

Rehabilitation and Social Aspects: Introductory Overview

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Overview

The central goal of rehabilitation is to restore the health and dignity of someone affected by an illness that may have caused physical, mental, or emotional hurt and that may have led to social problems, such as the loss of a job or the disruption of close relationships. This goal is sometimes referred to as tertiary prevention (primary prevention means that a person never develops the disease at all; secondary prevention involves treatment of an illness so that no lasting damage occurs; tertiary prevention seeks to minimize the effects of any permanent damage caused by an illness). Leprosy is a disease that leads to a variety of well-known physical problems, described elsewhere in this book, but the social and emotional consequences are often far more deep-seated and disruptive, lasting a lifetime. Rehabilitation in the field of leprosy is therefore an immense and wide-ranging challenge (1).

The ways in which a disease affects a person have been classified and defined as shown in Figure 1 (2). This diagram helps in understanding which aspects of a person's life are affected by an illness and need restoring. The diagram shows that an illness may damage a part of the body or a particular function and cause an impairment, such as a loss of sensation on the sole of the foot or a paralysis of muscles in the hand. Some impairments make it difficult to do certain activities, such as holding a cup, and thus put a limit on activities that are a normal part of life. Social participation may be restricted simply because of the disease itself, or because of a visible impairment (such as a skin lesion causing stigma and loss of acceptance in the community), or because of an activity limitation (such as being unable to walk).

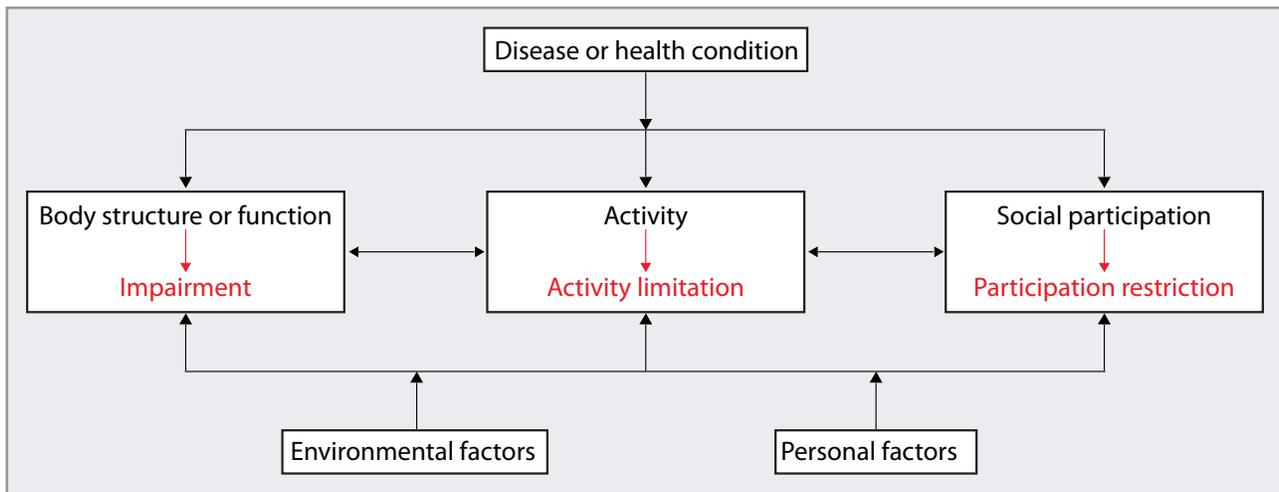


FIG 1 The International Classification of Functioning, Disability and Health. WHO 2001.

External factors in the environment may influence how a person is affected, and personal factors greatly influence how someone copes with these issues. Modifying a building’s environment to make it wheelchair-friendly, for example, greatly reduces the restrictions—one could also say ‘increases the freedom of movement’—experienced by someone who is unable to walk. A strong feeling of shame and self-stigma may be a personal factor that prevents someone with leprosy from attending public events.

Rehabilitation involves interventions to reverse the forces leading to impairment, activity limitation, and participation restriction. In general, medical and surgical interventions focus directly on impairments, but their goal is to mitigate the effect of those impairments on activity and participation. Hand surgery in leprosy, for example, may restore some aspect of hand function such as opposition of the thumb and forefinger. If successful, the surgery will enable that person to pick up and manipulate objects, and perhaps restore his or her ability to work, an important aspect of participation. If a medical or surgical intervention is not possible, activity limitations may be ameliorated by other strategies such as special training, the use of aids (such as a wheelchair or adapted footwear), or environmental modifications that make it easier for a disabled person to get around. These interventions have been pioneered by a range of professionals, including physical and occupational therapists. In a similar way, a wide range of interventions seek to directly reduce participation restrictions faced by those affected by leprosy, including enabling them to be more financially independent, either through employment or a disability pension. Encouraging employment is done in many different ways, from vocational training, to the provision of micro-credit, to advocacy and counseling.

The organization of rehabilitation interventions has changed dramatically in recent years. In the past, the focus was very much on the professional, biomedical remedies organized by hospitals and similar institutions. This approach was costly and underutilized resources that may have been available in the community. Initiatives by individuals and groups in the community gradually led to what is known as community-based rehabilitation (CBR) (3). CBR has grown in scope over the

years and now has strong links with community development and poverty alleviation—poverty and disability being very closely associated for obvious reasons (4).

A further development within the field of rehabilitation in leprosy is the realization that, in order to be truly restored to lives of dignity, those affected need to feel that they have more control over key areas of their lives. A certain level of empowerment is needed to provide the motivation for change, leading to normalization (5). This realization forms the basis for the self-care and self-help movements that have started to spread in areas where leprosy remains endemic (6). In a similar way, a greater focus on the problem of stigma, how to measure it and how to combat it, is being developed, as outlined in the last two chapters of this section.

References

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