Disease, illness and health: theoretical models of the disablement process*

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Handicap is the result of a process of disablement whose origin is a pathological condition (disease). According to some definitions of health (e.g., a state of complete physical, mental and social well-being), the classical biomedical concept is too restrictive to cover all the consequences of disease. New models have been proposed: the impairment–disability–handicap model presented by WHO, the situational handicap model, and the quality-of-life model. A unifying schema of the disablement process includes these concepts and provides a useful way of analysing the consequences of disease. Factors that modify the disablement process can be identified by their respective impacts, and provide operational guidelines for public health interventions.

Introduction

While life expectancy has slowly but steadily increased over the years, both it and the mortality rate are not adequate indicators of the real health status of populations. For instance, the presence of chronic diseases and chronic conditions (e.g., after accidents or as a result of genetic abnormalities) has led to growing concern and renewed interest in disability and disablement. Usually the consequences of disease are assessed in terms of mortality and morbidity, but in the context of extended life spans a medical diagnosis has become less important than the day-to-day problems confronting individuals as well as institutions and policy-makers. International comparisons show a major difficulty in the definition of disability and, more particularly, disablement. Disablement is a process related to disease. At first sight, health can be defined as the absence of disease, but is it only that? What is disease? What is health? The answers to these questions are a prerequisite to the analysis of any theoretical model. The models have to be constructed on clear definitions or concepts, which will guide the choice and the design of relevant instruments for testing.

Biomedicine, as defined in Western cultures, includes a wide array of knowledge, practices, organizations, and social roles dealing with "diseases". Disease is what physicians and biologists study: it signifies an abstract biological condition, independent of social behaviour, and manifests as a deviation from a narrow range of physiological and biological variables that are common to the human species.

Illness is the clinical situation of a patient suffering from a disease. Little consideration is usually given to the sufferer in this concept, much more being given to the disease itself. This attitude of separation is fostered by long-standing traditions in medicine, and of physicians, and has provided an abundant literature, including dramas, comedies, and even tragedies, as well as technical reports.

Health is certainly related to freedom from disease. But this negative, monofactorial definition can only be poorly applied to the emerging field of chronic diseases, in which the current distinction between the medical and social aspects of illness appears to be non-operant. At the present time, health has been defined as a complete state of physical, mental and social well-being; or the capacity to function optimally in the individual’s environment; or an adaptation to the environment (or milieu). Thus, the development of disease “does not simply eliminate or incapacitate an individual in some mechanical sense, but rather affects the individual’s capacity and performance as a participating member of a highly interdependent group” (4). Initially, these definitions were supposed to be unmeasurable. The

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recent focus of interest on disablement—conceived as a process leading to disability and handicap—has fostered the development of techniques to measure health as defined above (2).

Thus the shift over the past thirty years from (1) "survival" to (2) "freedom from disease", to (3) "the individual's ability to perform his daily activities", and to (4) the positive themes of "well-being" and "quality of life" explains and supports the four theoretical models that can currently be identified: the biomedical model, the ICIDH (WHO) model, the situational handicap model, and the quality-of-life model.

**Four models**

**The biomedical model**

The biomedical model is based on the concept of disease and has the following sequence: etiology→pathology→manifestation.

It has been criticized by many researchers, who state that biomedical diseases are usually inadequately considered to be "common" to humans and to social groups. Conversely it has been observed that biomedical diseases are not only defined by negative anatomical, biochemical, and physiological variables, but also by particular physical, cultural and social factors. Diseases are therefore neither invariable nor universal (13). Indeed, it should be taken into account that some variables related to disease are of prospective value for the assessment of the disablement process, at least as key elements for the introduction of the individual into the process.

The following three groups of useful biomedical variables have been identified: diagnosis and lesions, symptoms, and other related indicators (particularly physiological and economic).

(1) Certain diagnoses and lesions were observed long ago to be associated with a high probability of disablement. While diagnostic labelling may be inadequate to characterize the quality and severity of the disability and handicap, it may be a relevant and even valid portal of entry into the disablement process, and can be used as such in demographical and epidemiological surveys. However, it must be remembered that (i) there is no "linearity" between the type and severity of the diagnosis and lesions and the consequences of the "disease", and (ii) the degree of dependence expressed by the diagnosis remains unreliable compared to the valuable information it provides for the management of the disease.

(2) Symptoms are important for determining the medical management of acute cases (12). Nevertheless, it has been shown that symptoms such as chest pain on exertion, chronic productive cough, breathlessness, and pain in the calves on exertion (intermittent claudication) consistently reduce (in a given rank order) the daily activities that people perform. This order is modified with increasing severity and multiplicity of symptoms.

(3) Other related indicators, such as (i) blood glucose levels and respiratory or cardiac parameters, or (ii) consulting rates, number of days in hospital, and number of days of incapacitation, are potential indicators of possible disabling consequences. However, their real value in this respect has to be precisely assessed.

**The ICIDH model**

The World Health Organization in 1980 presented the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) to support the identification of the consequences of diseases (6). The construction of the conceptual model is based on four principal events:

— something abnormal occurs within an individual;
— someone becomes aware of this occurrence;
— the performance or behaviour of the individual may be altered as a result; and
— the awareness itself, or the altered performance or behaviour to which this gives rise, may place this person at a disadvantage relative to others (6).

This succession of events, from an interiorized to an exteriorized experience, culminates in a socialization of the experience which has three dimensions, represented as follows:

Disease → Accident → impairment → disability → handicap

Abnormality

The three key terms are defined below.

- **Impairment**: any disturbance to the body's mental or physical structure or functioning. The impairment is characterized by a permanent or temporary loss or abnormality of psychological, physiological, or anatomical structure or function in a tissue, organ, limb, functional system or mechanism in the body.
- **Disability**: a reduction or loss of functional capacity or activity resulting from an impairment. Disability is characterized by excesses or deficiencies of customarily expected behaviour or functions, and represents the objectification of impairments through their effects on everyday activities.
- **Handicap**: the social disadvantage resulting from an impairment and/or a disability, entailing a divergence between the individual's performance or status
and that expected of him by his social group. Handicap therefore represents the social and environmental consequences of impairments and disabilities.

These three dimensions have been discussed and, even if not yet universally accepted, are recognized as a basis for analysis and for the design of relevant instruments for assessing the disablement process. The development of measurements of physical functioning has followed this framework: from using impairment scales to measuring disability (functional limitations and activity restrictions) (5, 7) and subsequently handicap (fulfilment of social roles, mobility, physical independence, occupational abilities, etc.)

The main advantage of the ICIDH model is that it provides a common "language" for the numerous and various actors involved. This is probably due to the resolute shift away from the biomedical model. It is also incidentally an efficient teaching instrument. The model is applicable to individual assessment as well as to population surveys and samples (1). It is useful for prevention and planning. Finally, it avoids the usual partitioning between the medical and social consequences of disease (9, 10).

The main criticism against the ICIDH model is the excessive emphasis placed on individual experience as a source and support of the disablement process, to the prejudice of the role of the environment. Secondly, the temporal or causal sequence cannot be applied as a fully developed description of the disablement experience because it remains difficult to draw a clear dividing line between the various conceptual elements.

**The situational handicap model**

Disablement is a process which unfolds with time. More precisely, disablement is a variable depending on life situations which take place at different moments of the life process, and may vary with time. Life is a combination of macro-situations (school, housing, professional activities, sports, family life, etc.) composed of micro-situations (driving, moving in and out, opening doors, windows, cans, etc.), which all constitute a particular environment.

Handicap is the result of the encounter between disability and the environmental situations. The disablement process thus includes many aspects of the environment analysed in terms of situations. Disablement constitutes a social system functioning in a given environment. The description of the system corresponds to a description of its structure at a given time. It is an "open" system, exchanging permanently and regularly with both the cultural and biophysical components of the environment (8).

The analysis of the situational disablement involves separate analysis of (1) the individual biomedical, psychological, and social process, (2) the disabling situations experienced by the person or the group, and (3) the environment of the system, assembling cultural, ecological, physical, economic, legal, religious, administrative, and other aspects (3). This implies an internal and an external equilibrium of the system. Situational disablement tends towards a balance between individual, situational, and environmental inputs and outputs. This balance is necessarily readjusted from time to time, sometimes frequently.

The model also implies the integration of the individual into an environment, and of the environment into the personal experience; but through the concept of situation, it allows a differentiation of the individual experiences or systems. Conversely, it would be inaccurate and even dangerous to reduce the process of disablement exclusively to a situational experience, by erasing or ignoring the biomedical and psychological history of the individual. If such a danger remains theoretical in population surveys for instance, it might acquire practical importance when action is implied, particularly by well-meaning and over-enthusiastic institutions or agencies concerned with the social treatment of handicap.

**The quality-of-life model**

The term "quality of life" means different things to different people, reflecting a wide array of knowledge, experiences, perceptions, and values. Quality of life has been an implicit component of medical care since ancient times. More recently, the increasing participation of patients in health care has moved the centre of determination of quality of life from the physician to the person concerned.

Quality of life has often been a catch-phrase without a precise definition. It is usually admitted that quality of life is a multidimensional concept that covers several domains, motivations, or social indicators: e.g., functional status (self-care activities, mobility, physical and role activities); disease and treatment-related symptoms; psychological functioning; social functioning; spiritual or existential concerns; safety of the environment; adequate housing; decent and guaranteed income; love; respect; freedom, etc. It is usual to single out health-related quality of life (HRQOL), which can be defined as "the value assigned to the duration of life as modified by the social opportunities, perceptions, functional states, and impairments that are influenced by disease, injuries, treatments, or policies" (11).

Two conceptual frameworks apply to the quality of life model:

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 Operational considerations

Assessment of disability and handicap

The four models of the disablement process identified above complement one another. It is possible to distribute and combine them according to a unifying model (Fig. 1) of the disablement process. In such a model the role of the environment specific to the person or group, in its broadest meaning, appears to be fundamental. It will also be noted that handicaps are multiple and that they may result from one or several situations in everyday life, as well as from one or several biomedical problems. Medical or psychosocial rehabilitation procedures may alter the process in a positive way. This scheme applies to the developed as well as developing countries.

The following operational guidelines can be established from these models.

• The ICIDH concept, which represents the clearest, most consistent, cross-disciplinary framework, is a basis for common definitions and language, and a tool for the analysis of disablement, whatever the objectives of the analysis (population surveys or censuses, consequences of diseases, elaboration of policies, etc.)

• The ICIDH is a model for surveys of the prevalence of disablement. Its usefulness for surveys of the incidence of disabling chronic conditions remains questionable—the linearity of the chain of causality (impairment—disablement—handicap) remains to be demonstrated, and the types of transitions between the three dimensions have to be defined.

• Disease and impairment are primarily the concern of medical services. Disability and handicap, which are the fundamental components of the process of disablement, are the concern not only of rehabilitation clinicians, but also of professionals dealing with education, transport, housing, or employment of disabled persons, and, above all, of professionals and of the disabled persons themselves.

• Diagnosis, biomedical parameters, and health economy indicators are useful but not sufficient for the analysis of the disablement process and the design of measuring instruments.

• Disease and disability have very different definitions. The existence of a particular disease, whatever its potential severity, is not always associated with a corresponding disability. The same remark applies to the comparison of the definitions of impairment and disability.

• Classifying or defining the Healthy Life Expectancy measuring instruments and surveys according to the most suitable model to which they refer (biomedical = class I or type I, for instance, etc.) is to be recommended. This would facilitate the comparability of existing materials and the interpretation of collected data.

Disability is measurable. Specific measuring instruments exist, which give a score and a profile of disability for each individual. So it is possible to determine function-related groups of individuals. Handicap adds a degree of dependence, severity, and disadvantage to disability. Disability is a predictor of the adjustment to social life. Handicap is a component of the adjustment to social life. Thus, the most reliable indicators of disability (7) at present are the activities of daily living and locomotion; the most reliable indicators of handicap are physical independence (to be distinguished from autonomy) and mobility. Neither disability nor handicap is value-free, but handicap and quality of life depend very closely and singularly on cultural factors.

Handicap and the self-assessed quality of life related to it are the combination of three distinct elements:
Fig. 1. A unifying schema of the disablement process. The biomedical model embraces the items on the right (including etiology, cure, impairment and death). The ICIDH model is focused on the lower half of the diagram (including impairment, disability and handicaps). The situational model covers environment, handicaps and disability. The quality-of-life model is focused on handicaps only. The factors likely to modify (positively or negatively) the process of disablement are indicated in smaller type.

- the consequences of diseases, impairments, and disabilities;
- the history (medical and social) of the person;
- the relationship to the broadly defined environment.

Two of these elements are intrinsic to the person, one is extrinsic. The permanent interrelationship between extrinsic and intrinsic elements is complex, and probably varies with situations, tasks, places, etc.

It is of utmost importance to consider what can modify the sequence of events and factors which constitute the disablement process. Some of the modifying factors can be identified (Fig. 1).
- The disease itself, as it is classified for instance in the International Classification of Diseases (ICD). Each etiology, each pathology, obviously has its own handicapping potential. However, the age, the type of aging, and some particular frailty also have an influence on the disablement process, beyond merely initiating it.
- The treatment: the type, amount, availability, and side-effects of treatments can alter the course of the disablement process.
- The survival rate with chronic illnesses or impairments.
- The motivation to live with an impairment and/or to reduce the disability and the resulting handicaps. Motivation is certainly individual, but may sometimes have collective aspects.
- Rehabilitation work is aimed at preventing and reducing disability. It includes medical and psycho-social rehabilitation. Its availability and type should
be considered, with particular attention given to the necessity and availability of technical aids. Considerable differences may exist between and within countries. Developed countries usually try to rely more heavily on technical aids, which are theoretically cheaper than human assistance, but with limited success so far.

- **Visibility** of disabilities and handicaps substantially modifies the whole process. This has led to a general underestimation of the handicapping consequences of visceral disorders (e.g., urinary and faecal incontinence, cardiac and respiratory disorders). In the less developed countries, attention is exclusively or primarily devoted to blind or deaf persons, amputees, or those with limb atrophies, for instance.

- **The types of services** available, run by state or local governments, or nongovernmental organizations.

- **Community-based rehabilitation**, proposed by WHO for the developing countries, is also applicable to the developed countries and particularly to elderly people. It relies on the social interactions, within a geographic area, of persons with various ties, and not only on professional medical and psychosocial rehabilitation. The presence of such a supporting network permits continuous rehabilitation work to meet individual needs, and is likely to positively modify the disablement process.

- **Accessibility**: physical access to the environment, but also to services, benefits, etc. Accessibility is an important factor in the adjustment to handicaps, if these are considered to be the result of the encounters between persons and environments, and a fundamental component of the disablement process.

- **Family**: marital status, age, size, cohesion of the family, composition of the family, degree of acceptance of the family, the role assigned to the family by the professionals and the community; all these constitute a prime factor for an integrated outcome of the disablement process (consider, for instance, the problem of families having to cope with cases of dementia or stroke).

- **Demographic indicators**, such as the *population age-composition*, or *geographic factors* (rural areas vs cities). For example, the handicap resulting from urinary incontinence is somehow reduced in villages compared with big cities.

### Synthesis and conclusion

The end results of the disablement process can be analysed in terms of disability and/or handicaps. The best indicators are summarized below.

<table>
<thead>
<tr>
<th>Disability</th>
<th>Handicap</th>
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<tbody>
<tr>
<td>Locomotion</td>
<td>Mobility</td>
</tr>
<tr>
<td>ADL (activities of daily living) abilities</td>
<td>Physical independence</td>
</tr>
<tr>
<td>Communication/cognitive skills</td>
<td>Social interaction</td>
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Among the various dimensions of handicap, mobility is certainly the least culture-bound, but nevertheless remains culture-bound to a certain degree. Compare, for instance, the mobility required and expected from an old lady in Minnesota, Florida, or New York city; or in Denmark and Sicily, two distant parts of the European Economic Community. Physical independence and, above all, social interaction are more subordinate to the behaviours, knowledge, know-how, and abilities which constitute the culture of a human group or society.

Differences between countries in the field of disablement are based not only on economic development, but also on biophysical and cultural features, which determine, for instance, the efficacy ratio between human and technical solutions. International comparability calls for simplicity of questionnaires (e.g., four items, four questions); comparability within a country needs more comprehensive, precise, and specific questionnaires.

Scores or their equivalent, although simple to use and versatile, are less meaningful than profiles. Disability and handicaps are based on several components; the whole disablement process should be applied to any disease, diagnosis, or symptom with separate analysis of these components. At each level of the process, the interacting factors should be taken into account, and the corresponding prevalence rates calculated. This exercise, which can be applied to any type of economic development is useful for policy-makers as well as economists, clinicians, statisticians, or demographers. Some research is being conducted in this direction, with fruitful results so far.

The disablement process is thus a synthesis of medical, sociological, and anthropological analyses of individuals and their activities.

### Résumé

**Maladie, affections chroniques et santé:**
*les modèles théoriques d’analyse du processus de handicap*

Le handicap est le terme d’un processus qui est lié à l’expérience d’une maladie. La santé a été définie au départ comme l’absence de maladie. Mais cette définition est trop limitative et mono-
factorielle et s’applique mal en particulier au champ des maladies et affections chroniques. Dans le domaine des maladies chroniques en effet, la distinction entre les aspects médicaux et sociaux des affections n’apparaît pas suffisamment opérationnelle. Plus récemment, la santé a été définie, avec l’Organisation Mondiale de la Santé, comme un état de complet bien-être physique, mental et social, ou comme la capacité de l’individu à fonctionner de façon optimale dans son environnement, ou encore comme une adaptation de la personne à son environnement ou à son milieu. L’évolution de cette définition au cours des trente dernières années explique et soutient les quatre modèles d’analyse théorique du processus de handicap qui peuvent être couramment identifiés: le modèle biomédical, le modèle de l’Organisation Mondiale de la Santé (Classification internationale des handicaps: déficiences, incapacités et désavantages), le handicap de situation et la qualité de vie. Ces quatre modèles sont analysés, et regroupés dans un modèle unique du processus de handicap. À partir de ces modèles conceptuels, quelques conclusions peuvent être tirées sur le plan opérationnel. La Classification des Handicaps de l’Organisation Mondiale de la Santé constitue certainement actuellement le cadre conceptuel le plus clair, le plus cohérent et le plus interdisciplinaire, permettant un langage et des définitions communes, et constituant un bon outil pour l’analyse du processus de handicap. Il est certain qu’il s’agit d’un modèle plus facilement utilisable dans les études de prévalence du handicap que dans les études d’incidence, et des questions restent encore en suspens sur les relations des trois dimensions (déficience, incapacité et handicap) entre elles, et dans leur relation avec l’environnement et les maladies ou affections causales. Les paramètres biomédicaux, les diagnostics, ont une utilité en tant que porte d’entrée du processus de handicap. L’incapacité peut se mesurer et des instruments de mesure spécifiques existent actuellement, dont la qualité globale s’améliore régulièrement. L’évaluation du handicap et celle de la qualité de vie appréciée par les personnes sont la combinaison de trois éléments distincts: les conséquences des maladies, des déficiences et des incapacités, les antécédents médicaux et sociaux de la personne, et la relation de la personne à son environnement ou à son milieu définis au sens le plus large. Ces trois éléments dont deux sont intrinsèques à la personne et un extrinsèque, varient en fonction des situations, des tâches à accomplir, des cultures, des localisations géographiques, etc. Il est surtout d’extrême importance de considérer ce qui peut modifier la séquence des événements et des facteurs qui constituent le processus de handicap. On peut citer par exemple la maladie elle-même, les caractéristiques du traitement, le taux de survie avec une déficience ou une affection chronique, la motivation, le travail de rééducation et de réadaptation, la visibilité des incapacités et des handicaps, les types de service disponibles, l’existence de programmes de rééducation et réadaptation basés sur la communauté, l’accessibilité générale, le rôle de la famille, les indicateurs démographiques tels que la composition des âges d’une population, ou les facteurs géographiques. Ces éléments susceptibles de modifier le processus de handicap peuvent être dispo-sés le long du schéma général d’analyse, selon leur impact respectif, et permettent ainsi de guider les interventions de santé publique.

References