpatient rehabilitation team has aided growth in the job market for rehabilitation psychologists.

The accreditation standards promulgated by the CARF, has been one of the major source for the increased job market for rehabilitation psychologists.

Primarily all health care is rooted in a medical model, for better or worse and that invariably implies a diagnostic system. For most of the health care concerns, psychology uses the Diagnostic and Statistical Manual of Mental Disorders (DSMIV), American Psychiatric Association 1994). The chronic problems resulting in disability and requiring rehabilitation is covered by the International Classification of Impairments, Handicaps and Disabilities (ICIHD), which come under the WHO (1980).

Impairment refers to the medical condition itself on the other hand; disability refers to 'any restriction or lack of ability to perform an activity within what is considered normal for a human being.' Handicap refers to the disadvantages encountered by individuals because of impairment or handicap and reflects the interaction between the physical level, the functional capacity level and the level of social structures, support and attitudes.

The passage of the Americans with Disabilities Act (ADA, 1990), has been a major milestone in the movement for civil rights of persons with disabilities. Rehabilitation psychologists have been actively involved in providing testimony for passage of this legislation, as well as being involved after its passage in providing interpretative services to business and community groups regarding disabilities. In pediatric rehabilitation, the division has developed special interest sections. There are special centers for deafness as well. To bring together interests in rehabilitation, wellness, psycho-spirituality, and alternative healing, new committees on integrated health and living have been added. The division has also moved into the computer era, with a website through the American Psychological Association (APA). On professional psychology in general and rehabilitation in particular, the impact of managed care and health care cost containment continues.

1.3 What is Rehabilitation Psychology?

Rehabilitation has been described as a program that uses a combination of interventions to empower individuals with disabilities and chronic health conditions with the aim to help them achieve socially meaningful, personally fulfilling, and functionally effective interaction in their daily lives. Rehabilitation psychology is a branch of psychology that is related to the study and application of psychological knowledge, social principles and skills development for persons with disabilities and chronic health conditions. Another definition of rehabilitation psychology is it is the study and application of psychological principles on behalf of persons who have disability due to illness or injury. The aim of Rehabilitation Psychology is to maximize mental health, independent functional abilities, and social role participation across the life span of individuals with disabilities and chronic health conditions.

Rehabilitation psychologists, often within teams, assess and treat cognitive, emotional, and functional difficulties. They help people to overcome barriers to participation in life activities. They are involved in practice and research with the broad goal of fostering independence and opportunity for people with disabilities.

1.4 Definition

According to renowned psychologists, Maki and Riggar (2004), the term 'rehabilitation' refers to an integrated program of interventions that empower individuals with disabilities and chronic health conditions to achieve 'personally fulfilling, socially meaningful and functionally effective interaction' in their daily context.

American Psychological Association defined rehabilitation psychology as, 'rehabilitation psychology is the study and application of psychological principles on behalf of persons with physical, sensory, cognitive, developmental or emotional disabilities.'

Rehabilitation psychology is a specialty area within psychology that focuses on the study and application of psychological knowledge on individuals with disability and chronic health conditions with an aim of maximizing health and welfare, improving quality of life and social participation across lifespan. In other words, rehabilitation psychology can be seen as an important part of treating and preventing chronic health problems. It also involves practice, research and advocacy which aim at promoting independence and opportunity for people with disabilities.

Rehabilitation psychologists are trained and specialized to engage in a broad range of activities including clinical practice, consultation, program development, research, teaching and training, administration, development of public policy and advocacy related to people with disability and chronic health conditions. As a result, rehabilitation psychology services are spread across variety of settings including in acute care hospitals and medical centers, inpatient and outpatient physical rehabilitation unit, nursing homes and assisted living centers, and specialty clinic (for example, vision loss and low vision, cerebral palsy, multiple sclerosis, or deafness). Some of these facilities are operated privately while others are aided by the government (such as for war veterans).

1.5 Scope of Rehabilitation Psychology

The scope and application of rehabilitation psychologist is wide, as rehabilitation psychologist address various domains of one's everyday functioning, as per the World Health Organization (WHO)'s International Classification of Functioning, Disability and Health (ICF). Some of these are as follows:

- Assessment of an individual's physical, personal, psychological, cognitive, and behavioral factors and followed by developing an intervention plan accordingly.
- Assessment of an individual's neuro-cognitive status, sensory difficulties, mood and emotions, desired level of independence and interdependence, mobility and freedom of movement, self-esteem and self-determination, behavioral control and coping skills, individual's capabilities and quality of life to understand the client's perspective efficiently.
- It assesses the influence of culture, ethnicity, language, gender, age, developmental level, sexual orientation, geographical location, socioeconomic status and assumptions of difficulty on attitudes and the services which are given to the client.
- It explores the environmental barriers in participation and performance in day to day activities including accommodations and adaptation in the existing social structure.
- It includes research and teaching of psychology students and other health trainees about the requirements of people with special needs. It also focuses on development of policies for health promotion, and advocacy for persons with disabilities and chronic health conditions.
- It provides services within existing networks of biological, psychological, social, environmental, and political environments such as attorneys, courts, government agencies, educational institutions, corporate facilities, or insurance companies.

1.6 Goals and Objectives of Rehabilitation

It aims at helping individuals achieve an optimal level of physical, psychological and interpersonal functioning. In order words, rehabilitation psychology can be seen as an important part of treating and preventing chronic and disabling health problems. It also involves practice, research and advocacy with a broader goal of promoting independence and opportunity for people with disabilities.

The following are the main objectives of rehabilitation:

- Develop services for meeting psychological and social needs
- Improve social, emotional relationships between handicapped
- Enlarge free movement in the physical and social environments of the disabled and deprived.
- Study the social and psychological network of rehabilitation services centers with regards to disability and the laws and regulations.
- Goals need to be achievable and based on regular patient assessment of physical and non-physical consequences of the critical illness throughout their recovery.

To meet these objectives and goals, rehabilitation psychologists require intensive and extensive training in the following areas:

- Unique aspects of rehabilitation psychology

- Psychological assessment of persons with disability
- Impact of the environment on the people who are disabled
- Intervention and remediation procedures
- Rehabilitation practices and management strategies

Rehabilitation psychologists can be trained in the several ways. The following are the main ways in which they can be trained:

- In-service training
- Formal academic generic courses
- Short term courses
- Continuing education

1.7 Methods of Rehabilitation Psychology

A rehabilitation psychologist uses various methods to perform his or her own tasks. These are:

- Administration of standardized and non-standardized tests to assess cognitive and psychological functioning of the client, and use of behavioral observation and interviewing skills to get detailed information about the client.
- Evaluation and treatment of both individual and family members for improving coping and adaptation skills in both the client and the family members.
- Providing individual and group intervention by using counseling and psychotherapy, cognitive remediation, behavioral management and enhancing use of assistive technology for enhancing day to day functioning of the client.

1.8 Functions/ Role of Rehabilitation Psychologists

A rehabilitation psychologist performs several functions. Some being specific and some being general functions in general. The functions are enlisted as follows:

- He or she provides a holistic development to the client by working on his or her biological, psychological, social, environmental and even political environment of the client to assist the client through optimal rehabilitation goals via intervention, therapeutic support, education, consultation with other specializations, and advocacy.
- He or she focuses on improving functioning and quality of life of persons with special needs by restoring patient's physical functions and modifying the patient's physical and social environment.
- He or she provides clinical guidance and counseling services to both the individual in need as well as his or her family, primary caregivers and other significant people in the individual's social life and community to help the patient achieve optimal physical, psychological and interpersonal functioning.
- Rehabilitation psychology involves rehabilitation program development which includes educating the public, developing policies for injury prevention and health promotion, advocacy for persons with disabilities and chronic health conditions, research and teaching of psychology students and other health trainees about the requirements of people with special needs.
- Rehabilitation psychology involves case management which includes obtaining written reports regarding client's progress, developing rapport with physicians and other

rehabilitation health professionals and caseload management-which refers to the ability to manage a number of clients, within a given amount of time and provide optimum services.

- It focuses on providing a community-based rehabilitation service activity for integration and equalizing of opportunities in all aspects of the society.
- It involves vocational counseling and consultation which include services such as job development and placement, career counseling, vocational planning and assessment.

Another important function or key role of rehabilitation psychologist is to conduct research in the following areas:

- Development of new services patterns
- Short term counseling approaches and methods
- Construction of evaluation instruments
- Development of new rehabilitation techniques
- Conduct studies on attitudes measurements
- Multifaceted aspects of disability
- Psychological impact of disability
- Cognitive behavioral strategies in rehabilitation.
- Behaviorally oriented skills training
- Sexual issues of disabled individuals
- Barrier-free environment
- Community based rehabilitation

There are some unique functions which a rehabilitation psychologist performs:

- Identification of co-morbidities in the client which can affect his or her functioning.
- Use of efficient assessment tools for developing effective intervention strategies.
- Identifying client's strengths and abilities and developing on it and also identifying the risk factors which need to be taken into consideration while providing an intervention.
- The psychologist should also take into consideration cost and availability of resources for the client.

Rehabilitation psychologist serves a wider range of population which includes:

- Individuals with brain injuries
- Individuals with spinal cord injuries
- Geriatric population
- Individuals with neuromuscular disorder
- Individual with chronic pain disorder
- People with medical condition such as, Cancer, Multiple sclerosis, Developmental disorder, Psychiatric disability, Substance abuse, Deafness or hearing loss, Intellectual disability, Blindness and vision loss, Impairment by educational or other disadvantages.

Moreover, rehabilitation psychologist addresses behavioral and mental health issues faced by individuals affected by injury or any chronic condition that can lead to disability across lifespan. It includes issues such as:

- Emotional coping, mental and psychological status.
- Behavior that promotes positive adaptation to disability.
- Minor adjustment issues as well as severe psychopathology.

1.9 Role of Psychologist in Disability Rehabilitation

Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination. Rehabilitation psychologists support individuals as they cope with the mental and physical challenges their conditions present. They often teach their patients how to adapt and make lifestyle choices that promote good health. Rehabilitation psychologists are concerned with all of the factors in people's lives that contribute to their wellness and recovery, from the support they receive from family and friends to the relationships they have with their team of treatment providers.

The following are the main areas in which a psychologist works:

- Rehabilitation psychologist study and work with individuals with disabilities and chronic health conditions to help them overcome challenges and improve their quality of life.
- Rehabilitation psychologists support individuals as they cope with the mental and physical challenges their conditions present. They often teach their patients how to adapt and make lifestyle choices that promote good health.
- Intervening to reduce stress in the lives of vulnerable individuals, thus reducing the risk of mental illness and preventing re-hospitalization. Psychologists can do this by teaching stress management skills (for example, to identify stressors, manage stress, and solve problems), environmental management skills, and the social skills necessary to build their social networks.
- Researching the effects and managements of stress.
- Developing and applying measures to assess both the stress experienced by individuals and the internal and external resources available to cope with that stress.
- Rehabilitation psychologists are concerned with all of the factors in people's lives that contribute to their wellness and recovery, from the support they receive from family and friends to the relationships they have with their team of treatment providers.
- Rehabilitation psychologists assist individuals who have disabilities and chronic illnesses; the disability may be congenital or acquired — for example, an accident or stroke.
- Psychologists provide psychotherapy and administer assessments.
- It is also work at the societal level to make the lives of the disabled better.
- Psychologists treat might be physical, such as addiction or chronic pain
- Psychologists might work in a number of different health facilities. This can include hospitals, physical therapy centers, long-term care centers, drug and alcohol rehabilitation centers, psychiatric hospitals, and mental health clinics.

Keywords

Rehabilitation, centres, psychologist, APA, Therapy, Disability, Psychology

Self-Assessment

1. 'Psychology and Rehabilitation' was published by

A. NCPAD
B. ABRP
C. ADA
D. APA

2. When did Division 22 come into existence?

A. August 1958
B. August 1985
C. October 1958
D. October 1968

3. What is the full form of NCPAPD?
A. National Council on the Psychological Areas of Physical Disability
B. National Council on the Psychological Aspects of Disability.
C. National Council on the Psychological Aspects of Physical Disability
D. National Council on the Psychiatric Aspects of Physical Disability

4. The American Board of Rehabilitation Psychology (ABRP) was established in which year?
A. 1992
B. 1994
C. 1995
D. 1998

5. Name the recipient of the Distinguished Service Award 1988.
A. Brian Bolton
B. Leviton
C. Lyndon Johnson
D. George Wright

6. Who coined the term 'Soma to psychology'?
A. Lee Myerson
B. Nancy Kerr
C. Dembo
D. Kurt Lewin

7. The NCPAD published a newsletter, which kept division members up to date on organizational matters, as well as the Bulletin. Who was the first editor of the Bulletin?
A. Wilber Fordyce
B. Lee Myerson
C. George Wright
D. Brian Bolton

8. Who among the following is not the founding members of Division 22?
A. Dembo
B. Beatrice Wright
C. James Garrett
D. Leviton

9. Name the first recipient of the Distinguished Service Award for his research contribution who was also considered as a key person in arranging sponsorship of the early conferences defining the field of rehabilitation psychology.
A. James Garrett

B. Bob Yuker
C. George Wright
D. William Anthony

10. Who developed the Attitudes toward Persons with Disability Scale (ATDP)?
A. Brian Bolton, 1991
B. Bob Yuker, 1991.
C. James Garrett, 1992
D. Nancy Kerr, 1995

11. When was the Roger Baker Award initiated?
A. 1998
B. 1988
C. 1982
D. 1992

Answers for Self Assessment

1.	D	2.	A	3.	C	4.	C	5.	D
6.	C	7.	B	8.	B	9.	A	10.	B
11.	B								

Review Questions

1. Define Rehabilitation Psychology.
2. What do you understand by the Scope of Rehabilitation Psychology?
3. Describe the Goals and Objectives of Rehabilitation.
4. Mention the Functions/ Role of Rehabilitation Psychologists.

Further Readings

- Elliott, Timothy R. & Frank, Robert G.- Handbook of rehabilitation psychology, 3rd edition, Oxford University Press

Dr. RubinaFakhr, Lovely Professional University

Unit 02: Disabilities: Definition, Nature, Types and Characteristics of Various Disabilities as per Person with Disabilities, Mental Retardation, Learning Disabilities and Visual Disabilities

CONTENTS

Objectives

After completion of this unit, the students will be able to:

- Understand the meaning and definition of disability

- Know different types of disabilities
- Familiarize with the classification and characteristics of various disabilities

Introduction

Kazou (2017) Disability is any condition or impairments socially, cognitive, developmental, intellectual, mental, physical, sensory or combination of multiple factors that makes it difficult for a person to do certain activities or interact effectively with the surrounding world.

People with disability experience discrimination and social disadvantage. Social perceptions of disability explained social disadvantage in terms of individual impairment such as family circumstances, income and financial support, education, employment, housing, transport and environment (Barnes et al., 2012). Management of Persons with disability require a combination and continuous care from specialized medical, social, psychological personnel, vocational, and rehabilitation (Kurland, 2003).

According to WHO reports, 15% of the world's population lives with certain types of disability, of whom 2-4% experience substantial difficulties in functioning (Bickenbach, 2011). Based on 2010 population estimates, worldwide, 785-795 million people aged 15 years and older are disabled (WHO, 2010). World Health Survey estimates that 110 million people of which 2.2% have significant difficulties in functioning, in which the Global Burden of Disease Survey estimates 190 million 3.8% have severe disability, including children, over a billion people about 15% of the world's population (WHO, 2011). Lack of education among disabled is a barrier, whereby 54.7% belonged to illiterate category (NSSO, 2002). Hence, severe disability is significantly longer in women than in men (Courtney-Long, et al., 2015).

2.1 General Causes of Disability

Maxwell et al. (2007) explain different causes of disability as: Poisons and pesticides: chemicals can cause health problem; Poverty and Malnutrition: poverty people are most vulnerable to harm; Inherited disabilities: Spinal Muscular Atrophy and Muscular Dystrophy is some inherited disability; Nuclear Accidents: Survived people suffered from cancers especially in the thyroid gland; War: Explosions cause people to become deaf, blind, and lose their body parts; Poor Access to Health Care: Difficult labor cause damage; Illness: can cause disability; Medicines and Injections: Unnecessary and overuse of injected medicines; Use of needle or syringe without sterilizing can cause serious diseases, paralysis or spinal cord injury; Dangerous Working Conditions: Violence, and threats; and Accidents: Burns, falls, road accidents, and breathing or drinking toxic chemicals are a common those are among the source of disability.

In general term, disability may be associated with different conditions at birth that may affect functions later in life, including Cognition, Mobility and Other areas including disorders in single genes; and result of the mother's exposure during pregnancy to infections; Developmental conditions such as Autism; Injury, for example, traumatic brain injury; Long-standing condition, for example, diabetes; and progressive for example, muscular dystrophy.

2.2 Dimension of Disability

According to WHO (2011) There are three dimensions of disability: Impairment in a person's body structure or function, or mental functioning for examples loss of a limb, loss of vision or memory; Activity limitation: such as difficulty seeing, hearing, walking, or problem-solving; and Participation restrictions: such as working, engaging in social and recreational activities, obtaining health care and preventive services.

2.3 Types of Disability

There are different types of disabilities such as Physical, Intellectual, Sensory, and Mental illness the following are among them.

2.4 Physical Disabilities

It is the disability that affect a person's physical capacity and mobility ether in temporarily or permanently.

Types of Physical Disabilities

Acquired brain injury: Damage to the brain including: stroke, alcohol or drugs, infection, disease, or a lack of oxygen and cause trouble in processing information, planning, solving problems and experience changes in their behavior and personality.

Spinal Cord Injury (SCI): Accidents, cancer, arthritis, infections, blood clots, and degenerative spinal conditions can affect the ability to move through paralysis, it may affect many areas of a person's body and results in paraplegia, loss of function below the chest, or quadriplegia, loss of function below the neck.

Spinal Bifida: It can be mild to severe including paralysis or weakness in the legs, bowel and bladder incontinence, hydrocephalus that is too much fluid in the brain cavities, deformities of the spine, and learning difficulties, and it is likely caused by genetic and environmental factors.

Cerebral Palsy:People experience weakness, difficulty walking, lack of muscle control, problems with coordination and, involuntary movements in this type. Hence, lack of oxygen to the brain; Illnesses during pregnancy; Accidental injury to the brain, meningitis in young children, and premature birth are among the causes.

Cystic Fibrosis (CF): Is an inherited genetic condition affects body's respiratory, digestive, and reproductive systems and cause mucus to be thick and sticky hence, causing lung damage and recurrent infections. Symptoms are sinus infections, liver damage, diabetes, poor growth, diarrhoea, infertility, and low salt levels in the body, which causes problems such as fatigue, cramps, and dehydration.

Epilepsy:A neurological condition where a person has a tendency of recurring seizures due to a sudden burst of electrical activity in the brain and cause unusual movements, odd feelings or sensations and change a person's behavior to unconsciousness. Brain injuries, strokes, cancer, structural abnormalities of the brain, and other genetic factors can all cause disability.

Multiple Sclerosis (MS): It occurs when the myelin sheath becomes damaged, causing random patches or scars which interfere with messages sent through the central nervous system, affecting the brain, optic nerves, and spinal cord. Symptoms include fatigue, loss of motor control, tingling, numbness, visual disturbances, memory loss, depression, and cognitive difficulties.

Muscular Dystrophy: It is a group of genetic disorders that lead to progressive and irreversible weakness and loss of muscle mass. Signs and symptoms can include difficulty walking, trouble breathing or swallowing, restriction in joint motion, heart and other organ problems.

Tourette Syndrome: Is a neurological disorder involves involuntary and repetitive vocalizations, sounds, and movements called tics. Vocal tics can include sniffing, throat clearing, tongue clicking and grunting; Motor tics can include eye blinking, shrugging, nose twitching, head jerking, facial expressions, touching objects or people, spinning around. It is diagnosed between the ages of 2 and 21. A combination of genetic, environmental, and neurochemical are among the factors.

Dwarfism: It defined as an adult height of 4 feet 10 inches or less with the average height of someone with dwarfism being 4 feet (Mayo Clinic). There are two categories for dwarfism: Disproportionate dwarfism, some parts of the body are smaller, whilst other parts are average or above-average; and Proportionate Dwarfism, the body is averagely proportioned, and all parts of the body are small to the same degree. Children may experience a delay in developing motor skills, however, dwarfism does not have a link to any intellectual disability.

2.5 Intellectual/Cognitive Disability

It is the disabilities that are limited in how people are able to learn or function, have very low Intelligence Quotient (IQ) score, fewer limits and are able to lead independent lives in the future. Whereby, others have severe limits that make them dependent on others for care.

Intellectual disability occurs when a person has difficulty with general mental abilities. This may impact there: Intellectual functioning in learning, judgment, problem-solving, reasoning, and academic skills; Practical functioning, the ability to function and take care of oneself independently, such as performing personal care tasks; and Social functioning, the ability to function normally in society. According to the American Psychiatric Association, 1% of the population have intellectual disability. Around 85% of these people have mild case, whereby males are more likely to receive a diagnosis of intellectual disability.

Causes of Intellectual Disability: The condition develops due to disease; certain brain conditions; certain genetic conditions; fetal alcohol syndrome; brain malformations; infections; exposure to toxins; serious head injury; stroke; maternal disease; problems at birth; extreme malnutrition; insufficient medical care and any condition that impacts the brain and begins before the age of 18 years, or before birth. However, intellectual disability can also develop later in childhood or adolescence due to brain damage.

Symptoms of Intellectual: Some common symptoms include: significantly delayed motor skills, delayed speech or difficulty speaking, difficulty learning at grade/age-appropriate level, Poor memory, inability to understand consequences of actions, poor problem-solving skills, thinking logically and understanding of social rules, difficulty planning, remembering things, letting others know their needs, limited functioning in one or more daily activities, and difficulty regulating emotions and behaviors.

2.6 Types of Intellectual Disability

Mental retardation (MR)

is a generalized disorder appearing before adulthood, characterized by significantly impaired cognitive functioning and deficits in two or more adaptive behaviors with Intelligence Quotient score under 70? Syndromic mental retardation is intellectual deficits associated with other medical and behavioral signs and symptoms. Non-Syndromic mental retardation refers to intellectual deficits that appear without other abnormalities.

Classifying Abilities

The Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text version (DSM-IV-TR), classifies four different degrees of mental retardation as described below:

Mild Mental Retardation: Approximately 85% is in the mildly retarded. Their IQ score ranges from 50-70, can acquire academic skills up to about the sixth-grade level, and become fairly self-sufficient and in some cases live independently, with community and social support.

Moderate mental Retardation: About 10% are moderately retarded, have IQ scores ranging from 35-55, can carry out work and self-care tasks, acquire communication skills in childhood, able to live and function successfully within the community in supervised environments as group homes

Severe mental Retardation: About 3-4% are severely retarded, having IQ scores of 20-40, master very basic self-care skills and some communication skills and are able to live in a group home.

Profound mental retardation: Only 1-2% is profoundly retarded, with IQ score under 20-25, be able to develop basic self-care and communication skills, and often caused by an accompanying neurological disorder that need a high-level of structure with appropriate support and training.

2.7 Autism Spectrum Disorder

This is a range of conditions classified as pervasive developmental disorders in the Diagnostic and Statistical Manual of Mental Disorders (DSM). These disorders are typically characterized by social deficits, communication difficulties, stereotyped or repetitive behaviors and interests, and cognitive delays.

2.8 Classification of Autism Spectrum Disorder

Autism: It is used to describe disorders that are classified as pervasive developmental disorders that include autism, Asperger syndrome, Childhood dis-integrative disorder, Rett syndrome and Pervasive Developmental Disorder Not Otherwise Specified. These disorders are typically characterized by social deficits, communication difficulties, stereotyped or repetitive behaviors and interests, and/or cognitive delays.

Asperger Syndrome: It is characterized by significant difficulties in social interaction, alongside restricted and repetitive patterns of behavior and interests. It differs from other autism due to preservation of linguistic and cognitive development. Physical clumsiness and atypical use of language are frequently reported. Genetic basis is estimated cause.

Heller's Syndrome: It is a rare, has some similarity to autism, and sometimes considered a low functioning form of it, noted before a regression in skills or a series of regressions in skills, occurs from age 2-10, it can be very sudden, reacting to hallucinations.

Pervasive Development Disorder (PDD): The diagnostic of this refer to a group of five disorders characterized by delays in the development of multiple basic functions, including socialization and communication.

Retts Syndrome: Is a neurodevelopmental disorder that affects females. The clinical features include small hands, feet and a deceleration of head growth, repetitive hand movements, scoliosis, and constipation are also noted. They are prone to gastrointestinal disorders and up to 80% have seizures, no verbal skills, and about 50% of individuals affected are not ambulatory.

2.9 Learning Disability

The brains are wired differently and affects how they receive and process information, see, hear, and understand things differently; can lead to trouble with learning new information and skills.

2.10 Signs and Symptoms of Learning Disabilities and Disorders

The following are some warning sign: Preschool, have problems pronouncing words; Trouble in alphabet, numbers, colors, shapes, days of the week, buttons, zippers, snaps, learning to tie shoes; Difficulty rhyming, directions or routines, crayons, pencils, and scissors or coloring within the lines; Grades K-4 Trouble connecting letters and sounds, blend sounds to make words, confuses basic words consistently misspells words and makes frequent reading errors, trouble learning basic math, difficulty telling time, remembering sequences and to learning new skills; and Grades 5-8 signs have difficulty with reading comprehension or math skills, trouble with open-ended test questions and word problems, dislikes reading and writing, spells the same word differently in a single document, poor organizational skills, trouble following classroom discussions, and Poor handwriting.

2.11 Types of Problems in Learning Disability

Learning Disabilities in Reading (Dyslexia): There are two types of learning disabilities in reading. Basic reading problems occur when there is difficulty understanding the relationship between sounds, letters and words. Reading comprehension problems occur when there is an inability to grasp the meaning of words, phrases, and paragraphs. Symptoms include problems with: Letter and word recognition; Understanding words and ideas; Reading speed and fluency; and General vocabulary skills.

Learning Disabilities in Math (Dyscalculia): Ability to do math will be affected differently by a language learning disability, or a visual disorder or a difficulty with sequencing, memory or organization. May struggle with memorization and organization of numbers, operation signs, and number facts; and have trouble with counting principles or have difficulty telling time.

Learning Disabilities in Writing (Dysgraphia): It involves the physical act of writing or the mental activity of comprehending and synthesizing information. Basic writing disorder refers to physical difficulty forming words and letters. Expressive writing disability indicates a struggle to organize thoughts on paper. Neatness and consistency of writing, accurately copying letters and words, spelling consistency, and writing organization and coherence are among the symptoms.

2.12 Diagnosis of Intellectual Disability

Several tests are done to assess adaptive functioning such as IQ test, a score of 70–75 indicate intellectual disability; Interviews assess adaptive functioning in conceptual, social, and practical functioning; general medical tests; neurological tests; psychological tests; special education tests; hearing, speech, vision; and physical therapy evaluation.

2.13 Treatment and management of Intellectual Disability

Intellectual disability is a lifelong condition. Currently, there is no cure, people can learn to improve their functioning over time. Receiving early, ongoing interventions can often improve functioning and allowing someone to thrive. Most treatment plans focus on the person's: strengths; Needs; and support needed to function, such as receives proper care; psychological or psychiatric services; speech and language pathology or audiology service; therapeutic recreation; and rehabilitation counseling; adapted equipment or assistive technology. Accurate and early diagnosis, a child can make better due to resources available in the community.

2.14 Sensory Disability

According to WHO, Sensory disability usually refers to the impairment of the senses such as sight, hearing, taste, touch, smell, and/or spatial awareness. It covers conditions of visual impairment, blindness, hearing loss, and deafness. Visual Impairment and/or Blindness: Decrease or severe reduction in vision that cannot be corrected with standard glasses or contact lenses and reduces an individual's ability to function at specific or all tasks; Blindness: Profound inability to distinguish light from dark, or the total inability to see; Hearing loss: Decrease in hearing sensitivity of any level; and Deafness: Profound or total loss of hearing in both the ears (Crews, & Campbell, 2004).

2.15 Visual Disabilities

Globally, 2.2 billion people have a near or distance vision impairment, in 1 billion or half of these cases. Vision loss can affect people of all ages. The International Classification of Diseases 11 (2018) classifies vision impairment into two groups:

Distance vision impairment: It includes: Mild visual acuity worse than 6/12 to 6/18; Moderate visual acuity worse than 6/18 to 6/60; Severe visual acuity worse than 6/60 to 3/60; and Blindness visual acuity worse than 3/60.

Near vision impairment: Near visual acuity worse than N6 or M.08 at 40 cm. The availability of prevention and treatment interventions, access to vision rehabilitation including assistive products such as glasses or white canes, and whether the person experiences problems with inaccessible buildings, transport and information (Fricke et al., 2018).

2.16 Causes of Vision Impairment

Globally, the leading causes of vision impairment are: uncorrected refractive errors; Cataract; age-related muscular degeneration; glaucoma; diabetic retinopathy; corneal opacity; and trachoma. In low-income countries, congenital cataract is a leading cause, whereas in middle-income countries it is more likely to be retinopathy of prematurity. Uncorrected refractive error remains a leading cause of vision impairment in all countries amongst adult and children (Steinmetzet al., 2021).

2.17 Management and Treatment

There are effective interventions covering promotion, prevention, treatment and rehabilitation which address the needs associated with eye conditions and vision impairment. WHO world report on vision (2019) identifies key areas of work and activities in the prevention of blindness, including working with Member States and other partners to provide recommendations on feasible global targets for 2030; Observing and promoting World Sight Day; Ongoing development of technical tools to support the implementation of the World report on vision: and assess the provision of eye care services.

2.18 Mental Disability

According to DSM-IV, a mental disorder is a psychological syndrome associated with distress such as painful symptoms, impairment in one or more important areas of functioning, increased risk of death, or causes a significant loss of autonomy.

The American Psychiatric Association (2013) (APA) redefined mental disorders in the DSM-5 as "a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning'.

In 2019, common mental disorders include depression which affects about 264 million, bipolar, which affects about 45 million, dementia, which affects about 50 million, schizophrenia and other psychoses, which affects about 20 million people, Neurodevelopmental disorders. Hence, stigma and discrimination add the suffering.

2.19 Classification of Mental Disorder

Currently, there are two systems that classify mental disorders: International Classification of Diseases (ICD-10) Chapter V: Mental and behavioral disorders, since 1949 by WHO; and Diagnostic and Statistical Manual of Mental Disorders (DSM-5) produced by the APA since 1952.

2.20 Types of Mental Disorders

Anxiety Disorder: Is a fear that interferes with normal functioning, which include specific phobia, generalized anxiety, social anxiety, panic, agoraphobia, obsessive compulsive and post-traumatic stress disorder.

Mood Disorder: It is an unusually intense and sustained sadness, including melancholia, or despair, which is known as major depression or unipolar or clinical depression; Prolonged depression; and bipolar disorder which is known as manic depression.

Psychotic Disorder: Patterns of belief, language use and perception of reality such as delusion, hallucination, and thought disorder. It includes schizophrenia and delusion disorder.

Personality Disorder:it is the fundamental characteristics of a person that influence thoughts and behaviors across situations and time and it includes eccentric, such as paranoid, schizoid, and schizotypal personality disorders; types that have described as dramatic or emotional, such as antisocial, borderline, histrionic or narcissistic personality disorders; and those sometimes classed as fear-related, such as anxious-avoidant, dependent, or obsessive-compulsive personality disorders.

Eating disorder: It is a disproportionate concern in matters of food and weight that include anorexia nervosa, bulimia nervosa, excessive bulimia or binge eating disorder.

Sleep disorders: are associated with disruption to normal sleep patterns. A common sleep disorder is insomnia, which is described as difficulty falling and/or staying asleep, narcolepsy, sleep apnea, REM sleep behavior, chronic sleep deprivation and restless leg syndrome.

Sexual disordersinclude dyspareunia and various kinds of paraphilia that is sexual arousal to objects, situations, or individuals that are considered abnormal or harmful to the person or others.

Substance use disorder: It refers to the use of drugs, legal or illegal, including alcohol that persists significant problems or harm related to its use and includes substance dependence and substance abuse.

Dissociative disorder: It is a severe disturbance of self-identity, memory, and general awareness of self and surroundings including depersonalization or dissociative identity disorder, which was previously referred to as multiple personality disorder.

2.21 Causes of Mental Disorder

genetic, psychological, and environmental factors all contribute to the development or progression of mental disorders. Different risk factors may be present at different ages, with risk occurring as early as during the prenatal period such as unwanted pregnancy, lack of adaptation to pregnancy or substance use during pregnancy, maternal stress and birth complications including prematurity and infections; and infants neglected or not provided optimal nutrition; Social influences including abuse, neglect, bullying, social stress, traumatic events and negative or overwhelming life experiences, socioeconomic inequality, lack of social cohesion, features of societies and cultures, nutrition, drug use, chronic deceases and personality trait.

2.22 Assessments of Mental Disorder

It is carried out by mental health professionals such as psychiatrists, psychologists, psychiatric nurses and clinical social workers, by psychometric test and by observation and questioning. Treatments are provided by various mental health professionals. Psychotherapy and psychiatric medication is two major treatment options. Other treatments include lifestyle changes, social interventions, peer support and self-help.

2.23 Treatment and Management of Mental Disorder

Treatment and support for mental disorders are provided in psychiatric clinics or community mental health services and may include placebo effect; Lifestyle strategies, including dietary changes, exercise and quitting smoking may be of benefit; counselling and psychotherapy including family, counselor, public health professionals, peer support. A major option for many mental disorders is psychotherapy including Cognitive Behavioral Therapy (CBT); Dialectic Behavioral Therapy (DBT) and Interpersonal Psychotherapy (IPT); psychoanalysis; family therapy; humanistic approach; and eclectic or integrative approach; medication such as antidepressant, antianxiety including sedatives, mood stabilizers; antipsychotic; and stimulant; and Electroconvulsive therapy (ECT).

Keywords

- Disability
- Disorders
- Mental retardation
- ASD
- Classification
- Assessments and treatments

Self Assessments

1. What do you mean by disability?

A. Physical condition that affects person's mobility, physical capacity, stamina, or dexterity.
B. A physical disability is a physical weakness.
C. A Person who physically disable to perform certain task.
D. All the above

2. Which among the following is not the type of disability?

A. Physical disability
B. Mental disability
C. Learning disability
D. Climb disability

3. What is the most common type of cognitive disability?

A. Mild
B. Moderate

C. Severe
D. Average

4. What type of cognitive disability has IQ scores that range from 30-55?

A. Mild
B. Moderate
C. Severe
D. Average

5. What is the range of IQ scores for a mild cognitive disability?

A. 85-100
B. 65-85
C. 40-65
D. 55-70

6. Which of the following is an example of a Specific Learning Disability?

A. Mental
B. Retardation Dyslexia
C. ADHD
D. Autistic spectrum disorders

7. Which of the following is an example of intellectual disability

A. Dyslexia
B. ADHD
C. Mental Retardation
D. Autistic spectrum disorders

8. An example of a Developmental Disorder is:

A. ADHD
B. Dyslexia
C. Mental Retardation
D. Autistic spectrum disorders

9. Intellectual disability characterized by

A. Significant impairment in cognitive and adaptive behavior
B. Condition gone under constant change over years due to social and political compulsion
C. A and B Wrong
D. A and B Correct

10. The following is the characteristic of disability.

A. Intellectual
B. Physical
C. Sensory
D. All the above

11. Which of the following criteria can be used to define Intellectual disabilities?

A. Significantly below averages intellectual functioning

B. Impairments in adaptive functioning generally
C. These deficits should be manifest before the age of 18-years
D. All the above

12. What is intellectual disability?
A. Intellectual disabilities are disorders that originate before 18 years of age
B. Resulting from physical causes or non-physical causes such as lack of stimulation
C. Characterized by a limited mental capacity and difficulty with adaptive behaviors
D. ABC is correct

13. Which is not considered as a physical disability?
A. Spinal cord injury
B. Cerebral palsy
C. Toothache
D. Multiple sclerosis

14. What are the problem of disabled?
A. Education
B. Health
C. Finance
D. All the above

15. Identify the eating disorders.
A. Anorexia Nervosa
B. Bulimia Nervosa
C. Both
D. None

Review Questions

1. What is dysgraphia?
2. What are general causes of disability?
3. What are the different types of learning disabilities?
4. What are the intellectual disabilities? Discuss its treatment.
5. What do you understand by mental retardation?
6. Briefly discuss sensory disabilities.

Answers for Self Assessment

1.	D	2.	D	3.	A	4.	B	5.	D
6.	D	7.	A	8.	D	9.	D	10.	D
11.	D	12.	D	13.	C	14.	D	15.	D

Further Readings

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Unit 03: Models of Disability: Theories and Models of Adaptation to Disability, Adaptation Processes, Ways of Coping with Disability

CONTENTS

Objectives

After completion of this unit, the students will be able to:

- Understand the diverse models of disability
- Know different interventions for disability
- Familiarize with the adaptation and coping processes

Introduction

A disability is any condition of the body or mind that makes it more difficult for the person with the condition to do certain activities and interact with the world around them. Although people with disabilities sometimes refer to a single population, this is actually a diverse group of people with a wide range of needs. According to the World Health Organization, disability has three dimensions:

- Impairment in a person's body structure or function, or mental functioning such as loss of a limb, loss of vision or memory loss.
- Activity limitation such as difficulty seeing, hearing, walking or problem solving.
- Participation restrictions in normal daily activities such as working, engaging in social and recreational activities and obtaining health care and preventive services.

3.1 Adaptation Models

Adaptation is a term referring to the ability to adjust to new information and experiences. Learning is essentially adapting to our constantly changing environment. Through adaptation, we are able to adopt new behaviours that allow us to cope with change.

Adaptation models include

- Somatopsychology
- Stage models
- Ecological models

- **Somatopsychology**

Somatopsychologyprovides a framework to understand the influence chronic illness and disability (CID) on the psychological adjustment of the individual. It is rooted in Kurt Lewin's (1935, 1936) field theory, concerned with the influence of social factors on individual behaviour.

1) Wright's model (1960,1983) of adjustment to Chronic Illness and Disability

This model is based on the principles of somatopsychology and disability acceptance. He used the term acceptance instead of adaptation and adjustment. Acceptance is an outcome in which the CID is incorporated as part of the individual's self-concept and it is accepted as non-devaluing. CID is perceived as misfortune or value loss (Dembo, et al 1956). Wright developed a framework of coping versus succumbing to CID.

Succumbing: According to this framework, a person who is succumbing to CID emphasis its negative effects and neglects the challenge for change and meaningful adaptation. They deny or cover up CID and idolize normal standards and strive to reach unattainable standards of normal performance. Their behaviour focusses more on deficit behaviour rather than asset behaviour.

Coping: People who focus on their individual intrinsic and asset values and are oriented to what they can do is described as coping. People who are coping with CID experience changes in their value system that limits devaluation.

2) Schilder(1950), Livneh&Antonach(2005) Model

According to this model, self-concept & body image has roots in somatopsychological principles. These concepts can be seen to follow somatopsychological principles as they arise from the presence and resulting influence of CID on the psychological adjustment of the individual. Self-Concept and Body images are schemas or mental representations by which human perceive and identify themselves (Schilder, 1950). When these schemas are disrupted by the onset of CID, the person must reconstruct new or revised schemas by which they will perceive themselves. If the individual is able to successfully integrate changes caused by the CID into his/her self-perception successful adaptation is said to be reached (Livneh&Antonach 2005).

- **Stage Model**

The process of psychosocial adaptation to Chronic Illness and Disability has also been viewed as a sequence of stages similar to those experienced during grief. Stage model describes the process of adaptation to CID as a linear series of psychological stages through which one has to progress before finally reaching the stages of adjustment. According to this linear developmental approach to adaptation, the appearance of later stages is predicated on the resolution of earlier stages. Several theoretical models have been proposed to describe the psychosocial stages of adaptation to physical disability.

1) Unified model of adaptation to physical disability

Liveneh(1986) conducted an extensive literature review of more than 40 stage models and created a unified model of adaptation to physical disability, based on a synthesis of these models. He concluded that there are 5 broad categories

1. Initial impact: This is the first stage in the process of adaptation to a physical disability consisting of 2 separate sub stages a) shock: involves individual's initial or emergency reaction to the sudden onset of the disability or news of a disease diagnosis b) Anxiety: panic-stricken reaction on initially understanding the magnitude of the injury, diagnosis or psychologically traumatic event.

2. Defensemobilization: Encompasses the somewhat overlapping substage of bargaining and denial. Bargaining and Denial are similar because they both involve the expectation of recovery. Bargaining involves the person's expectation of recovery through restitution agreement or protest and Denial involves the expectation of recovery but without the deal making proposals and

protests. Bargaining is of shorter duration than denying reaction, involves a moderate level of suppression of CID and its consequences, in contrast to denial, which is more extensive level of suppression. Unnecessary risk taking and resisting help efforts are examples of behaviours observed during this stage. The individual makes effort to act as if nothing has happened and no physical limitations have affected their functioning level (Wright, 1960).

3. Initial realization: this is a period of great emotional turmoil, during which the reality of traumatic event and its consequences are being processed or realized for the first time. It includes subcategories of mourning, depression and internalized anger. Mourning and depression are similar reactions, mourning is of shorter duration and depression is of longer duration and of a more general and diffuses nature. Internalized anger is a manifestation of self-directed resentment and bitterness, associated with feelings of self-blame. Suicidal ideation, self-abuse or self-injurious behaviours can occur, particularly in those individuals who perceive themselves as the cause of the traumatic event along with passive-aggressive, uncommunicative and withdrawn behaviours.

4. Retaliation/rebellion stage: It is referred as expressed anger/aggression, in which anger and bitterness are projected outward. It is viewed as an attempt to retaliate against the functional limitations of CID. This stage is marked by the hostility toward other people, object or aspects of environment that are associated with the onset of disability. Overt modes of hostility such as verbally or physically abusive behaviours and passive aggressive behaviours uncooperativeness may be observed during this stage.

5. Reintegration/ Reorganization: This is the final stage of adjustment and is further categorized according to cognitive (acknowledgement), affective (acceptance) and behavioural (final adjustment) components. Acknowledgement is the first indication that the person has cognitively reconciled the permanence of the condition and its future implications. Acceptance and final adjustment are the final stages in adaptation process. The individual internalizes the functional limitation of CID into their self-concept and demonstrate self-approval and self-acceptance. During this stage individual implements his/her goals and mastery of new behaviours and social roles.

- **Ecological Models**

1) Liveneh&Antonak's Model (1997)

Liveneh and Antonak provided the review of some of the more influential ecological models of adaptation and found them to share certain conceptual and structural components. They found that there were 4 primary classes of variables that were important in the process of adaptation. The first three variables are interpersonal variables and the fourth is external variable.

1. Variables associated with CID,

2. Variables associated with sociodemographic or organismic characteristics of the individual

3. Variables associated with personality and behavioural attributes of the individual,

4. Variables associated with physical and social (external) environment.

1. CID related variables: Include characteristics that are directly CID related. They are cause of the condition, type CID, type of onset, extend of condition, degree of functional involvement, body areas affected, extend of brain and central nervous system involvement, age at diagnosis, age of symptom onset, chronicity, stability of condition, lethality and visibility.

2. Socio-demographic Variables: Include gender and gender-role identification, chronological age, life or developmental stage, ethnicity, socioeconomic status, state of general health, level of education, marital status, occupational attainment, job history, and existing vocational skills.

3. Variables associated with personality and behavioural attributes of the individual: Include coping strategies used, defence mechanism used, locus of control, perceived control, personal meaning of the condition, attitude towards health and sickness, personal values and beliefs, self-concept and ego strength, body image, cognitive competence of intellectual ability, acceptance of CID, premorbid psychosocial adaptation, previous experience of crisis of a similar nature.

4. Variables associated with physical and social (external) environment: Include social support systems, economic and institutional support, physical settings, attitudinal barriers or supports.

Specific variables in the first three classes interact with specific variables in the fourth class to determine the degree and speed of psychosocial adaptation to chronic illness and disabling conditions. Within ecological model, psychosocial adaptation is classified into

a) Earlier reactions: shock, anxiety, denial

b) Intermediate reactions: depression, internalized anger, externalized hostility

c) Later reactions: acknowledgement, acceptance, adjustment

2) Disability Centrality Model (Bishop,2005)

In his model, Bishop elaborated on the relationship between quality of life and psychosocial adaptation to CID. This model is an extension of Denvin's illness intrusiveness approach, in which CID serve as a disruption in individual's life, and can be interpreted by its impact on psychosocial wellbeing or quality of life (Denvins, 1994). Four components of the model include satisfaction, perceived control, impact of CID and its treatment and the importance of each domain to the individual. Bishop suggested that this model help the clinicians to gain a comprehensive picture of individual's adaptation and helps in rehabilitation planning and prioritizing interventions.

3.2 Adaptation Process

Hornby, 1982 explained adaptation process as categorized into seven stages

- Shock: The initial reaction of parents on being informed of their child's disability it is typically one of shock. Parents report feeling, confusion, numbness, disorganization and helplessness
- Denial: Shock is typically followed by a phase characterized by denial or disbelief of the reality of the situation. They may think that there must have been a mistake. It is understandable that they want a second opinion and this option should be made available to them
- Anger: When parents are beginning to accept the reality of the situation, they tend to experience anger about the fact that their child has a disability. They may search for cause of disability for someone to blame
- Sadness: Sadness may follow anger and is a reaction which more than any other, is reported to pervade the whole adaptation process. This sadness can be due to parent's grieving for the loss of the healthy child which they expected or it can be due to sadness about the loss of opportunities and ambitions which their children will not be able to fulfil.
- Detachment: Following sadness, parents experience a sort of detachment, when they feel empty and nothing seems to matter. Life goes on from day to day but it has lost its meaning. The appearance of this reaction is considered to indicate that the parent has begun to reluctantly accept the reality of the disability. It is therefore thought to be a turning point in the adaptation process
- Reorganization: It is reaction which follows detachment. It is characterized by realism about the situation and hope for the future. Parents begin to focus more on what their children may achieve and less on what they may miss out on
- Adaptation: Finally, they reach a point when they have come to terms with the situation and exhibit a mature emotional acceptance of their child's disability. They are fully aware of child's special needs and strive to provide for these.

3.3 Intervention Strategies For Individuals & Families Of Disabled

Disabilities are classified as acquired or congenital. There is a need to intervene so the person as well as families receives quality care and support. The ultimate aim of any intervention program is to improve the quality of life of persons with disability and their families. Also it should ultimately lead to reintegration of person into community living like any other normal individuals (social inclusion). So, interventions need to be holistic in nature helping the person and family to adapt and to adopt healthy way of living leading to the growth of person and family. In order to achieve this goal, the intervention strategies need to cover the following domains:

- **Medical Based Interventions**

Medical based interventions are intended to: find out the medical causes, provide a clear diagnosis, find out associated conditions, to provide appropriate treatment, and taking means to limit the extent of disability. The various interventions that come under this domain are as follows:

1. Early detection:

It involves identifying babies who are at risk of developing disability and having developmental delay. Early intervention refers to the introduction of planned programming deliberately timed and arranged in order to alter the anticipated or projected course of development. (Siegal, 1972). Babies who are at risk & with developmental delay will be the target group of this mode of intervention. It provides comprehensive interventions in the domains of physical, cognition, communication, social, emotional, sensory and adaptive behaviour.

2. Therapeutics:

- *Physiotherapy*: It employs physical methods to restore healing, including massage, hydrotherapy, remedial exercise etc. It helps the patient in movement restoration.
- *Occupational therapy*: It involves restoring, reinforcing & enhancing the function/ decreasing the impact of disability and thus promoting health through activities. Its primary goal is to help the individuals with compromised physical functioning to adapt to their impairments to regain their optimal function.
- *Speech therapy*: It is a therapeutic treatment to correct defects in speaking. Such defects may originate in the brain, ear, or anywhere along the vocal tract and may affect the voice, articulation, language development, or ability to speak after language is learned.

3. Pharmacotherapy:

It is given to reduce the impact of associated conditions & secondary complications of disability E.g.: fits, spasticity, hyperactivity, excessive cry, nutritional deficiency, infections, bed sore etc. It can also be given to control pain

4. Surgical interventions:

It is Disorder specific. E.g.: Cochlear implant, amputation, Shunt (hydrocephaly).

5. Lifestyle changes:

- Diet: There will be specific diet to be followed in certain disabling conditions. E.g., for autism: gluten free casein free diet and for epilepsy: ketogenic diet.
- Exercise increases flexibility & muscle strength which in turn helps to reduce pain. It can also have psychological benefits of decreasing anxiety & depression.

6. Assistive technology:

Any item or a piece of equipment/system whether acquired commercially, modified or customized that is commonly used to increase, maintain or improve functional capabilities of Person with Disabilities are commonly called assistive technology. It helps them to undertake Activities of Daily Living, pursue education, acquire movement in built environment, working and engage in leisure activities. It can be classified as Mobility devices, Postural supportive devices, Orthotic devices, Prosthetic devices, Self-help & communication devices and Recreational aids. They compensate for their limited action & promote independence. They aim to empower them to live with dignity and enhance Quality of Life.

- **Psychosocial Interventions**

These interventions help the person as well as family to adjust effectively to the condition. They include

1. Counselling:

It is an important step in the rehabilitation process and is a continuing process. It begins with the initial interview. The rehabilitation professionals need to translate the technical facts about the disabling condition of patient into simple language and communicate with empathy, openness but in a realistic manner. They need to provide adequate time for information, question, and further sessions for patients as well as families.

2. Psychoeducation:

Psychoeducation is providing scientific information about the disability, its symptoms, causes & management. It increases patient's self-efficacy and control and improves psychological and physical functioning.

3. Parent training:

Parent Training involve receiving guidance from the professionals in order to cope with their children's problem and facilitate their development. It is an effective technique to create awareness and to sensitize parents regarding the needs of child. It emphasizes on normal child development, child rearing methods and behaviour management. Professionals must be careful regarding how specific techniques can be communicated to parents because their application may be misunderstood and misused. They can be trained in advocacy skills as well as coping skills.

4. Psychotherapy:

- *Supportive therapy*: Focus is on prevention of emotional breakdown & teaching of new coping skills. This helps the patient/family to facilitate through the adaptive process
- *Behaviour therapy:* Based on the theories of learning, and aims at changing maladaptive behaviour and substituting it with adaptive behaviour. Different methods are employed to increase the desirable behaviour and decrease the undesirable behaviour.
- *Cognitive Behavioural Therapy:* Focus is on challenging irrational beliefs about the disability/condition and providing them coping skills to handle their condition. Eg "my disability is a punishment", 'It is impossible for a PwD to be happy'
- *Stress Management Techniques:* It provides training in various techniques to help people handle the stress of having disability. The following techniques are helpful: Progressive relaxation, meditation, biofeedback and guided imagery.
- *Group Therapy*: In Group therapy the groups consist of people facing same problem. It helps them to compare coping strategies, solutions to daily life problems and provide support to each other. They can share emotions & discuss topics such as physical problems, relationship with family/friends, finding meaning in life, &various other issues.
- *Family Therapy*: Focus is on problems in the family structure or communication pattern which helps to understand the dynamics of families. Interventions are designed to bring about constructive change in functioning of family as a whole.

5. Parent associations:

Parents have a feeling of solidarity towards other parents which leads to the formation of such associations. They receive emotional support and obtain information about services, benefits available for their children. It gives them a common platform to come together and fight for a cause. Nowadays not only parents, but also family members, volunteers, professionals and even friends of PwDs are joining such organizations.

6. Respite care:

Family is under continuous strain of taking care of PwD. They can't ask for temporary help from others because PwD has specific needs. As a result, family has restrictions in free time, ability to respond to urgent demands. Also, occupational restrictions become serious when both parents/single parents are working. Respite care helps families with such needs and provides care to PwD in place of the family.

- **Educational**

Aim of education is the development of total personality of the child by providing program of academic excellence, vocational orientation and cultural fulfilment. The primary task of education for a child with disability is to prepare the child to face the challenges of life and take up responsibility of citizen despite his/her disability. It also prepares him/her to adjust to sociocultural environment designed to meet the needs of normal. The difference lies in the method employed to teach the child and the means the child uses to acquire the information. These differences in methodology do not influence the content/goals of education. This form of education is referred to as Special education. It refers to classroom/private instructions involving techniques, exercises & subject matter designed for students whose learning needs cannot be met by a standard school curriculum.

- **Economic &Vocational**

It involves vocational training & employment. It aims at developing and enhancing the functional abilities of a PwD so that h/she is gainfully occupied resulting in economic contribution to self and family. It improves Quality of Life of PwDs, socially & economically mainstreams them, contributes to self-esteem. It is the toughest aspect of rehabilitation. The avenues of employment for the PwD can be unorganized and organized sector. Under Unorganized sector it could be Self-employment, Homework, Cooperatives formed by PwD and CBR. Under Organized sector it could be Open employment, Special employment, Sheltered workshop, transitory employment and On-the-job training centers.

- **Community Based Rehabilitation**

Disability requires lifelong management. Therefore, activities aimed at enabling PwD need to be community based as much as possible. CBR is an effective method of intervention; it is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all PwDs. Its primary objective is to improve quality of life of PwDs. It is implemented through the combined efforts of PwDs, families & communities and the appropriate health, education, vocational, social and empowerment services. Some of the advantages of community-based rehabilitation are more number of PwD can be reached, cost effectiveness, greater sustainability and improved Quality of Life. It makes social integration of PwDs possible.

Keywords

- Disability
- Rehabilitation
- Coping
- Models
- Intervention
- Adaptation

Self- Assessment

1. A child who reads 'top' as 'pot' falls in which category of learning disability?

A. Dyscalculia

B. Dyspraxia

C. Dyslexia

D. Dysgraphia

2. Which of the following are psychosocial intervention strategies for individuals and families of disabled?

A. Neuropsychological interventions

B. Respite care

C. Self-help group/ Parent association

D. All of the above

3. Which type of school does not come under the same category as the other three in not catering to CWSN?

A. Inclusive

B. Integrated

C. Multigrade

D. Special

4. Degree of severe hearing loss is:

A. 20-40 dB

B. 65-90 dB

C. 0-65 Db

D. 5 and up Db

5. Which of the following practices promotes inclusion in the context of children with disabilities?

    1. Barrier free access
    2. Assistive devices and appropriate technology-based tools
    3. Choice of regular or special schooling as well as home -based education
    4. Uniform structured curriculum and means of assessment

A. 1, 2, 3

B. 1, 2, 4

C. 1, 3, 4

D. 2, 3, 4

6. According to Liveneh (1986), how many stages are in the unified model of adaptation to a physical disability?

A. 3

B. 6

C. 5

D. 4

7. According to Liveneh&Antonakz's Model (1997), which of the following are CID related variables that were important in the process of adaptation?

A. Ethnicity
B. Lethality
C. Acceptance of CID
D. All the above

8. Orthotic and Prosthetic devices are…………… devices for medical based intervention strategies for individuals and families disabled.

A. Surgical
B. Therapeutic
C. Adaptive
D. Assistive

9. How many disability areas are covered under the Rights of Person with Disability (RPWD) Act,2016?

A. 7
B. 16
C. 21
D. 26

10. Optimizing access to tools and assistive technologies will help in inclusion of:
    1. Students with loss of vision
    2. Students with attention Deficit Hyperactive Disorder
    3. Students with Cerebral Palsy
    4. Students with extraordinary talent

A. 1
B. 2, 3
C. 1, 2, 3
D. 1, 2, 3, 4

11. In which year the Rights of Persons with Disabilities Bill was Passed?

A. 2016
B. 2005
C. 2012
D. 2010

12. Which of the following is a form of child abuse that is known to cause intellectual disability?

A. Shaken baby syndrome
B. Abused child syndrome
C. Battered baby syndrome
D. Damaged infant syndrome

13. What is the visual acuity for legally blind?

A. More than 20/200
B. Less than 20/200
C. Exact 20/200
D. None of the above

14. Which is not a type of speech disability?
A. Dysarthria
B. Cleft Palate
C. Dyspraxia
D. Amputation

15. Autism is a type of……………… disability.
A. Intellectual
B. Developmental
C. Physical
D. Other

Answers for Self Assessment

1.	C	2.	D	3.	C	4.	B	5.	A
6.	C	7.	B	8.	D	9.	C	10.	D
11.	A	12.	A	13.	B	14.	D	15.	B

Review Questions

1. What is Disability? Give examples.
2. Discuss adaptation models in brief.
3. What is stage model? Explain.
4. What are seven stages of adaptation process?
5. Discuss medical based interventions.
6. What are Psychosocial interventions?

Further Readings

- Rehabilitation counselling: approaches in the field of disability by Brown, R. & Robertson, S. (1992)
- Disability management in India: challenges & commitments by Mohapatra, C.S. (2004)

Unit 4: Psychological Assessment-Assessment of Cognition, Aptitudes, Psychopathology, Work/Vocational and Daily Functioning

CONTENTS

Objectives

This unit will enable you to:

- Understand the nature of psychological assessment
- Elucidate the basic meaning of psychological assessment;
- Evaluate the various assessment types of psychological assessment;
- Acknowledge daily functioning module of assessment

Introduction

Psychological rehabilitation helps disabled individuals to develop emotional, social and intellectual skills needed to live, learn and work in the community with the least amount of professional support. The main objective of psychological rehabilitation is to help individuals who have special needs so that they can lead a happy and confident life.

Assessment is the first step in psychological rehabilitation. Psychological rehabilitation intervention can be used in cases of mental disorders, harmful addictions and in wellness programs. It is a key to psychosocial and social integration difficulties that usually people undergo. These interventions give support in their daily lifestyles in the most independent and decent manner.

The main aim of this type of intervention is to focus on personal and social skills and lay a guideline for the affected people and their families. The assessment in rehabilitation is a trust-based relationship between client and psychologist. Psychologist must be well trained and has good interpersonal skills.

2.1 Meaning and Definitions

Essentially, psychological assessments involve the process of gathering data or critical information on a child's areas of development and growth. This can include cognitive ability (IQ testing), behavioral and emotional functioning, and academic skills, among others.

Early childhood psychological assessments are tools used to have a comprehensive understanding of a child's capabilities. This means parents are educated about their children's challenges and thus help them to address it. It can also serve as an early resource to improve their learning.

Thanks to these assessments, parents are able to augment their child's strengths and improve their areas of weakness. Moreover, physiological assessments make way for early interventions and support treatments that may be necessary for the child.

Psychological assessment can be as written, verbal and visual evaluations so that to assess the cognitive, aptitude, psychopathology, vocational and neurological functioning of children.

2.2 Assessment of Cognition

IQ evaluations in the form of cognitive assessments are essentially used to measure and determine a child's learning capacity by recognizing a kid's strengths and weaknesses on a cognitive level. This assessment makes it possible to establish a learning profile for a child that can be useful for an IEP or individualized education program that educators can utilize.

Cognitive assessments typically involve verbal comprehension tests, visual-spatial ability, cognitive processing speed, and reasoning skills. Moreover, cognitive assessments, just like psychodiagnostic ones, assist in the diagnosis of intellectual giftedness (Savant syndrome), ADD/ADHD, and autism.

2.3 Assessment of Aptitude

This assessment gauges a student's academic aptitude. Regardless of age, any student, either young or old can take it. Psycho-educational assessments are especially useful for children to realize their academic potential. Apart from this, they can also determine if the child has learning disabilities, so it can be addressed as early as possible.

Educators can take advantage of psycho-educational reports in formulating educational plans that are specific for the needs and academic ability of a child.

Numerical Reasoning Test

Measure the ability to work with numerical and problem solving skills.

Verbal Ability Test

Analyze skill of writing and effectively work with words.

Spatial Reasoning Test

Assess the ability of distance and direction.

Deductive Reasoning Test

Assesses the ability to work effectively with analytical abilities.

Inductive Reasoning Test

Measures the ability to access inductive reasoning.

Memory Retention Test

Assess the memory related to attention.

Attention & Error Detection Test

Measures trial and error problems through stimuli and also learn about span of attention.

2.4 Assessment of Psychpathology

This type of assessment is used to assist in the diagnosis of ADD/ADHD and ASD. It also sheds light on a child's behavior (disruptive or not), emotional functioning, moods, and personality, as well as mental and cognitive processing. Psychometric psychologists then interpret data to identify the most effective measure to address behavioral and developmental challenges.

In this assessment individual can get knowledge about mental impairment in the form of psychological symbols and symptoms. In it there are so many techniques by which we can measure like as an interview method, projective techniques and also behavioral assessment tools as observation and inventories.

2.5 Work/Vocational Assessment

A Vocational Psychological Assessment is a detailed assessment of psychological functioning and transferable skills, as well as formal testing of cognitive functioning, academic achievement, and vocational interests. The assessment results are provided in a detailed report, with specific, individualized recommendations to support successful vocational planning.

Vocational tests are used to assess interest, personality and abilities. It is also related to provide information about career or career counseling. We have so many inventories to measure interest of an individual to choose path about work/vocational related.

There are so many inventories which we can use like Strong Interest Inventory, Self-Efficacy Scale, Minnesota Importance Questionnaire and Self-Confidence Inventory etc.Because of these questionnaires person can predict their future platforms and can assess interesting factor that they are able for that career or not.

2.6 Daily Functioning

Webster (1990) defined functioning as activities or performance, 'a natural or proper action for which a person, office, thing or organization is fitted or employed'. An assessment of functioning may focus on global functioning or specific evaluation of skills and behaviors.

Daily functioning skills based mainly on the result of functioning for example an individual is a married and also have friends and employment tasks. In psychological rehabilitation assessment involves later in the process of assessment. Firstly, interview and observational skills are used to assess the person and then assessment of functional activities has been started.

Functional assessment in psychiatric rehabilitation and in functional assessment of daily can be used as in both symptoms and universal functioning also. The Behavior and Symptom Identification Scale (BASIS-32) a 32-item self-report measure includes items related to symptoms and role functioning to check daily functioning skills of an individual.

The date of September 8 was chosen as World PT Day in 1996. World Physiotherapy was established on this day in 1951. The day honours the world's physiotherapy community's togetherness and unity.

Summary

- Psychological rehabilitation intervention can be used in cases of mental disorders, harmful addictions and in wellness programs.
- Psychological assessment can be as written, verbal and visual evaluations so that to assess the cognitive, aptitude, psychopathology, vocational and neurological functioning of children.
- A Vocational Psychological Assessment is a detailed assessment of psychological functioning and transferable skills, as well as formal testing of cognitive functioning, academic achievement, and vocational interests.
- Cognitive assessments typically involve verbal comprehension tests, visual-spatial ability, cognitive processing speed, and reasoning skills. Moreover, cognitive assessments, just like psychodiagnostic ones, assist in the diagnosis of intellectual giftedness (Savant syndrome), ADD/ADHD, and autism.

Keywords

Rehabilitation: -A set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment.

Cognition: - Cognition refers to set of mental abilities and process of acquire knowledge andexperience with the help of thinking and cognition.

Aptitude: - Aptitude can be said as ability or capability to learn skill through experience and training.

Intervention: - A unique interrelationship between a client and a counselor, which aims to create a change and a growth in three main areas: Personal development, social adjustment, and professional development.

Psychopathology: -Psychopathology is the study of mental disorders in which we have to go through causes, symptoms, prevention and treatment.

SelfAssessment

1. Which of this is not correct for rehabilitation?

A. It helps only to develop emotional skills.
B. It can help only some individuals
C. It is a short-time process
D. It is helpful for those individuals who have special needs.

2. __________ involve the process of gathering data or critical information on a child's areas of development and growth. -

A. Physical agility test
B. Assessment
C. Physical examination
D. None of above

3. ADHD is basically related to –

A. Children
B. Young adults
C. Old age
D. None of above

4. Spatial reasoning test is related to

A. Memory
B. Numerical ability
C. Verbal ability
D. Distance

5. _________is a detailed assessment of psychological functioning and transferable skill.

A. Vocational psychological assessment
B. Aptitude assessment
C. Cognition assessment
D. Psychopathology assessment

6. Is aptitude relates to an individual special ability?

A. True
B. False
C. Can't say
D. None of the above

7. Cognition refers to –
A. Thinking
B. Mental ability
C. Attention
D. All of the above

8. Strong inventory is related to:
A. Aptitude
B. Cognition
C. Interest
D. Psychopathology

9. Is Psychopathology the study of mental disorders in which we have to go through causes, symptoms, prevention and treatment?
A. True
B. False
C. Can't say
D. None of the above

10. By which test we can assess verbal ability of an individual?
A. Vocational
B. Cognition
C. Aptitude
D. Attitude

Answers for Self Assessment

1. D	2. B	3. A	4. D	5. A
6. A	7. D	8. C	9. A	10. C

Review Questions

1. What are the salient features of rehabilitation?
2. Explain the process of cognition assessment?
3. Why psychopathology assessment is important?
4. Explain vocational assessment?
5. What is the difference between aptitude and cognition assessment?

Further Readings

- Elliott, Timothy R. & Frank, Robert G.- Handbook of rehabilitation psychology,3rd edition, Oxford University Press

Unit 5: Models of Disability and Rehabilitation: Biological Model

CONTENTS

Introduction

The models of disability and rehabilitation are explained in this chapter. There are numerous disability models that have already been explained by various authors. In this chapter, many models of disability will be addressed.

Objectives

Once you've finished reading this chapter, you'll be able to:

1. Differentiate between disability models.
2. Describe how the disability model helps people with disabilities.
3. Explain the purpose, elements, and different types of rehabilitation.
4. Describe how rehabilitation enables people with disabilities to leave in more regular lives.

5.1 Disability Models

In order for society and government to construct various methods to satisfy the needs of persons with disabilities, it is necessary to define impairment using models of disability (Todd, 1918). Two major ideas shape it. The first regards persons with disabilities as dependent on society, which can lead to paternalism, segregation, and prejudice. The second, meanwhile, views individuals with disabilities as consumers of society's goods and services, which promotes autonomy, human rights equality, and integration (Chin, 2021).

5.2 Biological Model or Biocentric Model, And The Medical Model

Goodley (2016) claims that the medical model of disability is also known as the bio-centric model of disability. It explains the person's physical or mental handicap caused by a sickness. A disabled individual is seen as a problem who requires special care and treatment (Mitra, 2018). Generally speaking, the organization for people with impairments uses a biological model specifically. According to this theory, disabilities are caused by a person's physical or mental limitations and have a biological basis; if the person is cured, these issues will no longer exist. On this basis, people with impairments are regarded as abnormal human beings who require medical attention and rehabilitation specialists.

According to Brickman et al. (1982), in this concept, a person's physical or mental limitations cause their impairment, which is unrelated to their social or physical circumstances. The model acknowledges that a challenging economic environment will limit a disabled person's employment options. Rehabilitation is essential since there is no other option than to accept the abnormality and give the necessary care to help the person with the impairment (Parsons, 1951). This approach holds that the individual is the one with the issue; hence, interventions seek to provide the person the necessary skills to deal with the abnormality (Deacon, 2013).

This approach makes the following four assumptions about how to assist those with disabilities:

1. Disability is a disease state that falls within the clinical framework, and it is characterized by a problem that is focused on the individual as a deviation from the norm in order to treat and resolve the issue and restore the individual to normalcy.
2. Professionals are trusted with determining the objective state of normality; the disabled and their families have limited opportunity to influence the decision-making process.
3. Because they are not viewed as completely human and lack the capacity to make their own decisions, people with disabilities are biologically and psychologically inferior to people with normal abilities.
4. Disability is seen as a personal tragedy that typically has an impact on a person's life (Retief, M., &Letosa, 2018).

The study of the nervous system, hormones, and genetics as they relate to behaviour is referred to as the "biological model" in psychology. This field's primary objectives are to investigate the interplay between the mind and body, neurological systems, and the impact of heredity on behaviour. As is well known, every thought, emotion, and behaviour has a biological basis. This means that biological factors account for the majority of disabilities (Deacon, 2013).

Three biological aspects can each assist in explaining human behavior in respect to normality and abnormality, and each of these biological aspects is relevant to the study of psychology. These three biological aspects are as follows:

1. Comparative approach: from this angle, it is possible to study and compare animals in order to comprehend both normal and pathological human behavior.
2. Physiology teaches how the nervous system, hormones, and the brain operate, as well as how changes in structure and function can affect people's ability or inability to behave in certain ways. For instance, a doctor may give medication to treat depression and anxiety because these conditions interact with the neurological system to alter behaviour.
3. Examining inheritance: these viewpoints describe the traits that an animal acquires from its parents and exhibits in order to behave like their ancestor

5.3 Disability and The Social Model

According to the model, impediments in the environment, in society, and in people's attitudes restrict persons with disabilities from fully participating in society. This refers to the loss or restriction of opportunities to participate in everyday life on an equal footing with others as a result of physical or social barriers (Mitra, 2018). Or, to put it another way, it is also known as the Minority-Group Model of Disability. From a sociopolitical perspective, Hahn (2002) contends that disability results from society's failure to adapt to the needs and aspirations of a minority of impaired people. It indicates that this limitation does not prohibit them from fully engaging in community life, hence, the model concludes that there is a problem in both society and the environment. According to the model, removing institutional, physical, and attitude barriers will improve the lives of persons with disabilities by providing them with the same chances as everyone else fairly (Hahn (2002).

5.4 Disability and The Bio-Psychosocial Model

This is the result of the interaction between biological, psychological, and social factors. According to the paradigm, biological, psychological, and social factors play a significant impact in how well people function and engage in activities when they have a handicap or illness (George et al. 2013). In this concept, social, psychological, and biological factors—rather than just medical or biological—are combined to provide a deeper understanding of the health status (Santrock, 2005).

5.5 Rehabilitation

The process of assisting a person in obtaining the highest level of function, independence, and quality of life is known as rehabilitation and is hotly debated on a global scale (Whittaker et al., 2021). Additionally, rehabilitation is a continuous effort that can be accomplished in a variety of methods (Shah, 2017). More than 15% of people worldwide have some form of disability. In light of the fact that 1 in 3 persons require rehabilitation services at some point throughout their sickness or accident, 2.4 billion people globally are dysfunctional and its effects on their everyday lives. The world's population is ageing, more people are losing function as a result of unmet rehabilitation needs among the most vulnerable and poor populations, and there are more conflicts around the world. The damage that was caused by rehabilitation cannot be undone. While rehabilitation aids in restoring a person to their ideal health, functionality, and well-being, it does not repair any damage caused by any causes. (Nagano et al., 2020).

Services for rehabilitation are required in a variety of contexts:

1. Skills for taking care of oneself, such as those required for feeding, clothing, washing, and performing sexual functions.
2. Physical care requirements: These include dietary requirements, medication, and skin care.
3. Needs for family support: Assistance with adjusting to lifestyle changes, money worries, and discharge plans, for example.
4. Psychological counselling: This sort of problem-solving for emotional, behavioral, and cognitive disorders.
5. Needs for pain management, such as prescription drugs and complementary pain management techniques; Skills connected to the workplace, are taught in vocational training.
6. Socialization abilities: Interacting with others at home and in the neighborhood.
7. Memory, focus, judgement, problem-solving, and organizing abilities are examples of cognitive capabilities.
8. Speech, writing, and other forms of communication are all examples of communication abilities.
9. Respiratory care includes things like ventilator care, if necessary, breathing exercises, and therapies to improve lung function.
10. Mobility abilities: including the ability to walk, transfer, and self-propel a wheelchair;

11. Education and training should cover the ailment, medical treatment, and adaptive approaches for patients and their families (Franklin, &Cheville, 2015).

5.6 Rehabilitation Component

Rehabilitation that is preventative takes place after a new diagnosis or the advent of new impairments. The major objective is to provide information, suggestions, and interventions to stop or delay the onset of new impairments in order to maintain a person's level of ability.

5.7 Restorative rehabilitation

It is primarily used after surgery, illness, or even acute situations like trauma or any sort of stroke. It focuses on therapies that address impairments like muscle strength, respiratory function, and cognitive impairment to gain the most complete return of function.

5.8 Supportive rehabilitation

It is also known as adaptive rehabilitation, aims to increase a person's mobility and capacity for self-care by giving them self-help tools and teaching them compensating shortcuts. It includes making infrastructure changes or providing assistive technology.

5.9 Palliative rehabilitation

This enables a disabled person to live with a high quality of life on a physical, psychological, and social level. It minimizes functional reliance and supports comfort, dignity, and quality of life by reducing symptoms like pain and oedema, preventing contractures, breathing aid, psychological well-being, relaxation, or the use of assistive devices (Timm et al., 2021).

5.10 Rehabilitation Phase

Phase One: Control Pain and Swelling

The fundamental rule is rest, ice, compression, and elevation; therefore, electrical stimulation provided by sports or physical therapists may aid to speed up this process.

Phase Two: Increase flexibility or range of motion

This stage focuses on extending a joint's range of motion or a muscle's flexibility. Athletes may receive manual stretching from a physical therapist or athletic trainer, or they may be given particular stretching exercises to perform on their own. Ideally, stretches during this period should last up to 30 seconds (Van, 2010).

Phase Three: Increase strength and start your balance training

Strengthening is the main objective. Prior to using elastic bands of different resistance, free weights, cuff weights, or weight equipment, isometrics that involve pushing against an immovable object may be performed (Van, 2010).

Phase four: Training for balance, proprioception, and a specific sport makes

During this stage, an athlete's ability to balance is minimal while still experiencing physical pain. Enhancing proprioception is a fantastic approach to aid in the prevention of injuries recurring (Van, 2010).

Phase Five: Gradual Return to Activity

The athlete gradually resumes full exercise during this phase. Exercises, techniques, or drills that can be used in games are demonstrated during sport training events. In this way, as the injured person heals, the therapist slowly advances them from simple exercises to those requiring more advanced competence (Van, 2010).

5.11 Rehabilitative Advantages

As stated by (WHO, 2017).

1. Reduce the negative effects of health problems, such as acute or chronic illnesses, diseases, or injuries, in order to support other health interventions and get the best results.
2. Gives people the tools they need to manage their own pain and other difficulties, therefore reducing the incapacitating impacts of chronic health conditions.
3. It has financial advantages for both people and society.
4. Reduce the amount of family support.
5. Assurance of everyone's physical and mental health (WHO, 2017).

5.12 Rehabilitation Therapy Types

There are other varieties of rehabilitation therapy; however, just the three major varieties of occupational, physical, and speech therapy will be covered here. Each type of rehabilitation has a specific function in assisting a patient in achieving full recovery, but they all aim to aid the patient in resuming an active and healthy lifestyle.

Occupational therapy: This form of therapy offers remedies to people who need specialist assistance to take part in daily tasks. Self-care routines, regular chores, and leisure pursuits are all included. By altering the way, a task is approached, the environment in which it is completed, or by assisting a person in developing the skills necessary to complete a task, therapists assist a person in making changes in things that hinder the ability to complete tasks like eating, dressing, completing schoolwork, and working. People of all ages require occupational therapy, including: Seniors with physical limitations; People with spinal cord injuries; Children with physical disabilities; Adults with depression; People who have lost the ability to hold a fork due to an injury; Children with physical disabilities; Corporate: Spinal cord injury victims, corporate executives, and someone who has had a catastrophic brain injury and lost cognitive function (Enderby et al., 2013).

Physical therapy: In this type of therapy, therapists treat patients who are in discomfort or are having trouble moving, interacting, or going about their daily lives regularly. Typical physical therapy include: Specialized stretches and exercises made to reduce pain, increase mobility, or build strength; practicing with mobility or balancing aids, such as wheelchairs, walkers, canes, or crutches; To relieve muscle discomfort and spasms, try massage, heat or cold therapy, or ultrasound; Cardiovascular strengthening; burn treatment; using orthotics (braces or splints) for burns; learning to utilize an artificial limb through rehabilitation; balance and gait retraining; and pain management (Hanks et al., 2015).

Speech-language pathologists: are sometimes known as speech therapists. With the use of communication exercises, this therapy can help cure a wide range of disorders relating to language, communication, voice, swallowing, and fluency in both children and adults with learning disabilities, stroke, neck or head cancer, Parkinson's disease, or dementia. Speech therapy's goal is to improve the patient's ability to communicate in more beneficial and effective ways (Enderby et al., 2013).

Common methods used by speech therapists include:

1. Language therapy exercises (language drills to practise communication skills).
2. Articulation training (demonstrating how to move the tongue to create certain sounds).
3. Therapy for swallowing and eating (tongue, lip and jaw exercises designed to strengthen the muscles of the mouth and throat)

The following elements or conditions may necessitate the services of a speech therapist:

1. Dyslexia causes problems with accurate and fluent reading.
2. Dyspraxia is the inability to regulate muscle function for speech, language, coordination, or movement.
3. Aphasia is a neurological disorder that results in a loss of speech or comprehension abilities.
4. Dysphagia is a problem in swallowing.
5. Having trouble speaking clearly and making sound mistakes is a sign of articulation issues.
6. Fluency issues – difficulties speaking naturally, like stuttering
7. difficulties with resonance or voice - issues with voice quality, loudness, and pitch
8. Oral feeding issues, such as drooling or trouble swallowing
9. Parkinson's condition
10. Spinal palsy
11. Missing palate
12. Dwarf Syndrome
13. A number of sclerosis
14. Alzheimer's disease
15. Throat, head, or neck cancer

5.13 Disability Rehabilitation Model

The medical paradigm, from which the rehabilitation model derives, sees the disability as a deficiency that has to be corrected by a rehabilitation specialist. Armstrong, Elliott, and (2019) Similar to the medical model, this paradigm sees the disabled person as in need of services such as training, treatment, counselling, or other assistance. People with disabilities have potential in both the medical and rehabilitative models. People with impairments are very capable of contributing to society, and the institutionalization and confinement policies that go along with the sick role are just unacceptable (Elliott, & Armstrong, 2019).

According to Jahan and Ellibidy (20017), research has shown that successful rehabilitation plans are based not only on medical judgments but also on other factors that affect health-related quality of life, such as social, cultural, and psychological factors. These factors are crucial to the rehabilitation process and should be taken into account alongside biological factors in order to improve health wellbeing. This concept aims to enhance the quality of life for people with disabilities and their families by empowering them to carry out their daily chores on their own and actively engage in society. This paradigm enables people with disabilities to have access to social, community, health, and employment services (Jahan, &Ellibidy, 2017).

Summary

In conclusion, medical professionals are the only ones who can effectively treat the effects of a handicap using methods like prosthetics, surgeries, and drugs. Over and above medical and social models, there is the biopsychosocial model. As a result, the medical model and the rehabilitation model are tightly intertwined. It focuses on the idea that a person with a handicap may swiftly overcome their impairment if they put out the effort and work with rehabilitation services. As a result, no single model of disability can be helpful on its own in helping persons with activity limitations lead regular lives again. The usage of these models in combination, however, is more beneficial and fruitful.

Keywords

The process of assisting a person in obtaining the highest level of function, independence, and quality of life is referred to as **rehabilitation.**

The biological model of disability is the theory that explains how a person's physical or mental impairment results from a disease.

The social model of disabilityholds that barriers in the environment, in society, and in people's attitudes are what keep people with disabilities from fully participating in society.

The biological, psychological, and social aspects of disability are included in the biopsychosocial paradigm.

Disability rehabilitation model: The medical model of rehabilitation views a disability as a deficiency that needs to be corrected by a rehabilitation specialist.

Self Assessment

1. Rehabilitation is
A. The process of assisting a person in achieving their maximum level of independence, function, and quality of life.
B. A physical condition that impairs a person's dexterity, endurance, or mobility
C. Achieving a standard of living
D. None of the aforementioned.

2. The following ailments or conditions may necessitate the services of a speech therapist:
A. Parkinson's disease.
B. Cerebral palsy.
C. Cleft palate.
D. A, B, and C

3. A condition in which one has trouble speaking correctly and makes sound mistakes
A. Multiple sclerosis.
B. Articulation problems.
C. Huntington's Disease.
D. Down syndrome.

4. Which phrase best describes dyslexia?
A. Difficulty swallowing
B. A loss of ability to understand or express speech due to brain damage
C. Difficulty reading accurately and fluently
D. Difficulty controlling muscle function for movement, coordination, language or speech

5. Resonance or voice problems
A. Difficulty with voice pitch, volume and quality.
B. Difficulty with eating, swallowing or drooling.
C. Difficulty with the flow of speech, such as stuttering.
D. Difficult feeding problems.

6. There are 2.4 billion people in the world who are
A. Well
B. Normal
C. Dysfunction and impact their daily life.
D. Normal and abnormal

7. One in three individuals requires
A. Counselling services

B. Medical services
C. Psychological services
D. Rehabilitation services

8. Larger than
A. 25% of the world population are disabled.
B. 15% of the world population are disabled.
C. 35% of the world population are disabled.
D. 45% of the world population are disabled.

9. Rehabilitation
A. Does not undo the damage caused by any causes.
B. Undo the damage caused by any causes.
C. Both undo and does not undo the damage caused by any causes.
D. None of the above.

10. The disability model.
A. Social
B. Medical
C. Biopsychosocial
D. All the above

11. Increase Strength & Start Balance/Proprioception Training, Describe Which Phase of Rehabilitation
A. Phase 1
B. Phase 2
C. Phase 3
D. Phase 4

12. What does the social model of disability mean according to which of the following statements?
A. Disabilities are disorders that originate before 18 years of age.
B. Resulting from physical causes or non-physical causes such as lack of stimulation.
C. Characterized by a limited mental capacity and difficulty with adaptive behaviors.
D. ABC are incorrect.

13. According to this theory, a person's physical or mental limits cause disability. Which type of disability model is described well in this sentence?
A. Biological model
B. Social model
C. Psychological model
D. All the above

14. Education and training: One of the topics covered by this is patient and family education and training on the condition, medical care, and adaptive approaches.
A. Social model
B. Medical model

C. Psychological model
D. Rehabilitation.

15. The issues with oral feeding.
A. Difficulty with eating, swallowing or drooling.
B. Difficulty with hearing, swallowing or drooling.
C. Difficulty with walking, swallowing or drooling.
D. Difficulty with sleeping, swallowing or drooling.

Answers for Self Assessment

1.	A	2.	D	3.	B	4.	C	5.	A
6.	C	7.	D	8.	B	9.	A	10.	D
11.	C	12.	D	13.	A	14.	D	15.	A

Review Questions

1. Identify the key variations among the models of disability.
2. How rehabilitation enables persons with disabilities to lead normal lives again.
3. Describe the stages of the rehabilitation process using an example.
4. Describe forms of rehabilitation therapy.
5. List and describe the four elements of rehabilitation.
6. Describe how the social model differs from the medical paradigm.
7. Describe the premise behind aiding those with disabilities.
8. Describe the ailments that call for speech therapy.
9. Analyze the various areas that the rehabilitation programme covers.
10. Describe how the Rehabilitation model compares to the biopsychosocial model of disability in terms of effectiveness.

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Unit 6: Sociological Model of Rehabilitation Psychology

CONTENTS

Objectives

- People with mental illness and other psychiatric concerns sometimes need help in different aspects of their lives including work, living, social, and learning environments. One approach that can help these individuals manage symptoms and improve functioning is known as psychosocial rehabilitation.
- Psychosocial rehabilitation is a treatment approach designed to help improve the lives of people with mental illness.
- Its goal is to teach them emotional, cognitive, and social skills to help them live and work in their communities as independently as possible.

6.1 Goals of Psychosocial Rehabilitation

Regardless of what form psychosocial services take, core goals include helping people feel:

1. Empowered: Each individual needs to feel that they are able to set their own goals and have the power and autonomy to pursue those aims.
2. Hopeful: People may be left feeling demoralized as a result of their condition. Rehabilitation focuses on helping clients feel hopeful about the future.
3. Skilled: Rehabilitation aims to teach people skills to help them manage their condition and live the life they want to live. This includes life skills, work skills, social skills, and others.
4. Supported: Mental health professionals offer support and help clients build relationships and social connections in their community.

6.2 Psychosocial Rehabilitation Principles

There are a number of key principles of psychosocial rehabilitation that help guide how mental health professionals working in this field approach their work. These principles include:

- All people have potential that can be developed.
- People have a right to self-determination.
- The emphasis is on the individual's strengths rather than their symptoms.
- Each person's needs are different.
- Professional services should be committed and take place in as normalized an environment as possible.
- There is a focus on a social model of care (as opposed to a medical model).
- It is centered on the present rather than fixated on the past.

Rehabilitation psychologists assist individuals who have disabilities and chronic illnesses; the disability may be congenital or acquired -- for example, an accident or stroke.

Psychologists provide psychotherapy and administer assessments. Assessments may be neurological (testing memory and other cognitive functions) or psychological (assessing emotional handling of disability-related issues). Rehabilitation psychology duties may overlap with those of health psychologists. Rehabilitation psychologists sometimes work alongside neuropsychological specialists. They often collaborate with other health and medical professionals, for example, physical therapists.

The specialty developed as a result of the need to reintegrate veterans, but today's rehabilitation psychologists more often work with the civilian disabled population, including the elderly. Some rehabilitation psychologists specialize in working with children. At Rusk's Pediatric Outpatient Psychology Service, for example, psychologists treat children with conditions ranging from spina bifida to traumatic brain injury. They provide comprehensive evaluations, conduct individual and family therapy, write educational prescriptions, and carry out neuro-rehabilitative interventions as needed.

Rehabilitation psychologists also work at the societal level to make the lives of the disabled better. They carry out research and may be involved in program development and administration. Those in vocational rehabilitation improve lives for individuals with psychiatric illnesses as well as physical ones.

The Division of Rehabilitation Psychology (Division 22 of the American Psychological Association) would like to see psychologists at the forefront: developing new service delivery models. Division 22 also strives to see more psychologists employed as directors in programs like sub-acute traumatic brain injury and work restoration.

Rehabilitation psychology is part of an occupational group that has been projected by the BLS to see 22% growth in the 2010 to 2020 decade.

6.3 Approaches Used in Psychosocial Rehabilitation

- Psychosocial rehabilitation is based on the idea that people are motivated to achieve independence and are capable of adapting in order to achieve their goals.
- To achieve this, psychosocial rehabilitation uses a combination of evidence-based best practices and emerging, promising practices. No matter what the specific strategies are, the focus is on restoring social and psychological functioning.
- Specific psychosocial rehabilitation treatments can vary considerably from case to case depending upon a person's needs and the resources available. The process is highly individualized, person-centered, and collaborative.
- Effective rehabilitation involves a comprehensive plan that addresses the client's life and functioning. A psychosocial rehabilitation professional is usually only one part of the process. The plan is often overseen by a psychiatrist, clinical psychologist, or licensed counselor and typically involves working with the client individually and in community settings.

6.4 The Increasing Need for Community-Based Programmes

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disability may be congenital or acquired -- for example, an accident or stroke. Psychologists provide psychotherapy and administer assessments. Assessments may be neurological (testing memory and other cognitive functions) or psychological (assessing emotional handling of disability-related issues). Rehabilitation psychology duties may overlap with those of health psychologists.

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Rehabilitation psychologists provide services with the goals of increasing function and quality of life for persons living with disability, activity limitations, and societal participation restrictions. Because disability impacts multiple areas of a person's life, rehabilitation psychologists provide services within the network of biological, psychological, social, environmental, and political environments to assist the persons served in achieving optimal rehabilitation goals via intervention, therapeutic support, education, consultation and interdisciplinary collaboration, and advocacy.

6.5 General Objectives of Community-Based Rehabilitation Programs:-

- Improve the functional capabilities of disabilities persons as much as possible through rehabilitation.
- Community activation and mobilization to achieve environments, information and ways to communicate free of obstacles in order to create a society that included a comprehensive and an inclusive that Disabled people will have the equal opportunities and enjoy full participation.
- Enable disabilities persons and their family's decision-makers at all levels of community-based rehabilitation programs, and create public awareness that effects on the local policies and ensure access for disabilities persons to all aspects of life in the community.

6.6 The Key Principles of Community-Based Rehabilitation: (C.B.R)

- The rehabilitation is right for disabled people and that comes to response to their needs and based on social justice, dignity and equality of opportunity and equality of rights and duties.

- Strengthening (or) reinforcement and enabled special-needs persons, their families, and their organizations an essential basis for the integration of these people and their Participation them in their communities.
- On one side, the community orientations and situations, and on the other hand Strengthening, enabling and activating the resources and the experiences of the local societies it is the fundamental guarantee for the Community participation in planning implementation and follow-up (the local community plan for disability)
- Freeing and providing and simplify the transfer of knowledge and experience are the basic necessities to use the available potential and based on what exists.
- The integration and comprehensiveness work to ensure the success of rehabilitation in the frame of overall development.
- Community-based rehabilitation is based mainly on the rehabilitation of society to accommodate disabilities persons and integrate them in the path of the general life and it doesn't be limited Preparing disabilities persons.
- Community-based rehabilitation seeking to provide access to services (quality) are available, are geographically accessible to potential citizens financially, do not distinguish against disabilities persons, and quality (general, technical, and administrative).
- Community-based rehabilitation depends on the curve of my rights community (reference of legal texts, matter, enable, post, non- distinguish).

The family system is a powerful source of environmental influence to consider. Family forms a context for a great deal of human development it is a site where individuals learn behaviors through operant conditioning (reinforcement and punishment of their behaviors) and observational learning (behavioral models), as well as become socialized into their culture, social norms, and social roles. The physical environment established by a family can also influence development and behavior through constraints and opportunities provided to individuals for example, ease of access to alcohol, tobacco products, or other psychoactive substances. Family social relationships influence a person's motivation for social conformity or deviance, as well. Family can be a source of stress to which a person might respond with substance use, or a source of resilience and protective factors that reduce the probability of engaging in substance misuse.

The family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities. Preamble, UN Convention on the Rights of Persons with Disabilities (United Nations, 2006)

Defining the family presence in rehabilitation counselling has been a perennial issue often engaged, but never fully resolved. Family members have been recognized for their influence on rehabilitation process and outcomes (Sutton, 1985; Westin & Reiss, 1979). Academics have argued the potential role of family therapy models within rehabilitation counselling (Millington, 2012; Power & Dell Orto, 2004). Family experience with service has been explored from a systems perspective (Cottone, 2012). Ecological models have been employed to justify families as partners in service and as service recipients (Kelley & Lambert, 1992; Power, Herschensohn, & Fabian, 1991). The specialized knowledge of family counselling has become part of the qualified rehabilitation counsellor identity (Leahy, 2012). Despite these advances, the family discourse has not translated into a sustained movement in research (Bryan, 2009), practice (Frain, Berven, Chan, &Tschopp, 2008; Freedman &Fesko, 1996), training (Riemer-Reiss &Morrissette, 2002), or policy (Kneipp& Bender, 1981).

What accounts for this gap between intent and achievement? The premise of this book is that rehabilitation counselling's failing with the family is a problem of models. Originally shaped by the values and epistemology of a psych medical model, rehabilitation counselling struggles with the residual effect of a worldview that it has ostensibly left behind. A new social construction is requiredto make sense of the proper relationship between service and family. The social movement has provided one on a global stage. Rights-based advocacy, as part of the movement, changed the meaning of disability and reoriented the relationship between family and care at an international level. Rehabilitation counselling has embraced this movement in principle, but has not addressed the conceptual work of constructing a new model for the family around movement values.

Rehabilitation counselling for families is cast as community counselling, with family as first community. The discipline's identity in this new context is explored through the applied values of the fundamental mission. An argument is made that rehabilitation counselling in the family has three distinct transactional expressions in identity, power, and capital.

6.7 Family Ethos in Rehabilitation Counselling

Finding the family ethos in rehabilitation counselling begins with an understanding of community values. John Dewey, an American educational philosopher and contemporary of the psychologist William James, argued that ethical behaviour is a social and humanistic pursuit. For the individual, it is the pursuit of a satisfying life within social institutions, that is, in community. For society, it is the pursuit of policy that provides a satisfying community life for its citizens. We pursue the good life through the moral behaviour of the individual and the collective. The path is always a challenge. There is no simple concordance of the good, the right, and the virtuous; no imperative rule or immutable truth that precludes thinking (Field, 2005). Directed at living an ethical life or building an ethical profession, the path to moral behaviour is always a social process of discovery. The ethos that emerges from experience is a rational, value-laden extension of our epistemology (see Tarvydas, 2012). Our professional identities are driven by our values and shaped by reflective praxis.

The special identity of rehabilitation counselling (Maki &Tarvydas, 2012) is negotiated in the lived community experience of disability. It is unique among counselling specialties in that it exists in the space of society's ethical failure in this specific regard. The profession was legislated into being to address the exclusion of people with disabilities from society. Rehabilitation counselling is society's ethical policy response to that injustice. Rehabilitation counsellors are agents of social justice (see Marini, 2012), advancing an applied theory and practice of community values.

Miller and Millington (2002) described the ethos of the profession (the moral character of the profession as it is expressed through action) in terms of the historical democratic ideals of equality, liberty, and fraternity. These values guide professional practice, infusing both process and outcome with meaning:

Equality is a reciprocal respect and regard for the unique nature of the individual and a valued recognition for his or her distinctive contribution to the whole, without consideration of physical or mental function. Accordingly, all are valued equally. Due respect and regard are expressed through the equitable allotment of resources. Each person is provided what he or she needs and receives it such that he or she is able to utilize it in the expression and development of his or her potential whatever that potential may be.

Liberty is the space created by this transaction in equity that allows for the expression and development of individual potential. Liberty is the freedom to choose one's path through one's intentional and unencumbered actions. Through the expression and development of the individual's potential, each person makes a distinctive contribution to the whole. Because it is only through cooperation that this becomes possible, both the individual and the community come to appreciate and desire that cooperation.

Fraternity is that shared space beyond liberty where people are free to choose their associations, free to align their work with the cooperative of community. Fraternity directs our actions because what we seek to achieve together is viewed as worth achieving by each participant. It produces in us a desire to continue to work together in order to sustain what we have achieved. Disability legislation is an expression of these values' writ large. To realize a democracy, however, legislation must find expression through the good work of local community action (Dewey, 1916). Rehabilitation counsellors as agents of the democratic ideal on behalf of people with disabilities are citizen professionals (see Doherty, Mendenhall, & Berge, 2010) and the instruments of that good work. Rehabilitation counselling philosophy (Maki & Murray, 1995) is derived from these community values and this ethos. Rehabilitation counselling is a value-driven profession (Tarvydas, 2012) anchored in community by a fundamental mission of full community inclusion (Szymanski, 1985).

6.8 Family Voice in Community

The fundamental mission links rehabilitation counselling with an evolving, global social movement. The history of democracy in the United States is told in the narratives of marginalized and disenfranchised peoples who united in common cause to resist oppression; negotiate their identities; trade in the marketplace; and claim their share of liberty, equality, and fraternity. People with disabilities have been engaged in this political struggle for decades and family has figured prominently in their action. As rehabilitation counselling has been a party to the movement, it is within this advocacy frame that the emerging family voice is most clearly heard.

6.9 Advocacy Roots for Rehabilitation Counselling

Counselling has its roots in the social reform movements of the 19th century (Sales, 2012) and the programmatic governmental response in the early 20th century (Elliott &Lueng, 2005). Vocational counselling was created to meet an urgent public need to facilitate the rapid shift of the population from rural/agriculture to urban/industrial life and work (Savickas& Baker, 2005). Rehabilitation counselling was an early offshoot of vocational counselling conceived in spirit as a government-sponsored alternative to charity for veterans with disabilities following World War I. It was established in principle under the Vocational Rehabilitation Act of 1920. A detailed account of vocational rehabilitation (VR) counselling in legislation is beyond the scope of this chapter. However, the political subtext of the profession's evolution is clear: Community advocacy defines and advances rehabilitation counselling through the promise of inclusion.

6.10 Medical Model Obfuscates Family Role

The family connection to VR counselling was strained by the residual paternalism of the charity movement, the epistemological constraints of the psych medical model (Cottone& Emener, 1990) that gave them legitimacy, and the subtle social oppression of a society that was designed to exclude. The language, structures, and functions of rehabilitation were forged in a medical model, and rehabilitation counselling was a party to the process. In the medical model, disability was pathology within the person that required a diagnosis and a "cure." Assessment focused on a statistical approximation of normality to which the client, by definition, fell short. Strategies were arranged by experts. Treatment was meant to resolve shortcomings. Failure only proved the model's assumptions of client inadequacy. Services in such a climate tended to institutionalize and segregate (Nosek, 2012) people with disabilities. Vocational evaluation often culled out those who required the most support for being "too disabled" (Cottone&Cottone, 1986). Sheltered workshops promised competitive employment, usually without success. People were warehoused in nursing homes and hospitals far from family and any sense of community. All of this was expertly done for the good of the client. Typically, neither the client nor the family was asked to define what "good" meant.

The medical model has no active role for the family. When disability is in the body, its impact on significant others is a tragedy that falls outside of service. When experts control the language, the client has no voice. When the science is reductive, the social network is invisible and the issues of family are not recognized. For all the good intent, the medical model falls short for all rehabilitation professions, but particularly for rehabilitation counselling, which had democratic values in its theoretical bones (Wright, 1983).

6.11 Social Movement, Social Model

The social model arose as a rejection of the medical model (Stubbins, 1984). Disability was redefined as a social construction (Oliver, 1983) imposed on people as "systematic patterns of exclusion that were—quite literally—built into the social fabric" (Hughes & Patterson, 1997, p. 328). The social model reinterprets psychological wellness in terms of the relationship between impairment and the disabling effects of the environment. It focuses on the political, the importance of personal resistance, and group advocacy in claiming an identity within the community.

The initial social model was complete in its rejection of medical hegemony (Oliver, 1990). The confluence of interests across disability groups aligned in the rejection. A political community of practice arose with the movement; it was the shared vision, history, and emerging language of a true disability community based on civil rights. Rejecting the medical model was the beginning of the normalization of disability. Disability was embraced in the social model as an authentic part of the human experience, to be accepted on its own terms, and celebrated for what it contributes to community (Remley, 2012). The full meaning of disability, its value and its challenges, came from a complex of social relationships (Llewellyn & Hogan, 2000), not from the person in isolation. The medical perspective was eventually rehabilitated back into the social model's worldview (Shakespeare, 2006), but without the power to ascribe meaning beyond the physical structure and function of impairment.

6.12 The Family Voice Emerges

The socio-political perspective recognized the importance of family and provided a platform and a voice. Family became a central theme in the disability studies literature. Family experiences across cultures, disabilities, and roles opened up the dialog to consider the impact of disability within the family and on the relationship between the family and the larger community. Families figured prominently in the collective response of the recovery movement in substance abuse (White & Savage, 2005) and mental health, giving rise to unprecedented family engagement in advocacy, treatment, and community-based peer support (Howe & Howe, 1987).

Family activism within the disability movement influenced the course of legislation. The Individuals with Disabilities Education Act and the Americans with Disabilities Act recognized the family support role in preserving the rights of the family member. Title 1 of the 1998 Amendments to the Rehabilitation Act identifies families as direct recipients of support services and training designed to empower them as informed consumers within the VR system (Section 103(a) [17]). Family access to services is contingent on instrumental impact on client employment (34 CFA 361.5(b) [23]), but offers extensive support and liberally inclusive family criteria. Compensable services include interpreters, support groups, information resources, peer networks, counselling (referrals to therapy beyond the scope of VR), day care, respite, financial management, and education. Family is defined as any person with a substantial interest in the client's welfare who lives within the home.

The empowering family trend has continued. The Family Medical Leave Act advanced employment protections to families coping with emergency care. President Obama included family leadership in policy development around the "year of community living" initiative (ca. 2009–2010). Family efforts were key in advocating for improved access to information, one-on-one counselling, and streamlined services for home-based care (Perez, 2012).

6.13 Rehabilitation Counselling Responds to the Family Voice

Rehabilitation counselling has attempted to move in concert with policy trends. What should have been the watershed moment for systems change, the 26th Institute on Rehabilitation Issues (IRI, 2000) addressed the emerging family ethos in VR counselling and proposed a way forward to more family-integrated and family-responsive service. Families were to be supported in their caring roles. VR's propensity for poor communication with family and the resulting unwarranted lowering of family expectations of VR service delivery were identified as systemic barriers to client success. The IRI recognized that client-centered service was not defined by the client in isolation, but the client embedded in family. The client had a right to choose who "family" was and to direct family roles in VR service partnership. As bona fide stakeholders in the VR process, family members had rights to informed choice and autonomy. Family was not simply to be recognized; it was to be understood. The family was to be respected in its diversity with sensitivity to its changing needs and accommodated accordingly. The family offered specialized knowledge, skills, connections, and resources that were essential for long-term successful employment outcomes. And with that, the family moved from the periphery to the core of rehabilitation counselling practice at least in (emerging) theory.

Proclamation was the easy part. The 26th IRI was literally a summation of what was already expressed in legislation. Its recommendations were merely guidelines describing what the family in rehabilitation counselling should look like. What the recommendations did not include was any strategy for implementing family inclusion in VR practice. This shortcoming was recognized within the IRI and it foreshadowed the historic lack of progress made since:

Yet, even when we understand the value of and need for family involvement, even when we are empowered to act, we remain hesitant. Perhaps our hesitancy arises, in part, from confusion over the role and function of the rehabilitation counsellor. Our profession continues to struggle with the limitations of the medical model, which focuses on disease and deficits. When such pathology dominates our thinking, we continue to look for evidence of disease, deficiency, or malfunctioning when we should shift our primary focus to family strengths. We should assess those strengths and work with the family rather than working around the family or standing in opposition to the family. As vocational rehabilitation enters the 21st century, our challenge must be to create a new model that creates a true partnership between people with disabilities, families and rehabilitation professionals. (IRI, 2000, p. 44)

6.14 Family, Theory, and Rehabilitation Counselling

Rehabilitation counselling's science and practice is predicated on the values of human rights. Rehabilitation counselling transacts specifically in the gap between society's egalitarian aspirations for its citizenry and society's failure in achieving these just ends. Defined as it is by these community transactions, rehabilitation counselling's identity is differentially expressed across settings, developmental across time, and always in the context of the gap. Rehabilitation counselling is embedded in a social movement and defined by the search. It is a transitional profession (Miller & Millington, 2002) with a dynamic identity that requires constant challenge and revision.

The family conundrum at the center of this identity issue is not a feature of rehabilitation counselling; it is a passing symptom of professional growth. Rehabilitation counselling evolves in its role and function, albeit unevenly, in response to societal change because rehabilitation counselling science is not simply a description of the world as it is, but the investigation of what makes a more humane world. Rehabilitation counselling is a science of social construction where empirical observation is charged with meaning. The social construction of rehabilitation counselling requires a social psychology that embraces liberation.

6.15 Social Construction of Disability and the Family

Lewin (1935) is known in rehabilitation counselling for the ubiquitous citations of his conceptualization of behaviour as a function of the person and the environment. The gestalt of Lewin's work reveals the deep connections of theory to rehabilitation counselling values, to the pursuit of systems change, and to the irreducible nature of family and community. Lewin's understanding of the social nature of psychology is a proper framework for engaging the family in rehabilitation counselling.

Lewin's theoretical work was unified by his dedication to applied social science in the service of advocacy. He was concerned with the issue of power and its ability to eclipse social justice for the disenfranchised (Burnes, 2004). The origins of social psychology are inseparable from the values of democracy in Lewin's strongly held belief; society's complete commitment to democratic values was its only protection from the worst extremes of social conflict (Burnes, 2004). Gordon Allport went as far as to aver that Lewin's corpus of theory was the epistemological complement to Dewey's educational philosophy. "Without knowledge of, and obedience to, the laws of human nature in group settings, democracy cannot succeed. And without freedom for research and theory as provided only in a democratic environment, social science will surely fail" (Allport, 1948, p. xi). Lewin sought to improve the circumstances of the individual through planned change in the group and saw his theoretical themes of field theory, group dynamics, change theory, and action research as interdependent components of planned change at the individual, group, and societal levels.

6.16 Field Theory

Lewin's famous $B = f(P, E)$ equation addresses the interdependent physical, psychological, and sociological characteristics of lived experience. The function establishes the inseparability of the individual and the "life spaces" he or she navigates (Hall &Lindzey, 1978). Behaviour is enmeshed in a complex network of proximal and distal influences; that is, vector forces that push and pull-on self-expression. We shape, and are shaped by, our environments through unceasing reflexive transactions.

6.17 Group Dynamics

The evolving social identity that binds individual to group manifests through group dynamics. Through "interdependence of fate and task," individual behaviours coalesce in fraternal collaboration. A complex and reciprocal social system arises where identity is negotiated group-to-individual and individual-to-group (Smith, 2001).

6.18 Change Theory

Continuity of group behaviour creates a social equilibrium not easily changed by individual action. Group change is best affected through collective action. Intentional change is initiated by a disruption of the status quo, a shared desire for transition to a new state, and a consensus that the effort to change is worth the risk (Schein, 1996). Change is accomplished as new models of behaviour become engrained in habit; new structures and traditions crystalize around social transactions; equilibrium returns; and a new identity emerges for group and individual (Burnes, 2004).

6.19 Action Research

The means to direct intentional change in constructive ways is accomplished through action research. Action research was meant to empower (minority) groups to address and resolve local problems and to identify general laws of group life through the application of basic social research. Group members collaborate through a cyclical process of planning overall goal and incremental steps, implementing change, and evaluating outcomes. Outcomes have three purposes, to evaluate the action against the goal, provide an opportunity to learn from the experience, and inform the next iteration (Lewin, 1946).

Lewin interpreted Dewey's educational philosophy into an applied science of advocacy for oppressed groups. The practice that followed would facilitate democratic social change toward fuller participation in a more democratic society (Smith, 2001). Lewin and Dewey shared the social constructionist view, later professed of the disability rights movement, that planned change is not authoritarian but egalitarian in a process that combines research, education, and management to community-enhancing ends (Hatch, 1997).

6.20 Extension in Rehabilitation Psychology

Lewin's social psychology provided a system alternative to the clinical appraisal of psych medical tradition. Wright's seminal work (1983) in the somatopsychological and psychosocial dynamics of physical disability was a turning point. She conceived a value-laden set of principles that recast disability as a complex phenomenon embedded in a social system (World Health Organization [WHO], 2002) and set the precepts for the nascent field of rehabilitation psychology.

6.21 Impact of the Social Context

Human beings are by nature social creatures that fail to thrive without care (Bowlby, 1969) and for whom isolation is the ultimate punishment. We seek out social attachment and negotiate who we are through social learning. We are constantly engaged in proximal social processes (Bronfenbrenner & Morris, 2006) with the people, things, and information that populate our environment. Through this sustained activity, we develop habits of behaviour, thinking, and feeling that define our social identity (Sluzki, 2010). Our social identities are contextually dependent and constantly in flux. As we move from role to role, we find that social identities are the compromise between what we believe ourselves to be and what society will allow. We flourish where we are accepted, and we struggle to adapt where we are not.

People with disabilities find themselves assigned to an identity (Goffman, 1963) not of their choosing (Barker, Wright, Meyerson, &Gonick, 1953), historically one of stigma and devaluation (Dembo, 1982). The social lessons taught and learned are embedded in the disabling context, for example, the attitudes of others (Shontz, 1977), inaccessible physical environments, policies that create dependency, and language that denies respect. To these insults, add the pervasive professional negative bias (Dunn & Elliot, 2005) of a disability industry that reifies its assumptions of deviance in the population it purports to serve (see Cottone&Cottone, 1986; Tremain, 2005). These contextual barriers, often invisible to those who do not live the experience, are a far greater threat to positive adjustment than the functional aspects of impairment (Shontz, 1977).

6.22 Impact of Advocacy

Early researchers drew parallels between the struggle of people with disabilities and the marginalization and disenfranchisement of other minority groups (Barker et al., 1953). The minority meme resonated with people with disabilities and their families (Meyerson, 1988). It made empiricaland intuitive sense and, for the first time, provided for an activist response to one's position as outsider (Fine & Asch, 1988). This collective activist response is the impetus for action in Lewin's action research. The disability rights movement moved special education into the mainstream, sheltered employment into competitive employment (with supports), and institutionalization into independent living. Research did not lead these movements, but responded to them as part of a larger system of change.

The disability rights movement has encouraged an epistemological shift from interindividual traits to intraindividual relationships; from psychological states to ecological processes; from individual counselling to counselling in systems. Theoretical constructs have evolved accordingly. Families are recognized as the most proximal of many nested and networked social systems (Bronfenbrenner, 1977) in which the person with a disability interfaces. They are constituted of a complex of social-emotional bonds (Dembo, Leviton, & Wright, 1975) interacting in dyadic (parents), triadic (parents and child), and higher order exchanges (e.g., female members of the extended family) that provide the scaffold for group and individual identity and the tools for adapting to change (see Bateson, 1972; Minuchin, 1985).

6.23 Evolving Constructs

Systems thinking redefines disability in the social sphere. Impairment is a personal experience, but disability resides in the relationships that connect people. Disability happens to a family as well as an individual, and the response to it can be registered at both levels. For example, rehabilitation psychology was predicated on the psychosocial framework of coping with disability (Wright, 1983) a construct with both inter- and intraindividual interpretations. An individual's response to environmental stressors is dependent on cognitive appraisal (Lazarus, 1993) of the situation, the consequent perception of self-efficacy, and the choice and implementation of coping strategies. Each impacts the next in succession. Generalized practice of effective coping strategies across contexts and time (Maddux, 1995) creates psychologically resilient individuals. Self-appraisal of a supportive social network raises an individual's perceived self-efficacy in problem solving and thereby encourages self-directed change-making in his or her world, and stress reduction (Bandura, 1997). Similarly, groups are collectively more effective when their members are confident in their abilities to overcome obstacles (Bandura, 1998). The concept of coping has expanded to strategies of social support (Pierce, Sarason, &Sarason, 1996). The perception of strong social support provides a degree of affective coping simply by its presence. Supportive relationships lead to more positive and accurate assessment of self and support network efficacy. Support within specific dyadic relationships, especially spousal support, has been found to be effective in rehabilitation settings (Revenson &Majerovitz, 1990). Networks of supports, most notably families, enhance individual coping with challenges in the rehabilitation process (Porrit, 1979).

Resilience, once reserved to describe individual's ability to "bounce back" following personal loss, has now taken on an additional systemic application in describing families (Walsh, 2003). Resilience is recognized in the synergistic relationship between the individual and the group. The person is simultaneously an extension of the family and feature of its resilience, and a recipient of family support and the resilience it affords. This is particularly poignant for people with disabilities and their families. The key to coping with the stressors around disability, foremost among these being community exclusion, is to find strength in the family and purpose in the community (Li & Moore, 1998).

6.24 Systems in Rehabilitation Counselling

Cottone's (1987) systemic theory of VR represents the first steps taken in building a rehabilitation counselling framework that bridges family and service structure (Cottone, Handelman, & Walters, 1986). The theory posited that the degree of "fit" between the service systems governing rehabilitation practice and the family systems governing client participation was an influential arbiter of rehabilitation success, perhaps more important that the person × environment fit that the system itself espoused. Cottone and Cottone (1986) proposed that VR actually functioned as a complex system for screening social deviance before it functioned in its formal capacity. In their critique of vocational evaluation, they suggested that vocational evaluation recommendations were heavily influenced by counsellor expectations and agenda, making it more of a tool for preserving the organization than a resource for advancing the client's goals (Cottone&Cottone, 1986).

Preliminary research suggested that social relationships were more influential in determining employability determinations than psychological evidence (Cottone, Grelle, & Wilson, 1988), specifically in regard to clients with nonphysical disabilities. It was Cottone's contention that family-oriented rehabilitation counselling would provide a more effective point of client engagement in a self-serving service system. The professional community's response to this call was underwhelming, despite the ethical questions raised for state VR and the implied need for organized family advocacy.

In 2012, Cottone renewed his call for systems applications in rehabilitation counselling in further explorations of the role of families. For Cottone, the inclusion of family in rehabilitation process requires a rejection of the psych medical model and its Newtonian trait/factor worldview for the Lewinian-inspired relational worldview of field theory. Cottone saw systems theory leading to a true paradigmatic change for the profession, then and now. But paradigmatic change comes slowly and unevenly. Today, systems theory has a broader appeal and a more receptive audience in rehabilitation counselling. With family in the vanguard, we have both an impetus and a framework for progress.

6.25 Sense of Community: A System of Inclusion

Moving to a systems model creates a language that includes the family in the social discourse of disability, but to what end? What is the relationship between the family experience of disability and the fundamental mission of full community inclusion? How is rehabilitation counselling supposed to engage this relationship on behalf of its client? Coming out of a quasi-psych medical worldview, these questions were difficult to even ask. Rehabilitation has adopted a biopsychosocial model to expand its explanatory power, but the activities and participation of the ICF (WHO, 2002) give us only the mechanics of inclusion. These advancements in construct do not yet capture the dynamics of the relationships through which community is actually expressed. Community is like music in this sense. It is expressed only in the moment of exchange between players. It is a subjective experience that lives in the collected and collective memory of those moments.

McMillan's "sense of community" (2005) provides a vocabulary upon which we may build a "sense of family." Sense of community reflects the basic human need for affiliation, group cohesion, psychological attachment, and personal bonding. Sense of community is an empirical theory rather than a normative one. Sense of community describes the phenomenon of people coming together. McMillan (1996) conceptualized the affective "sense" of community in psychosocial terms, revealing both its human nature and the demands humans place on it. Sense of community arises from lived experience of community inclusion, framed by four community transactions (McMillan, 1996; McMillan &Chavis, 1986): (a) membership/spirit, (b) influence/trust, (c) need fulfilment/trade, and (d) shared emotional connection/art.

6.26 Membership/Spirit

The first sense of community, or perhaps the deepest, is the sense of belonging to something larger than oneself. It is a primal drive (gemeinschaft), evident in every social gathering. Individuals derive their identity and a concordant sense of well-being from the safety and welcoming acceptance afforded by membership. Members share symbols and rituals that bind them in affiliation and mark them as insiders. Membership is the spirit in esprit de corps, and the allegiance to the corps can run very deep.

Spirit grows in finding common ground. The novice shares increasingly personal and sensitive information about him- or herself within the space of the community. The community members share similar stories and secrets in turn. McMillan and Chavis (1986) referred to this as "freedom from shame." Such sharing is a risk taken through a call and response. The individual reveals, "Here I am." The community responds, "One of us." The danger is when the community does not respond or rejects the call outright. Shame and humiliation are the death of community and the denial of identity. The more we risk in self-revelation, the higher the emotional stakes, the deeper the meaning of membership.

6.27 Influence/Trust

Communities exist to serve the membership. Structures and processes form around these intents as strategies and plans, rules and regulations, roles and functions. Structure and habit allow for specialization and more effective pursuit of community goals and impart a comfortable predictability and trust among members. People are drawn to order. It creates a framework for identity and makes relationships among members clear.

Order requires a subjugation of individual freedoms to the common good. It is part of the dues of membership and part of the assumed social identity. Order and community cohesion are sustained through the negotiation of authority and responsibility among members. Individuals are attracted to groups that can leverage their collective influence (e.g., labour unions, advocacy groups) in areas of individual interest. Members are more willing to acquiesce to authority when they believe they have input into its exercise. Community is most successful when authority is responsive to and works in service of the membership (McMillan &Chavis, 1986). Trust evolves from the perceived benefit of compliance, equity of power relationships, and the predictability of consequences. An individual's sense of community is enhanced if he or she has a say in what the community does, sees the community as working in his or her interest, and believes that he or she is being treated fairly within it.

6.28 Integration of Fulfilment of Needs/Trade

Having established a sense of belonging and an orderly environment within which to act, the economic work of community may commence. Trade is the engine of community. It is the essence of Gesellschaft, that is, membership as personal benefit. Community action is shaped around the collective leveraging of individual resources.

Individuals exchange economic, social, psychological, and political capital in the internal community marketplace, which advances both community cohesion and individual prosperity in all dimensions. Cohesiveness comes from a proper matching of needs to resources. Sense of community is advanced when the individual's contribution is valued, he or she can fulfil his or her needs, and he or she is free to trade in equity.

6.29 Shared Emotional Connection (1986)/Art (1996)

Community is a process reified by its history and the artifacts it creates. Community histories are replete with origin stories, recollections of pivotal moments in history, the journeys of heroes, and cautionary tales of members gone wrong. Buildings and monuments are testament to the history. Celebration and ceremony mark the milestones of life, honour membership, and instil faith in the constancy and relevance of the group.

This is the fruition of the sense of community, the celebration of one's part in the whole. In the sense of transaction, it circles back to the first sense, membership and spirit. But now the novice is the master. He or she transacts in wisdom as one who listens to the initiate's story and responds with the group's secret mythology to include the novice as "one of us."

6.30 Family as First Community: Implications for Rehabilitation Counselling

Synomorphy describes the natural systems "fit" that occurs between standing patterns of group behaviour (e.g., shopping) and the features of the nonbehavioral environments in which they occur (e.g., business hours, malls, advertisements, public transportation; Barker, 1968). Fit in this sense is a self-organizing process, where form follows function and function follows form. It is possible to deduce one knowing the other and to find them paired wherever either is found. Lewin (1951) used this concept to study measures of economic interdependence and demonstrated that Synomorphy could be explored at multiple levels (e.g., the economic interdependence of city, neighbourhood, or family). The same can be said for Dewey's conceptualization of big "D" democracy's dependence on small "d" participation of local communities, and the origins of democracy in the education of the individual within a democratic system. McMillan similarly bridged sense of community theory to couples (McMillan, 1997) and the families they evoke. Thus, the thread of community runs unbroken from the broadest contexts of philosophy, to society and its problems, through professional praxis and its solutions, down to the family and its lived experience with disability. Family is the first synomorphic instance of community and thus the most immediate experience of inclusion available to the client or counsellor. If community inclusion is the fundamental mission of rehabilitation counselling, the most sensible strategy for pursuing it would be to start with its function in the family and work outward.

6.31 Strengthening Community in the Family

The sense of family arises out of collaborative participation in instrumental tasks that achieve goals that are collectively valued (Verdon Schott, de Witte, Reich raft, Buntinx, &Curfs, 2009). The degree and character of a family member's active inclusion in the business of the family provide social learning content about his or her role and efficacy in the world. A client-centered approach to community inclusion begins with an evaluation of the familial relationships. How does the individual express her- or himself in family rituals of membership? How does the individual negotiate the authorities and obligations of his or her role within the family structure? How does the individual contribute to and draw from the collective family resources? For each of these issues add, "... and how does the family respond?" Unlike the questions and contexts that opened this chapter, these are questions that can now be entertained.

Each member of the family will experience the phenomenon of disability differently, but it is a shared experience that contributes to group identity. Deepening the sense of family requires sharing these personal experiences (in culturally appropriate ways), reflecting upon them, and responding to them in intentional and inclusive ways. A strong sense of family shared by all members is the optimal foundation for advancing the goals of rehabilitation counselling in the community at large.

6.32 Strengthening Family in the Community

Individual family members draw strength from their trade with multiple communities beyond the family. These may be communities of practice that revolve around work, school, or other shared interests. They may be geographically bound or virtual. These communities may be an individual pursuit of one family member, the family as a whole, or a subset. In every permutation, the experience of disability follows the individuals into other memberships, as it is a part of their identity. It is part of the stories they tell. When they negotiate their role in the organization, they negotiate within the experience of disability. When they trade in resources, the experience of disability contributes in some fashion for good, ill, or otherwise.

Families are nested and networked in a community of their own making. The groups they join, they join because it serves a family need. Peer and advocacy groups may trade in disability specific knowledge, support, and connections designed for individuals or families. Cooperatives may serve a broader mission (e.g., fair trade products, culture and the arts) that builds inclusion into service. Even strictly social groups (e.g., work-sponsored bowling teams) potentially provide linkages between the family and desired resources that may serve the client (e.g., job openings). Rehabilitation counselling in the community engages family efforts in marshalling existing community resources and expanding their social network to strategic advantage.

6.33 Family and the Rehabilitation Counselling Ethos

An unbroken thread runs from the values that unite the profession, community, and family, to the models that make sense of the disability experience, to the practice of rehabilitation counselling. Community values resonate through the relationship with the family. At the point of transaction, they take on the look of action research. The client invites the family and the counsellor to collaborate on problems of mutual concern. Employment is often the proximal reason for the gathering, but the family's perspective is complex and extends over the course of years. They see employment as the first step in a career. They see the career as part of a social life beyond work and home. They see the arc of a social life into old age. And each family member sees him- or herself in the family narrative or he or she sees none of this, and that is the problem. The client and his or her family set about the task of visioning an objective and planning the steps required. They share, negotiate, and settle on something worth doing. They proceed, succeed or fail, and then share their perspectives in review. Then they repeat the process. Along the way, they acquire knowledge and learn new skills. This is what families do.

The rehabilitation counsellor engages the family process as a resource designed to facilitate the work of families through three community-based transactions:

Identity provides the working alliance and space for psychosocial support as persons with disability and their families negotiate life challenges. Identity is rooted in the democratic ideal of liberty. It asks, "Who am I (who are we) in the face of change?" It is realized in the exchange of the personal with the collective in search of belonging—the spirit of family and community.

Power provides a voice for the family seeking social justice, alone and in the collective. Power is rooted in the democratic ideal of equality. It asks, "What do I (we) direct and what directs me (us)?" It is realized in the exchange of authority and responsibility in search of an empowered sense of justice—the sense of structure, stability, and trust.

Capital provides networks and networked resources for the development, implementation, and evaluation of planned action. Value is rooted in the democratic ideal of fraternity. It asks, "What do I (we) have to offer and what is proffered in return?" It is realized in the exchange of capital, real and social, in search of sense of enrichment and quality of life.

We can recognize the familiar in these transactions as they track closely to traditional counselling, advocacy, and case management roles. Here the roles are unified in community values. Dealing with the family requires all three orchestrated in delivery. As we attend to each in the coming chapters, it will become apparent that they are facets of a single irreducible whole, much like the fundamental mission that drives them.

Review Questions

1. Who are entitled to receive social rehabilitation services?
2. What changes were made to the social rehabilitation system in 2016?
3. What is the difference of a rehabilitation program, a plan of action and a rehabilitation plan?
4. In which cases will a case manager visit me at home?
5. If I submitted an application for social rehabilitation before the year 2016, if and how will the changes that took effect on January 1st, 2016 affect me?
6. If I have a current rehabilitation plan and received social rehabilitation services on the basis of said plan in the previous year, how will the changes affect me?
7. What is the reason behind the evaluation of rehabilitation needs and what does it mean for individuals applying for the service?
8. What does the evaluation of rehabilitation need mean for a disabled person?
9. If I have a current rehabilitation plan that was prepared before the year 2016 and I am turning 16 this year, will I be able to use services on the basis of the target group of children or persons of working age?
10. Is it required to reapply for rehabilitation if a child for whom a rehabilitation plan was prepared with the purpose of establishment of disability is awarded a disability?

Self Assessment

1. With Barbiturate and Benzodiazepine Abuse and Dependency, sedative intoxication is generally associated with:

A. Slurred speech
B. Uncoordinated motor movements
C. Impairment in attention and memory
D. All of the above

2. Which of the following is derived from the hemp plant "cannabis sativa"?

A. Opium
B. Marijuana
C. MDMA
D. Crack

3. A synthetic form of opium was developed by Germany during WWII. This is known as?

A. Prednisolone
B. Cortisone
C. Methadone
D. Polyheroin

4. A long-term user of cocaine may well develop symptoms of other psychological disorders, such as:

A. Major depression
B. social phobia
C. Eating disorders

D. All of the above

5. A motivational syndrome in cannabis users suggests that those who use cannabis regularly are more likely to:
A. Exhibit apathy
B. Exhibit loss of ambition
C. Have difficulty concentrating
D. All of the above

6. Lysergic Acid Diethylamide (LSD) starts to take effect around 30 to 90 minutes after taking it and physical effects include:
A. Raised body temperature
B. Increased heart rate and blood pressure
C. Sleeplessness
D. All of the above

7. Individuals with Hallucinogen Dependency can spend many hours and even days recovering from the effects of the drug some hallucinogens - such as MDMA - are often associated with physical 'hangover' symptoms. Which of the following are MDMA hangovers?
A. Insomnia
B. Fatigue
C. Drowsiness
D. All of the above

8. Which of the following is an important factor in substance abuse?
A. Whether the substances are regularly used by other family members
B. Whether the family environment is rural or urban
C. Whether you are a twin
D. Whether you are born in the winter

9. The alcohol intoxicated individual has less cognitive capacity available to process all on-going information, and so alcohol acts to narrow attention and means that the drinker processes fewer cues less well. This is known as:
A. Alcohol myopia
B. Alcohol dependency
C. Alcohol abuse
D. Alcohol amnesia

10. In substance abuse, the term self-medication refers to?
A. Amelioration of psychological distress thorough substance use
B. Doctors prescribing their own drugs
C. Motive for using a substance
D. Deciding the drug of choice

11. Community-based services to offer support in substance abuse consist of self-help services such as?

A. Alcoholics Anonymous
B. Crack
C. Cannabis Collective
D. Hashish Home

12. Drug-prevention schemes targeting young people and their parents who may be specifically at risk provide:

A. 24-hour telephone help lines
B. Internet web-sites
C. Treatment, and availability
D. All of the above

13. Local community drug prevention schemes have used which of the following?

A. Peer-pressure resistance training
B. Peer pressure
C. Peer promotion
D. Peer propaganda

14. Which of the following are treatments offered by residential rehabilitation centres?

A. Group work
B. Psychological interventions
C. Social skills training
D. All of the above

15. In aversion therapy clients are given their drug followed immediately by another drug that causes unpleasant physiological reactions such as nausea and sickness. Rather than physically administering these drugs in order to form an aversive conditioned response the client to imagine taking their drug followed by imagining some upsetting or repulsive consequence. The variant on aversion therapy is known as:

A. Covert sensitisation
B. Inverted de-sensitization
C. Overt desensitisation
D. Covert habituation

UNIT – VIISupport Systems

UNIT 7: Support System: Group Dynamics,Self Help groups,Self-advocacy movement, Community awareness, Community based rehabilitation

Contents

Objectives

This unit will enable you to: -

Understand the nature of support groups;

Elucidate the basic meaning of group dynamics;

Evaluate the self-help group and self-advocacy movement;

Acknowledge rehabilitation related to community.

Introduction

Support groups are those groups in which people come together on a daily base. They can meet at any clubs or meetings or anywhere else. They provide support to each other and they shared their experience about rehabilitation for patient. Support groups are basically for those who want extra support in their life. Support groups are always ready to provide a new lifestyle, support structure and supportive colleagues. To achieve success in starting years is attending meeting regularly.

Support groups are built by individuals who needs same therapy means support groups are for those who are in a team and they set a common goal. Support groups are always ready to motivate and to help and these groups play always a basic role in recovery for needy people and for their loved ones.

Support group has form two types of groups in which first is group therapy session keep by a psychotherapist for those group members who have similar goals. These group are treated with a similar recovery plan and all members are to be counseled together by counselor. It is also known as group counseling or group psychotherapy.

The other support groups are co-workers led. These groups are held in informal settings. Support groups are important because these types of groups offer a skill-building activities to the peoples and this type of an experience can be aid to their future achievement goals. The support groups always open new doors for coping strategies and also influence insights so person can get a successful rehabilitation. Support groups can be considered as a powerful weapon so it will motivate the other one and they can get a better life.

2.1. Meaning and definitions

According to APA,"a group similar in some ways to a self-help group in that members who share a problem come together to provide help, comfort, and guidance."

Support groups are form with those peoples whose have same experience in their life, these groups can be same in on same ground that e.g. any disease or disorders. Support groups shares personal experience on same ground. These groups filled a gap between doctors as medical treatment and a need of emotional support.

Support groups are work as nonprofit advocacy, organization and clinic and these groups are led by professionals, psychologists, doctors, nurses and social workers. Support groups reduce anxiety, stress. They improve quality of life of peoples. They learn about health, economic or social resources.

2.2. Group Dynamics

Group dynamics is the study in which we study how people come together, which factors effect to cohesion and co-operation and also how groups effect to outsider groups. Basically, group dynamic is the explaining way of roles, behaviors and communication between groups.

Structure of group is primary key to influence on groups. How group is formed, how they build their trust on each other and how members in group are connected to each other. Healthy group interaction is the most important factor to form and to maintain group dynamic. The dynamics of a group depend heavily on its goals. In order to survive, humans have an innate propensity to set long-term as well as short-term goals.

According to McGrath (1984), a group accomplishes its objectives by first creating ideas, selecting among alternatives, haggling over solutions, and then carrying out activities. To fulfill both the group's aims and the individual ambitions of each member, being a member of a team can be a significant source of encouragement. Group dynamics is based on the group cohesion, group think and structure of the group.

There are two types of Group dynamics-

1. **Formal Group Dynamics-** Groups formed by an organization or other body to accomplish a certain aim those with formal group dynamics. Its formation is intentional, and the group size is frequently big. The hierarchy within the group is essential and formal group dynamics are more professional.
2. **Informal Group Dynamics**- Informal group dynamics are more prevalent in groups that develop more naturally and typically result from an opportunity or organizational necessity. Smaller groups typically experience this kind of group dynamic. Members opt to join the group, and approval is typically not necessary. Although informal group dynamics lack a clear structure, they can still have an impact on formal group dynamics.

TUCKMAN's Approach of group Dynamics-

Group development is a dynamic process and it is flow from 5 stages-

1. Forming- The formation of a group occupies the first phase of its existence. Members in this stage are known for seeking either a job (in a formal group) or another reward, such as status, affiliation, power, etc (in an informal group). At this stage, members either engage in active activities or display disinterest.

2. **Storming-** The emergence of dyads and triads in this group indicates the progression to the next stage. Members look for people who are like them or who they are familiar with and start a deeper self-sharing. As the subgroup receives more attention, the group becomes more distinct, and tensions between the dyads or triads may manifest. Pairing is a typical occurrence. Conflict will arise about who will run the group.

3. **Norming-** It is the third stage in which team members start to take responsibility and set standards rules and regulations for the team.

4. **Performing-** In this stage of a group's development, participants engage in the work and perceive the group as a whole. Each member contributes, and the group as a whole includes the authority figure. In order to ensure the efficacy of the group's process of group, group norms are observed and collective pressure is applied.

5. **Adjourning-** It is the last stage or closing stage of temporary group. For permanent group the above four stages are important.

2.3. Self Help Group

Gerald Goodman and Marion Jacobs predicted that self-help groups will become the nation's “treatment of choice” in the next 10 to 20 years.

Self-Help Groups (SHGs) are unofficial organisations where people gather to discuss how to better their living circumstances.It can be characterised as an identity, consensus informational group of individuals with a common socioeconomic background and the intention to work together to achieve a common goal.SHG use the concept of "Self Help" to facilitate growth and reduce poverty.People with disabilities and their family members participate in groups to resolve common problems, enhance their individual strengths, and improve their quality of life.

Social help groups are basically needed for social integrity, gender equity, financial inclusion and also the alternate source of job.

By assisting others, we can achieve this through mutual assistance. A self-help group can be joined for a variety of issues, including:

- behavioural health issues
- mourning and loss
- parenting and drug usage
- weight management or loss
- caregiver assistance.

Sternlicht asserts that support groups have a variety of advantages that could be advantageous for people interested in self-help:

Mutual assistance-When facing hardships in life, connecting with others can make you feel more supported and less alone.

Network construction-You might find it easier to keep on track and connect with relatable people if you create a support network with others who have similar life experiences or goals.

A higher sense of self- Making great life choices and encouraging others to do the same may make you feel more empowered, which may boost your self-esteem

Fostering optimism- Observing the development of others may give you hope for your own position.

2.4. Self-AdvocacyMovement

Self-advocacy is, quite simply, the act of defending oneself and one's rights. Self-advocacy is a word of personal identification that emphasizes one's political power and right to self-decision for thousands of disabled individuals around the world. It is also a civil rights movement that stands up for people of all racial, ethnic, and religious backgrounds who have historically been routinely mistreated, abused, imprisoned, and misunderstood.

Self-advocacy is a movement driven mostly by and for people with mental retardation who are taking charge of their own life, making their own decisions, and speaking up for themselves and other people with disabilities. The larger disability rights movement and a separate movement that focuses on important issues are both a part of self-advocacy.Self-advocacy is a separate movement that focuses on important concerns for people with developmental disabilities while also being a part of the greater disability rights move.

2.5. Community Awareness/Community Based Rehabilitation

Awareness regarding disability means to educate to the people for disability. It is to be educated that people must be assured that they never discriminate to the disable persons because disability discrimination is unlawful.

A community development method called community-based rehabilitation (CBR) attempts to improve the quality of life for those who have impairments and their families while also ensuring their inclusion and engagement in society.CBR was first introduced by WHO as a plan to give more people with disabilities accessible to rehabilitation programs just at local level, but now it has extended into a significantly extensive and multisectoral strategy for community-based inclusive development.

Community based rehabilitation creates a greater understanding of the variety within the community, including the diversity in how elderly people, children, and individuals with impairments function.

3rd December is celebrated as world disability day.

2.6. Summary

- Support groups are always ready to provide a new lifestyle, support structure and supportive colleagues. To achieve success in starting years is attending meeting regularly.
- The support groups always open new doors for coping strategies and also influence insights so person can get a successful rehabilitation.
- Group dynamics is the study in which we study how people come together, which factors effect to cohesion and co-operation and also how groups effect to outsider groups.
- Self-Help Groups (SHGs) are unofficial organisations where people gather to discuss how to better their living circumstances. It can be characterised as an identity, consensus informational group of individuals with a common socioeconomic background and the intention to work together to achieve a common goal.

2.7. Keywords

Rehabilitation- Rehabilitation is care that can help you get back, keep, or improve abilities that you need for daily life. These abilities may be physical, mental, and/or cognitive (thinking and learning).

Storming-This stage begins to occur as the process of organizing tasks and processes surface interpersonal conflicts. Leadership, power, and structural issues dominate this stage.

Self Help Groups -Self-help Groups (SHGs) are informal associations of people who come together to find ways to improve their living conditions. They are generally self-governed and peer-controlled.

Community- A group of people with a common characteristic or interest living together within a larger society.

2.8. Self-Assessment

1. __________can be considered as a powerful weapon so it will motivate the other one and they can get a better life.

a. Self-help groups

b. Support groups

c. Self-advocacy movement

d. Community awareness

2. Which stage is showing about team members start to take responsibility and set standards rules and regulations for the team?

a. Forming

b. Storming

c. Adjourning

d. Norming

3. Are support groups work as non-profit organization?

a.True

b. False

c. Can't say

d. None of the above

4. Is Community development method known as also community-based rehabilitation?

a. True

b. False

c. Can't say

d. None of the above

5. Which type of group formation is intentional, and the group size is frequently big?

a. Informal

b. Formal

c. Simple

d. All of above

6. CBR was first introduced by whom?

a. ICD

b. DSM

c. WHO

d. ICSSR

7. Which factor is responsible to make great life choices and encouraging others to do the same may make you feel more empowered, which may boost your self-esteem?

a. mutual assistance

b. network construction

c. higher sense of self

d. fostering optimism

8. ________ is a movement driven mostly by and for people with mental retardation who are taking charge of their own life, making their own decisions, and speaking up for themselves and other people with disabilities.

a. self-advocacy

b. community-based rehabilitation

c. community awareness

d. self-help groups

9. The fourth stage of group dynamic is –

a. Norming

b. Forming

c. Storming

d. Performing

10. Is informal group dynamics lack a clear structure, they can still have an impact on formal group dynamics?

a. True

b. False

c. None of the above

d. Can’t say

Answers				
01	02	03	04	05
b	d	a	a	b
6	7	8	9	10
c	c	a	d	a

2.9. Review Questions

1. What is group dynamics? Explain Tuckman's approach of group dynamic?
2. Discuss Self-help groups?
3. Describe community-based rehabilitation?
4. Write a note on self-advocacy movement?
5. Describe about support groups?

Further Readings

Elliott, Timothy R. & Frank, Robert G.- Handbook of rehabilitation psychology,3rd edition, Oxford University Press

Unit 8: Disability Dealing with Families

CONTENTS

Objectives

- To know family's reaction to disabilities
- To understand cognitive styles and family therapy related to Disability
- To familiarize with coordination with multidisciplinary team

Introduction

If you are a family member who cares for someone with a disability, whether a child or an adult, combining personal, caregiving, and everyday needs can be challenging.

The impact of having a family member with an intellectual handicap can be felt by the entire family, including the parents, siblings, and extended family. It is a one-of-a-kind shared experience for families that can have an impact on all aspects of family life.

On the plus side, it has the potential to extend perspectives, boost family members' knowledge of their inner strength, strengthen family togetherness, and stimulate community ties. The time and financial costs, physical and emotional strains, and logistical challenges of caring for a disabled child or adult, on the other hand, can have far-reaching consequences. The consequences will most likely be determined by the type and severity of the ailment, as well as the family's physical, emotional, and financial resources.

Caring for a disabled family member can cause stress, impair mental and physical health, make it difficult to locate adequate and inexpensive childcare, and influence decisions regarding career, education/training, having more children, and relying on government assistance. It may be linked to feelings of guilt, blame, or low self-esteem. It has the potential to draw attention away from other parts of family life. Medical care and other services may have astronomical out-of-pocket prices. All of these potential consequences could have an impact on the quality of family connections, living arrangements, future partnerships, and family structure

8.1 Families' Reaction to the disabilities

Caring for a disabled family member can cause stress, impair mental and physical health, make it difficult to locate adequate and inexpensive childcare, and influence decisions regarding career, education/training, having more children, and relying on government assistance. It may be linked to feelings of guilt, blame, or low self-esteem. It has the potential to draw attention away from other parts of family life. Medical care and other services may have astronomical out-of-pocket prices. All of these potential consequences could have an impact on the quality of family connections, living arrangements, future partnerships, and family structure.

Refusing to admit that your child has a disability is known as denial. Parents make excuses for their children's academic failures because they refuse to admit that their children have a disability. Instead, they may blame their child's difficulties on teachers or a spouse. Alternatively, they may accuse the child of being lazy and refuse to give special education assistance.

Denial occurs for a variety of reasons. Recognizing a disability can be extremely frightening for some parents. Denial stems from a parent's great fear of their child struggling in life or being rejected by others, which is frequently a parent's worst nightmare.

Kandeland Merrick have complied results from studies about families having a child with a disability. The birth of such a child usually follows five stages: "denial, anger, bargaining, depression and acceptance." Parents usually react with "psychological stress, a feeling of loss and low self-esteem." The child is "disappointing" and a "social obstacle" leading to shame and embarrassment." Parents may direct their anger toward others, their partner, the physician, or other families who do not have this stress. Some parents bargain with their higher power: e.g. If you heal my child of the disability, I'll quit drinking or... They may feel guilt, that the child is a punishment for a past sin. They may overly protect this child who is a symbol of their failure. The frustrations of finding specialized help, managing added costs of care, maintaining social communications may mean that the parents aren't able to communicate with each other. It is usually the mother who assumes more responsibility, so that the father often feels neglected by his wife who is busy with the child. A report concerning Down syndrome in Israel found that 25% of families abandon the child in the hospital. One United State study found that "the divorce rate was ten times larger in families with a disabled child than in the general population." Whether the child is placed in an institution or kept at home the grief of the loss of an expected normal child is a life-long "chronic sorrow." Parents need to talk with a competent professional about their reactions and strategies for coping.

Sibling reactions:Gretchen Cook and others report that siblings of children with disabilities need a place to vent their feelings and help them cope with the family situation. Siblings often report that they are ashamed or embarrassed by their sibling with a disability and don't have the words to explain to their pals why their sibling is different. They often feel guilty for having those aversions, feel that they don't deserve to have friends or a successful life, and even wish that they be punished with a disability. They often report that they feel neglected because their parents are overburdened with care for their sibling. They may worry that they could "catch" the condition or that they carry the gene so that their children will be disabled. They may resent the extra burden of caring for the brother or sister, which is placed on them at an early age and worry that they may have to take over long-term care. On the other hand, those children who have open communication with their parents were better at establishing relationships with friends. Later in life the sibling often feels that he/she benefitted because of the responsibility placed on them--they feel they understand that people are different and that they have learned how to manage difficult situations.

Children's reactions:People having a disability do not want to be labelled: e.g., the blind girl. They want to be known as an individual and to share experiences with others based on like interests. They want opportunities to be independent and to have access to transportation, jobs, and socialization. When they receive love and respect they develop self-assurance, which makes it easier for others to know them.

8.2 Coping styles

Caregivers, their family members, and their host families have built close and trusted connections as a result of their participation in Home Sharing / Short Breaks.

The Host Family, according to the parents, is a great step toward community inclusion.

For other parents, simply comprehending the gap between their desires for their child and the disability that exists exacerbates their emotional and cognitive efforts to adjust to the situation. They can be experiencing sadness, depression, or embarrassment. Some people may wonder "why me?" and believe they are being punished for past crimes or poor actions. Depending on the severity of the handicap and the size of the coping demand, some parents may consider suicide for their kids or for themselves. These sentiments indicate a universal desire to find inner serenity.

Recognize and embrace parental dominance as a normal part of the adjustment process and offer support. Adjustment, on the other hand, can hasten the acceptance process. It can, in turn, provide a majority of competent and supportive parents to aid educators and other associated workers in the difficult effort of satisfying all of the children's requirements.

Developmental disability refers to a range of conditions including intellectual disability, cerebral palsy, autistic spectrum disorder, learning disability, epilepsy, etc., Most childhood disabilities are referred to as developmental disabilities, defined as any physical or mental condition that may impair or limit a child's ability to develop cognitively, physically, and emotionally compared to other children. Most of the disabilities unlike physical, which are noticed at birth, get undiagnosed until a child enters a school. It is difficult for parents to identify a developmental disability as they are normally not aware about the developmental stages of a child and more so if it is their first child. Professionals often have difficulty diagnosing a specific disability at such an early age, so the term developmental delay is utilized to qualify a child for services in infant and preschool programs.

A disabled child's family adjusts on several aspects in life to suit his needs. The physical and mental stress associated with raising such children could be multimode. Caring for such children can be a physically and mentally tasking job, depending on the type of disability resulting in compromised quality of life (QOL) of the carers too. While treating and rehabilitating the disabled children, the needs of the carers are seldom thought about. It is quite possible that even the carers need help to cope with the physical, mental and emotional stress they bear while caring for their loved one. QOL as defined by the World Health Organization (WHO) is an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns. Coping strategies can be defined as “the cognitive and behavioral efforts required to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.”

Care that is given to a normal child itself is taxing for the parents many a times and to provide a higher level of lifelong care to a child suffering from long-term functional limitations may be strenuous for the parents and thereby may be affecting their QOL. Becoming the parent of a child who has some disability can be a time of great stress and change. The birth of a disabled child can influence the relationships of all the family members. It also requires a reassessment of the family functioning. Majority of family’s cope with the situation relatively well and are able to continue their life normally. However, coping with a physically or intellectually disabled child is a highly individual process, and there is evidence to suggest that some families may never adjust fully to this event. Coping requires a cognitive reappraisal of the situation to manage it properly. A number of studies have concentrated on the degree to which families with disabled children feel stress, how they manage, what factors support them, and what coping strategies they use.

Over the last 50 years, right to education has evolved in India inspired by a host of factors including judicial interpretations, enactment of special laws, and amendment to the constitution. The constitution of India has made education a fundamental right for all children including the children with disabilities in the age group of 6–14 years. Section 26 of Persons with Disabilities Act (1995) affirms the capacity of Indian state to afford free education beyond 14 years of age, particularly in the context of children with disabilities.

According to the Census (2001), there are 2.19 crore people with disabilities in India who constitute 2.13% of the total population. This includes persons with visual, hearing, speech, loco motor, and mental disabilities. Seventy-five per cent of persons with disabilities live in rural areas, 49% of disabled population is literate and only 34% are employed. The earlier emphasis on medical rehabilitation has now been replaced by an emphasis on social rehabilitation. Approximately 3–5% of the population of children experience or get affected with physical, intellectual, and mental health problems according to the National Health Survey.

The Persons with Disability Act, 1995 is built on the premise of equal opportunity, protection of rights and full participation. It provides definitions of disabled person by following the medical model. According to the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, “person with disability” means a person is suffering from not <40% of any disability as certified by a medical authority (any hospital or institution, specified for the purposes of this act by notification by the appropriate government).

It is also important to note that caring for a child with disability does not equally affect all parents. There are families who cope well despite the adversity. There could be number of factors that can affect the QOL of carers which could include severity of the disability of the child, presence of cognitive or behavioural problems, socioeconomic status of the families, lack of education, low social support, etc., Therefore, the following study has been undertaken to assess the QOL and also the kind of strategies used by the carers of disabled children.

The first stage

The parent may be taken aback and cry or get depressed. Parents may occasionally show their feelings through physical outbursts or inappropriate laughter.

The second stage

This is a continuation of stage one, and some parents may ignore or try to avoid their child's impairment in some other way. In an attempt to influence reality, some parents would look for or propose various actions. Some people may try to "negotiate" for a different reality or "shop for a cure."

The third stage

Parents may be enraged at this point. They may express their wrath in the form of rage, or they may withdraw and become inactive as a result of deep guilt feelings. It is normal for people to verbally attack anyone who they believe is to blame for their sad situation, including shifting the blame on the original diagnostician or any supportive professionals. If the parents are angry, guilty, or both, experts must recognize that this is a very positive step in the transition process and not become defensive if they are attacked.

The fourth stage

Parents come to terms with the knowledge that their child has a handicap. In some cases, one or more members of the family may become depressed. Shame, remorse, helplessness, and anxiety can all arise because of a new heavy burden of obligation. For some parents, withdrawing and attempting to hide their child, particularly from friends and strangers during structured or routine social interactions, may be the first sign that they have begun to accept their child's impairment. Any tendency toward or display of conduct that leads in abnormal isolation of one or more family members, on the other hand, must be avoided or removed.

The Fifth Stage

This is the acceptance stage, which means the parents have earned unconditional favorable regard for their child. Experts disagree about whether this stage of adjustment includes parents who simply accept their child's condition, known as neutrality, or a critical new stage of cognition in which parents not only learn to understand and appreciate their child, but also strengthen their skills in coping with life's challenges and in helping their child, themselves, and others. The school encourages parents to become team members in a program with caring professionals, and frequently paraprofessionals, that are structured to satisfy all the child's needs are highly connected with reaching this stage.

This is the sixth stage

Parents can reassemble their life and enjoy living again, anticipate a future, and speak freely about their kid. They may objectively discuss and participate in the design or delivery of instruction.

8.3 Family Counselling

Other complications can cause setbacks in adjustment, such as unanticipated experiences of being socially rebuffed by friends and strangers or being treated inappropriately by poorly informed educators, even after parents find acceptable ways to cope with their child and their lives by following a healthy path beyond acceptance of their child's disability. The arduous process of remaining in the highest degree of adjustment is only made more difficult by such recurring bad experiences. Parents, like professionals, are acutely aware of the inhumanity of those who show little or no empathy or compassion for disabled people or their caregivers. Parents and children commonly regress into states of anger, frustration, or other earlier stages of feelings and behaviors as a result of other people's actions rather than circumstances.

Most parents require assistance in order to go through the stages of adjustment in a positive and timely manner. At least until their child reaches the usual and customary developmental milestones, their progress toward a level of reasonable acceptance, closure, and reconstruction includes an accurate understanding of reality. Professionals can assist parents in finding a happy medium between their expectations and reality. For example, no need exists to engage in prediction about what a 4-year-old child will be able to do when s/he has reached the age of 21. While most parents want and need professionals to be honest as a condition of being seen as trustworthy and credible, they do not require information that is grim and full of doom and gloom.

As their child progresses through the stages of development, the majority of parents will come to comprehend the realities and ramifications of their child's success. This is especially true if parents believe that educators prioritize the needs of their children when creating educational and related services. These stages of grief, pain, and acceptance are not experienced by all parents. However, as professionals, we must be prepared to assist parents in navigating these stages if necessary.

Every family is different, with its own patterns and experiences, and every child's family is the most significant social institution. Family is defined as "interacting communication networks in which each member influences and is influenced by the characteristics of the family system". Adversity has the potential to either enhance or weaken family bonds. In the face of adversity, some parents and families adapt successfully and remain resilient. However, not all of them are successful in adapting. Adaptability is defined as a family's ability to adapt its rules, responsibilities, and power structure in response to situational and developmental stress, according to Olson's Model. In general, systems theory emphasizes circular causality – a concept that events are linked by a succession of interconnected loops. In these families, an undesirable pattern known as 'fusion and triangulation' might occur, putting the family's mental health at risk.

The interaction of experienced stress, available coping resources, and the ecological circumstances in which the individual family functions determines family adaptability. Parents are the foundation of the family and have a significant impact on their offspring. This emphasizes the necessity of dealing with special-needs families. Having a special kid is typically a watershed moment for parents, necessitating a paradigm shift in expectations and a shift in vision.

Parents of children with exceptional needs were interviewed. Children share life tales with themes that include an obvious trauma (child's diagnosis), followed by the parent either moving forward and solving/coping with these life difficulties or stagnating and at times regressing from where he or she started. It's critical to acknowledge the distinct set of parents who were able to cope effectively despite various pressures and to apply what we've learned to help and support parents who require assistance and good coping skills.

Being a caregiver is a challenging responsibility. Add disability into the equation, and it can exponentially strain the commitment. Such relationships can, however, also be very rewarding. I understand the intricacies of the dependent-caregiver relationship because I have a physical disability and require daily assistance to maintain a healthy lifestyle at home, which has proved to be very helpful throughout my career as a therapist and life coach.

For parents, physical caregiving usually ends when their child reaches the age of maturation—around age 18. But this is not always possible for children with chronic disabilities, who rely on 24-hour care.

While physical disabilities may not affect the individual's mental capacities, their physical needs can still be that of a young child. For example, I am a 24-year-old working woman. But in order for me to get to work and see my clients, I must first have assistance with dressing, preparing meals, transportation, and other daily needs. While such tasks can, at times, feel taxing and overwhelming for my mother or any caregiver, it’s extremely important for caregivers to monitor their attitudes toward the individuals who receive care.

The attitudes, emotions, and mindset of caregivers are easily transferred to the individuals who need care, and can have a significant impact on their mood and the way they view themselves. Negative emotions from caregivers may leave people with disabilities feeling like a burden, which can be detrimental to their mental and physical health and recovery. Caregivers can minimize negativity by maintaining their own physical and psychological health.

One way for caregivers to alleviate stress is to develop a strong support network of family and friends that can lend a helping hand or listening ears when caregivers become overwhelmed. There is nothing wrong with asking for help; at times, it is necessary.

Caregivers must also maintain healthy relationships with their spouses, partners, and other children. Ignoring these critical relationships leads to loved ones feeling alone and withdrawing from the caregivers—causing further burden and isolation. Sadly, many couples separate as a result of the strain. To avoid this, caregivers and their spouses or partners should set aside regular date nights when they can enjoy activities outside the home or have a romantic night in. Caregivers should also schedule time to spend with their other children who do not have disabilities. As they often think of themselves last, caregivers need time for themselves. Support systems should be called upon to temporarily care for the individual with the disability so that the caregiver can take this necessary time.

Maintaining open communication is critical for healthy relationships between caregivers and those receiving care. They should feel comfortable expressing their feelings and find a balance between care and having as 'normal' a life as possible. Compromising on the timing of care needs allows both individuals to enjoy other activities. For parents, it is often difficult to suppress their natural parental instincts once their dependent children achieve adulthood. An individual who still need needs physical care may have grown to be mentally self-reliant and wants to make decisions independently, without feeling constant parental judgment.

In my experience, the constant reliance on my parents was very challenging during my teenage years. I felt that I had no privacy. In a way, I felt trapped. I saw my friends getting older and gaining more independence from their parents, while I was still being picked up from parties by my mother. Unavoidably, our relationship has been affected in both positive and negative ways. I have some negative feelings about my lack of privacy; my parents feel constrained about their inability to come and go as they please. As an adult, however, I am grateful for the sacrifices my parents have made to give me a good life. Because of our family dynamics, we are a stronger, more open family and communicate very well with each other.

Seeking therapy or counselling is helpful to learning how to cope with giving and receiving care and maintaining healthy relationships throughout the process. In family sessions, therapists act as mediators and help caregivers and individuals with disabilities communicate their needs and feelings to one another, so that both sides feel respected. Caregiving is best with a team. Learning how to come together, share responsibilities, and maintain equality of attention leads to positive outcomes in health and overall happiness. With the right system in place, caregiving can bring families closer than ever with a tremendous amount of love.

The majority of adults and children with disabilities receive support for their daily living from a family caregiver. As such, families are and will continue to be the largest providers of care and support for individuals with disabilities in the United States (Larson et al., 2015). Because family members play an integral role in meeting the needs of individuals with disabilities, promoting family resilience has strong implications for health and wellbeing of all family members.

Despite the widespread acknowledgement of the importance of families in quality of life for people with disabilities, there is a concerning lack of guidance to define and identify best practices and policy for effectively supporting families (Burke, Lulinski, Jones, & Gallus, 2018; Hewitt, Agosta, Heller, Williams, &Reinke, 2013).

The practice of marriage and family therapy (MFT) inherently assumes the interdependence between personal and relational functioning as influenced by contextual factors. This clinical framework suggests M/CFTs are ideally trained to meet the unique needs of families of people with disabilities, Yet, the majority of MFT training curricula do not routinely address clinical training or supervision related to disabilities. As a result, many M/CFTs consider therapy with families impacted by disabilities as outside their scope of practice. Systemically informed professionals have an opportunity to play a key role in bridging the gap to address the growing need for accessible mental health services that support individuals with disabilities and their families by managing risks and enhancing resilience.

Individual and relational outcomes

While some families and relationships of individuals with disabilities develop strong coping strategies to function quite well (Bayat, 2007), research also illustrates that unique challenges can negatively affect the health and wellbeing of many families (Brown, Anand, Alan-Fung, Isaacs, & Baum, 2003; Greenberg, Seltzer, &Greenley 1993; Jokinen & Brown, 2011). Due to the added caregiving responsibilities that are necessary for individuals with disabilities, members of families affected by disabilities have an increased prevalence of physical, psychological, and relational distress (Brown, Whiting, Kahumoku-Fessler, Banford Witting, & Jensen, 2020; Pilapil, Coletti, Rabey, &DeLaet, 2017). Parents, spouses, and siblings of children with disabilities experience higher rates of mental health concerns such as anxiety and depression when compared to families of typically developing children (Marquis, McGrail, & Hayes, 2020). Caregivers in particular have higher rates of health problems and report a variety of physical symptoms like migraines, heart conditions, and sleep problems (Lee, Park, Matthews, & Hsieh 2017). These mental and physical health effects lead to reports of decreased quality of life and general wellbeing (Arora, Goodall, Viney, Einfeld, & the MHYPEDD team, 2020; Pilapil et al., 2017).

In addition to the physical and psychological outcomes of individual family members, families affected by disabilities are also affected by greater relational concerns. Parents of children with developmental disabilities face difficult and unique challenges to meet the needs of a child with a disability, which leads to greater marital and relational strain. Previous reports that suggested nearly 80% divorce rates among parents of children with disabilities have been shown to be misleading, as there are differences according to family size and child development stage. However, there is still a disproportionately high divorce rate among parents of children with a disability compared to parents of typically developing children when number of children was comparable (Namkung et al., 2015).

While parenting and co-parenting a child with a disability poses significant challenges, couples in which one or both partners has a disability also face unique relational difficulties. A growing area of clinical interest is dedicated to exploring couple therapy approaches that are appropriate for addressing the unique needs of adults with disabilities. Romantic partners of individuals with a disability experience similar trends in mental and physical health decline as parents. For example, neurotypical partners of people with autism spectrum disorder (ASD) experience physical health decline, negative self-image, and a profound loss of hope (Bostock-Ling, Cumming, & Bundy 2012; Lewis, 2017). Couple therapy approaches should address discrepancies in relationship expectations for adults with a disability and their romantic partners, as inconsistent relational expectations are associated with unmet emotional needs and poor relationship satisfaction (Parker & Mosley, In Press; Strunz et al., 2017).

Social support

Many of the adverse physical, mental, and relational health effects described by family members of individuals with disabilities are compounded by a lack of social support. Families often explain that there is a notable deficit in available social support, which they generally attribute to two main reasons: 1) family members' lack of free time to socialize with friends and family due to the added caregiving responsibilities, or 2) societal stigma associated with disabilities that may be attributed to personal shame and embarrassment of family members or the disapproval and ostracization by others (Recio, Molero, Garcia-Ael, & Perez-Garin, 2020). Unsurprisingly, caregivers of individuals with intellectual and developmental disabilities were disproportionately affected by the social distancing measures implemented during the recent COVID-19 pandemic. Not only were caregivers unable to access their already strained social supports, professional support services were also significantly reduced due to school and professional clinic closures (Chung, 2020; Willner et al., 2020). An unexpected outcome of the pandemic has been a surge in research that demonstrates promising findings in the evaluation of online platforms (e.g., Facebook) as a means of social support for caregivers. Clinicians working with families affected by disabilities can support caregivers by connecting them with appropriate online platforms to increase social support, which acts as a protective factor against the harmful effects of caregiver stress and burnout.

Although having a family member with a disability may result in greater demands on family resources, the presence of family coping strategies, social support, and community resources can effectively reduce the stress associated with having a loved one with a disability (Asberg, Vogel, & Bowers, 2007). Research indicates that access to social support and interventions that promote adaptation to meet everyday challenges helps families mitigate many of the negative effects often noted as outcomes in family research (Caldwell, Jones, Gallus, & Henry, 2018; Jones & Gallus, 2016; McConnell & Savage, 2015).

Despite the additional obstacles and challenges, parents also describe positive outcomes, such as patience, compassion, and family cohesion amidst the overwhelming struggles of caring for a child with a disability (Sim, Cordier, Vaz, &Falkmer, 2019). Greater resiliency is noted among families that are able to ascribe a positive meaning to adversity or seek the benefits of caring for a family member with a disability. It is therefore essential for M/CFTs to consider ways to identify and build on families' strengths and inherent competence to overcome the challenges they face.

Greater resiliency is noted among families that are able to ascribe a positive meaning to adversity or seek the benefits of caring for a family member with a disability.

Contextual influences and intersectionality

The conceptualization of intersectionality (Crenshaw, 1989) enables a complex understanding of the ways in which race, gender, class, sexuality, ability and other dimensions of social, cultural, and economic determinants intersect to shape daily life and social structures. Disabilities are an important, albeit often overlooked, representation of diversity and contextual considerations. Varied abilities and needs among individuals with disabilities are associated with differences in the experiences and challenges families encounter across the lifespan. As such, identifying associated contextual and social factors is critical for clinicians to conceptualize the impact of disability on individuals and families. However, the intersection of disability with other important sociodemographic factors are often overlooked. Due to diagnostic overshadowing of disabilities over other key elements, individuals with disabilities and their families are frequently assumed to share the same experiences, needs, and strengths regardless of gender, age, religion, socio-economic status or other determinants (Goethals, De Schauwer, & Van Hove, 2015).

Families of those with disabilities broadly experience financial strain due to added medical expenses and difficulty maintaining full-time employment outside of the home (Liu, Dokos, Fauth, Lee, &Zarit, 2019). The loss of income has a different impact on families according to other contextual factors that influence access to treatment. Families that maintain access to the necessary disability treatments despite the loss of income experience far fewer adverse outcomes in personal and relational functioning. Marginalized and underserved populations, such as racial/ethnic minority families or those living in rural communities, often experience even greater negative effects of caregiving due to lack of appropriate resources. For example, Hispanic and African-American youth are more likely to receive the appropriate frequency of necessary treatments if they are school-based (as opposed to healthcare clinics) services (Siller, Reyes, Hotez, Hutman, &Sigman, 2014). However, schools that are located in rural communities have fewer school-based services and are often deemed by the U.S. Health Resource and Services Administration as Health Professional Shortage Areas. Therefore, individuals with disabilities living in rural communities experienced disproportionately higher rates of unmet treatment needs (Karpur, Lello, Frazier, Dixon, & Shih, 2019). There is an opportunity for MFTs to support families who are disproportionately affected by disabilities by engaging in an expanding body of disability treatment research related to care coordination.

Coordinating care

Recent U.S. trends in disability-related specialty care, which we will discuss in further detail, are strongly associated with negative effects among family members by further limiting access to appropriate providers (Parker & Killian, 2020). In addition to providing routine support for daily living, family members of individuals with disabilities also assume a primary role in advocating for and accessing appropriate supports and services (e.g., education, transportation, healthcare). Among the common barriers to accessing effective supports and services for individuals with disabilities are the availability and affordability of care (Douma, Dekker, &Koot, 2006; Krauss, Gulley, Sciegaj, Wells, & Taylor, 2003).

The American Academy of Paediatrics (2014) has proposed that care coordination is a vital service that improves access to multi-provider treatments and supports the added challenges that family members of people with disabilities face. There are various, specialized disciplines that are focused on addressing the medical (e.g., neurology), psychological (e.g., applied behaviour analysis), and educational (e.g., special education) needs associated with disabilities. The growing trend toward decentralization of these disability subspecialties further limits access to treatment providers for many patients. Families must endure increasingly long wait periods for appointments and are often required to drive long distances to attend appointments. In extreme, but not uncommon circumstances, some treatments may not be available at all due to the growing number of healthcare provider shortage areas in the United States that disproportionately affect individuals with disabilities (Martinez et al., 2018). Barriers to accessing appropriate supports and services place an excessive burden on family resources (i.e., financial, time) that are strongly associated with adverse effects to caregivers’ mental and physical wellbeing (Pilapil et al., 2017; Parker et al., 2020).

8.4 Coordination with Multidisciplinary Team

Multidisciplinary teams consist of several members, each of whom plays a key role. For example, Lorraine is a special education teacher who serves several middle school students in an inclusion setting. One of her students, Charles, has a specific learning disability in written expression, along with type 1 diabetes. Charles's condition, classified as a health impairment, requires frequent monitoring and sometimes affects his learning.

Lorraine's role, in addition to providing and monitoring classroom and testing accommodations, is to serve as the leader of the multidisciplinary team. Lorraine manages the flow of information on Charles, writes or updates his Individualized Education Program (IEP), and schedules and leads meetings that concern him.

In addition to Lorraine, Charles's multidisciplinary team consists of his mother, his general education teachers, his physician, the school nurse, and the school counsellor. In key years, such as when Charles transitioned from elementary school to middle school, his multidisciplinary team also included the district's transition coordinator.

Charles' mother, as with any parent or guardian of a special education student, serves as his advocate. Sometimes, if a child's parent is unable to fulfil this role, an advocate is appointed to speak and act in the child's best interests. As her son's advocate, and with specific parental rights in the special education setting, Charles' mother has the role of approving or rejecting specific services for Charles.

Each one of Charles' general education teachers plays a contributing role on his multidisciplinary team by speaking to his current educational needs. They provide accommodations as prescribed in Charles' IEP and help Lorraine monitor his learning and progress.

While Charles' physician does not normally attend meetings, she monitors Charles' diabetes and health and provides information to the team. The school nurse aids Charles in monitoring his condition during the school day, communicating with Lorraine and his mother as needed.

Managing a chronic disease can be stressful for an adult, let alone a pre-adolescent. The school counsellor meets with Charles as needed to help him cope with the normal stresses of school, along with the daily strains associated with diabetes.

Procedures for Collaborating

Because so many factors can affect the success of a multidisciplinary team, procedures for collaboration are crucial. A key function of any multidisciplinary team is to collect and organize background information so that its members have a complete picture of a student's strengths and needs in order to make informed decisions.

Remember, Lorraine serves as the leader for Charles' multidisciplinary team. One of her main responsibilities is to help its members understand what information is needed and to facilitate meetings to discuss that information.

Organizing people in self-help groups serves different purposes, depending on the situation and the need. Such a forum can help people to be visible members of the larger community. Members can support one another through sharing information on referral services and other available resources, help make decisions on family and individual matters, etc. Self-help groups with the support of other such groups can advocate jointly to obtain services, aids, and equipment, and for integration into the larger community.

In case of disabled, the SHGs can be formed with 5 members. Many Exclusive SHGs possibly cannot be formed because of many reasons but inclusion of PWDs in normal group is very much possible. The SHGs are encouraged for saving within the range of Rs. 20 to Rs. 100/- and they rotate this common pooled resource within its members on minimum rate of interest. Each group usually has a leader called the President/Secretary. These leaders maintain the record of transactions, meetings etc and initiate steps for grading and financial linkages. As per PWD ACT, 1995; 3% reservation has been kept for PWDs under poverty alleviation programme. The SHGs of PWDs may be linked with Government schemes such as NHFDC SGSY, Mission Shakti & financial institutes like NABARD. Some funding agencies like CASHE, CARE, BASIX, Action Aid etc. are also supporting SHGs. Identification of feasible and viable venture, long term market, linkages, quality product and competitive rates are the key factors of success of SHGs.

NHFDC- National Handicapped Finance & development Corporation

SGSY- SwarnaJayanti Gram SwarojgarYojana

NABARD- National Bank for Agriculture & Rural Development

Summary

Disability places a set of extra demands or challenges on the family system; most of these demands last for a long time (Murphy 1982). Many of these challenges cut across disability type, age of the person with the disability, and type of family in which the person lives. There is the financial burden associated with getting health, education, and social services; buying or renting equipment and devices; making accommodations to the home; transportation; and medications and special food. For many of these financial items, the person or family may be eligible for payment or reimbursement from an insurance company and/or a publicly funded program such as Medicaid or Supplemental Security Income. However, knowing what services and programs one is eligible for and then working with a bureaucracy to certify that eligibility (often repeatedly) is another major challenge faced by families. Coordination of services among different providers (such as a physician, physical therapist, occupational therapist, dietician, social worker, teacher, and counsellor) who often are not aware of what the other is doing and may provide discrepant information is another challenge faced by families (Sloper and Turner 1992). While care coordination or case management is often the stated goal of service programs, there are many flaws in implementation. Families experience the burden of this lack of coordination.

Keywords

Coping styles, developmental disabilities, census, the persons with disability act, family counselling, relational outcome, autistic spectrum disorder, self-help group.

Self Assessment

1. Caregiving to the disabled person is challenging.
A. True
B. False

2. Denial may be found in the field of disability.
A. True
B. False

3. Section-28 of PwD Act, 1995 affirms that the capacity of Indian State to afford free education beyond 14 years of age.
A. True
B. False

4. According to Census 2001, there are 2.19 crore people with disability in India.
A. True
B. False

5. Families of disabled face family stress when the cost of medical apparatus is highly demanding.
A. True
B. False

6. Self Help Group can be formed with -------- members.
A. 3
B. 5
C. 7
D. 9

7. Some ------ is associated with disability.
A. Custom
B. Stigma
C. Task
D. None of them

8. Full form of MFT is-------

A. Mixed Male Female Therapy
B. Marriage and Family Therapy.
C. Male & Females Therapy
D. None of them

9. There are ------- types of caregivers.
A. 1
B. 2
C. 3
D. 4

10. Respite is a -------- for caregivers.
A. Recreation
B. Orientation
C. Compensation
D. None of them

11. Siblings feel --------- for the disabled.
A. Jealous
B. Guilty
C. Friendly
D. None of them

12. Coping of caregivers are ---------- parameter in disability.
A. Important
B. Unimportant
C. Casual
D. None of them

13. The Persons with Disability Act was published in --------
A. 1990
B. 1992
C. 1995
D. None of them

14. People with disability does not have -------- friends.
A. Good
B. Bad
C. Jealous
D. None of them

15. How many stages are there in QOL?
A. 4
B. 5
C. 6
D. 8

Answersfor SelfAssessment

1.	True	2.	True	3.	False	4.	True	5.	True
6.	B	7.	B	8.	B	9.	B	10.	A
11.	B	12.	A	13.	C	14.	A	15.	C

Review Questions

1. What are the families to illness?
2. Write a note on the epidemiology of the disabled people in India.
3. Briefly elucidate the stage of Quality of Life.
4. Discuss briefly about The Persons with Disability Act, 1995.
5. Write a note on Family Counselling.
6. What do you know about individual & relational outcome?
7. Explain social support for the PwD.
8. What do you mean by contextual influences and intersectionality?
9. Write a note on Coordinating Care.
10. How the caregivers can coordinate with Multidisciplinary Team?

Further Readings

- Quality of Life by Alison Carr, et. al. BMJ Books.2002
- Quality of Life- An Interdisciplinary Perspective by ShrutiTripathi, et. al. CRC Press,2022.

Unit 09: Models of Rehabilitation

CONCEPTS

Objectives

- To understand different models of Rehabilitation
- To know the implementation of these models.
- To familiarize with the interrelation of these models with regard to Rehabilitation.

Introduction

Rehabilitation is the process of supporting a person in reaching his or her full physical, psychological, social, vocational, and educational potential while taking into account his or her physiologic or anatomical disability, environmental restrictions, as well as his or her desires and life plans.

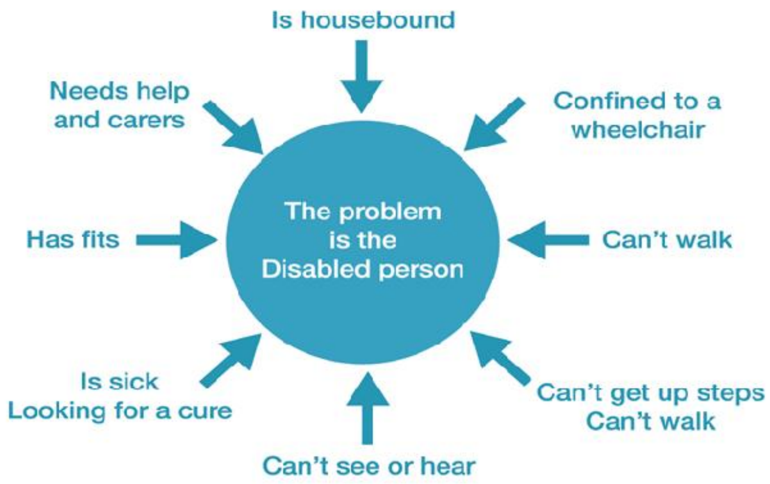
According to WHO, "Rehabilitation is the combined and coordinated use of the medical, social, educational, and vocational measures for training and re-training the individual to the highest possible level of functional ability

Models of rehabilitation are, the medical model, psychological model, socio-culture model and institutional model.

9.1 Medical Model of Rehabilitation

In the field of medical science, the medical model of disability came into prominence. The medical model is also known as the biomedical model; Disability is viewed as an illness or medical problem that affects an individual. This paradigm of disability is also known as the personal-tragedy model.

The Medical Model of Disability



This is a diagram of the traditional Medical Model of Disability, which the Social Model was developed to challenge.

The medical model of disability focuses on the medical components of a disability and attempts to "cure" a person of their condition so that they can return to a functional state as closely as feasible. This has been a popular way of thinking about disability in the past, and it continues to be so now. Instead of the problem being with the environment around them, the fault being with the person who has the condition. Medical practitioners are the ones who can heal the effects of a disability using things like prosthetics, surgery, and drugs.

- The medical model and the rehabilitative model are inextricably linked. It is based on the notion that if a disabled person makes an effort and works with rehabilitative services, they will be able to overcome their handicap.
- Many disabled people, as well as disability studies experts and advocates, criticise this paradigm for its limited vision of people's whole lives, both despite and because of their impairment. Many disabled persons believe that their impairment is an intrinsic part of their identity, rather than something that can be fixed. The social model of disability frequently criticises the medical paradigm.

9.2 Psychological Model of Disability:

The psychological impact of disability Models that attempt to explain the emotional reaction to impairment rather than the disability itself are likely the most commonly utilized in psychology studies of disability. The following models were used:

life-events models, in which the emotional response to the life. event that precipitated the impairment/disability is investigatedmental health models, in which disorder rates are analyzed

Disability is viewed as a stressor in stress models, with high levels of anxiety elicited by residents.

People with mental illness and other psychiatric concerns sometimes need help in different aspects of their lives—including work, living, social, and learning environments. One approach that can help these individuals manage symptoms and improve functioning is known as psychosocial rehabilitation.

Psychosocial rehabilitation is a treatment approach designed to help improve the lives of people with mental illness. Its goal is to teach them emotional, cognitive, and social skills to help them live and work in their communities as independently as possible.

Regardless of what form psychosocial services take, core goals include helping people feel:

Empowered: Each individual needs to feel that they are able to set their own goals and have the power and autonomy to pursue those aims.

Hopeful:People may be left feeling demoralized as a result of their condition. Rehabilitation focuses on helping clients feel hopeful about the future.

Skilled:Rehabilitation aims to teach people skills to help them manage their condition and live the life they want to live. This includes life skills, work skills, social skills, and others.

Supported:Mental health professionals offer support and help clients build relationships and social connections in their community.

Psychosocial Rehabilitation Principles

There are a number of key principles of psychosocial rehabilitation that help guide how mental health professionals working in this field approach their work.4 These principles include:

All people have potential that can be developed.

People have a right to self-determination.

The emphasis is on the individual's strengths rather than their symptoms.

Each person's needs are different.

Professional services should be committed and take place in as normalized an environment as possible.

There is a focus on a social model of care (as opposed to a medical model).

It is centered on the present rather than fixated on the past.

Psychosocial rehabilitation treatments are multidisciplinary and often biopsychosocial in nature. This perspective recognizes that mental illness impacts multiple areas of life, including the biological, social, and psychological systems.

Not only are each of these systems affected by mental health, but they are also inextricably interlinked. When something affects one area, it is bound to have an influence on other areas aswell.

In light of this, psychosocial rehabilitation takes a whole-person approach and recognizes that other mental health professionals and physicians may be needed to make contributions to the treatment process. Individual care may require a mixture of services and effective treatment.

For example, a person with a mental illness may need psychosocial rehabilitation services that target basic living and social skills, but they might also need treatment involving medication and psychotherapy. The treatment of their condition targets the person’s specific symptoms, while rehabilitation focuses on the recovery and reintegration process.

Who Can Benefit from Psychosocial Rehabilitation?

Many people can benefit from psychosocial rehabilitation, but not all people with mental illness require it. For some, medication, therapy, or a combination of the two may be sufficient to restore functioning. Rehabilitation can be useful when people need additional recovery assistance to help them restore functioning.

Those who might benefit from psychosocial rehabilitation include:

People who need help restoring their full functioning after treatment

Those who are disabled and need ongoing assistance in multiple life domains

Individuals who, while functional, feel that they need a boost of support and assistance

People who lack the supportive environment and resources they need to achieve full functioning

People with chronic and severe psychiatric conditions can benefit from psychosocial rehabilitation services. It can help them learn basic skills that allow them to function and cope with their condition. People with intellectual and cognitive disabilities can benefit from gaining life, social, and self-care skills.

The time following the diagnosis of a mental health condition is a period of major transition. Patients may lose some functionality but new approaches may allow them to manage their condition better. Their illness may have made it difficult to go to school or work, or to maintain supportive relationships with others. Many aspects of life can be affected, including the person's employment status, housing situation, and family life.

Once the underlying condition has been addressed through treatment, psychosocial rehabilitation focuses on helping people find the skills and support they need to live full, satisfying lives.

Approaches Used in Psychosocial Rehabilitation

Psychosocial rehabilitation is based on the idea that people are motivated to achieve independence and are capable of adapting in order to achieve their goals.

To achieve this, psychosocial rehabilitation uses a combination of evidence-based best practices and emerging, promising practices. No matter what the specific strategies are, the focus is on restoring social and psychological functioning.

Specific psychosocial rehabilitation treatments can vary considerably from case to case depending upon a person's needs and the resources available. The process is highly individualized, person-cantered, and collaborative.

Effective rehabilitation involves a comprehensive plan that addresses the client's life and functioning. A psychosocial rehabilitation professional is usually only one part of the process. The plan is often overseen by a psychiatrist, clinical psychologist, or licensed counsellor and typically involves working with the client individually and in community settings.

Builds on Strengths

Rather than simply focusing on areas of weakness, psychosocial rehabilitation focuses on empowering clients and building on their existing capabilities. These abilities help form a foundation upon which other important life skills can be developed through observation, modelling, education, and practice.

Some specific areas that psychosocial rehabilitation might address include skills, training, and experiences designed to boost:

This might be accomplished through one-on-one educational sessions that focus on specific skills, or it might involve incorporating training and experience in other life domains such as cooking or recreation. Such experiences allow people to practice their abilities in a safe environment, with supervision and support from a psychosocial rehabilitation professional.

Is Holistic

This type of rehabilitation strives to address areas of the person's life that contribute to their overall physical and psychological well-being. Professionals who work in this field provide a range of individual and community-based psychological services.

In determining each patient's needs, mental health professionals look at the physical and social environment, develop a service plan, and collaborate with other professionals.

Psychosocial rehabilitation providers look at each client's situation and help determine what they need to live and function as independently as possible. This frequently involves locating those services in the community and coordinating their delivery.

Is Person-Oriented

The client plays a role in setting goals for what they hope to accomplish in psychosocial rehabilitation. Each client's goals are individualized based upon their specific needs or concerns.

The rehabilitation process is not about the therapist deciding what the client's goals should be. Instead, the client determines what they want to achieve. The focus is then on providing the support and resources they need to make these goals a reality.

Psychosocial Rehabilitation Activities

Psychosocial rehabilitation activities include those related to basic living skills, family relationships, peer and social relationships, employment, education, recreation, health, and wellness.

Work

Working is beneficial for mental wellness and can help people feel productive, which is why vocational assistance is an important component of psychosocial rehabilitation.

Finding and maintaining work can often improve social connections, boost self-esteem, and improve one's overall quality of life.

Psychosocial rehabilitation workers can assist clients with finding and maintaining employment. This might include helping clients develop vocational skills, connecting the client to employment services in the community, assisting with career planning, and providing transportation assistance.

Another activity related to this aspect of the psychosocial rehabilitation process is assistance with filling out job applications or practicing job interviews. In other instances, clients may work in temporarily or supported work settings where they are able to develop and practice skills.

Housing

Psychosocial rehabilitation may involve connecting clients with safe, affordable, and appropriate housing. Clients may live independently in their own homes or in family homes. Other housing situations may include group homes, residential services, and apartments.

Depending on the client's needs. housing support exists on a continuum. It ranges from fully staffed, round-the-clock supportive care to minimally staffed or fully independent living.

Relationships

Social skills and interpersonal functioning are important parts of psychosocial rehabilitation. Skills training may focus on activities designed to help clients better function in their social worlds, including family, work, school, friendships, and romance.

This is accomplished by teaching skills related to emotional understanding, interpersonal problem-solving, verbal and conversational abilities, and nonverbal communication.

Community Functioning

One of the overriding goals of psychosocial rehabilitation is to help those with mental illness become better integrated within their community. Rehabilitation professionals often work with clients in community settings and locations.

For example, a child receiving psychosocial rehabilitation services may work with a mental health professional in school settings, but also spend time on social outings to local businesses, doctor's offices, libraries, and other locations. Practicing social and life skills in these settings allows the child to gain experience and rehearse interactions they might face as part of daily life.

Effectiveness of Psychosocial Rehabilitation

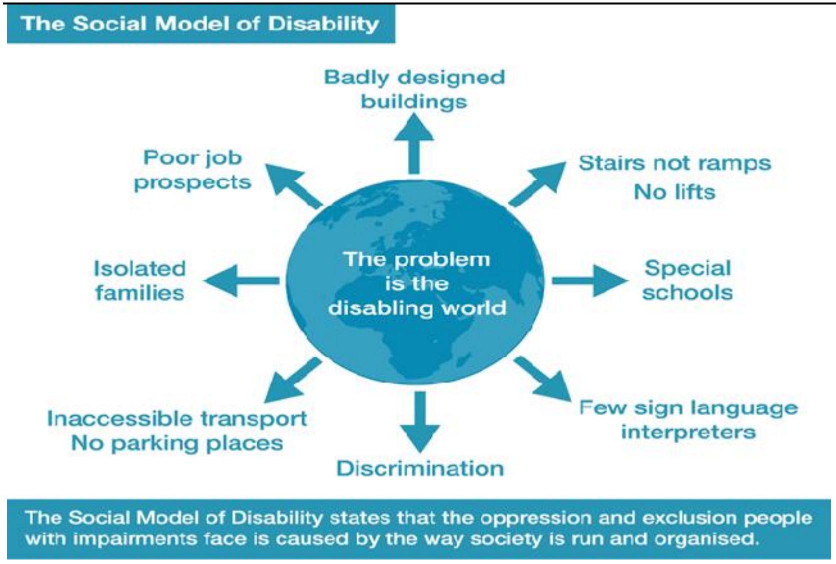
Research investigating the outcomes and effectiveness of psychosocial rehabilitation treatments is still ongoing, but there is evidence indicating these approaches have an overall beneficial effect.

Can Improve Life Skills

A study of patients with schizophrenia and affective disorders found that psychosocial rehabilitation was linked to significant benefits in a variety of areas—including family relations, communication, community participation, self-care, money management, transportation, and vocational abilities.

9.3 Socio-Cultural Model of Disability

The social model of disability is a way of looking at the world that disabled people have created. People are disabled, according to the social model of disability, by societal impediments such as buildings without a ramp or accessible toilets, or by people's attitudes, such as presuming people with disabilities can't perform particular things. The social model assists us in identifying obstacles that make living more difficult for people with disabilities. By removing these barriers, people with disabilities gain more independence, autonomy, and choice.



The Social Model of Disability

The Social Model of Disability states that the oppression and exclusion people with impairments face is caused by the way society is run and organised.

It claims that people have impairments, but that oppression, exclusion, and prejudice experienced by persons with impairments are caused by the way society is administered and organized, rather than by the impairment itself. The social model helps us recognize barriers that make life harder for people with disability. Removing these barriers creates equality and offers people with disability more independence, choice and control. The Social Model not only recognizes society as a source of disability, but it also gives a framework for describing how society goes about impairing people with disabilities. The Social Model, often known as a "hurdles approach," is a "route map" that identifies both the barriers that hinder persons with disabilities and how these barriers might be removed, mitigated, or countered by other types of support.

Barriers in social models:

Language:

Language encompasses far more than just words. It represents our society, our viewpoints, and even our actions. The Social Model rejects phrases like 'handicapped,' 'wheelchair-bound,' and'retarded,' because they promote negative stereotypes about disabled people and, more importantly, portray them as powerless victims. Instead, it concentrates on terms like "disabled person" and "wheelchair user.”

Physical Barrier:

Physical hurdles that disabled people’s experience on a daily basis include the lack of lifts, poorly constructed buildings, and the use of stairs rather than ramps. That's before we consider poor lighting, a lack of parking spaces, inconvenient public transportation, poorly maintained public spaces, and inaccessible toilets and homes.

Attitude Barrier:

These are social and cultural attitudes and assumptions about people with disabilities that explain, justify, and perpetuate prejudice, discrimination, and exclusion in society; for example, assumptions that people with certain disabilities can't work, can't be independent, can't have sex, shouldn't have children, need to be protected, are "childish," "dangerous," should not be seen because they are upsetting, are scroungers, and so on.

Communication:

These include information and communication challenges, such as the dearth of British Sign Language interpreters for Deaf individuals, the lack of hearing induction loops, and the lack of information in various accessible forms such as Easy Read, plain English, and large print.

9.4 Institutional Model:

This model emphasizes institutional, environmental and attitudinal discrimination as the real basis for disability. Thus, it is the society at large which disables the person with disabilities through discrimination, denial of rights, and creation of economic dependency.

Institutional based rehabilitation sets the policy and directions with care standards of homes for children and young persons with rehab or disability-related cases. The care framework in the rehabilitation aims to guide and support the patients at every step, from the homes to their re-entry into the society. Rehabilitation is acknowledged as an opportunity when self-care, family support arrangement, and community options are not enough.

The role of rehabilitation is viewed as a significant help for a person to improve his overall mental and emotional behavior. It offers intervention programs which follow an institution-based rehab that aims to equip the person with life skills and knowledge to handle personal issues. It is the institution's goal to help the patient to function in everyday life.

Institutional Based Rehabilitation Services

Rehabilitation Process – The rehabilitation process and social reintegration preparation phases extend beyond its functions. The process helps the patient restores the respective areas of his life. It allows him to integrate fundamental factors that affect his decision making and commitments. It brings back the individual's sense of responsibility to his families, school and society. The process enables him to have a smooth transition back to his healthy way of living.

Institutional Rehabilitation Aftercare Services –After the rehabilitation process, the patient is given proper support and monitoring, provided with the help of his family. The aftercare service continues to provide service that takes care of the person's mental, emotional, and behavioral alterations. This type of service tries to reinforce positive values that assist in the reintegration of an individual's life back to his home and community. Not only the process helps him understand the things he needs to do, but it also gives him the chance to get jobs and rebuild their relationship with respective families.

Institutional Rehabilitative Strategies– Two key strategies are part of this service. First is the holistic assessment. This strategy assesses the patient in three areas such as education, personal mastery, and socio-emotional development. With the use of the relevant tools, these services objectively and efficiently identify the needs and risk factors of the patient. These set of tools are supervised timely with specific interventions through the creation of individual care plans in every core area that need assessment. The second strategy is the Individual family and work. The family members are brought together with the patient to conduct a formal conference. This strategy allows both sides to address their behavior that needs to be altered to adjust their relationship for the better.

Institutional Rehabilitation Programs -This program primarily focuses on essential factors such as therapy, holistic education, personal mastery of habits and self–discipline. In the therapeutic program, the service motivates the patient to rethink everything, assess reasoning, react to sessions and manage relationship building. For the education program, the service provides sessions for restoring self-belief and strengthening the foundation for future learning. The personal mastery of habit focuses on strength and weaknesses. It broadens horizon, adapts to skills, and explore opportunities. And self-discipline manages to evaluate the person's overall capability to adjust to stressful situations.

Restorative Institutional Rehabilitation – This program focuses on restoring lives, empower transformation and recreate the patient's future. It possesses a multidisciplinary approach in its work that draws plans from a variety of fields such as psychology, education, criminology, and social work.

Institutional rehabilitation plays a significant role towards re-establishing the life of its patient back to the society. It provides a safe environment for improvement and a foster care program during the rehabilitation process. The institution maximizes the strength and potential of its patient, not only for himself but also for his families and the community.

Summary

Models assist understanding by allowing one to examine and think about something that is not the real thing, but that may be similar to the real thing. People use a variety of models to obtain a clearer understanding of a problem or the world around them. Such models include physical models, three-dimensional graphical models, animal models of biological systems, mathematical or ideal models, and computer models. When relationships are highly complex, however, as they are in rehabilitation processes and other areas of human endeavor, it is seldom possible to develop models that are quantitatively predictive. Nevertheless, it is often possible to establish rough relationships between various variables that are observable.

Models based on partial knowledge are often called conceptual models. Conceptual models may help people to think about behaviors of components in complex systems, even though they may not yield quantitative answers. They may allow one to understand general relationships without the necessity for an extensive verbal or written description. In this way they are like an out-of-focus picture that partially reveals relationships. It is common in science and engineering to use models to help develop hypotheses that can be examined experimentally, but even as models assist scientists in moving forward with new understanding, they are abandoned for new versions. Experimental results may suggest that the models must be altered or even abandoned in favor of new models.

The prevailing wisdom about the causes of disability has changed in the last several decades. In the 1950s, impairment of a given severity was viewed as sufficient to result in disability in all circumstances; in contrast, the absence of impairment of that severity was thought to be sufficient grounds to deny disability benefits. Thus, the American Medical Association's Committee on Medical Rating of Physical Impairments stated that "competent evaluation of permanent impairment requires adequate and complete medical examination, accurate objective measure of function, and avoidance of subjective impressions and nonmedical factors such as the patient's age, sex and occupation" (American Medical Association, Committee on Medical Rating of Physical Impairment, 1958).

Keywords

Rehabilitation, Medical Model, disability, psychosocial rehabilitation, holistic, person-oriented, social rehabilitation, socio-cultural model, barrier, institutional model,

Self Assessment

1. There are four models of Rehabilitation.

A. True

B. False

2. Medical Model is also known as biomedical model.

A. True

B. False

3. Medical Model deals with emotional reaction to disability.

A. True

B. False

4. After care centre is related to Institutional model.

A. True

B. False

5. All Models are not conceptual Models.

A. True

B. False

6. Rehabilitation is a process of --------- a person.

A. Supporting

B. Segregating

C. Neutralizing

D. None of them

7. ------- Model is known as Personal Tragedy Model.

A. Psychological
B. Institutional
C. Socio-Cultural
D. Medical

8. There are ------ goals of Psychological Model.

A. 1
B. 2
C. 3
D. 4

9. -------- Model is highly individualized.

A. Psychological
B. Institutional
C. Socio-Cultural
D. Medical

10. ------- Model is a way of looking the world what the disabled people have created.

A. Psychological
B. Institutional
C. Socio-Cultural
D. Medical

11. There are ----- barriers in social model.

A. 2
B. 4
C. 6
D. 8

12. There are ---- kinds of services in Industrial Model.

A. 2
B. 3
C. 4
D. 5

13. All Models are known as-------- Model.

A. Effective
B. Conceptual
C. Experience
D. None of them

14. -------- Model was to cure a person so that he can come to functional state.

A. Psychological
B. Institutional
C. Socio-Cultural
D. Medical

15. ------- Model deals with the emotional reactions to impairment.

A. Psychological
B. Institutional
C. Socio-Cultural
D. Medical

Answersfor SelfAssessment

1.	True	2.	True	3.	False	4.	True	5.	False
6.	A	7.	D	8.	D	9.	A	10.	C
11.	B	12.	D	13.	B	14.	D	15.	A

Review Questions

1. What is the role of Models in Rehabilitation?
2. Briefly elucidate the Medical Model.
3. Write the salient features of Psychological Model.
4. What are the characteristics of Socio-Cultural Model?
5. Briefly narrate the Institutional Model.
6. What are the barriers of Socio-Cultural Model of Rehabilitation?
7. How these Models help the disabled persons in dealing with the coping in daily activities?
8. What are the initiatives are taken by WHO in executing these Models?
9. What the roles of caregivers in these Models?
10. Which Model of Rehabilitation is the best to your view? Why?

Further Readings

- Quality of Life by Alison Carr, et. al. BMJ Books.2002
- Quality of Life- An Interdisciplinary Perspective by ShrutiTripathi, et. al. CRC Press,2022.

Unit 10:CommunityBasedRehabilitation

CONTENTS

Objective

- To understand the concept of Community Based Rehabilitation
- To familiarize with the goals and components of Community Based Rehabilitation
- To know the role of professionals and community in Rehabilitation

Introduction

Community Based Rehabilitation (CBR) is a local area improvement technique that targets at upgrading the living of people with disabilities (PWDs) in their community. Community Based Rehabilitation was started by WHO under the Declaration of Alma-Ata in 1978 to upgrade the QOL for individuals with PwDs; meet their essential requirements; and guarantee their consideration and cooperation. While at first a methodology to expand access to recovery administrations in asset compelled settings, CBR is presently a multi-sectoral approach attempting to work on the evening out of chances and social consideration of individuals with handicaps while battling the unending pattern of poverty and incapacity. CBR is carried out through the joined endeavors of individuals with inabilities, their families and networks, and pertinent government and non-government wellbeing, instruction, professional, social and other services.

10.1 Goals of Community Based Rehabilitation

Advocating &creating awareness: PwDs get the equal rights to take part in every economic project also they can possess an ability to access services in microfinance & business advice.

Pre-vocational training:Measures are generally executed to assist schools & educational institutes to provide good quality education/ training to persons with disabilities. Pre-vocational training helps to improve their basic knowledge other than developing the quality of theoretical education.

Vocational training:All NGOs of disabled people and government bodies help to organize vocational training programmes to enhance the practical skills & knowledge of the people with disabilities.

Self-employment:CBR programme targets to offer self-employment scope by taking some initiatives such as business advice, microfinance & provisions for loans.

Mainstreaming: Mainstreaming of training programmes is a primary goal of CBR. This can empower the people with disabilities within the community to access as well as integrate into the inaccessible programmes for work & vocational training.

10.2 Components of Community Based Rehabilitation

Making positive attitudes towards PWD's: CBR is very important for ensuring the equalize the opportunities for PwDs. A positive attitude among the community members can be created by making them involved in the method of design & execution of the programme, and by transferring of the knowledge about the different disability issues to the members.

Providing functional rehabilitation services: The majority of persons with disabilities require support in order to reduce or eliminate the impact of functional disabilities or restrictions. Community-Based Rehabilitation, must provide the ultimate solutions in some communities where professional treatments are not available.

Making macro and micro income-generation opportunities:PWDs have a constant desire to participate in macro and micro income-generating activities. They also require financial credit from a variety of existing systems. Income-generating activities in rural communities and villages must emphasize proper vocational skills.

Developing training and educational opportunities: People with disabilities are entitled to the same educational and training opportunities as everyone else. These opportunities enable them to remain content in society. Professional services may be unable to establish these opportunities in some communities; CBR trainers should be able to provide basic levels of assistance to people with disabilities in those communities.

Providing care facilities:CBR communities offer a variety of services to persons with disabilities who have no family or friends, or whose relatives are incapable of caring for them. These amenities assist them in surviving in society. Day-care facilities are available for relief families who work or require recreation for any other reason.

Prevention of disabilities:The most important strategy to avoid the causes of impairments is to eat well. Disabilities can also be reduced by recognizing any type of disability in children and intervening early in their development to reduce the impact of their handicap.

Monitoring and evaluation:The efficiency and efficacy of all components of a CBR programme, which exist both within the community and in service delivery areas outside the community, is dependent on the management's effective practices. These operations should, in general, be measured on a regular basis, and personnel should be well-versed in management techniques. To ensure that the program's objectives are realized, data should be collected, examined, and appraised.

10.3 Role of Professionals

As a community rehabilitation specialist, you'll help people discover their strengths while also recognizing and responding to their limits. The goal is to help patients live and work more independently after suffering from a debilitating illness or disability. This could include assisting people in obtaining housing, social activities, jobs, and other life skills that will help them gain independence as they recover from their injuries.

You'll work with people from various walks of life, including wounded employees, military veterans, adults with learning difficulties, deaf or blind people, physically challenged persons, people with mental health issues, and people who are addicted to drugs or alcohol. You'll also collaborate with other health-care professionals, such as social workers.

Professionals' Participation in Cbr Programmes

yourself to be one, or not? What are the good things about professionals?

What things are not so good? To what extent do you fulfil these criteria?

Which of the people you work with, are professional and what makes them different from the others? What do you have in common with these different groups? Could you aspire to change yourself and your activities, to match those of the people you admire the most? Do you want to be considered a professional at all? If so, why? If not, why not? The responses to the above questions reflect the definition adopted for a professional, which according to the Oxford English Dictionary, is a person who follows an occupation or 'calling', together with other people who have the same 'calling'. It assumes a similar educational experience with jointly maintained standards and involves using thisknowledge and skills to earn a living. Using these criteria to examine the professional status of CBR workers, I think we would all agree that they have a common occupation or calling, and most use their knowledge and skills to earn their living, some of course, are volunteers. But do CBR workers have a similar educational experience with jointly maintained standards? Perhaps the more important question we need to ask here is, is it desirable for CBR workers to have a similar educational experience with jointly maintained standards, or is their diversity and flexibility their strongest ingredient?

Another question we might like to consider is: if CBR became a profession in its own right who would benefit most? the CBR professional or the people with disabilities? For most of the present century it has been considered 'honorable' to be a professional. Traditionally, professionals work hard, serve other people, can be depended upon for their good judgment and can be turned to, for help, in times of trouble. Many CBR programmes were and still are, started by established professional groups such as therapists, doctors, and teachers. Many CBR programmes are run by professionals and controlled by professionals. BUT IS THIS A GOOD THING?

Advocacy has been mentioned as a suggested activity throughout the CBR guidelines. Advocacy can be undertaken in different ways and by different people, e.g., self-help groups or disabled people's organizations might advocate as a group to influence decision-makers to create change and ensure inclusive policies and programmes for people with disabilities. This element however focuses on self-advocacy, meaning individuals speaking up for themselves.

Successful advocacy depends on important messages being communicated and heard. However, many people with disabilities experience barriers to communication, so frequently their voices are not heard and they have few opportunities to influence decisions on the issues, policies and services that affect their lives. The Convention on the Rights of Persons with Disabilities highlights the importance of communication for people with disabilities. Article 9 calls on States parties to ensure that persons with disabilities have access on an equal basis with others to" … information and communications, including information and communications technologies and systems …" and Article 21 confirms the right to" … freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice …".

Self-advocacy and effective communication are an important part of the empowerment process for people with disabilities. This element highlights the important aspects of each of these and provides basic suggestions for activities which can be carried out by CBR programmes.

10.4 Role of Community

The ability to fully be a part of their community is the most significant benefit of community inclusion for people with disabilities. People with disabilities are kept engaged in community integration programmes, which give them opportunities to learn, work, and play alongside their peers. You'll work with people from various walks of life, including wounded employees, military veterans, adults with learning difficulties, deaf or blind people, physically challenged persons, people with mental health issues, and people who are addicted to drugs or alcohol. You'll also collaborate with other health-care professionals including social workers, physiotherapists, and speech pathologists to provide comprehensive care. Individuals with disabilities who participate in the community are able to interact with others and move around independently. People with impairments are more likely to acquire mental diseases such as depression, anxiety, and dementia as a result of social isolation and loneliness. People with impairments build a network of support systems through community engagement, which helps them avoid mental diseases.

The community-based rehabilitation (CBR) matrix, which was described in the introduction, consists of five components (Health, Education, Livelihood, Social and Empowerment) and their associated elements. It provides a basic framework which can be used to develop new CBR programmes. Even though a common matrix now exists, each CBR programme will continue to demonstrate unique differences because it is influenced by a wide range of factors, e.g., physical, socioeconomic, cultural and political factors. This chapter will be a guide for programme managers to provide a basic understanding of how to select the components and elements for a CBR programme, which are relevant and appropriate to local needs, priorities and resources.

While all CBR programmes are different, there is a universal sequence of stages that help to guide their development. These stages are usually collectively referred to as the management cycle, and comprise: Situation analysis (Stage 1), Planning and design (Stage 2), Implementation and monitoring (Stage 3) and Evaluation (Stage 4). This chapter will describe the management cycle in more detail to help programme managers understand the important aspects of each stage and to develop effective programmes that are inclusive of all key stakeholders and ultimately meet the needs of people with disabilities and their family members.

Please note that this chapter does not present a fixed approach which every CBR programme must follow. Because programmes are often developed through partnerships with others, e.g., governments or funding bodies, these may provide the necessary guidelines about how programmes are to be developed. In addition, while this chapter focuses mainly on the development of new CBR programmes, it will also be useful for strengthening existing ones.

10.5 Ethical Issues

People with disabilities (PWD) are more likely than others to live in poverty, not participate in their communities or in the workforce, and be denied access to basic rights.1–3 In many contexts around the world, PWD have limited institutional supports and resources available to them as they seek to meet their daily needs and develop the full range of their capabilities, and recognizing these realities prompted the development of the community-based rehabilitation (CBR) approach. Emerging from a World Health Organization (WHO) proposal after the 1978 International Conference on Primary Health Care and the Declaration of Alma-Ata, it has since become a widespread development practice that aims to support PWD, particularly in settings in which institutional rehabilitation programmes are ineffective or not widely available.4 In 2004, the International Labour Organization; the United Nations Educational, Scientific, and Cultural Organization; and WHO endorsed an updated definition of CBR as "a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities." Diverse commentators have proposed conceptions of CBR that emphasize elements such as the promotion of human rights, the balancing of fundamental power inequalities, and the fulfilment of basic needs.

Alongside evolving definitions of CBR, there has been a lively discussion of the purpose, principles, and commitments that underlay CBR programmes and practices. Several authors have identified a range of ethical considerations as being important for the CBR model and for the implementation of CBR projects. A key contribution to the analysis of ethical issues in CBR was a 2002 article by Turmusani and colleagues,1 which canvassed ethical issues for CBR in low- and middle-income countries. Ethical considerations have also been raised by other authors writing about the practice, policy, and politics of CBR, as well as its evidence base.10–13 In light of the continued evolution of the CBR movement and ongoing discussions of CBR ethics, we reviewed the academic literature related to CBR to investigate how it addresses ethical considerations.

This commentary provides both theoretical and practical insights into the concept of community-based rehabilitation (CBR) and its application in developing countries. In doing so it explores current practices in CBR and the debate surrounding them, namely the ethical question and how this may impact on future CBR. The main argument in this account is that disability is a development issue; with widespread poverty, inequality and violation of human rights, and should be addressed within the broader context of community development which may include strategies such as CBR. A review and analysis of recent literature on CBR has been conducted including the review of a number of empirical research documents from various CBR initiatives in developing countries. CBR has increasingly been under scrutiny in terms of the extent to which these have succeeded in delivering rehabilitation services to those in need in the community as well as the permitted level of participation and control of disabled people over the rehabilitation process. Many programmes have been unsustainable and it has been difficult to evaluate their full usefulness to disabled people. These issues raise an ethical question about CBR being an appropriate strategy for the rehabilitation of people with impairments in developing countries. This background emphasizes that new directions in CBR need to be put in place in order to maximize the realization of the ultimate goal: the greatest participation for disabled people in all spheres of life. Effective rehabilitation programmes should allow people with disability to have greater control in the nature of their rehabilitation and that the role of professionals and other stakeholders is one of allies and resources in the rehabilitation process. Moreover, the participation of community members in the rehabilitation policy should be assured.

Physiatrists are rehabilitation specialists trained to care for patients with complex medical conditions, including brain injury, neuromuscular disorders, spinal cord injury, musculoskeletal injuries, pain syndromes and cardiopulmonary disorders. As the leader of an interdisciplinary team, physiatrists are accustomed to actively engaging multiple clinicians simultaneously and empowering patients in key decision-making processes. Because this unique paradigm is not typically employed in other areas of medicine, it is imperative that physiatrists have a firm understanding of the possible ethical scenarios they may encounter. This article will provide an overview of bioethical principles and how they are applied within the field of physical medicine and rehabilitation.

In 1978, the Belmont Report was published which outlined three main bioethical principles which ultimately became accepted by all medical fields

Respect for persons (autonomy for those with decisional capacity and protection for those lacking capacity)

Benevolence and non-maleficence (do good, do no harm)

Justice (equal treatment regardless of social, financial, sexual, or cultural factors)

Furthermore, the American Medical Association Journal of Ethics specified five ethical considerations in rehabilitation:2

Scarce resource allocation and the potential for discrimination against disabled people

The ethics of accommodating people with disability and chronic neuromuscular disorders, including medical settings

Identifying optimally inclusive nomenclature and terminology (e.g., “physical diversity” rather than “disability”)

Conflict between the goals of promoting acceptance and accommodation for persons with disability on one hand and securing resources for restoration of functional efficiency and meaningful mission on the other hand

The ethics of rehabilitating persons with neurological and behavioral disorders with anosognosia (deficits of awareness), in which maximizing rehabilitation may mean abandoning or overriding patient autonomy.

These ethical considerations are important to address as it helps construct public health policies promoting greater diversity, tolerability, and functionally appropriate environments for patients who are often poor, underserved, marginalized, and physically disabled.

Several aspects of physiatrist practice are applicable to the aforementioned ethical principles and considerations, including (A) informed consent and determination of decisional capacity, (B) addressing patients who refuse treatment/discontinue treatment, (C) providing patient cantered care and justice, and (D) research/education.

A. Informed Consent and Decisional Capacity

Informed consent and decisional capacity are virtually inseparable; together they constitute the foundation for ethical clinical practice. Informed consent represents an interactive process between the physician performing the procedure and the patient. This process provides patients with information regarding the purpose of treatment, treatment options, risks and benefits of the procedure, and the opportunity for them to indicate their understanding prior to giving or withholding consent. Once consent is provided, a document reflecting this discussion is signed by both patient and physician and is included in the medical record.

Consent for research purposes is obtained in order to carry out research studies in an informed setting. Research consent includes a description of the investigational study, the possible risks and benefits, contact information for study staff, and status of the study being reviewed by an institutional review board. It is important to note that both informed and research consent are for ensuring patient safety, and allows the patient or healthcare proxy to partake in the decision-making process.

Competence and capacity are often used interchangeably in clinical practice, but it is important to distinguish them. Competence is a purely legal concept which can only be formally determined through legal proceedings. Capacity is determined by a physician, and is an essential element in the informed consent process for medical treatment. The patient populations whose capacity to make medical decisions are most commonly questioned include: elderly, mentally ill, and/or mentally disabled adults; patients with head injuries; and patients who object to a recommended treatment. suggests three simple questions which the physician can ask when determining decisional capacity:

- Does the patient understand the disclosed information?
- Does the patient appreciate the consequences of the choices?
- Does the patient use reasoning to make his/her choice?

Decisional capacity of patients receiving rehabilitation treatment may vary based on a number of different factors including:

Patients whose communication is affected by aphasia/dysarthria, or impaired comprehension of the language being used will require alternative communication strategies for the former and interpretive services for the latter.

The patient's decisional capacity needs to be regularly evaluated since there is a continuum of treatment rather than a series of isolated events such as diagnostic and/or therapeutic procedures. Furthermore, while determination of decisional capacity rests exclusively with the physician, the setting and communication of treatment goals involves all members of the rehabilitation team.

Surrogate decision makers named in legal documents such as Power of Attorney or Living Will become active if and when the patient chooses to and/or no longer possesses decisional capacity. Physicians should become familiar with state laws dealing with advanced directives, and should not hesitate to consult legal representatives or a bioethics team when necessary. It is also recommended for physiatrists to obtain next of kin and health care proxy information to protect patient information and privacy.

In institutional settings such as hospitals and nursing homes or home health agencies, there may be a conflict between the administrative requirements for standards of care and those of the rehabilitation team. However, physiatrists and the interdisciplinary team are positioned to provide a more realistic assessment of patient preferences and practical options.8 Insuring a safe home environment as a primary goal for a home care agency could reflect caregivers' fear of patient injury despite that patient's desire for greater independence, even if it results in an increased risk. A similar scenario occurs in nursing homes or rehabilitation units whose administrative policies stress the need to prevent falls, while the rehabilitation team and patient strive for maximal independence in ambulation.

B. Refusing or Discontinuing Treatment

Respect for patient autonomy during rehabilitation includes the right to refuse treatment. Occasionally this can present the physiatrist with an ethical dilemma, as illustrated in an article published in 1989 documenting the case of a C3 quadriplegic admitted to a rehabilitation unit who decided that he preferred to die rather than live as a quadriplegic. Thus, an ethical conflict arises due to the patient refusing nutrition while the rehabilitation team is aware that there may be a clinical improvement over a period of weeks or months. Therefore, it is incumbent on the physician and rehabilitation staff to discuss these factors with the patient and family so that they can make decisions regarding future quality of life with a realistic perspective. When refusal of treatment has potentially dire or even fatal implications, immediate referral for bioethics and legal consultation is indicated.

More commonly, physiatrists encounter patients who decline to undergo inpatient or outpatient rehabilitation therapies. In this situation, even if medical/rehabilitation professionals are of the opinion that it offers major benefits and that there would be negative consequences without it, the patient's autonomy must be respected as long as decisional capacity is not impaired.6 There are many valid reasons for refusing rehabilitation, including:

Concerns about loss of home services

A patient's need to provide care or support for a spouse with medical problems

Preference for the home environment as location for rehabilitation care

Financial concerns.

Terminating rehabilitation should reflect a consensus amongst medical staff, patient, and family. However, other factors may lead to discontinuing or changing treatment such as reaching the limits of insurance coverage, lack of functional improvement, medical issues interfering with treatment, or inadequate participation or cooperation by the patient. Terminating or changing treatment should be approached by the physiatrist and/or rehabilitation team discussing the reasons for terminating treatment and alternative options such as therapy at home, transfer to longer term facilities, or outpatient follow-up care. Detailed chart documentation of this discussion is necessary, especially if the patient or family disagree with the decision. If indicated, the patient's decisional capacity should be reassessed. If conflict persists after these discussions, it may be necessary to involve legal and/or bioethics consultants.

Often times, patients with severe impairments such as spinal cord injuries and/or traumatic brain injuries, find it difficult to conceive of their "new normal" or life after their injury. It is the role of the physiatrist to guide patients and their families through these changes.

C. Ethics in Patient Cantered Medical Care and Justice

In their role as the leader of an interdisciplinary team, physiatrists develop personalized plans of care for patients with disabilities in order to optimize their quality of life. Physiatrists must carefully and judiciously consider the following seven core elements of patient cantered care outlined by the New England Journal of Medicine in 2017

Mission and values aligned with patient goalsCare is collaborative, coordinated, accessible

Physical comfort and well-being are top priorities Patient and family viewpoints respected and valued Patient and family always included in decisions Family welcome in care setting Full transparency and fast delivery of information Physiatrists need to also address the many clinical barriers patients may encounter in order to ensure justice is provided. Jonsen et al. proposed that these clinical problems can be subdivided as four priorities or topics to examine, review, and manage in the course of the patient's care:

Medical indications Patient preferences according to the principle of respect for autonomy Assessment of patients' expected quality of life Context, such as economic constraints, standard operating and laws.

At times justice can be difficult to achieve for patients who are differently abled. It may be challenging to reach consensus about a patient's treatment plan because health care clinicians may rate the quality of life of patients with disability or chronic illness lower than the patients rate it themselves, fostering disagreement between patient and treatment team. This ultimately places these patients at a disadvantage. Recently there has been a paradigm shift in medicine toward a more patient-cantered approach.

D. Ethics in Research and Education

Whyte has explored some of the ethical ramifications of rehabilitation research as illustrated by efficacy studies. The concept of clinical equipoise is central to such research, meaning that there is a real uncertainty about whether or not a treatment is beneficial. The three concepts of autonomy, beneficence, and justice, as enumerated by Blustein1 need to be scrupulously observed. Selection bias in the choice of subjects and selective use of inappropriate statistics to influence conclusions are particularly to be avoided.

A recent article by Fronteradiscusses how scientific article publication has been growing, and is becoming ever more important in the field of physical medicine and rehabilitation. This requires physiatrists understand the elements of scientific article writing, levels of scientific evidence, current rules of scientific reporting, and the importance of preventing scientific misconduct.

The principles of bioethics should be considered a core competency and should be included in all physiatry residency curricula. Since many large academic medical centers have a bioethics team with consultative services, physiatrists should avail themselves of this resource when faced with challenging cases. Also, since physiatrists can offer a valuable perspective on chronic disease and disability, their inclusion and participation in bioethics committees is recommended.

In terms of graduate medical education, residents face varying levels of comfort and mastery with performing procedures as their training progresses.16 There is still the ethical dilemma for physicians to balance academic education and competency with patient care and safety. Residents learn to balance evidence-based research and expert opinion with the patient's level of acceptance or denial of her/his situation. Residency education involves learning to educate patients on best practices. It is not uncommon for physicians to have to re-educate patients if they have been exposed to incorrect community hearsay or misinformation.16 Finally, residents, like their attendings, face barriers with access to healthcare and a lack of resources necessitating enhanced teamwork to ensure justice for their underserved populations.

E. Future Trends in Rehabilitation Ethics

In 2013, Hunt and Ells developed the Patient-Centered Care Ethics Analysis Model for Rehabilitation (PCEAM-R) to guide ethical rehabilitative care given the complexity of the care team, patient's degree of impairment/disability and a variety of possible interventions.

The six steps of the PCEAM-R are:

Identify the ethical issue(s) to address: What is at stake and for whom?

Collect information: What do we need to know to be able to evaluate the issue(s)?

Review and analyse: Do we need to reformulate the issue(s) and what can help us better understand it?

Identify and weigh options: What are our options and what rationales support them?

Make decision(s): What is the best option and how should we implement it?

Evaluate and follow-up: What was the outcome and how can we learn from it?

This six-step process for ethical decision making is theoretically grounded in the International Classification of Functioning Disability and Health and has a sufficiently detailed list of questions to provide a comprehensive and balanced assessment of each patient's situation.17 This may be the best method for the practice of physiatry to ensure justice for all patients of differing abilities.

The inclusion of ethical issues within the rehabilitation process is an encouraging development, since they ought to be routinely part of physiatrists' thinking. As new developments in medical and surgical care preserve the lives of many individuals whose injuries or diseases would previously have been fatal, it can be anticipated that a growing number of patients with severe physical disabilities will require physiatrist care, and will bring with them an increasing number of complex ethical challenges.

Summary

Community Based Rehabilitation (CBR) is a community development strategy that aims at enhancing the lives of persons with disabilities (PWDs) within their community. Community-based rehabilitation (CBR) was initiated by WHO following the Declaration of Alma-Ata in 1978 in an effort to enhance the quality of life for people with disabilities and their families; meet their basic needs; and ensure their inclusion and participation. While initially a strategy to increase access to rehabilitation services in resource-constrained settings, CBR is now a multi-sectoral approach working to improve the equalization of opportunities and social inclusion of people with disabilities while combating the perpetual cycle of poverty and disability. CBR is implemented through the combined efforts of people with disabilities, their families and communities, and relevant government and non-government health, education, vocational, social and other services (WHO).

It emphasizes utilization of locally available resources including beneficiaries, the families of PWDs and the community. According to the UN Convention on the Rights of Persons with Disabilities, comprehensive rehabilitation services focusing on health, employment, education and social services are needed to enable PWDs/CWDs attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life (UN, 2006).

Recommendations to develop guidelines on community-based rehabilitation (CBR) were made during the International Consultation to Review Community-based Rehabilitation which was held in Helsinki, Finland in 2003. WHO; the International Labor Organization; the United Nations Educational, Scientific and Cultural Organization; and the International Disability and Development Consortium – notably CBM, Handicap International, the Italian Association Amici di Raoul Follereau, Light for the World, the Norwegian Association of Disabled and Sights avers – have worked closely together to develop the Community-based rehabilitation guidelines? More than 180 individuals and representatives of nearly 300 organizations, mostly from low-income and middle-income countries around the world, have been involved in their development.

Keywords

Community based rehabilitation, ethics, aphasia, quadriplegic.

Self Assessment

1. There are six steps in PCEAM-R

A. True

B. False

2. Informed consent is not necessary in Therapy.

A. True

B. False

3. Ethical issues are important factor for PwD.

A. True

B. False

4. Community Integration Programme give opportunities of learning many skills to PwD.

A. True

B. False

5. There is a universal sequence of stages to guide the development of PwD.

A. True

B. False

6. Health Belief model was introduced in -------

A. 1950

B. 1962

C. 1980

D. 1982

7. Self-Advocacy & effective communication are a part of------- process.

A. Validity

B. Socializing

C. Empowerment

D. None of them

8. Successful -------- depends on important messages being communicated & heard.

A. Achievement

B. Advocacy

C. Advertisement

D. None of them

9. ------ is a primary goal of CBR.

A. Mainstreaming

B. Advocacy

C. Adjustment

D. None of them

10. In 1978 Convention of WHO, --------- of QOL for the PwD.
A. Inclusion
B. Exclusion
C. Upgradation
D. None of them

11. One biggest risk factor of health is ---------
A. Home situation
B. Ambition
C. Life Style
D. None of them

12. CBT has extensive popularity in the last -------- decades.
A. 2
B. 3
C. 4
D. 5

13. The majority of PwD require --------- service.
A. Monitoring & Evaluation
B. Functional Rehabilitation
C. Prevention of Disabilities
D. None of them

14. Which year the Belmont Report was published?
A. 1978
B. 1968
C. 1988
D. 1998

15. Physicians should familiar with------- law.
A. National
B. State
C. Local
D. None of them

Answersfor SelfAssessment

1.	True	2.	False	3.	True	4.	True	5.	True
6.	B	7.	C	8.	B	9.	A	10.	C
11.	C	12.	B	13.	B	14.	A	15.	B

Review Questions

1. What are the goals of Community Based rehabilitation?
2. What are the components of Community Based rehabilitation?
3. What are the roles of professionals in CBR?
4. Discuss about the professional participation in CBR Programmes.
5. What is the role of community in disability?
6. Briefly elucidate the ethical issues related to disability.
7. Write in brief about informed consent & decisional capacity.
8. What are the consequences of not following ethical issues in Profession?
9. Explain PCEAM-R.
10. To what extent, the professionals are participating in CBR programme?

Further Readings

- Quality of Life by Alison Carr, et. al. BMJ Books.2002
- Quality of Life- An Interdisciplinary Perspective by ShrutiTripathi, et. al. CRC Press,2022.

Unit 11: Health Behavior

CONTENTS

Objectives

- To know the theories of behavior change
- To understand intervention strategies for individuals, families of disabled
- To familiarize with Behavior Modification & Cognitive Therapies in Rehabilitation.

Introduction

Health is a state of complete emotional and physical well-being. According to WHO 1948, "Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. In 1986 WHO made further clarifications, "A resource for everyday life, not the objective of living". Behavior is an act or action by a person in response to a particular situation or stimulus. So, health behavior means actions taken by any person which affects their health positively or negatively. It includes actions that lead to improved health, such as eating well and being physically active, and actions that increase one's risk of disease, such as smoking, excessive alcohol intake, and risky sexual behavior. It is important to consider that not everyone has the means and opportunity to make healthy decisions. Policies and programs put in place have marginalized some population groups and communities, keeping them from the supports and resources necessary to thrive.

A key factor of people's health is connected with the behavior of an individual. One of the biggest risk factors now a days recognized is lifestyle. Lack of physical exercise, high calorie intake and excessive alcohol consumption, leading to obesity, high cholesterol levels and high blood pressures are the result of disturbed lifestyle.

11.1 Theories of Health Behavior Changes

The models and theories designed by behavioral scientists to understand and influence health behaviors. As theories has advanced, scientists have more interested in behavior changes over understanding why individuals engage in particular health behavior as well as the physiological & environmental input to health behavior change. There are many theories on health behavior changes such as health belief model (HBM), social cognitive theory (SCT), relapse prevention (RP), self-determination theory (SDT), Incentives/affect, and last but not the least socioecological models.

Health behavior changes, we want to improve health and well-being, consider the leading causes of death such as cancer, heart disease etc. A health-related behavior plays an important role in not develop these conditions. So many expect about behavior influences our health standard not the least is our dietary habits. So, understand human behavior and designing intervention is interconnected.

Health belief Model (HBM) is introduced in 1950 by social scientist in order to understand the failure of the people to adopt disease prevention strategies or screening tests for the early detection of disease. The health belief model suggests that person's belief in a personal threat of an illness or disease together with a person's belief in the effectiveness of the recommended health behavior or action will predict the likelihood the person will adopt the behavior. This model drives from psychological and behavioral theories with foundation that the two components of the health-related behavior are first the desire to avoid illness or consciously get well if already ill and second, they believe that a specific health action will prevent or cure illness ultimately an individual's course of action often depends on the person's perception of the benefits and barriers related to health behavior. There are six constructs of the health belief model. The first four constructs were developed as the original tenant of the health belief module and the last two were added as research about health belief model evolved. First in line perceived susceptibility, refers to an individual's subjective perception of the risks acquiring an illness or disease. An example of these is when a person was exposed to other person with an illness, he or she might think that he or she is more vulnerable in getting that disease. Second perceived severity, an individual on the seriousness of contracting an illness. An example, fluctuations on number of cases of a certain illness may affect the general public's perception of its severity. Third perceived benefits, an individual's perception of effectiveness of various actions to reduce threat of illness or cure an illness an example of these is promotion and applying preventive measures to prevent being infected by a disease or illness. Fourth perceived barriers refer to an individual's feelings on obstacles in performing recommended health actions, example of these is factors such as inconvenience, costs, life style changes and others with affects a person perception. Fifth is cue to action, the stimulus needed to trigger an action on the obstacles to performing recommended health standards, an example, person experiences of symptoms or illness of a family member. Sixth is self-efficacy refers to the level of an individual's confidence in his or her ability to successfully perform a behavior an example, a person who has a healthy lifestyle feels confident about-facing daily activities amidst prevalence of a certain illness.

Social cognitive theory has been used to investigate modifiable lifestyle factors that are associated with weight gain. This theory describes that behavior is a product of the individual's learning history their intellectual and physical capacities and their present perceptions of their environment. It focuses on people having agency to make choices and attain goals concepts involving social achievement outcomes and self-influences are part of a dynamic system that are in constant interaction with one another specific concepts such as self-efficacy agency and self-regulated learning are fundamental in social cognitive theories. We look at two main ideas from this theory, firstly learning by observing others is a key part of social cognitive theory here we may ask what causes a person to learn and perform specific behavior and skills modeled by others well several factors play a role first we learn through observation we have to pay attention. Imagine someone learning how to play basketball from more experienced player paying attention would include both selective attention which is paying attention to the correct cues and information such as how you can dribble a basketball as well as sustained attention that is maintaining focus during a basketball practice. Second you need retention perhaps through practice the person can remember the steps learning how to properly dribble the basketball toward the basket. Third once we understand a behavior the production phase helps makes the behavior smoother with more and more practice and feedback from the experienced player. Lastly, we should include more motivation to pay attention and reinforcement to maintain learning through persistence. The role model can help reinforce the production of the behavior by complementing the good form in shooting the basketball. Another main concept in social cognitive theory is self-efficacy, people beliefs about their abilities have a profound effect on those abilities. Ability is not a fixed property where is huge variability in how you perform. People who have a sense of self efficacy bounce back from failure they approach things in terms of how to handle them rather than worrying about what can go wrong. There are four sources in self-efficacy, first mastery experiences are our own personal and direct experiences these are usually the most powerful sources of self-efficacy information for example if you are learning how to draw your success is ultimately attributed to your ability persistence and effort. Second there is degree of physiological arousal that affects self-efficacy as you learning to draw are you anxious and worried which lowers efficacy or are you excited and psyched which tend to efficacy. Third there are vicarious experiences where someone else models' accomplishments as you learn to draw yo may watch a YouTube channel or tv shows that models how to draw the more closely you identify with the artists of that show the greater the impact on self-efficacy. Lastly social persuasion from teachers or peers can be helpful social persuasion alone can't create enduring increases in self-efficacy but it can lead to a momentary increase in self-efficacy. This enabling student to make better efforts or try hard enough to succeed.

Relapse prevention targeted specifically to behavior change. Relapse prevention was to describe the process of relapse's behavior. A key aim is to avoid or to learn how to cope with high-risk situations. A risk of relapse is identified in two categories one is immediate determinants and covert antecedents. It is an interesting feature in which the person is aware that conscious goals related to recovery often succumb to the physiological symptoms of withdrawal, negative affective states, and the emotional tipping point created by the abstinence violation effects. The one of the best technique specific to relapse prevention is mindfulness. The mindfulness has been successful in countering the influence of negative affective states on the likelihood of relapse, and enhancing individuals' abilities to cope with distress.

Self-determination theory in which goal-driven behavior are regulated are given importance. The feelings of interest, enjoyment, or satisfaction, and it is theorized that this produces self-motivated, or self-determined behavior. The important outlined in this theory are positioned to be innately valued, aligning the content of one's goals with an individual's core needs for example, an exercise goal formed for the explicit purpose of looking better to one's peers, an extrinsic personal goal, will lose salience more rapidly than an intrinsic exercise goal emanating from the value of human connection and focused for the purpose of being able to engage with one's grandchildren or to foster a relationship with friends.

Incentives/ affect is associated with particular outcomes of a health behavior are evident in the model. An interest in the affective determinants of health behavior, including work on both reflective and reflexive affect. A reflective affect is revered to as subjective liking and it's cognitive based on the other hand reflexive affect has been associated with core liking which is related to a function of contextual stimuli and associations. As per previous researches reflexive affect maybe more helpful in predicting further behavior than reflective affect. A key factor of these model this can help at various levels of influence, including the individual, community, state or national level.

11.2 Intervention Strategies for Individuals

To enable people with disabilities to contribute to creating opportunities share in the benefits of development and participate in decision making may be required by many communities.

Many communities working to break this cycle between disable by empowerment of individuals/families/organizations and by breaking down barriers in society. Those community-based activities are designed to meet the basic needs of people with disabilities and enable access to health, education and professional opportunities.

There is no consensus on how certain behaviors are best supported. Model and theories need to be used to facilitate and evaluation.

11.3 Families of Disabled

Due to the disability impact on family a set of extra demand or challenges for long time on family.

And those demand or challenges can be varied because of disability type, age of the person with disability, and type of family in which the person lives. These challenges can be financial burden due to medical treatment, education, social services, accommodation, transportation, and special food. Finding appropriate therapy or treatment one is eligible for and then working with an institute to certify that eligibility which can be regular follow up is a major challenge faced by family. Next major challenges faced by family is coordination with service providers such as physician, physiotherapist, counsellor, psychiatrist, occupational therapist, dietician, social worker, teacher etc.

The everyday routine task dependency of disable person on his/her family leads to exhaustion and fatigue, tired (physically and emotionally) energy of family members. There are bunch of challenges that creates emotional strain, including worry, guilt, anxiety, anger and uncertainty about the causes of disability, need of other family members, future, and so on.

Due to all of this in major way family life changed. Care for disabled person responsibilities may lead to change in planning of the families. Mostly female caregivers take responsibilities for disabled person, due to emotional attachment, or our Indian culture, thus changed their work role.

Emotional attachment in between primary caregivers and person with disability, such as mother of child with disability, can impact on the time spending with other family members, father rarely spend time with his disabled child this makes marital conflict in between husband wife or family. The unequal share of families' resources of time, energy, and money, family needs go unmet.

11.4 Behavior Modification & Cognitive Therapy

In health behavior change, knowledge of what is useful is very crucial for achieving improvements in health and preventing disease. Many communities growing in this field and recognition of this and a lot of work has been undertaken to Damien the best approach. Previous researches revealed that the use of such theory in designing and implementing health promotion programs improves their effectiveness. One of the best techniques is cognitive therapy.

Cognitive behavioral therapy is a treatment for emotional and behavioral issues that aims to help an individual to identify and modify dysfunctional thoughts, assumptions and patterns of behavior. It helps to explores the range and factors that influence one's behavior due to environmental or reinforcement (external) and thoughts (internal). This therapy helps to set goal and self-monitoring which is based on the belief that all behavior is learned and can be unlearned.

People with learning disabilities have a particular need of help both with learning skills and with unlearning problem behaviors, and particular methods exist to supply this need. Behavioral management has much in common with teaching and management methods in general but includes some special features. It is applicable to both children and adults, although naturally the context in each case will differ.

It is important to emphasize at the outset that there is no one method that should be prescribed for any one problem. The first essential is to study the individual concerned - his or her likes and dislikes, circumstances, idiosyncratic behavior patterns, history, family set-up, and so on. Only following that study will a treatment program me, tailored to the characteristics of the individual and to his or her environment, be arrived at.

There are however certain procedures that will normally be considered.

- Changing the Surroundings
- Positive Reinforcement
- Differential Reinforcement of Other Behaviors
- Extinction
- Time Out from Positive Reinforcement
- Functional communication training
- Stimulus Control
- The Least Restrictive Alternative
- Fading programs

Definition

Problem, or challenging, behavior, is defined as: 'behavior of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behavior which is likely to seriously limit or deny access to and use of ordinary community facilities' (Emerson et al 1988). It is important to note that such behaviors are shown by only a minority of people with intellectual disabilities - 6.1% (Emerson 1995, p.24).

Changing the surroundings

It may be possible to lessen a challenging (problem) behavior by altering the person's circumstances to make it less likely that the behavior will occur. For example, a young man who could not tolerate noisy places and caused so much disruption that he was no longer taken out to shops and cafes, was given a headset and a portable cassette player with tapes of music that he liked. When he used these they screened out the other noises and he could then be taken out. (See Donnellan et al 1984). By itself this may not change the behavior but it can help to allow other methods to be put into place and to take effect.

Positive Reinforcement

Many of the methods described here involve the use of positive reinforcement. This is defined as: anything which, when it follows a behavior, increases the likelihood of that behavior occurring again. So, a preliminary to most programs is the search for and identification of whatever is likely to have that effect for this individual. No assumptions are made as to what this will be - anything assumed to be a reinforce 'for most people' will not do unless it is known, or can be shown to be, a reinforce for this individual. The search for reinforces should be wide-ranging, taking in sensory stimulation - lights, sounds, music, tastes, smells - preferred activities, favorite foods and drinks. Social reinforces - attention, approval, praise, hugs - are powerful reinforces for some people but ineffective for others, and for others still may actually be aversive, so cannot be invariably relied on. Whatever is finally selected, it is crucial that it is of great interest to the person concerned, and can be shown to increase any behavior that it regularly follows. Used to increase appropriate and to teach new behaviors, it works best when given after every occurrence of the behavior, at least at first.

In some cases, the normal response to a behavior, that would normally be thought of as unpleasant and leading to a decrease in any behavior it follows, may have a contrary effect for a person with a learning disability. One example of this is remonstrance, disapproval or anger. A person with a learning disability, if he or she enjoys attention, may relish the attention involved in the scolding; even angry attention may be better than none. If this is the case then the scolding will act as a reinforcer, and will result, not in a lessening but rather in an increase of the behavior, as the person realizes that this is a good way of ensuring that people attend to him or her.

Differential Reinforcement of Other Behaviors

One way of diminishing a challenging behavior is to build up other behaviors, by deliberately reinforcing them, to compete with the target one. These other behaviors may be those that are incompatible with the problem one, i.e., it is impossible for the person to do both behaviors simultaneously. So a girl who frequently poked her eyes with her fingers, damaging her sight, was provided with a piece of apparatus which produced sounds and noises that she loved when she pressed its switches with her fingers. While she pressed the switches and heard the sounds, she could not at the same time poke her eyes, and the eye-poking diminished.

Sometimes it is not possible to identify a behavior that is incompatible with the target behavior. In this case all other behaviors may be reinforced, apart from the target one. Here it is the absence of the target behavior that is reinforced: the person receives reinforcement for each period of time (five minutes, ten minutes, half an hour or more, depending on the person and on the behavior) during which the target behavior has not occurred. The person learns that he or she has a better time when not displaying the target behavior, and so will display it less.

Next, two methods used to reduce problem or challenging behaviors by withholding reinforcement.

1. Extinction

Behaviors that are followed by a reinforce are maintained or strengthened. This may happen also, inadvertently, with a challenging behavior. If the reinforce for this challenging behavior can be identified it may be possible to determine that it will never again follow the behavior. Without reinforcement, the behavior should eventually die out (extinguish).

There are two caveats. First, the reinforce must be one that can be controlled. Second, the behavior must be expected to increase initially (the 'extinction burst').

Regarding the first of these: if, for example, it was thought important to reduce a person's masturbation, extinction would not be a suitable method to choose because the reinforcement cannot be externally controlled; if the person masturbates the reinforcement will inevitably follow. Some other method must be looked for.

Secondly, if a reinforce, which can be controlled, is prevented from following the behavior, then initially this can result in an 'extinction burst'. The person finds that the expected reinforcement is not forthcoming, so tries a repeat of the behavior. If still there is no reinforcement the person may raise the level of the behavior (worsen it). If the reinforcement is rigorously withheld, no matter how much worse the behavior becomes, the behavior should then begin to lessen, slowly at first and then more rapidly.

As the behavior worsens during the extinction burst it may be that the worker in charge of the program me cannot tolerate the increased level, gives in, and gives the reinforcement. In this case the person learns that, even if the original level of the behavior will not be reinforced, an exacerbation of it will. From then on it is likely that the behavior will be worse than it was originally. So it is of the utmost importance that, when the use of extinction is considered, the process is carefully thought through, including whether it could be kept up through an extinction burst. If there is any doubt about this, it would be better not even to attempt extinction but to use another method.

2. Time Out from Positive Reinforcement

Often referred to as Time Out, but the full title is important. Time out from positive reinforcement is an option where the problem behavior usually happens when the person is already in a reinforcing situation - eating favorite food, enjoying music, TV, a social situation. Whenever the behavior occurs, the reinforcement is temporarily suspended. So, if the person very much enjoys a social situation, time out could involve him or her being removed from the situation, perhaps to another room, for a short period (say, five minutes, or even less). But, if the person is not interested in social interaction, removing him or her to another room would not remove the reinforce and would be pointless, even possibly reinforcing (in allowing the person to escape from a situation he or she dislikes). So, time out essentially does not mean the invariable use of a time-out room. On the other hand, it has been effective where, for example, the person is fond of music, which is playing, or of TV, and on the occurrence of the behavior the music or TV is briefly turned off.

Functional Communication Training

Sometimes a challenging behavior appears to function in people with a learning disability as a way of 'asking' for something. It may be a way of asking for attention, or for a tangible item, or for something to be stopped - a task perhaps, or an aversive situation. In such cases an effective treatment may be to teach the person to use a word or sign to ask appropriately for what they want. So if children are misbehaving in order to get the teacher's attention, teaching them to say or sign 'Come here please' can result in a reduction of the misbehavior. Similarly, if they were misbehaving in order to escape from a too-difficult task teaching 'Help please' can also bring about a lessening of the misbehavior.

Stimulus Control

Certain stimuli lead to certain kinds of behavior - rain prompts us to put on a mackintosh, a red traffic light to stop the car. Without these stimuli, these behaviors might not occur. Similarly, it is possible for a stimulus to become associated with a behavior that is permitted - reinforced - while the absence of the stimulus indicates that the behavior will not be reinforced. These conditions can be put to use to help to manage difficult behaviors.

A 13-year-old boy was causing major problems in school, among them the relentless questioning of staff. Although this sounds a trivial problem, the tensions it produced led on to other difficulties including physical aggression. The boy was given a sticker to wear on his shirt, and was told that when it was on his shirt his questions would be answered. When it was not on his shirt his questions would not be answered; he should wait until the sticker was back on his shirt. At first the sticker was removed very briefly - for 15 seconds, four times in every hour. His questioning dropped off in frequency very rapidly, within three weeks, even when he was wearing the sticker, and the other associated problems declined too.

Stimulus control can be a useful method in some situations. However since, like extinction, it allows for some occurrence of the behavior, it is not suitable for tackling behaviors that are dangerous either to the person or to others.

Deliberately Programming Reinforcement

Some of the methods described above involve the withholding or removal of reinforcement. It is then important to ensure that the person gets reinforcement at other times - our aim is to improve, not impoverish, the person's life. So, for example, if the reinforcer were attention, which was withheld when the behavior occurs, the person should receive plenty of attention at other times: not necessarily for any markedly virtuous but simply for acceptable behavior. This precaution will also make it less likely that other problem behaviors will emerge to take the place of the original one.

The Least Restrictive Alternative

In work with people with learning disabilities we have an ethical obligation to cause them as little distress as possible. Therefore, in tackling a challenging behavior we should at the outset select a method which, while having at least some prospect of being effective, is the least aversive option available (changing the surroundings, differential reinforcement of other behaviors, etc.). Only if this is shown convincingly to fail will other, more stringent, methods, be tried.

Fading Programs

When a program me has been put into practice and has been effective, the question arises as to how to end it. This applies particularly to methods that involve giving reinforcement (differential reinforcement of other behaviors, stimulus control). As a rule, the principle is that it should not be stopped abruptly but gradually tailed off. If the reinforcement is suddenly stopped the likelihood is that the behavior, which had improved, would worsen. So instead, the reinforcement can be given at gradually lengthening intervals; for gradually increasing standards of behavior; or where appropriate, the reinforcement may be transferred to a new target behavior. Another strategy is to give the reinforcement at irregular intervals - some short, some longer - so that the person cannot predict exactly when it will arrive. This can make it less problematic for the person when the intervals become generally longer, until eventually the reinforcement, for this behavior, comes to an end.

If the program me has been devised with an appropriate goal - that of improving the person's life - then when it succeeds the person should experience the improvement, finding new sources of pleasure and enjoyment. This too should help to make deliberate reinforcement less necessary.

Cognitive behavior therapy (CBT) is an evidence-based intervention that is well-suited for use with clients with disabilities and can be leveraged to reduce distress and to promote well-being and empowerment. Therapists can begin to develop disability cultural competence through attention to frameworks for understanding disability that incorporate biopsychosocial, familial, and sociopolitical factors; by gaining self-awareness and challenging ableist attitudes; and by attending to the reality of minority experiences and oppressive contexts when working with clients to change behavior and challenge dysfunctional attitudes and cognitions. This chapter highlights the complexity of disability by drawing attention to the socioenvironmental context of disability and the ways in which thoughts, feelings, and behaviors can be addressed in therapy without minimizing the real constraints that are imposed by environments that limit access. It presents clinical data from two individuals with disabilities who received CBT. (PsycInfo Database Record (c) 2020 APA, all rights reserved)

The American Psychological Association (2002) has included cultural competence in working with people with disabilities as a standard in its "Ethical Principles of Psychologists and Code of Conduct." However, the field is still in its infancy in achieving such cultural competence, with few disabled people represented in the field of clinical psychology and little formal training available for conducting therapy with disabled people. The goal of this chapter is to move beyond the individually oriented deficit model in conceptualizing the difficulties experienced by clients with disabilities and discuss the utility of cognitive-behavioral therapy (CBT) with disabled people. To foster a broader conceptualization, we discuss the emerging recognition of disability as a cultural identity and contrast it with historical perspectives on disability, followed by research on psychological resources that aid people living with disability. Finally, examples of the use of behavioral and cognitive strategies to improve adjustment among persons with disabilities are described and illustrated. Although the issues we present are broadly applicable across diverse impairments, we have chosen to focus primarily on physical and sensory disabilities. We begin with a brief overview of the components of disability culture, followed by a discussion of the ways in which disability has been conceptualized within psychology and other disciplines, thus setting the stage for examining CBT applications within this diverse community.

Cognitive behavioral therapy (CBT) has extensively popularized particularly in the last three decades. As a standard therapeutic approach, CBT has been widely applied in solving numerous mental related problems. As will be seeing later in the paper, majority of persons with learning disabilities are the ageing population and this population is on the rise. This implies that that the evidence base of their mental problems requires intensive care, therefore, the world countries ought to ensure that there is a comprehensive range of psychotherapies who would cater for the increasing population of persons suffering with learning disabilities.

Cognitive Behavioral therapy (CBT) is contemporary an accepted and effective method of treating people with learning disabilities, this is evidenced by the reducing numbers of persons suffering from learning disability illnesses. However, as the paper shows, there is an immediate need to support the education practices as well as developments contributing to the emotional requirements of persons with learning disabilities.

A discrimination is offered between disability and handicap. Common cognitive schemes and irrational beliefs of people with physical disabilities are explored. The development of belief systems from a social learning perspective and several cognitive assumptions of parents and families of children who have physical disabilities are presented. Finally, certain self-evaluative beliefs specifically related to physical disability are examined in terms of how they relate to self-image and, concomitantly, behavior. The article offers information arrived upon from the author's clinical practice as well as the author's personal experience as a person with a physical disability.

Summary

Despite the recognized importance of maintaining and improving the health status of persons with disabilities, there has been little research conducted to determine their health care attitudes and behaviors and what interventions might serve to enhance their health. Using Pender's Model of Health Promotion (1987), this study investigated the factors associated with the occurrence of health promoting behaviors among 135 adults with disabilities. Staff and peer counsellors from two Independent Living Centers in Texas administered the questionnaires and conducted brief semi-structured interviews with participants. Seventy-three percent of the sample rated their current health as good or excellent. Findings from both interviews and questionnaires suggest that participants are more likely to define health as being able to function well than as simply the absence of illness. High scores on Adaptive definition of health, the Self-Efficacy-Scale, age, and low scores on the Barriers to Health Promotion Activity for Disabled Persons scale accounted for 31% of the variance in scores on a self-report measure of health promoting behaviors. These findings suggest that interventions which address self-perceived barriers to health promotion, work to build participants' sense of mastery of their health behaviors, and encourage a definition of health that is broader than simply absence of illness may be more effective than those that focus only on information about good health practices.

An individual's disability can play a major role in his/her life: whether it's positive or negative. But overcoming the challenges and developing confidence is vital and admirable. As a society, it is our utmost duty to allow people with disabilities to experience a life they deserve.

An individual’s disability can play a major role in his/her life: whether it’s positive or negative. But overcoming the challenges and developing confidence is vital and admirable. As a society, it is our utmost duty to allow people with disabilities to experience a life they deserve. We are all different but very much alike at the same time.

The importance of disability awareness has been given prominence over the recent decades, making it easier for the people with disabilities and the society to develop empathy for one another. Disability awareness helps in subsiding the stereotypical mindset of the society, hence providing vast opportunities for everyone to get involved in creating a positive, inclusive society for all.

Keywords

Incentives, cognitive theory, replace prevention, self-determination theory, health belief model, disability, caregiver, behavior modification, cognitive therapy, extinction, time-out.

SelfAssessment

1. An individual’s disability can play a major role in his/her life.
A. True
B. False

2. Pender proposed health model in 1977.
A. True
B. False

3. CBT is not effective among disability population.
A. True
B. False

4. APA has included cultural competence in working with people with disabilities.
A. True

B. False

5. Certain stimuli lead to certain kind of behavior.
A. True
B. False

6. People's health is related to people's ----------
A. Feeling
B. Knowledge
C. Behavior
D. None of them

7. Social cognition theory investigates ----------- lifestyle factors.
A. Direct
B. Modifiable
C. Never changing
D. None of them

8. A reflect affect is revered to -------- likings.
A. Subjective
B. Objective
C. Neutral
D. None of them

9. Cognitive Behavioral Therapy is a treatment for ------ & behavioral issues.
A. Social
B. Official
C. Emotional
D. None of them

10. Sometimes normal response to a behavior is thought of-----------
A. Pleasant
B. Unpleasant
C. Euthymic
D. None of them

11. Without reinforcement, the behavior should eventually --------
A. Repeating
B. In the same speed
C. Extinguish
D. None of them

12. There are ---- methods to reduce problem or challenging behavior by withholding reinforcement.
A. 1
B. 2
C. 3

D. 4

13. CBT has got extreme popularization in the last ------- decades.

A. 1

B. 2

C. 3

D. 4

14. Self- influence is ----------- of a dynamic system.

A. Not a part

B. A part

C. An equal of

D. None of them

15. One biggest risk factor of health is -----------.

A. Home situation

B. Ambition

C. Life style

D. None of them

Answers forSelfAssessment

1.	True	2.	False	3.	False	4.	True	5.	True
6.	C	7.	B	8.	A	9.	C	10.	B
11.	C	12.	B	13.	C	14.	B	15.	C

Review Questions

1. Briefly elucidate the theories of human behavior changes.
2. Describe different Models of behavior change.
3. Describe the intervention strategies for individuals
4. Cite with examples, briefly describe families of the disabled.
5. Define the role of behavior modification in disability.
6. Describe the characteristics of Cognitive Therapy in disability.
7. What is the role of reinforcement in disability?
8. What is the relation between Behavior Modification and Cognitive Therapy?
9. Write about the health status of the caregivers in the field of disability.
10. Write about the changing scenario of health behavior over the decades.

Further Readings

- Disability, Health & Human Development by Shaun Grech et. al. Palgrave Macmillon.2017
- Understanding Disability & Inclusive Practices by Supriya Singh. Shivalik Prakashan.201

Unit 12: Caregivers

CONTENTS

Objectives

- To know the impact of disability on Family.
- To understand the role of caregivers in Rehabilitation
- To familiarize with the challenges on Mental Heal Issues.

Introduction

A caregiver is a person who is taking care all the needs or concerns of a person with short or long-term limitations due to illness, injury or disability. There are two types of caregivers one is professional such as nurses, doctor, ward boy, paid attendant and second category is family caregivers such as blood relationship, neighbors, or close friends. Both the caregivers play a vital role in health care.

To understand the importance of a caregiver, think of health care as three pillars. A person or patient as one pillar; professional caregivers (doctors, nurses, etc.) act as another; and the third pillar is the person who is recipient the care from others. So, we can say that it’s a team work.

One of another name for family caregivers is informal or unpaid caregivers. They are getting different type of rewarding; caregivers can also be at higher risk of negative health consequences. These may include stress, depression, difficulty maintaining a healthy lifestyle, and staying up to date on recommended clinical preventive services.

12.1 Impact of Disability on Family

Having a family member with any type of disability/disease/disorder can have an effect on the entire family such as the parents, siblings, and extended family members. It is an unusual experience for families and can affect all aspects of family functioning.

Stress can be increased due to caring for a disabled family member, physical as well as mental health, which makes a person or family to take any affective decisions about work, education, and finding society support. This may be associated with guilt, blame, or reduced self-esteem. And this may also divert the attention from one aspect to another aspect of family functioning. Due to high medical care increase the financial burden on the family members. All of these things impact on the potential effects on the quality of the relationship between family members, their future relationship in between family, and their living arrangements.

On the other hand, there is a positive side also, it can provide a wider prospective, increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community. At the same time, the time, financial costs, physical, emotional demands, logistical complexities are connected with caring for a disabled person. The impacts will likely depend on the type of condition and severity, as well as the age, gender, relationship, physical, emotional, and financial of the family and the resources that are available.

One of the supports that family caregivers may need to enable them to continue to care for their family member at home are short breaks. Short Breaks give them a break from their role as career and also provide their family member an opportunity to be with others and benefit from new experiences.

Having a family member with an intellectual disability can have an effect on the entire family; the parents, siblings, and extended family members. It is a unique shared experience for families and can affect all aspects of family functioning.

On the positive side it can broaden horizons, increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community. On the other hand, the time and financial costs, physical and emotional demands, and logistical complexities associated with caring for a disabled child/adult can have far-reaching effects. The impacts will likely depend on the type of condition and severity, as well as the physical, emotional, and financial wherewithal of the family and the resources that are available.

For families, caring for a disabled family member may increase stress, take a toll on mental and physical health, make it difficult to find appropriate and affordable child care, and affect decisions about work, education/training, having additional children, and relying on public support. It may be associated with guilt, blame, or reduced self-esteem. It may divert attention from other aspects of family functioning. The out-of-pocket costs of medical care and other services may be enormous. All of these potential effects could have repercussions for the quality of the relationship between family members, their living arrangements, and future relationships and family structure.

Families are telling us that one of the supports that they may need to enable them to continue to care for their family member at home are short breaks. Short Breaks give them a break from their role as career and also provide their family member an opportunity to be with others and benefit from new experiences.

12.2 Role of Caregivers

An involvement and support of the family play a vital role in a patient's recovery after a disability, injury or illness. Usually, family caregiver plays a vital part in the rehabilitation process for a number of reasons: number one is positive attitudes, second is reinforcement from family members can motivate patients' commitment to recovery and third is to help them adapt to new physical challenges or limitations.

Support by family and motivate them can also help patients to deal with issues of self-esteem and their condition. Family members know the patient better (in nature) then profession caregivers they can assist the rehab staff in determining ways to motivate their loved one and maintain open communication between the patient and the rehabilitation team this help the rehabilitation team to make rapport more quickly with patient.

Family members are affected by the patient's condition and often become co-managers of the patient's care. Family and caregivers both may experience changes in daily routine activity due to caregiving that create stress within the family. For example, a spouse or son or daughter in a caregiving role may need to rearrange their work schedule, decrease their hours, or even take a leave of absence to manage his or her responsibilities. There may be a change in living arrangements, issues that arise with childcare, financial problems due to medical bills or unemployment that contribute to pressures on the family.

Family caregivers required emotional and psychological support of their new responsibilities. While caring for a loved one can be exhausting and at times over whelming. Most common experiences experienced by caregivers are feelings of burden, alone, sadness, stress and also physical and emotional health problems. A copping way for family caregivers is to find a support group. Talking with others who faces the same problem/issues/challenges can help caregivers and provide an opportunity to share resources and tips.

A support group usually focuses on a specific situation or condition. support groups have been formed by community members with the same condition or by someone interested in it, such as a family member. In some cases, support groups are organized by nonprofit organizations. Others are provided by Burke staff who are considered experts in a particular area of healthcare.

Caregiver duties & responsibilities are as follows: -

Personal care is not uncommon in some disabled family members to struggle with day-to-day tasks. As the signs of aging progress, simple things like getting dressed, bathing or brushing teeth can become tiresome. In some cases, they may even be painful. Due to that many of loved ones neglect their hygiene because of their daily routine. In other words, responsibility of caregivers is to assist as much as needed by the disabled person to keep up with their daily personal hygiene routine.

Toilet using, grooming, or yoga and exercising is much easier with the help of a qualified caregivers but it's very difficult for family caregiver if this task were carried on for long time.

(ii) Meal planning and food preparation food restrictions, preferences, and requirements make it difficult for many disabled persons to receive their daily nutrients.

(iii) Transportation is a big concern for the disabled people. To bring them to the doctor or any other places it's very difficult for caregivers because of regular follow up at doctor or therapist. Here caregiver duty is to provide transportation to and from activities as well as be there to assist disabled in and out of wheelchairs as needed.

(iv) Companionship, decreased quality of life due to loneliness and depression are common issues disabled person. While relative's visits and social activities may occur from time to time, many disabled people feel alone in between engagements. To supervise disabled people while also giving them someone to talk to on a daily basis.

(v) Medication management, sometimes few numbers of medications consuming by disabled person and that number could grow or decrease, depending on individual needs and diagnoses. Some disabled person may not possess the mental capacity to remember whether or not they have taken specific pills. So, it is difficult to monitor medications and consumption among the disabled person.

(vi) General health care, at home care may not be able to perform checkups or in-depth health procedures, they are qualified for health monitoring and basic care. They can follow a care plan and monitor the disabled person to ensure that no changes occur. If there is any issue arise the caregivers should need to immediately consult with doctor or therapist.

(vii) Family support, it is difficult for a family member to come to terms with the signs of disability that their disabled family member may display. Many caregivers don't know how to help or how to cope with the situation. They need to take education, ideas and methods to make family life easier.

To find for the right professional caregiver is not an easy task because the professional caregiver should be the right combination of knowledge, ability, and empathy to fulfill the role. That's why so many people end up taking care of their family members' needs by themselves.

The family members as caregivers are often juggling their own lives, along with acting as a caregiver for a disabled person in their home. Unfortunately, this is not a tenable situation as family members may have all the caregiver skills which their loved one required.

One of the most important factors in a patient's recovery after a disability, injury or illness is the involvement and support of the family. Usually, the patient's family is the caregiver and thus plays a vital part in the rehabilitation process for a number of reasons: Positive attitudes and reinforcement from family members can inspire patients' commitment to recovery and help them adapt to new physical challenges or limitations. Family support and encouragement can also help patients deal with issues of self-esteem related to their condition. And because family members know the patient best, they can assist the rehab staff in determining ways to motivate their loved one and maintain open communication between the patient and the rehabilitation team.

Approximately 65 million people—or 29 percent of the U.S. population—provide care for a loved one that is disabled, chronically ill or aged. Family members are affected by the patient's condition and often become co-managers of the patient's care. As a result, they may experience changes that create stress within the family. For example, a spouse or son or daughter in a caregiving role may need to rearrange their work schedule, decrease their hours, or even take a leave of absence to manage his or her responsibilities. There may be a change in living arrangements, issues that arise with childcare, financial problems due to medical bills or unemployment that contribute to pressures on the family.

But caregivers shouldn't feel alone in their situation. By working together with the rehabilitation team, the patient and family can help lessen the adverse effects of these changes and work toward finding realistic solutions. First and foremost, families need to become educated about a loved one's condition and prognosis and involved in the development of the rehabilitation plan. The more caregivers learn—by communicating with the health care team and taking advantage of educational programs offered at the hospital— the better prepared they are to care for their loved one at home. At Burke, for example, family members are encouraged to attend and participate in treatment and training sessions in order to become aware of their loved one's progress and learn safe and effective techniques to assist them. Families and caregivers have ongoing access to information about available services and resources that can help the patient successfully transition to the next phase of rehabilitation.

In addition to education, family caregivers need support for the emotional and psychological aspects of their new responsibilities. While caring for a loved one is undoubtedly rewarding, it can also be exhausting and at times overwhelming. Caregivers commonly experience feelings of burden, isolation, loneliness, depression and anxiety and research has shown they are at risk for physical and emotional health problems.

One of the best ways for family caregivers to cope is to find a support group. Talking with others who face the same challenges can help caregivers feel less isolated and provide an opportunity to share resources and caregiving tips.

There are many benefits to participating in a support group:

- Feeling less lonely
- Social interaction in a safe environment
- Sense of empowerment
- Improved coping skills
- Venue to speak openly and honestly about your feelings
- Reduction in stress, depression or anxiety
- Better understanding of what to expect with your situation
- Information about new medical research
- Opportunity to gain information about treatment options

A support group usually focuses on a specific situation or condition. At Burke, there are support groups for ALS, Amputees, Aphasia, Pulmonary, Osteoporosis, Spinal Cord Injury, Traumatic Brain Injury, Stroke, and young-onset Parkinson's. There's also a support group dedicated entirely to the "well spouse" that provides peer support and education about the unique issues facing the caregiving partner in a couple.

Some of Burke's support groups have been formed by community members with the same condition or by someone interested in it, such as a family member. In some cases, support groups are organized by nonprofit organizations. Others are provided by Burke staff who are considered experts in a particular area of healthcare.

In addition to joining a support group, there are several ways that you as a family member can ease the day-to-day stress of caregiving. First, don't be afraid to ask your family and friends for assistance. It may help ahead of time to make a list of all the caregiving tasks required, and then determine which activities you can realistically accomplish on your own and which ones you'll need help with. Second, take care of yourself: exercise regularly, eat right, get enough sleep and keep up with regularly scheduled doctor's appointments. Third, make it a priority to meet regularly with friends and do things you enjoy. By taking time to relax and recharge, you'll feel more energized and better able to care of your loved one.

12.3 Challenges and Mental Health Issues

Caregivers often find they have less time for activities like chores, spending time with family & friends, hobbies, or running errands. Those who maintain full or even part-time employment may have difficulty in keeping a healthy work-life balance.

They'll quickly become overwhelmed if precautions, plans, and proactive measures are not in place to combat the many issues that emerge.

One of the biggest challenges faced by caregivers is time management. Caregivers often sacrifice much of their schedule to care for their loved one, even if it means a lesser quality of life for themselves. It's important, then, to understand that there are ways to provide care without sacrificing your own mental and physical health. This starts with effective time management skills.

Most people who claim they don't have enough time for themselves are unaware of how much time they waste intermittently throughout the day. Therefore, the single best time management tactic starts with keeping a daily diary.

Second most common issue faced by caregivers is lack of privacy. To provide adequate care, close proximity is somewhat of necessity, sometimes as close as living with a loved one. In that case, it may seem difficult to find time alone for any extended period of time.

Depending on how advanced an illness or ailment may be, some patients need round-the-clock care. Eating, bathing, light exercise, medication–these tasks can take up large chunks of a caregiver's day.

A general lack of privacy can lead caregivers to feeling depressed, lonely even. The world feels small when you're only interacting with your loved one every day. Although it may be difficult to ask for help

Strain on relationship is another issue faced by caregivers. Caring for a loved one can take away time from relationships with others, just as much as it can take away time from self. Dinner dates, hobbies, and other activities with friends and family may seem difficult to attend.

Practicing honesty with others is of great importance. Let your friends know your schedule ahead of time, and if you are going to be late with an event, call in advance. Caregivers can feel like they're a burden to their friends if they are constantly late or absent. If you are open and honest, your friends will understand.

Conflict about care is also the issue for caregivers. If you split responsibilities with a sibling, friend, or another family member, you may find from time to time–perhaps often–arguments about caregiving duties getting in the way. This is common, as conflicts can emerge regarding scheduling, level of care, medication, and more.

Conflict with loved one is another challenge for caregiver. When you're inside all day with the same person–no matter the situation or dynamic–there is going to be tension at times. Human beings are complex creatures with a plethora of wants and needs. Sometimes these wants and needs are drastically different from other individuals, and this is where conflict emerges.

This can be even more difficult to handle when dealing with a loved one whose needs are immediate and necessary. The relationship between caregiver and patient can also become toxic if a patient begins to take the caregiver for granted, taking advantage of their kindness and asking for more than they need.

Stress, caregivers should covet stress management. Routinely, they may find their days not going according to plan. Problems will arise when you least expect it. Physical stress dealing with a loved one can induce various kinds of stress that physically manifests. Pain, anxiety, even hair loss, is your body's way of signaling that you're overloaded with stress and need a break. Emotional stress managing expectations goes hand in hand with stress management. Be careful in expecting things to go exactly as planned, and certainly do not expect other people will have your best interests in mind. Just this small change in perspective can help you manage your mood better.

Isolation, the daily drudgery of menial tasks associated with caregiving can leave caregivers feeling isolated. You're normally dealing with the same person and problems day in and day out with seemingly no end in sight. Friends and family members, knowing your situation, rarely call or text–they don't want to bother you. Or perhaps, because you are so busy with caregiving, you stopped answering the phone, and now the phone rarely rings. You look to your loved one for support, but they're medicated or too tired to keep up a conversation.

Depression, many of the aforementioned issues are not singular issues existing in a vacuum. These problems usually come with more problems, and those problems domino down the line until caregivers are neck deep in depression, feeling completely defeated. A caregiver's primary task in dealing with depression relies on their ability to experiment and try new things as well as speaking to professionals who can advise.

But, first, you need to gauge the severity of your depression. Is it clinical depression or just a general feeling of malaise and lack of motivation? The former needs an evaluation from a medical professional like a psychiatrist.

Guilt can spring up from time to time in the caregiving journey, although it may not be as obvious as other emotions. Caregiver guilt normally arises during caregiving in three specific ways: Guilt over inadequate care (even if only perceived), Guilt over neglected relationships, Guilt over negative feelings towards your loved one.

The end of the caregiving experience, unfortunately, ends with a loved one passing on. While some of the issues on this list can be avoided with careful planning and proactivity, grief is something many caregivers will experience during their caregiving journey. It's an unavoidable part of life.

When a caregiver's loved one passes on, they may feel like a part of them has passed on, too. Much of a caregiver's identity can be tied into the caregiving process, routinely bringing them a sense of purpose. When that ability is taken away, even if a loved one is simply moving to an outside facility, caregivers may feel an intense, stinging sense of loss.

Fatigue, when an individual takes on the caregiving challenge, they are essentially committing to two schedules: their own and their loved ones. Without help, many caregivers run around frantically, cramming tasks while haphazardly finishing others. At the end of the day, they feel drained with little energy to offer.

Sleep Loss, it's important that a caregiver has energy in order to take care of themselves first and their loved one second. Sleep loss or lack of deep sleep can wreak havoc on a caregiver's life, leading to poor energy levels throughout the day. This, in turn, leads to half completed tasks, unscheduled daytime naps, falling asleep at work, and even dangerous behavior like falling asleep while driving.

Finances, caregiving can be extremely expensive, almost too much for one person to manage. Medication, medical devices, transportation, and surgical procedures are costly. Many caregivers have to get more than one job in order to make ends meet.

Health risks associated with caregiving include (but are not limited to) stress, sleep issues, a weakened immune system, depression, and anxiety. These risks are normally attributed to a confluence of factors like lack of help, lack of rest, finance troubles, poor self-care and more.

When person experience an injury or trauma, he/she may have psychological and emotional response to this injury and mental health issues may be triggered, such as depression, anxiety, eating disorders. There is evidence that support that mental health issues may inhibit outcomes of rehabilitation process so good mental health increase the outcomes of rehabilitation of your patient. Depression is common for about one third during inpatient rehabilitation that interfere with patient quality of life and functional activities.

Psychological responses/ mental issues

The effect of injury on mental health and psychological response isn't predictable it extends from the time immediately after injury, to the post-injury phase, rehabilitation phase and finally with return to activity. These emotional reactions and mental response to injury are normal. But if the symptoms are unresolved or worsen over time it becomes a problem. These responses effect on the time of rehabilitation.

Sadness.

Lack of motivation, the patient will find it is difficult to maintain his motivation without predictable time of return to their activity and full recovery as it is generally unknown like concussion

Changes in appetite, for example athletic injury may reflect on one's appetite they may feel they don't deserve to eat as they are injured or the failure of their performance.

Depression and suicidal ideation.

Sleep disturbance.

Experience emotional symptoms including feeling of sadness or irritability as a direct result of the brain trauma.

Denial of injury severity and they think the injury isn't bad as the health care providers say.

Fear of re–injury: the patient tends to analyze the situation to find out what went wrong, and how to avoid it next time, in patients with emotional and mental health reactions may create overthinking and unhealthy level that in turn hinder the rehabilitation process.

Concussion and psychological reaction to concussion such as depression, treated by cognitive therapy and physical rest.

Isolation.

Irritation.

Anger.

How to support mental health issues

1- Education, explain to the patient about the the injury and the recovery process, the demonstration should be introduced in the way the patient can understand well, and misinformation from internet should be corrected.

2- Build trust, listen to your patient to make a medical diagnosis but also to assess and monitor their emotional state, experience a range of emotions that make it difficult for care network members to establish connection.

3- Set goals, help patient to be motivated, to complete their rehabilitation by setting short- and long-term goals to achieve.

4-Create a network support between your patient, family members, and friends.

Depression is considered the first or second response in patient with trauma according to many researchers. Once the patient goes through depression it emotions of disbelief, denial movement, anger. And may find themselves dealing with anti- depressant but this isn't the only treatment it's a behavior-change strategy.

It is important for the rehabilitation team members to take care of depression symptoms and emotional difficulties during the process of rehabilitation.

Stroke patients:depression in stroke patient may considered to be biological process that correlates with the size and location of the area affected on brain. It is called post-stroke depression and may slow the recovery rate, hinder patient outcomes, negatively effects on lower functional status and stroke survivors' quality of life, and secondary complication. Depression believed to be more common in stroke patients with aphasia than those without and when it was treated medically the studies show decrease in the mortality rate. As our goal of rehabilitation is to improve one's adaptation to a disability in cope with functional improvement, the physician will sometimes need to deal with depression before dealing with physical rehab.

Athletic injury rehab: the rehab process may be affected by psychological responses such as loss of identity, fear, anxiety, loss of confidence, denial of injury, rapid mood swing, and unreasonable fear of re-injury. Though using goal setting, cognitive structures, maintain patient motivated, and psychological support are helpful strategies for faster recovery and cope with process of rehabilitation and social strategy.

In critical care:after discharge from critical care younger and older patients showed significant incidence of long-term cognitive and psychological dysfunction that impact on long-term function and quality of life.

Summary

Family members are also affected by your disability. In many cases, they may become co-managers of your care. They may undergo many changes as a result of your disability. For example, your family members may also grieve your loss of ability. Severe injury, chronic disease, or disability may mean a change in family roles. For example, a housewife may need to return to work after her husband's disability. A son may need to adjust his work schedule to help care for an elderly parent. These changes can cause stress and conflict in the family. Financial problems due to medical bills or unemployment can occur, adding more stress on the family. Changes in living arrangements, childcare issues, and community re-entry can all pose new problems.

Family acceptance and support can help you deal with issues related to self-esteem and self-image after disability. Positive attitudes and reinforcement from loved ones often help you work towards recovery. Family participation, flexibility, and open communication can overcome many barriers associated with disability. Families who inspire hope can help you adjust and become more confident in your abilities.

While your family are motivated to take care of you, the emotional and physical toll of caregiving can be overwhelming at times. First of all, consider the amount of caregiving that is expected of families outside the rehabilitation facility. Most caregivers are unpaid family members or friends that provide full- or part-time care, even when you also have a healthcare professional.

As a result, caregivers have unique stress. Caregivers often feel unprepared for their caregiving role. Often, they feel isolated, anxious, and depressed. An additional concern is maintaining good communication with the healthcare team and other available resources.

Caregivers must be educated to meet the demands of your rehabilitation plan. In fact, they should be included in the development of this plan.

Not only should caregivers be educated for their role, they must also be supported. Whether this is a counseling program or a problem-solving supportive team interaction, support helps diminish the isolation and anxiety associated with caregiving.

Caregivers must also find time for themselves, away from their caregiving roles. This perhaps is the most important, yet least available, coping strategy that may be accessible to caregivers. The importance of caregivers cannot be underestimated in your successful rehabilitation. As caregivers gain confidence, they and their loved ones, should find caregiving less stressful and more rewarding.

Keywords

Caregivers, trauma, coping skills, recovery, disability, potential.

Self Assessment

1. There are two types of Caregivers.
A. True
B. False

2. Stress can be increased due to caring for a disabled family member.
A. True
B. False

3. Family members are not affected by the patient’s condition.
A. True
B. False

4. To find out the right professional caregiver is an easy task.
A. True
B. False

5. There are many benefits to participate in a social group.
A. True
B. False

6. There are ----- ways to support mental health issues.
A. 2
B. 3
C. 4
D. 5

7. Caregivers should go for coping strategies for------
A. Themselves
B. Others
C. Patients

D. None of them

8. Depression of stroke patients may be considered as---------
A. Psychological
B. Biological
C. Statistical
D. None of them.

9. Changes in appetite may be a symptom of ---------
A. OCD
B. Hysteria
C. Depression
D. None of them

10. There are ------- benefits to participate in social group.
A. 3
B. 5
C. 7
D. 9

11. About------ of the US Population provide care for a loved one.
A. 20%
B. 29%
C. 30%
D. 39%

12. Stress can be -------- due to caring for a disabled family member.
A. Increased
B. Decreased
C. Same
D. None of them

13. Doctors, nurses are --------- caregivers.
A. Family
B. Primary
C. Professional
D. None of them

14. Short breaks -------- be given to the caregivers.
A. Should
B. Should not
C. No difference
D. None of them

15. Family caregivers know ---------- than Professional caregivers about the disabled person.
A. Lesser
B. Equal

C. Better

D. None of them

Answersfor SelfAssessment

1.	True	2.	True	3.	False	4.	False	5.	True
6.	C	7.	A	8.	B	9.	C	10.	D
11.	B	12.	A	13.	C	14.	A	15.	C

Review Questions

1. Briefly elucidate the role of caregivers for PwD.
2. What are the duties and responsibilities of the caregivers?
3. Explain the benefits of participating in a social group.
4. What are the challenges of the caregivers for dealing with PwD?
5. What are the mental health issues of PwD?
6. How we can support mental health issues of PwD?
7. Briefly describe the impact of disability on family.
8. What are the roles of professional caregivers in disability?
9. What may be the mental health issues of the caregivers of disabled persons?
10. What are the techniques to be adopted to cater the mental health issues of the caregivers?

Further Readings

- Quality of Life by Alison Carr, et. al. BMJ Books.2002
- Quality of Life- An Interdisciplinary Perspective by ShrutiTripathi, et. al. CRC Press,2022.

Unit 13: Quality of Life

CONTENTS

Objectives

- To understand the concept of quality of life of the persons with disability
- To familiarize with different domains of quality of life
- To know various assessment techniques of quality of life

Introduction

The purpose of modern health care is to improve quality of life (QoL). It's often mixed up with the term "standard of living." Standard of living, on the other hand, relates to the possession of riches or material items. Although having a specific amount of square feet of living space in the United States or owning oxen in Ethiopia makes a visible impact in people's lives, it does not always imply higher happiness or well-being; lottery winners demonstrate this.

The World Bank's international data on annual per capita income shows that after income reaches a crucial level – $13,000 in 1995 – the strong link between subjective well-being and money becomes progressively slack and dispersed. Furthermore, standard-of-living gains do not appear to make a major difference in people's QoL in the world's wealthiest countries, a conclusion that policymakers find confusing.

The best way to define and quantify QoL is still up for dispute. Its definitions in the 1970s have terminological similarities to stress concepts. At a time when stress was perceived as a phenomenon that outstripped people's resources, these resources needed to be appropriate in terms of meeting people's wants, needs, and capacities in order to give a satisfactory QoL. Since then, definitions have placed a greater emphasis on people's subjective impressions of crucial aspects of their lives, examining the various meanings attributed to these experiences in particular. People's perceptions of their QoL are influenced by how they interpret life's experiences (e.g., as stressful or pleasant). "An individual's perceptions of his or her functioning and well-being in diverse realms of life," defined Wenger et al. (1984). People's perceptions of their internal states, such as muscle tension or happiness, and the external events that impact them from their environment, such as moving jobs or being bereaved, are increasingly recognized as a rich interaction and balance Skevington (2007).

13.1 Concept of Quality of Life

Quality of life is defined by the WHO as “individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. It is a wide notion that encompasses a person's physical health, psychological condition, amount of independence, social interactions, personal views, and relationships to key environmental factors in a complicated way.

This concept is based on the idea that quality of life is a subjective assessment that is influenced by cultural, social, and environmental factors. (As a result, the terms "health status," "living style," "life satisfaction," "mental state," and "well-being" are insufficient to describe quality of life.) WHO (2012)

People have varied expectations, people may be at different places on their illness trajectory when their quality of life is measured, and the reference value of their expectation may fluctuate with time.

The first issue arises because expectations are formed through prior experiences and are thus highly specific. They vary from person to person and are influenced by social, psychological, socioeconomic, demographic, and other cultural factors. People's ties with their environment have a strong influence on their quality-of-life expectations. This could result in fundamental differences in assessments of the impact on quality of life. For example, as a technique of successfully living with ageing, older persons have described the necessity to adapt to their changing circumstances.

The second flaw is that the magnitude of the impact is dependent on when the measurement is taken. It's hard to tell when a measurement was taken based on an individual's disease trajectory using current methods. Furthermore, people' reactions to disease are highly individual: no one-size-fits-all approach is followed by all. This means that, even in a clinical study when all patients' quality of life is measured at the same time (and after the same length of therapy), they may still be in various stages of their condition.

The third issue emerges because people's expectations are continuously changing as a result of their experiences: they are constantly moving towards an ever-changing point of balance. Quality of life is a dynamic concept, according to psychological, social, and health services studies. People's techniques for evaluating or quantifying their quality of life evolve over time and in response to a variety of situations. As a result, its meaning is inherently unstable Carr, et al. (2001)

13.2 Domains

According to Lawrence (2011), In the 1960s, applied research on social indicators sparked QOL research in the health and social sciences. Then it was claimed that there were just a few quantitative metrics that might reveal whether or not there were tendencies toward or away from social progress. Several scholars claimed that objective indicators generated from official statistics were not the only way to assess socioeconomic situations. They claimed that the significance of these indications could be deduced from the aggregation of individual replies using subjective indicators. This method has been applied to a wide range of social and psychological issues, including health and well-being.

QOL is a multifaceted notion that is difficult to define and quantify. This explains why there are so many different conceptual and methodological interpretations. In general, QOL is a subjective assessment of an individual's level of contentment with his or her life, particularly those aspects thought to be essential. This popular definition of QOL equates life satisfaction and subjective well-being. QOL is measured using two subjective dimensions: first, the relative importance of many aspects of daily life, and second, the level of personal satisfaction with each of these aspects. Health (defined as the absence of disease) is commonly included as a subcomponent of physical (and sometimes psychological) well-being, according to a variety of typologies of components. Table 1 reproduces Flanagan's well-known typology.

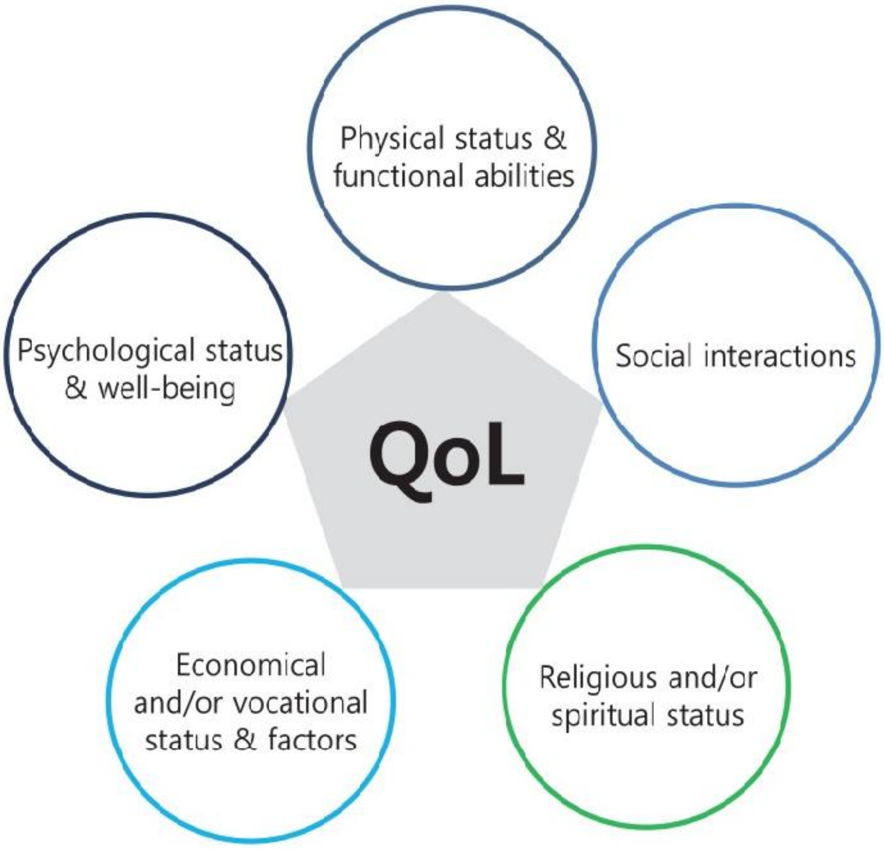
Psychological Domain is used to assess the quality of life of psychological health, such as affective states (feeling happy, optimistic, satisfied, and interested in life, in contrast to feeling negative, anxious, or depressed), memory and attention span.

To evaluate the psychological domain of quality of life (PDQoL), anxiety and depression levels of infertile women with endometriosis versus non endometriosis who applied for Assisted Reproductive Technologies (ART).

This prospective case-control study compromised a total of 105 women who applied for IVF/ICSI program. Ninety-three women were divided into two groups as endometriosis (n = 37) and non-endometriosis (n = 56) after 12 patients who refused to participate in the study were excluded. The WHOQOL-BREF questionnaire, Beck Depression and Anxiety Inventory scales were used to determine the psychological stress levels.

Women with endometriosis seem to be more susceptible to depression and anxiety than women without endometriosis. Although infertility treatment outcomes are not found to be significantly affected, the impact of depression and anxiety over ART treatment success merit further research.

Domain	Literature-based indicators
Emotional well-being	Contentment, self-concept, and lack of stress
Interpersonal relations	Interactions, relationships, and supports
Material well-being	Financial status, employment, and housing
Personal development	Education, personal competence, and performance
Physical well-being	Health and health care, activities of daily living, and leisure
Self-determination	Autonomy/personal control, goals and personal values, and choices
Social inclusion	Community integrations and participation, community roles, and social supports
Rights	Human (respect, dignity, equality) and legal



13.3 Assessment

The 8+1 indicators of quality of life

The following 8+1 indicators have been defined as an overarching framework for measuring well-being based on academic research and many projects. Because of potential trade-offs, they should ideally be examined simultaneously:

- Material living conditions (income, consumption and material conditions)
- Productive or main activity
- Health
- Education
- Leisure and social interactions
- Economic security and physical safety
- Governance and basic rights
- Natural and living environment
- Overall experience of life

Material Living Conditions

The three sub-dimensions of material living standards are income, consumption, and material conditions (deprivation and housing). Income is a crucial indicator because it influences the majority of the other indicators in the framework. This sub-dimension contains a variety of metrics derived from national accounts and household surveys (net national income, household disposable income based on the EU-SILC). The same is true for consumption, where certain aggregated measures (real individual household consumption per capita) are collected from national accounts and additional household consumption indicators will be created in the future from the Household Budget Survey. In addition, joint measures of income, consumption, and wealth are being developed, with the potential to provide the most comprehensive picture of household circumstances. However, for the time being, the wealth aspect of this framework is covered under the sub-dimension Economic safety. The indicators chosen for this sub-dimension are likewise based on the EU-SILC. Material conditions (poverty and housing) give crucial additional information to these money-based approaches.

Productive or Main Activity

Three sub-dimensions of the productive or main activity dimension are measured: quantity of employment, quality of employment, and other main activity (inactive population and unpaid work). Every day, residents' lives are filled with a variety of activities, the most notable of which is their work. Working hours, balancing work and non-working life, safety and employment ethics are some of the indicators used in the European Union to quantify this element of quality of life, and they largely come from the EU-LFS, as well as the Structure of Earnings Survey) and administrative data. Because not everyone is employed, it's critical to include indications for the unemployed and unpaid work in this dimension. Unpaid labor is, in reality, a significant indication of both qualities of life and gender equality. The only possible source of comparable data on this topic is Time Use Survey data, although it is collected on a voluntary basis and does not cover all EU Member States.

Health

Health is an important aspect of residents' quality of life and can also be viewed as a type of human capital. Poor health has the potential to stymie societal progress. Physical and/or mental issues can also have a negative impact on one's subjective well-being. In the context of Quality of Life, the health status in the European Union is usually measured through three sub dimensions: health outcome indicators such as life expectancy the number of healthy life years and subjective assessments of own health, chronic diseases and limitations in activity, health determinants and access to healthcare.

Education

Education plays a critical part in the lives of citizens in our knowledge-based economies, and it is a key component in determining how far they develop in life. The type of work a person will have been determined by their level of schooling. Individuals with restricted abilities and competencies are frequently barred from a wide range of employment and, in certain cases, miss out on opportunities to achieve important social goals. They also have a lower chance of achieving economic success. On a societal level, it is also the most essential form of human capital.

Leisure and social interactions

When attempting to quantify an individual's well-being, the importance of networks and social ties should not be overlooked, as they have a direct impact on life satisfaction. This dimension is measured in the European Union through two sub-dimensions, the first of which is leisure activities. Quantity (how frequently individuals spend time with people at sporting or cultural events) and quality (their pleasure with time use) are measured, as well as (lack of) access to this sort of activity due to a lack of resources or facilities.

Economic security and physical safety

The importance of security in citizens' lives cannot be overstated. The ability to prepare ahead and weather any unexpected changes in their economic and larger environments has an impact on their quality of life. Physical and economic safety are measured in terms of two sub-dimensions: physical safety (e.g., the number of homicides per country from police records and the proportion of those who believe there is crime, violence, or vandalism in the area where they live) and economic safety.

Governance and Basic Rights

The ability to participate in public debates and have a say in how public policies are shaped is an important feature of quality of life. The governance and basic rights dimension has three sub-dimensions: faith in institutions and public services, discrimination and equal opportunities, and active citizenship. A crucial part of democratic societies is providing citizens with adequate statutory protections. Citizens' participation in public and political life is essential for good government (for example, through active citizenship actions such as attending a demonstration, sending a letter to those in office or signing a petition, indicator collected in the 2015 SILC Ad Hoc Module).

Natural and Living Environment

Over the previous few decades, environmental preservation has occupied a prominent position. In the most recent Eurobarometer on the subject, which was conducted in 2017, 94 percent of Europeans stated that environmental protection was very important to them. Pollution of the air, water, and noise can have a direct influence on people's health and countries' economic development. Environmental indicators are critical for assessing the quality of life in Europe and the world at large.

Overall experience of life

Life satisfaction (cognitive appreciation), affect (a person's feelings or emotional states, both positive and negative, typically measured with reference to a specific point in time), and eudemonics (a sense of having meaning and purpose in one's life, or good psychological functioning) are the three sub-dimensions used to assess one's life.

Measures such as the linear analogue self-assessment scales, the Functional Living Index — Cancer, and the Breast Cancer Questionnaire are designed for repeated use before, during, and immediately after treatment. The purpose of the repeated measures is to assess patients' short-term responses during the course of therapy.

Global assessment measures, such as the Spitzer Quality of Life Index, are designed to reflect the quality of life following the impact of disease and management or to reflect global changes in assessments over a long period of time. Investigators have used the Spitzer Quality of Life Index for repeated assessments during the course of therapy (Coates et al. 1987, Levine et al. 1988), but the scores tend to be less responsive to short-term clinical changes than the disease-specific measures.

The basic issue is the use of quality-of-life measures to assess short-term against long-term responses to therapy. For example, Levine et al. (1988) stopped taking assessments when patients withdrew from treatment or relapsed. Conversely, Chubon (1987) used the Life Situation Survey to compare the quality of life of patients in chronic care and rehabilitation programs with those of healthy subjects.

There is a problem with repeated self-assessment during the course of therapy. Investigators have found it difficult to maintain high self-assessment completion rates over several weeks (Finkelstein et al. 1988, Raghavan et al. 1988) and were not able to use the assessments because of missing values. Levine et al. (1988) minimized the problem by having nurses interview the patients during clinic visits; this procedure, however, added considerably to the time and costs of the study. If these measures are to be used repeatedly, the time and costs of maintaining high response rates over multiple assessments must be considered.

13.4 Global and Specific Indicators of Quality of Life

Quality-of-life research has included the study of levels of economic, political, social, and psychological well-being resulting from varying governmental and economic systems, as well as policies and public programs related to health. Schuessler and Fisher (1985) wrote that quality-of-life research began in the 1960s with the Report of the President's Commission on National Goals in the United States. Most specialists agree that the term "quality" has the same meaning as "grade" or "rank," which can range from high to low or best to worst.

What elements of life are to be so graded? The units of analysis can be as large as a nation. Countries can be ranked on their economic systems and on the types and amounts spent by governments on social programs relative to expenditures on industry and the military. At the level of the individual, the elements can be objective (for example, job, income, shelter, and food) or subjective (happiness, sense of well-being, self-realization and the perceptions of the worth and value of life, and the like).

The best known studies of the quality of life of individuals are those of Andrews and Witney (1976) and Campbell and colleagues (1976, 1980) at the Institute for Social Research at the University of Michigan. Both teams of investigators asked questions about the domains of life satisfaction, including work, marriage, leisure activities, family, housing, and neighborhood. They developed a global measure of satisfaction by combining the scores in a general measure.

Quality of life studies in the health sector are more limited in scope. In the health sciences, the task at hand is to assess the impact of disease and its management, including interventions, on the well-being of the patient. The health states of the individuals may influence their quality of life without determining it. As Ware (1987) noted "jobs, housing, schools, and the neighborhood are not attributes of an individual's health, and they are well outside the purview of the health care system."

Health care researchers have developed numerous measures of quality of life over the past two decades, and several review articles have commented on those so far available. Their use in assessing the outcome of health care interventions has become popular. As we have seen in Chapter 2, recent studies have reported on the quality of life of men with mild to moderate hypertension undergoing antihypertensive therapy, of women with advanced breast cancer undergoing chemotherapy, and of cancer patients in hospice programs.

Although a variety of studies purport to assess quality of life, there is remarkably little agreement about the underlying concepts or theoretical framework that the measures represent. These measures may include clinical symptoms (for example, pain, nausea, vomiting), functional disability (Katz Activities of Daily Living), health status measures (RAND health status measures, Sickness Impact Profile), and measures of life satisfaction and psychological well-being.

The World Health Organization (WHO) has defined health as a "state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity." Ware (1987) argues that five health concepts are inherent in this definition: physical health, mental health, social functioning, role functioning, and general well-being. He takes a conservative approach to the study of quality of life in the health sciences. Because the goal of health care is to maximize the health component of the quality of life, he suggests that the measures be restricted to assessing health status.

Spitzer (1987) includes the burden of symptoms in his operational definition of health. He would restrict the assessment of the attributes of health to those who are definitely sick. He sees little point in extending the studies of quality of life in health care to the ostensibly healthy, but few writers in the field agree with this point of view.

Wenger et al. (1984), McDowell and Newell (1987), and Kane and Kane (1981) offer systematic reviews of a number of measures used in quality-of-life studies, including functional disability indices, health status scales, and measures of life satisfaction. In their reviews, these authors discuss the reliability and validity of a number of the measures and their uses in health care studies. We list the instruments they treat in the section entitled "Three Sources of Descriptive Information for Quality-of-Life Measures." This chapter focuses on measures developed specifically to assess quality of life.

Summary

Measures may focus on the symptoms, complaints, disabilities, and disruptions in life that are specific to the clinical condition under study. Indeed, the disease-specific approach has been advocated in the study of arthritis, heart disease, and the evaluation of chemotherapy.

Alternatively, one can assess the quality of life resulting from the overall consequences of disease and management on the functional capacities and patients' perception of well-being. The more global measures cover a number of dimensions within a summary score. For example, the Quality-of-Life Index developed by Spitzer et al. (1981) includes one item for each of the following dimensions: activities of daily living, principal activities, health, outlook, and support. Similarly, measures of life satisfaction and general well-being are global in perspective.

Other measures, such as the linear analogue self-assessment scales developed by Priestman and Baum (1976) or the Breast Cancer Questionnaire (Levine et al. 1988), are designed so that patients may repeatedly assess their symptoms and report their physical and emotional responses to adjuvant chemotherapy. The resulting scores show the patients' immediate and specific responses to disease and treatment.

Objective measures are based on variables that can be observed and recorded by various testing procedures and assessors. Measures of disease activity, remission of symptoms, presence of side effects, changes in functional capacity, ability to carry out usual activities, and family and social activities are phenomena that can be observed and recorded. These variables are important determinants of quality of life, and agreement can be reached about changes in status that have occurred.

Subjective measures provide opportunities for individuals to express their thoughts, knowledge, attitudes, moods, and feelings. Subjective phenomena may be related to particular diseases or types of therapy, or they may be more global.

Although researchers and policymakers tend to make much of the distinction between objective and subjective measures, both are probably necessary when assessing quality of life, and both require investigations into their reliability and validity. It is perhaps surprising that the objective measures often are not as well standardized as the subjective measures; objectivity does not automatically mean that measures are reliable and valid.

Some quality-of-life studies maintain one perspective or point of view. Yet it is becoming increasingly common for researchers to employ a mix of perspectives and methods in assessing quality of life. We have reviewed what is known about the conceptual framework, reliability, validity, and uses of specific measures. In any study, several tools may be combined to provide information on various perspectives: subjective and objective, disease-specific and global, clinical endpoints and long-term outcomes, and so on.

Keywords

Quality of life, World Health Organization, Persons with Disability, WHOQOL, Global and Specific Indicators, Governance

Self Assessment

1. The purpose of modern health care is to improve Quality of Life.

A. True

B. False

2. The definition of Quality of Life in 1970, has no similarities on stress concept.

A. True

B. False

3. Quality of Life is defined by WHO is ‘individual’ perception of their position of life.

A. True

B. False

4. Quality of Life is multifaceted notion that is difficult to define and quantify.

A. True

B. False

5. Psychological domain is used to assess the cognitive aspects of Quality of Life.

A. True

B. False

6. There are ------- sub dimensions of maternal living standard.

A. 2

B. 3

C. 4

D. 5

7. Andrews and Whitney studied Quality of Life in --------

A. 1971

B. 1976

C. 1981

D. 1986

8. ------- defined health as a ‘state of complete physical, mental & social wellbeing’.

A. APA

B. UNICEF

C. WHO
D. None of them

9. Quality of Life is a -------- assessment.
A. Subjective
B. Objective
C. Correlational
D. None of them

10. Citizens should be provided -------- statutory protection.
A. Inadequate
B. Adequate
C. Least
D. None of them

11. ------- sub dimensions of the productive or main activity dimension of Quality of Life.
A. 2
B. 3
C. 4
D. 5

12. There are ------ indicators of Quality of Life.
A. 3+1
B. 4+1
C. 6+1
D. 8+1

13. Contentment and lack of stress is related to-------
A. Interpersonal relations
B. Material well being
C. Emotional well being
D. None of them

14. Financial status, employment and housing is related to------
A. Interpersonal relations
B. Material well being
C. Emotional well being
D. None of them

15. According to ------------, applied research on social indicators sparked quality of Life researches in the health and social sciences.
A. Lawrence
B. Carr
C. Wenger
D. None of them

Answers forSelfAssessment

1.	True	2.	False	3.	True	4.	True	5.	True
6.	B	7.	B	8.	C	9.	A	10.	B
11.	B	12.	D	13.	C	14.	B	15.	A

Review Questions

1. Explain the concept of Quality of Life.
2. Briefly elucidate the domains of Quality of Life.
3. Explain in details the measurement of Quality of Life.
4. Explain the sub dimensions of the measurements of Quality of Life.
5. Briefly elucidate global & specific indicators of Quality of Life.
6. Explain the contribution of World Health Organization in Quality of Life.
7. Cite with examples the changing scenario of Quality of Life.
8. Analyze Quality of Life in respect to persons with disability.
9. Explain the subjective & objective measures of Quality of Life.
10. How Quality of Life is related to modern health care system?

Further Readings

- Quality of Life by Alison Carr, et. al. BMJ Books.2002
- Quality of Life- An Interdisciplinary Perspective by ShrutiTripathi, et. al. CRC Press,2022.

Unit 14: Adjustment & Well Being

CONTENTS

Objectives

- To know the concept of adjustment & well being
- To familiarize with personality variables in PwD
- To understand the mediators & moderators of psychosocial adjustment & well being

Introduction

Well-being, as a construct of long-standing interest in the field of psychology, requires further attention for its primary preventative potential in supporting workplace health and performance (Zelenski et al., 2008; Heuvel et al., 2010). While mental health professionals try to restore workers' well-being who are experiencing psychological distress, primary preventive and health promotion experts work to promote well-being and improve factors that protect persons from the harmful consequences of psychological risk. (Hage et al., 2007).

The study of health promotion and well-being is gaining popularity as a variety of social, economic, biological, psychological, and cultural elements threaten the attainment of well-being. Young people in Italy, for example, are growing up in an era of fast social upheaval, job insecurity, and high unemployment. Many youth and young adults face threats to their well-being as a result of economic insecurity, unpredictable and shifting job prospects, and a growth in the number of individuals living in poverty (Masten, 2014; Di Fabio and Bucci, 2016; Di Fabio and Palazzeschi, 2016).

Individuals and society experience well-being as a positive state. It, like health, is a daily resource that is influenced by social, economic, and environmental factors. The ability of people and civilizations to contribute to the world with a sense of significance and purpose is referred to as well-being. Focusing on well-being aids in the tracking of equitable resource allocation, general thriving, and long-term sustainability. The resilience, capacity for action, and readiness to overcome problems are all factors that contribute to a society's well-being.

The Geneva Charter for Well-Being was endorsed by attendees at the 10th Global Conference on Health Promotion in December 2021, which was organized by WHO. It identifies five critical areas for action:

1. Design an equitable economy that serves human development within planetary boundaries.
2. Create public policy for the common good.

3. Achieve universal health coverage.
4. Address the digital transformation to counteract harm and disempowerment and to strengthen the benefits.
5. Value and preserve the planet WHO (2021)

14.1 Personality Variables in PwD

Personality traits prior to the onset of illness or disability may influence how well an individual psychologically adjusts after the illness or disability has occurred. Previous research has shown that after the onset of a disability, people initially experience sharp drops in life satisfaction, and the ability to regain lost life satisfaction is at best partial. However, such research has not investigated the role of individual differences in adaptation to disability. We suggest that predictability personality determines the speed and extent of adaptation. We analyzed measures of personality traits in a sample of 11,680 individuals, 307 of whom became disabled over a 4-year period. We show that although becoming disabled has a severe impact on life satisfaction, this effect is significantly moderated by predictability personality. After 4 years of disability, moderately agreeable individuals had levels of life satisfaction 0.32 standard deviations higher than those of moderately disagreeable individuals. Agreeable individuals adapt more quickly and fully to disability; disagreeable individuals may need additional support to adapt.

Intellectual disabilities (ID, formerly mental retardation) have multiple causes. For example, there are many genetic causes. Brain injuries can cause an intellectual disability. Some types of medical conditions can also affect the brain's development.

These different causes mean each person's disability is unique. There is no single set of shared traits or features. For example, there are no personality traits common to people with ID. However, certain specific syndromes that cause ID have personality characteristics associated with that particular syndrome. For example, children with Williams's syndrome tend to be outgoing. However, by definition, all people with ID have limited intellectual functioning. These limitations often create some commonly observed difficulties.

One such problem is impulse control. You may recall that people with ID have trouble connecting cause and effect. This in turn causes problems with impulse control. For instance, suppose a child sees yummy, hot cookies coming out of the oven. The child wants to grab one immediately. If not controlled, this impulse will cause a nasty burn. Experience is usually a great teacher. So, most children only make this impulsive mistake once or twice. They form a connection between the hot cookie (cause) and the burn (effect). They learn to control the impulse to grab a cookie right out of the oven. However, this is not so easily learned by people with ID. This poor impulse control leads to many unpleasant consequences.

A related problem is poor frustration tolerance. When an impulse is inhibited, it requires the ability to tolerate a bit of frustration. This ability is called frustration tolerance. Frustration tolerance is an important developmental skill. It allows people to comfortably endure the small frustrations of everyday life. This in turn serves to limit the unpleasant consequences associated with impulsive behavior. Returning to the previous example, it is frustrating to inhibit the impulse to grab a cookie. However, it avoids the consequence of a nasty burn.

Frustration tolerance also enables people to build confidence. When we attempt to solve problems, our initial efforts may fail. This can be very frustrating. Without frustration tolerance, people give up. As a result, they do not put forth any effort. Clearly, if we make no effort to solve problems, we cannot develop the skills we need to solve them!

Poor frustration tolerance is not the only problem. This is coupled with many more opportunities to become frustrated. Return to the prior example of a child's impulse to grab a hot cookie. If a caregiver attempted to stop the child from grabbing the cookie, it frustrates the child. She would not readily understand her caregiver's benevolent motivation. It bears mentioning that not all people with ID become easily frustrated. This example simply illustrates that the opportunities for frustration are significantly increased.

The increased opportunities for frustration highlight the importance of frustration tolerance. People respond to frustration in different ways. Some people respond in an impulsive, stubborn, and aggressive manner. Others respond with passivity, withdrawal, and compliance. Poor frustration tolerance may cause aggression toward caregivers. It may also lead to self-injurious behavior. These behaviors are observed in some people with ID.

Another common difficulty is low self-esteem. Self-esteem naturally develops as children learn to solve problems. The ability to solve problems builds self-confidence. However, limited intellectual functioning makes it difficult to solve problems. Skillful problem solving requires sustained attention and persistence in the face of difficulty. These abilities are limited in persons with limited intellectual functioning. Thus, a low self-esteem may develop. Psychiatric disorders related to low self-esteem, such as depression, may accompany intellectual disabilities. However, many people with ID are quite happy and content. They don't exhibit problematic behavior.

14.2 Mediators and Moderators of Psychological Adjustment & Well being

The 5 Approaches to Health Promotion

1. Health Promotion Model (HPM)

Pender's Health Promotion Model is predicated on the notion that people's experiences influence their health outcomes. Health promotion models are concerned with investigating people's attitudes toward health and their own experiences with it. To understand most of people's health-related decisions, the theory suggests looking at their lifestyles, psychological health, and social and cultural surroundings. For example, not eating fresh vegetables since one grew up without eating produce is one approach to understand why someone may suffer from a serious ailment such as obesity.

2. Health Belief Model (HBM)

According to the Health Belief Model idea, a person's belief in a diagnosed ailment, together with their perception of the success of a therapy, predicts their chance of making a change. If a person has a difficult-to-diagnose condition, it may be more difficult to priorities therapy for the reason.

Based on this concept, health professionals may take urgent action by informing someone that they are either vulnerable or have a significant medical condition. Furthermore, they may anticipate that a person may doubt the medical approach if they do not experience the symptoms and display fear toward medical counsel.

3. Transtheoretical Model (TTM)

Following this initial outcome, an informed recommendation of risk factors that potentially worsen sickness may be made. In more extreme cases of noncompliance, healthcare leaders must design HBM-based interventions.

When a healthcare expert warns a patient about a potential medical concern and educates them on preventive measures, the patient may believe them but refrain from taking immediate action. This option is based on the premise that when someone receives health-related information, they may consider it before acting on it. As a result of such behavior, the transtheoretical theory specifies six stages that a person may go through:

Pre-contemplation: while being aware of the medical condition, the patient does not intend to act.

Contemplation: the patient is preparing to act with purpose.

Preparation: The patient decides on a course of action and sets a deadline.

The patient decides on a course of action.

Maintenance: the patient concentrates on not relapsing and sticking to the plan in their everyday activities. Some people may have this for a few months, while others may experience it permanently. A recovering alcoholic, for example, may experience relapses and remain in the maintenance stage their entire lives.

Termination: the patient is actively healthy and has no desire to revert to previous behaviors.

4. Theory of Reasoned Action (TRA)

Although not a model, this theory is highly regarded in the HBM and is treated separately. According to the notion, a person will act in a certain way on a health issue based on their willingness owing to subjective norms. Norms are frequently the outcome of a person's social and environmental surrounds, as well as their perceived influence over that conduct.

A healthcare expert, for example, might ask a young man if his tight circle of friends believes he should incorporate exercise into their daily routine. Researchers at Iran University of Medical Sciences utilized TRA to assess the effectiveness of an educational intervention aimed at increasing breakfast consumption among children and adolescents in a medical study.

5. Diffusion of Innovation Theory (DOI)

Another theory that fits under community and organizational participation paradigms is Diffusion of Innovation (DOI). The theory looks into how a new thought or health practice spreads in a social structure or society and what factors determine how quickly the idea or behavior is accepted.

The type of invention, communication methods, time, and social structure all influence the adoption of new ideas. The DOI model "highlights the uncertainties associated with new behaviors and helps public health program me implementers identify approaches to overcome these uncertainties," according to the Health Communication Capacity Collaborative.

Personality dimensions such as openness and agreeableness have been found to be associated with prejudice levels towards several minority groups. Yet these variables have been mostly ignored by existing research into attitudes towards people with intellectual disability (PWID), which has primarily focused on contact and demographic variables. The current study investigated the relationship between personality dimensions and attitudes toward PWID.

Background Personality dimensions such as openness and agreeableness have been found to be associated with prejudice levels towards several minority groups. Yet these variables have been mostly ignored by existing research into attitudes towards people with intellectual disability (PWID), which has primarily focused on contact and demographic variables. The current study investigated the relationship between personality dimensions and attitudes toward PWID. An online survey was completed by 466 adult participants recruited through a variety of sources. The survey consisted of a well-validated attitude survey, the Big Five inventory, contact related and demographic questions.

Because personality traits are relatively stable in adulthood and have widespread influences on behavior, they have the potential to affect the disablement process. Yet, there have been few prospective studies of the association of personality with disability risk, and cross-sectional studies have yielded inconsistent results. One obstacle to the progress is that such a diverse array of personality traits has been examined that it is difficult to integrate findings across studies. In the past decade, the big five taxonomy of personality has gained wide acceptance. Because the model is relatively new, however, few studies have related it to disability, and most of these have focused on neuroticism and extraversion to the exclusion of the other three traits.

At baseline and annually thereafter, participants had a uniform clinical evaluation, with examiners blinded to previously collected data. The evaluation included assessment of selected risk factors, medical history, cognitive testing and neurological examination. The diagnosis of dementia was made by an experienced physician using National Institute of Neurologic and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association criteria [6], as reported in detail elsewhere.

Public attitudes towards persons with intellectual disabilities (IDs) have a significant effect on potential community integration. A better understanding of these can help target service provision and public awareness programs.

14.3 Promotion of Well being

The principle underlying this Call to Action is that, with good health, persons with disabilities have the freedom to work, learn and engage actively in their families and their communities. Health and wellness are not the same as the presence or absence of a disability; they are broader concepts that directly affect the quality of a person's life experience. Research and clinical experience have shown that persons with disabilities can be both healthy and well (Krahn 2003). And good health opens the door to employment and education for persons with disabilities, just as it does for persons who do not have disabilities.

This Call to Action's goals and strategies for action, too, are based on a growing body of scientific knowledge and evidence-based practice about disability, health and wellness. They also recognize the costs of inaction in both human and economic terms. The impetus for this Call to Action has been the recognition that health is a key to realizing the goals of the President's New Freedom Initiative (NFI) for persons with disabilities. Only with accessible, comprehensive health care and wellness promotion services can all persons with disabilities enjoy the intent of the NFI: full, engaged and productive lives in their communities.

Surveys have found that a substantially lower percentage of persons with disabilities than those without disabilities report their health to be excellent or very good (28.4% versus 61.4%) (Centers for Disease Control and Prevention 2004a). While at risk for the same ailments and conditions as people in the general population (for example, injury, obesity, hypertension and the common cold), persons with disabilities also are at specific risk for secondary conditions that can damage their health status and the quality of their lives (Kinne et al 2004; Rimmer et al 1996; Hough 1999; Simeonsson and Leskinen 1999). Yet, particularly when it comes to access, many health and wellness programs do not address the needs of persons with disabilities.

Healthy People 2010, the national health promotion agenda, has included health indicators designed to measure how America is promoting the health of per sons with disabilities, to prevent secondary conditions and to eliminate health disparities that now affect per sons with disabilities. It identified four main misconceptions that continue to plague how disability status has been perceived: (1) disability is equated with poor health status; (2) public health should focus only on preventing disabling conditions; (3) no standard definition of disability is needed for public health purposes; and (4) the environment is not a factor in the genesis of disability.

These Healthy People 2010 goals are reflected in those of the Call to Action, which calls for: (1) public knowledge and understanding about disability, (2) provider training and capacity to see and treat the whole person and not just a person's disability, (3) health and wellness promotion for persons with disabilities, and (4) access to needed health care services for persons with disabilities. The balance of this section discusses these goals.

GOAL 1: People nationwide understand that persons with disabilities can lead long, healthy, productive lives.

Despite progress in science, technology and advocacy, disabilities of all kinds are still equated—incorrectly and by too many people—with ill health, incapacity and dependence. Welner and Temple (2004) point out that the misperception remains that "only a person who is physically agile and neurologically intact can be considered healthy." Similarly, with regard to individuals with mobility difficulties, Iezzoni (2003) has observed that "much of society still holds persons with mobility difficulties individually responsible for problems…." Early disability advocate and sociologist Irving Zola (1982) suggested some believe that mobility difficulties are a weakness or personality defect to be overcome. Age-old perceptions, misunderstandings and fears, while still prevalent, are far from the reality of disability today.

The reality is that with accommodations and sup ports, ample access to health care, engagement in well ness activities and the impetus that comes from supportive friends and families, persons with disabilities can— and do—lead long, productive, healthy lives. Issues about disability and the lives of persons with disabilities increasingly are becoming part of the American consciousness and are beginning to be addressed.

GOAL 2: Health care providers have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity.

Health care providers and their staff may harbor many of the same misconceptions about persons with disabilities as are found in the general public. Too often, health care service programs and personnel have not adopted the biopsychosocial approach to disability. Reports from persons with disabilities suggest that health care providers often focus on their disabling condition rather than on other health issues that might be of concern to the individual (Panko Reis 2004). In part, this is the product of the historical "compartmentalization" of health care education and training.

As a result, individuals with disabilities often encounter professionals unprepared to identify and treat their primary and secondary conditions and any other health and wellness concerns. For example, when it comes to persons disabled by mental illness, health care providers need to be aware of and respond to the full array of medical, physical, psychosocial, cultural and spiritual issues associated with—and separate from—an individual's mental disorder. They need to recognize that mental illnesses, as other disabling conditions, need to be treated within the larger context of the individual, including the range of other health care needs that might require medical attention (U.S. Department of Health and Human Services, 2000; U.S. Department of Health and Human Services 2003).

Secondary Conditions

The presence of a particular disability is not the only factor a health care provider should consider when working to meet ongoing, quality health and wellness needs of a person with a disability. Rather, the health care provider should also pay close attention to the person's full range of health concerns, including the onset of possible secondary conditions. These are medical, social, emotional, family, or community problems for which a person with a primary disabling condition is at increased risk (Marge 1988; Simeonsson and Leskinen 1999; Krause and Bell 1999; McMillen et al 1999; Wilber et al 2002).

Some have suggested that the high direct health care costs of disability are a result of insufficient attention early on to secondary and other health needs of individuals with disabilities. The result is increasing numbers of persons with multiple, complex and often preventable, chronic conditions and a health care system insufficiently prepared educationally, structurally and economically to recognize and address those needs (Panko Reis et al 2004; U.S. Department of Health and Human Services 2003; Institute on Disability and Development 2003). The vast majority of these secondary conditions can be mitigated with early intervention; many can be prevented altogether.

Some individuals with disabilities develop no specific secondary health issues related directly to the condition or conditions accompanying their disabilities. Rather, they require only a routine regimen of ongoing health care. However, many persons with disabilities experience secondary conditions directly related to their disability.

A recent Centers for Disease Control and Prevention-supported study by Kinne and colleagues (2004), the first population-based prevalence study of its kind, suggests why clinical attention to secondary conditions among persons with disabilities is a critical element in the quality-of-life equation. They found that 87 percent of persons with disabilities reported experiencing a secondary medical condition.

Persons of all ages with disabilities are susceptible to secondary conditions. For example, unrecognized and untreated depression coupled with another kind of disability potentially places children at risk for poor school performance, developmental delay lost potential as adults in the workforce and community, and suicide (U.S. Department of Health and Human Services 2003). Depression also is not an uncommon secondary condition among adults with such potentially disabling illnesses as diabetes, arthritis and heart disease. In persons of all ages, mobility limitations can lead to decubitus ulcers (pressure sores), lost muscle tone and gait instability. Substance use disorders occur more often in persons with a disability than in the general population. This includes problems related to the abuse of prescription medications as well as illicit drugs (Moore and Li 1998; Heinemann et al 1991; Fann et al 1995). Moreover, an injury such as a hip fracture, may give rise to fears about loss of independence, triggering depression, lowered immune function and factors that can exacerbate or increase the risk for still other secondary conditions. These issues take on particular significance for older adults, who run a greater-than-average risk of multiple disabling conditions than do younger individuals (National Institute of Mental Health 1999).

GOAL 3: Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.

Healthy living is a positive concept—a concept that has been highlighted through health promotion and disease prevention efforts for people of all ages, from smoking cessation to obesity control, from the value of exercise to the benefits of mental health. Maintaining good health by adopting healthy lifestyle choices, both physical and mental, is a key component of a satisfying life. It is a goal of the U.S. Department of Health and Human Services, and embodied in both its HealthierUS Initiative and the objectives for Healthy People 2010.

When it comes to persons with disabilities, healthy behaviors and a drive toward positive health across the life span need be no different than it is for persons who do not experience disabilities. Indeed, for persons with disabilities, health promotion efforts can be of critical importance. Studies have shown that individuals with disabilities can run a higher-than-average risk for such preventable chronic problems as osteoporosis, obesity, diabetes and heart disease (Center et al 1998; Walsh et al 2001; Coyle and Santiago 2000; Nosek 2000; Pitetti and Tan 1990; Rimmer et al 1993; Rimmer et al 1996). Similarly, research has shown that by engaging in healthful behaviors such as exercise, persons with disabilities can lower the risk of these common chronic problems. Further, they can prevent additional disability-related losses (for example, muscle tone, bone density and dexterity) and increase overall mental and physical wellbeing (Compton et al 1989; Janssen et al 1994; Santiago et al 1993; Thomas 1999).

GOAL 4: Accessible health care and support services promote independence for persons with disabilities.

Without regard to the number and types of health care issues facing an individual with disabilities, access to the full range of all health care and services to meet his or her specific needs is a key factor that can affect his or her health throughout a lifetime. It is clear that, at present, existing health care and wellness systems— including the providers who staff them, as noted earlier—are not sufficiently responsive to the needs of these individuals. In part, this may be the product of gaps in training and education. As a result, access to prevention, screening, diagnosis, treatment and services for both disability- and no disability-related health care can be limited, incomplete, or misdirected.

International Day of Disabled is not confined just to physical conditions, but it also encompasses mental disabilities like autism, down syndrome to neurological problems like multiple sclerosis.

Unfortunately, India is far behind in providing various comfortable facilities for the disabled. Our government buildings, hospitals, public places still lack ramps, there are no specially designed restrooms for those with physical disabilities, our public transport doesn’t offer any extra support system for them during travel.

A poor treatment and a negative comment can affect their self-esteem, confidence, performance at work place and push them into further depression.

If you have a loved one, a colleague or come across even a stranger with disabilities, read the following on what you could do to make their lives better.

Make Changes:

If you are expecting a visitor with certain disability at home or in office, try making few simple changes that would make them feel comfortable. Place necessary items within their reach in restrooms, bedrooms, offer to help with items in shelves or cupboards. Also try and respect their daily routine and if there is a sudden change in the daily activities help them to cope up with the transition.

The COVID-19 pandemic and the subsequent stringent lockdowns, with rigorous social distancing norms and having to wear face masks at all times in public places have no doubt affected the ease of living for persons with disabilities as well, all over the world. Nevertheless, in these difficult times, when we are all going through various challenges on the personal, professional and health fronts, some simple steps help to ensure that disabled people can obtain what they need on a daily basis and assure one and all of an inclusive, cooperative and kind society.

Respect Personal Space:

People with disabilities need their own space and may not like others touching their mobility aids without permission, as you may not know how to handle their equipment. If you want to move their wheelchair, ask for permission. Always knock on the doors before you enter the room, like you do with others. Do not discuss their disability with others.

Engage in Positive Conversations

While maintaining social distancing is the need of the hour to halt the further spread of coronavirus infection, keep in mind to not completely isolate the disabled in your community. Meet with visually challenged or physically handicapped people and talk to them about constructive topics like work, family, music or discuss happy memories from the past. This helps persons with disabilities have a sense of belonging and uplifts their overall mood and mental health in these tough times.

Offer Help with Medical Support

While it is quite simple for us to stock up on all our nutrition supplements and immunity boosters, go for health check-ups, consult a doctor online, besides buying any medications for other pre-existing conditions, it is not so easy for disabled people to acquire their healthcare needs amidst current partial lockdowns. Identify these people in your neighborhood, sit down with them and help them order all their medicines online, set up doctor’s appointments virtually or take them to a nearby clinic for their routine medical check-ups.

Ensure They Receive Day-To-Day Needs

In these times of widespread infectious disease, it is very important to eat healthily and take meals on time. During the day, check up on your neighbors with disabilities, to make sure they have ample groceries and foodstuffs stocked up in their homes, to avoid going out frequently. In case they find it difficult to do so, go ahead and help them purchase their essential supplies online, ensure it gets delivered to their homes and their caretakers, house help is present every day to cook meals and provide them with nourishing food.

Ask Before Offering Help:

Don't assume that people with disabilities would always require some assistance in leading their lives and the first step is to treat them as equals. Understand that they know more about their needs and how to handle their day-today lives. In case, if you want to extend any support, ask first. Understand their needs and learn about specific details on how you can assist.

Speak Clearly, And Listen:

If you have a loved one or colleague with mental or developmental disabilities, always use simple words. Don't use complex terms, explain your views in simple sentences and allow them to make their own decisions. Practice restraint and patience while dealing with those with speech disability as they take some time to finish their sentences. Do not try to interrupt the flow of speech by trying to complete their sentences.

Make Them Feel Confident:

Few disabled people may suffer from lack of self-esteem and confidence. Remember, many of them don't like sympathy and don't stare at them. Always make eye contact while talking and do not try to strike up a conversation around their disabilities. If you are conversing with a person in a wheelchair sit down and talk face-to-face, instead of talking down to them.

Summary

Disability refers to the interaction between individuals with a health condition (e.g., cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g., negative attitudes, inaccessible transportation and public buildings, and limited social supports).

Over 1 billion people are estimated to experience disability. This corresponds to about 15% of the world's population, with up to 190 million (3.8%) people aged 15 years and older having significant difficulties in functioning, often requiring health care services. The number of people experiencing disability is increasing due to a rise in chronic health conditions and population ageing. Disability is a human rights issue, with people with disability being subject to multiple violations of their rights, including acts of violence, abuse, prejudice and disrespect because of their disability, which intersects with other forms of discrimination based on age and gender, among other factors. People with disability also face barriers, stigmatization and discrimination when accessing health and health-related services and strategies. Disability is a development priority because of its higher prevalence in lower-income countries and because disability and poverty reinforce and perpetuate one another.

Disability is extremely diverse. While some health conditions associated with disability result in poor health and extensive health care needs, others do not. However, all people with disability have the same general health care needs as everyone else, and therefore need access to mainstream health care services. Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) reinforces the right of persons with disability to attain the highest standard of health, without discrimination. However, the reality is that few countries provide adequate quality services for people with disability.

Keywords

Cerebral Palse, Down Syndrome, Intellectual disability, accessible health, support service, persons with disabilities, health care providers.

Self Assessment

1. Well being is a long standing interest in Psychology.

A. True

B. False

2. Individuals & society experience well being as a positive state.

A. True

B. False

3. Intellectual disability formerly known as handicapped.

A. True

B. False

4. Frustration tolerance enables people to build confidence.

A. True

B. False

5. Persons with disabilities cannot live a long & healthy life

A. True

B. False

6. Global Conference on Health promotion was organized by----------

A. UNICEF

B. WHO

C. UNAIDS

D. None of them

7. This conference identifies ------- critical areas.

A. 2

B. 3

C. 4

D. 5

8. HBM stands for ---------

A. Health Behavior Model

B. Health Based Model

C. Health Belief Model

D. None of them

9. The patient is preparing to act with the purpose.

A. Pre-contemplation

B. Contemplation

C. Termination

D. None of them

10. The patient is actively healthy & has no desire to revert to previous behavior.

A. Pre-contemplation

B. Contemplation

C. Termination

D. None of them

11. ------- conversation is the need of the hour for PwD.

A. Positive

B. Negative
C. Neutral
D. None of them

12. PwDshould feel --------
A. Disturbed
B. Confused
C. Confident
D. None of them

13. There are ------- steps can be taken for the adjustment & wellbeing of PwD.
A. 3
B. 5
C. 7
D. 9

14. People's experience ----- their health outcome.
A. Influence
B. Has no relation
C. Has no effect
D. None of them

15. The difficulty of PwD is ------- self-esteem.
A. High
B. Low
C. Extreme
D. None of them

Answers for Self Assessment

1.	True	2.	True	3.	False	4.	True	5.	False
6.	B	7.	D	8.	C	9.	B	10.	C
11.	A	12.	C	13.	C	14.	A	15.	B

Review Questions

1. What do you mean by adjustment & wellbeing in Persons with disabilities?
2. What are the personality variables for the persons with disabilities?
3. What are the mediators & moderators of psychological adjustment & wellbeing?
4. Write a note on promotion of wellbeing.
5. What are the goals of wellbeing?
6. What aspects we should consider to deal with PwD?
7. Write a note on Geneva charter of wellbeing.
8. How wellbeing varies in different types of disabilities?
9. Briefly describe different approaches to health promotion.
10. What are the roles of caregivers in promoting wellbeing to PwD?

Further Readings

- Disability, Health & Human Development by Shaun Grech et. al. Palgrave Macmillon.2017
- Understanding Disability & Inclusive Practices by Supriya Singh. Shivalik Prakashan.2015