

Evaluation of Care for the Disabled Mentally Ill: Theoretical Issues

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Summary. A precondition for the discharge from an institution of the chronically disabled mentally ill is the availability of adequate alternative facilities and services, optimally meeting their social and mental health needs and allowing as much quality of life as possible at the lowest possible cost. Only a few studies have found alternative care to lead to better outcomes than treatment in good-quality hospitals with respect to illness course and social disablement. Therefore, it is an important question whether extramural care and of what type is better and possibly less expensive than traditional inpatient treatment and for which patients. Health data collected at the national and regional levels provide a basis for continuous monitoring of utilization of services. Such data, however, usually have the limitation of being aggregate in nature and not including contacts with social services. These deficits can be avoided by using cumulative case registers, recording if possible all contacts of the socially disabled mentally ill with intramural and extramural mental health and social services and covering a defined catchment area. Because the disabled mentally ill, depending on their own resources and those of their family and the community at large, have basic needs differing in each individual case, as well as various specific needs determined by the illness which they cannot meet on their own, it is necessary to provide a variety of facilities and services and to coordinate their work. Evaluation and cost-effectiveness investigations of complex packages of care yield generalizable results only if the forms of care under study are defined precisely enough. A precondition of a satisfactory causal analysis of the effectiveness of care programmes and services is sufficient external and internal validity and the use of a design

allowing all relevant intervening variables to be controlled for. Because of the problems posed by quasi-experimental designs and controlled case studies in the evaluation of the care of the chronically mentally ill, an observation design will be discussed that allows a more or less reliable analysis of cause and effect, thanks to the inclusion of relevant intervening variables and the partialling out of their effects on outcome. In the evaluation of community services for the disabled mentally ill, it must be taken into account that outcome and costs depend on the system aspect in as much as during the transition from intramural to extramural care severely disabled patients with a greater need of care, consequently producing higher costs, are discharged from hospital to community care in increasing numbers.

Key words: Care – Evaluation – Disabled – Mentally ill

Changes in the Care of the Socially Disabled Mentally Ill

Care of the socially disabled mentally ill is undergoing drastic changes. The reform process is characterized by a transition from long-term residential care provided by mental hospitals to extramural care provided by a variety of alternative or complementary services in the community. The governing principle is that every disabled person should receive the care optimally meeting his or her psychiatric and social needs and allowing as much quality of life as possible at the lowest possible cost.

The reform programme as such, particularly the deinstitutionalization of chronically mentally ill and disabled patients, is associated with considerable

risks, both physical and mental. It is only in selected cases that we know the new forms of care lead to better outcomes with respect to illness course and social disablement than treatment in good-quality mental hospitals. Whether they are also less expensive is being much debated (Häfner and an der Heiden 1989).

Therefore, it is more urgent than ever to look into the question whether extramural care (and of what type) is better and less expensive than traditional inpatient treatment and for which patients. Techniques of objective assessment of psychopathology, impairment, social functioning and quality of life as well as methods of case-related documentation of service provision have been developed that can be regarded as prerequisites for evaluative research.

Subjects and Criteria in the Evaluation of Services for the Socially Disabled

Levels of Evaluation

We distinguish three levels, i.e. the evaluation of (1) the mental health sector as part of a national system of health and social services, (2) a community mental health service in a defined catchment area, and (3) individual facilities and programmes for the socially disabled mentally ill (Table 1). Health care at these levels differs not only in terms of the criteria by which its effectiveness is measured, but also in terms of the type of data recorded, cost issues and control mechanisms.

Information on the functions and costs of a health service depends on the extent to which the provision and utilization of services are statistically recorded. In this respect there are great differences between the European countries. In most countries hospital statistics providing aggregate data are available. Data, if at all available, on the utilization of outpatient medical and social services – of crucial importance in the care of the disabled mentally ill – are usually marred by the fact that information on diagnosis and disability is inadequate or unreliable.

In view of these limitations of national health data, methods of global system evaluation should be adopted, as they are practised in indicator models in the field of national economics, where they can be based on the homogeneous measure of monetary value, which, when applied to qualitative health data, poses considerable problems. The minimum of evaluation that should be conducted at the national level to manage and control a mental health system is a continuous monitoring of the services available, their utilization and costs as well as indicators of their effectiveness and deficits. As the routinely compiled

national health statistics do not make detailed and qualitative changes visible, such information can only be obtained at a lower level of a health service system or by selective studies.

At the level of a community mental health service, provided patient-related data are collected, criteria for goal achievement, output and process indicators can be defined on the basis of the individual needs of the disabled. In this way it is possible to answer the question as to which forms of care meet the needs of disabled people adequately and at the lowest possible cost. There are five preconditions that must be fulfilled (Table 2): (1) development of model programmes and assessment of their effectiveness and costs; (2) estimation of needs and identification of target groups for the services required; (3) assessment of availability of the services needed; (4) organization and coordination of the individual components to a well-functioning network ensuring, for example, correct referral of the disabled according to their needs; and (5) cooperation between the services with regard to all aspects of care for an individual patient.

Preconditions 4 and 5, the coordination and cooperation of the various components of a community mental health service offered to the socially disabled mentally ill, are especially often neglected in practice and also as a structural indicator in evaluative research. It should be borne in mind that different needs, e.g. for accommodation, treatment and work, which used to be provided for by the traditional mental hospital under one roof, are now usually met by multifarious small-scale facilities, each of them offering different types of treatment and, furthermore, counselling the patients families, employers etc.

Depending on the dimensions and degree of impairment and the resources of the individual patient, his/her close social network and the community at large, care has to be given at various levels of need.

The *basic needs* for care refer to the unspecific forms of support that the mentally ill require in various areas of life due to primary or secondary social disablement, as defined by Wing (1987), in the same way as otherwise socially disabled or disadvantaged people do: (1) accommodation and support in activities of daily living; (2) work and occupation; (3) social integration; and (4) leisure activities.

Under the heading "*specific needs*" we have subsumed measures of therapy, training or other comparable forms of help necessitated by the specific nature of the deficits and risks resulting from schizophrenia or severe affective disorder or other illnesses: (1) treatment of symptoms and prevention of relapse; (2) training of deficits and compensatory skills; (3) promotion of individual coping strategies; (4) family education and therapy.

Table 1.

Levels of mental health care research	Selected instruments of evaluation
1. Mental health care sector as part of a <i>national</i> health and social service	Monitoring of morbidity, health indicators and utilization of services
2. <i>Community</i> mental health service	Case register
3. <i>Individual</i> facilities and programmes for the socially disabled mentally ill	Detailed studies of programmes and facilities

Table 2. General objective and subjects in the evaluation of care for the socially disabled mentally ill

1. <i>General objective:</i>	Every disabled person should receive the care optimally meeting his/her psychiatric and social needs and allowing as much quality of life as possible at the lowest possible cost.
2. <i>Subjects of evaluation:</i>	2.1 (Evaluation of model programmes): assessment of effectiveness, risks and costs of programmes and facilities 2.2 (Demand): estimation of needs and identification of target groups for the services needed 2.3 (Supply): assessment of availability of programmes and facilities needed 2.4 Evaluation of the organization and coordination of existing services in terms of their utilization by target groups and covering of individual needs 2.5 Evaluation of cooperation between services and effectiveness and costs of their share in the care of individual patients

Table 3. Levels of basic needs for care and corresponding services for the socially disabled mentally ill

Needs for care:	Services offered:
1. Accommodation and support in activities of daily living	Psychiatric homes, group homes, sheltered apartments etc.
2. Work and occupation	Occupational training, work counselling, sheltered workshops etc.
3. Social integration	Community services, lay initiatives, self-help groups etc.
4. Leisure activities	Patient clubs, lay initiatives etc.

Table 4. Levels of specific needs for care of the socially disabled mentally ill

1. Neuroleptic medication and prevention of relapse
2. Training of deficits and compensatory skills
3. Promotion of individual coping strategies
4. Family education and therapy

Combination of Forms of Care

The eight levels of need for care of the socially disabled mentally ill listed in Tables 3 and 4 with the equivalent services and interventions illustrate the complexity of the task of caring for this target group. In the evaluation of services, outcome criteria, such as indicators of comprehensiveness or quality of care, should be based on these categories of needs.

Socially disabled mentally ill individuals are incapacitated in different areas of functioning to different degrees. Their needs for care are also determined to different degrees by premorbid deficits in education, vocational training and primary and second-

ary disadvantages in socioeconomic, occupational or communicative respects. The conditions in the community, particularly the availability of or deficits in the financial, social and occupational resources and the attitudes in the general population towards the mentally disabled, decisively influence the outcome of rehabilitation (Goldstein and Caton 1983; Mezzich and Coffman 1985). In addition, needs for social help, rehabilitation and treatment vary over time due to relapses and improvement in social functioning during the course of the disease. A highly flexible mental health care system able to cope with a high likelihood of misplacements and deficits in the provision of care is therefore required. It also goes without saying that a continuous evaluation of the composition and efficacy of the programmes is indispensable (Dencker et al. 1988). The complexity of the care of the socially disabled mentally ill has implications for evaluative research in practice. Owing to the impossibility of considering all the details in a study design, it is necessary to group together some categories of services or interventions in large-scale evaluative studies, e.g. when extramural care is com-

pared with traditional care. Because several details have an impact on intervention effects, which are assumed to differ depending on the particular needs and risks of the patients treated, a careful description of the patient group and the programme under evaluation is also required to obtain generalizable results. Comparisons of poorly defined packages of care (this applies to numerous studies comparing extramural with traditional forms of care; cf. Bachrach 1982) do not yield generalizable results.

Methodological Problems

The outcome and risks of complex intervention programmes are usually studied on model projects. If sufficient external validity is provided, the results of such single studies can be used in the planning and controlling of services for the socially disabled. One limitation of such studies is that they look into only a limited number of services over a limited period of time. Since a continued evaluation of the whole network of care with regard to its functioning as a system is required, continuous, patient-related recording of the utilization of all facilities and services provided within such a network is indispensable.

The instrument most suitable for this purpose is a cumulative psychiatric case register, in which all contacts of a population in a defined catchment area with all psychiatric and social services offered to the target group are recorded. This means that not only the utilization of hospital care, but also that of outpatient services, complementary facilities and all social agencies must be documented. Provided this is the case, the functioning of the network of services can be monitored continuously by indicators such as length of hospital stay, proportion of patients with adequate after-care or those getting out of contact after discharge.

Designs for a Causal Analysis of Effectiveness

In order to be able to draw generalizable conclusions about the effects of an intervention, the study design must be of sufficient internal validity, i.e. changes in the outcome variable must be attributable to the intervention variable. This requires the proof of the observed changes not having been brought about by a third, unobserved or confounding variable. The study design must also be of sufficient external validity, i.e. the results must be applicable to other comparable conditions. This means that the target population, the variables studied and the contextual factors must be representative of analogous conditions

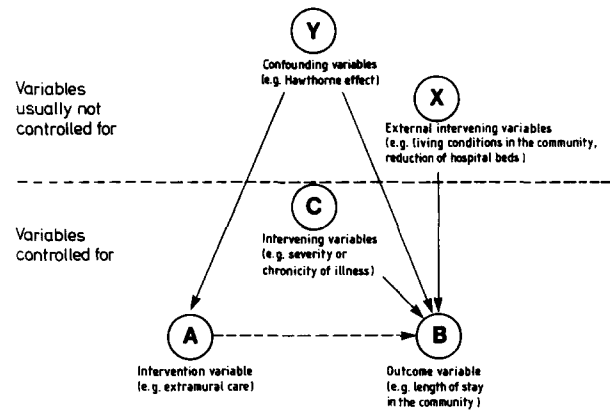


Fig. 1. Model of a design for the evaluation of causal effects

in a larger collective for which generalizations will be made.

Figure 1 tries to illustrate the point. The variables depicted below the broken line are usually included in evaluative studies. Here the effect of a measure A (independent variable) on an outcome variable B, in this case length of stay in the community, is studied. Variable C, standing for the needs and risks of the patients and exemplified by severity of illness or degree of disability, also has an impact on the outcome variable B, but does not correlate with the independent variable A. The problem can be solved by selecting a control-group design, which means that two groups receiving different forms of care and matched with regard to the intervening variables, i.e. severity and chronicity of illness, are compared with each other.

The fourth category of variables, depicted as X in Fig. 1, is also not associated with the intervention variable A, but exerts influence upon the outcome variable B. Examples of such variables are the living conditions in the community or a rapid reduction of hospital beds. They frequently remain uncontrolled for and thus their share in the outcome is not considered. Further, the confounding variables Y, correlating both with the intervention variable A and the outcome variable B, have to be taken into account. An example is the Hawthorne effect, which can play an important part in the outcome of model programmes in particular.

While the variables C and X determine the internal validity, i.e. the causal relationship between intervention and effect, the variable Y is of importance for the external validity, i.e. the generalizability of the results. To the extent that the effects of the intervention are accounted for by the variable Y, in our example the Hawthorne effect, the results will be of limited applicability to other populations. To avoid this fallacy an experimental procedure has mainly

been used. In mental health services research, especially in the case of functional psychoses, however, random assignment of patients to various treatment strategies is difficult to accomplish. Only in a few cases is a "mirror-image" or an ABABA design, i.e. the consecutive application of the intervention studied and a control treatment on the experimental group, practicable.

The alternative method is an observation design, in which all variables assumed to be relevant are carefully determined and their share in the effect of the intervention variable partialled out by linear regression, for example. The advantage of this design is that it is applicable to the natural conditions of complex psychiatric care programmes. A liability is that a fairly large number of variables must be taken into account and there is no certainty that all intervening variables are known. Nevertheless, the observation design, relying on explicit measurement and analysis of additional variables (Hodapp 1984; an der Heiden et al. 1989), represents a practicable procedure for the analysis of the effectiveness of complex systems of care. In addition, such studies yield data for direct cost-effectiveness analysis.

Limited financial resources make studies of efficiency necessary. In analyses of cost-effectiveness the direct and indirect costs and the material and non-

material effects of the services provided are determined in monetary terms. The question as to what extent it is at all possible to measure qualitative changes at the mental or social level by monetary valuations is a matter of current controversy.

Cost-efficiency analyses allow a more flexible adjustment of the measurement of effectiveness to the operationalization of goals. The effects of an intervention are contrasted with the costs. A less sophisticated approach is a descriptive cost analysis (Sorensen and Grove 1987), which consists in the assessment of crude output quality and/or quantity, the statement of costs in relation to output (cost accounting/cost analysis) and the determination of the costs of components of psychiatric care (traditional budget reports). In mental health services research these methods are in an embryonic stage and have so far been used very little.

Comparison of Mental Health Care Programmes by Separate Assessment of Effectiveness and Direct Costs

Jones et al. (1980) followed up two cohorts of first-admitted schizophrenic patients ($N = 55/51$) in Manchester, retrospectively over 4 years. They compared

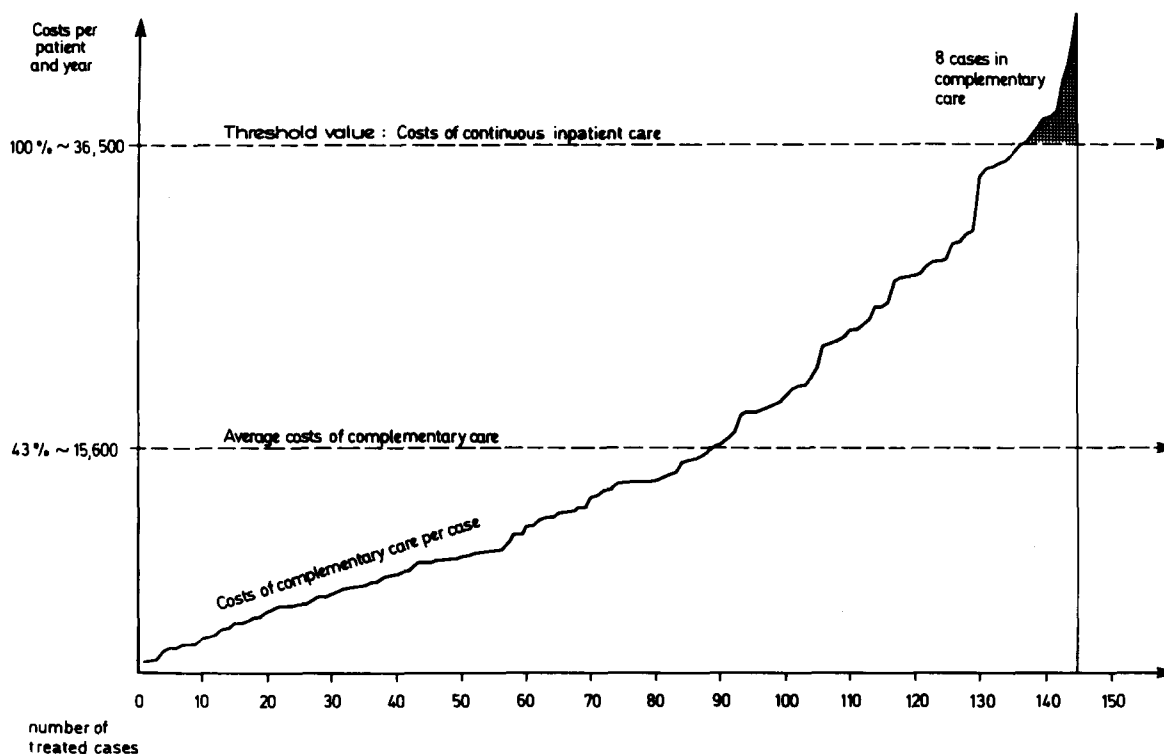


Fig. 2. Average costs and costs per case of complementary care as compared with average costs of continuous inpatient care in Mannheim (FRG) [Reproduced from Häfner et al. 1986]

the global therapies practised in a psychiatric unit of a district general hospital and in an area mental hospital in terms of costs, clinical and social outcomes. From the results of this study it can be concluded that a large number of social and illness variables have to be considered, in order to be able to interpret the differences in outcome and costs correctly.

By comparing the costs and effectiveness of different therapeutic strategies administered to the same target populations, it is possible to conclude which programme involves the lowest costs.

By studying representative populations of chronic schizophrenics Hess et al. (1986) in Berne (Switzerland) and Häfner et al. (1986) in Mannheim (FRG) compared the costs of the total network of extramural services offered in defined catchment areas with those of continued psychiatric hospital care on the basis of directly measurable costs of psychiatric and social services. Both studies showed that the costs of extramural care, including readmission when relapses occurred, were more than 50% lower than the costs of continued hospital care (Fig. 2).

By analysing the distribution of the costs per case Häfner et al. showed that the findings are applicable only under certain conditions. With the discharge of increasing numbers of disabled long-stay patients from hospital, the costs of extramural care per case and, consequently, the average costs of community care will increase, as the more intensive care of the severely ill and disabled will produce considerably higher costs than that of less severely disabled patients discharged before them. At the same time the psychiatric inpatient population will change, as fewer slightly ill and increasing numbers of severely ill patients producing higher costs will be admitted.

Obviously, the system aspect of mental health services is an important frame of reference for the generalization of the results of small-scale evaluative studies. In order to apply the results of such studies to the target group of all socially disabled of a particular category, the system aspect must be taken into account by employing an epidemiological design. This can be accomplished by, for example, comparing the study population and the total target group served in the same catchment area in terms of relevant variables by using simultaneously collected case register data. A comprehensive and continuous documentation of the utilization of the whole network of services

by the population of a catchment area thus becomes of decisive importance for the interpretation of results yielded by studies covering only selected patient groups and limited time periods.

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