Bewoners of patienten? Een beschrijving van de gevolgen van chronische psychiatrische stoornissen bij bewoners van verblijfsafdelingen, sociowoningen en beschermde woonvormen

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SUMMARY

RESIDENTS OR PATIENTS ?

The consequences of chronic psychiatric disorder amongst residents of wards and sheltered homes on the mental hospital grounds and sheltered homes in the community.

This thesis describes the application in psychiatric epidemiology of a classification published in 1980 by the World Health Organisation: the International Classification of Impairments, Disabilities and Handicaps (ICIDH). The objective of the ICIDH is to improve information on the consequences of disease. We assessed the impairments, disabilities and handicaps of three residential groups of psychiatric patients: residents of long-stay wards, of hostels on the hospital grounds and of hostels in the community. The applicability of the ICIDH to the practice of psychiatry was found to be unsatisfactory. In this study two new instruments were used, the Classification of Intellectual and other Psychological Impairments (CIPI) and the Groningen Social Disability Schedule (GSDS).

Chapter 1 stresses the importance of assessing the consequences of psychiatric disorders in the long-stay population, not only because of their serious psychopathology and disablement, but also because the government is planning to move patients from the mental hospitals to hostels in the community.

Chapter 2 gives a short history of the way in which people with signs of deviant behaviour have in the past become institutionalised. The number of mentally ill who were restrained increased especially during the seventeenth and eighteenth century. Until the nineteenth century all sorts of people that appeared useless, a burden on, or a nuisance to society, were brought together in hospitals, prisons, workhouses, houses of correction. In the nine-

teenth century the confinement of the mentally ill became more specific. Most of them were transferred from the prisons and workhouses to mental hospitals. In some of these hospitals, the staff tried to implement their optimism in the therapeutic value of moral standards, regular work and relaxation ('moral treatment'), with a minimum of coercion ('non restraint'). However, the growing number of admissions led to overcrowded institutions, a deterioration of the level of care and an increasing lenght of stay. Changes in society and a fastly increasing proportion of old people had its effect on the growing number of admissions and increasing lenght of stay. The discharge rate of about 50% in the middle of the nineteenth century decreased gradually. Mental institutions became terminal stations. For many old people with physical handicaps, it was the only place of refuge. During the first half of the twentieth century, mental institutions in many countries became places of pessimism and despair. In the United States and in Germany many patients were sterilised. In Germany tenth of thousands of patients were murdered, under the disguise of euthanasia, by the National Socialists.

Chapter 3 describes the process of deïnstitutionalisation, which started in most countries during the fifties and sixties, a process that continued until the eighties. It was brought about by the growing criticism of institutionalisation and by optimism about the newly available drugs and psycho-social rehabilitation. In the fifties and sixties most of the discharged patients could succesfully return to their families. In the United States, where the largest decrease in hospital beds took place, most discharged patients were transfered to nursing and boarding homes. In its entirety, the institutional sector in the United States did not change. Of this sector, the percentage of beds in mental hospitals declined from 40% to 20%, while the percentage in nursing homes increased from 20% to 50%. In West Germany, a comparable 'transinstitutionalisation' from the mental hospital to the 'Pflegeheimen'took place,

where the most disturbed and disabled patients were just as badly. In the sixties, in England centres for day-care and day-treatment were established on a large scale, fulfilling an important function in the care of chronic mental patients. Mental patients were not tranferred to nursing homes on a scale comparable to the United States. In Italy the circumstances in the mental hospitals were poorer than in other Westeuropean countries. Longterm hospitalisation became illegal after a law to this effect was adopted in 1978 by the Italian parliament. Deïnstitutionalisation, already in progress, increased. The alternatives for long-term hospitalisation are diverse in number and quality. There are effective community centres, with a wide range of facilities. In other places, many patiënts were left behind in old mental institutions. In the wards of the general hospitals, where psychiatric patiënts are allowed to be admitted for a limited period of time, agressive and psychotic patiënts are treated with high doses of medication, in an environment which is inadequate. In the Netherlands, between 1955 and 1975, the reduction in number of psychiatric beds was only 17%, much less than the reduction of 66% in the United States. In the seventies, the reduction in beds was mainly the result of the transferal of patiënts to institutions for the mentally retarded and to psychiatric nursing homes. As in other countries, during the eighties the size of the long-stay population stabilised.

In **chapter 4** the characteristics of chronicity in psychiatric disorders are analysed. We look into the course of schizophrenia, the most frequent diagnosis in longterm patients. More or less independent of the course of psychopathology, social functioning of schizophrenic patients often has an outcome which is less favourable than that of psychopathology. Patients with an unfavourable outcome had more often had a bad childhood, and they frequently came from a broken family. Inadequate social functioning and poor performance in school or at work, before the appearance of schizofrenic symptoms were

unfavourable prognostic signs.

Chapter 5 begins with a description of the 'vulnerability model', a model which views schizophrenia as a disease causing vulnerability for too many or too few stimuli. The 'positive' syndrome, including the core psychotic phenomena of delusions and hallucinations, is discussed as a consequence of certain overstimulation. The 'negative' syndrome, similar to the 'clinical poverty syndrome', involves the absence of normal functioning and consists primarily of flattened affect and poverty of speech. Some people view this negative syndrome as a psychosocial artefact. Others consider it as necessary protection of the vulnerable person against too many stimuli. The negative syndrome is associated with poor social functioning. Depressive symptoms are frequently found during the course of schizophrenia and are associated with poor social functioning. It can be difficult to differentiate negative symptoms from depressive symptoms. Another problem is the differentiation of these syndromes from the side-effects of antipsychotic drugs such as akinesia and akathisia, giving rise to behaviour similar to the negative and depressive syndrome. Distinguishing these syndromes in chronic schizophrenic patients using antipsychotics, is of major concern in order to choose the right treatment. It is argued that regular evaluation of psychopatholgy is necessary in chronic schizophrenia, because its course fluctuates and many biological, psychological and social factors influence schizophrenic vulnerabily and the appearance of symptoms.

Chapter 6 describes the concepts of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) published in 1980 by the World Health Organisation. We discuss the operationalisation of the different levels in which a psychiatric disorder manifests itself: symptoms, signs (impairments), disabilities in social functioning, and the reaction of the environment (handicap). The following instruments for the assessment of the consequences of disease are used in this study: the Present State Examination (PSE), the Classification of Intellectual and

other Psychological Impairments (CIPI), the Groningen Social Disability Schedule (GSDS) and the Social Behaviour Assessment Schedule (SBAS). For the assessment of the daily practices and rules restricting the behaviour of the residents, we used the Hospital Hostal Practice Profile (HHPP). This chapter ends with the formulation of the research questions.

Chapter 7 describes the sampling procedure and the characteristics of the setting in which the patients lived. Ninety six patients, aged under sixty five, were examined. In the psychiatric hospital the patients hadf stayed for at least two years. Thirty five in long-stay wards (PV) and twenty five in sheltered homes on the hospital grounds (SW) were interviewed. In the sheltered homes in the community (BW) another thirtythree patients were interviewed. Most of them had spent many years in a psychiatric hospital. Demographic characteristics, the psychiatric diagnosis and the average dosis of prescribed antipsychotics are presented for each setting. The SW had the smallest number of staff, its residents had the greatest autonomy and the least care and supervision. The BW had more staff and offered more supervision and control than the SW. The PV had the highest number of staff, and the residents had the least autonomy. Based on all interviews and all other information, the residents were classified according to axis-1 of the DSM-III. Of the residents of the sheltered homes in the community (BW), a quarter were classified as schizophrenics (excluding residual schizophrenic disorder and 'in remission'), another quarter had no diagnosis, besides borderline intellectual functioning (estimated IQ between 70 and 85). In the hospital (SW and PV) about half of the residents had active schizophrenia. Of the residents in the wards, one out of five had an organic disorder. Almost all residents received antipsychotics, most frequently and in the highest doses in the psychiatric hospital. The residents interviewed in the hospital were representative of the population of patients in all dutch hospitals with regard to age, sexe and psychiatric diagno-

ses . The same applied to the residents interviewed in the sheltered homes in the community (BW) when compared with a sample of residents of similar sheltered homes in the Netherlands.

In **chapter 8** the findings with the Present State Examination (PSE) are presented. In the wards (PV) one third of the residents could not be interviewed adequately. The other interviews revealed that the residents in the PV had the most severe symptoms, particularly delusions and hallucinations. The residents of the SW reported more symptoms than the residents of the BW. In the hospital (PV and SW) many residents had symptoms of anxiety and depression. About fifty percent of the residents with the diagnosis of schizophrenia had symptoms of social unease, tension and restlessness. Also PSE-syndromes of depression were frequently found among these schizophrenic residents.

In **chapter 9** four scales of impairments are constructed, using factor analysis of the scores on the majority of the items of the Classification of Intellectual and other Psychological Impairments (CIPI). The scales were called the positive, manic, negative and depressive CIPI-syndromes. The syndromes were found amongst all diagnostic categories. Residents with a schizophrenic disorder had high scores on all four syndromes. Residents of the PV had the highest scores, and residents of the BW had the lowest scores. High doses of antipsychotics were significantly correlated with the negative syndrome. High scores on the depressive syndrome were often found amongst residents with high doses of antipsychotics.

Chapter 10 describes social functioning of the residents, assessed with the Groningen Social Disability Schedule (GSDS). Significantly more residents of the wards (PV) were more seriously disabled in various roles than residents of the sheltered homes in the community. The serious disabilities of many residents in the PV as well as in the SW, may stand in the way of large scale deïnstitutionalisation. PV residents differed most from the other residents in their selfcare. Half of the PV-residents

showed a serious disablement in this role. In the hospital (PV and SW) nearly all residents were seriously disabled in the professional role, and in the BW 'only' half of the residents. Comparing the different diagnostic categories, we found that residents with a schizophrenic disorder had the most serious social disabilities. A third of them were seriously disabled in their selfcare. Residents with an organic, a neurotic or no DSM-III axis-1 disorder were functioning relatively well in their social role. In their professional role only some residents with an organic disorder or no DSM-III axis-1 disorder were functioning fairly well. The severity of the disabilities could only to a limited degree be explained by their symptomatology (PSE) and impairments (CIPI). Disabilities were most strongly correlated with the negative CIPI-syndrome, and somewhat less strongly with the depressive syndrome. The positive syndrome correlated most strongly with a disabled parental role.

In **chapter 11** we discuss the last 'level' of the consequences of disease, that of handicaps. We operationalised handicap as a reaction of the environment to problem behaviour of the patient. We presented a key-figure, usually the nurse or the manager of the sheltered home, with about 24 categories of behaviour listed in the Social Behaviour Assessment Schedule (SBAS). We asked if such behaviour was present during the past month and if other residents reacted with friction or if the staff had intervened. Selfneglect and irritability were the most frequent behaviours leading to a reaction. Although withdrawal was the most frequently encountered behaviour of the SBAS-list, it had seldomly provoced a reaction. In the wards (PV) we saw most problem behaviour, in the BW least. Problem behaviour in the PV gave more frequently rise to a reaction than in the SW or BW. The kinds of problem behaviour and the frequency of reactions differed between the diagnostic categories. These findings indicate that problem behaviour among residents with different psychiatric disorders needs a differentiated management. In

general, only problem behaviour of patients with serious symptomatology evoked reactions of the environment.

Chapter 12 provides a summary and discussion of the findings. It begins with an evaluation of the usefullness of the ICIDH-model and the instruments employed in this study. The regular application of an instrument for assessing observable impairments is recommended in the care of the chronically mentally ill. It should be used for the evaluation of fluctuations in the course of the disorder, effects of psycho-social changes, the effectiveness of antipsychotics and the occurence of side effects. These side-effects may partly account for the negative and depressive CIPI-syndromes, that were strongly associated with disabilities and problem behaviour. This chapter ends with some critical remarks about governement policy, aimed at extensive reallocation of residents of psychiatric hospitals to sheltered homes in the community. It is argued that 'normalisation' or 'rehabilitation' is not realised by putting patients in other locations. The serious consequences of their disease need professional attention. Reallocating many hospital-residents may change the kind of population living in sheltered homes. Keeping psychiatry outside its doors may lead to negligence.