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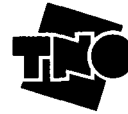

K 24

Divisie Volksgezondheid
Wassenaarseweg 56
P.O. Box 2215
2301 CE Leiden
The Netherlands

www.tno.nl

T +31 71 518 18 18
F +31 71 518 19 20
Info-VGZ@pg.tno.nl

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Economic research in mental health care: existing and emerging themes and issues for future research

Date	December 2001
Author(s)	S. Kavanagh
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1 Introduction

Government policy encourages extramuralisation and flexibility in service provision for people with mental illness (Ministerie VWS, 1999). However, providing alternatives to traditional long-stay hospitals requires inputs from a variety of health, welfare and housing organisations with knock-on effects on their budgets. Unfortunately, as our initial review (Kavanagh and Steenbekkers, 2000) demonstrated, there is insufficient evidence available on the likely costs to these different stakeholders (ambulatory health services, general practitioners or local authorities) resulting from extramuralisation. More generally, there is little available information on the cost-effectiveness of different service configurations for the care of people with mental illness. There were just three relevant economic studies in this area: two aimed at reducing/shortening admission to hospital(Vlaminck, 1990; Wiersma et al. 1991), while a further study examined reprovision for long stay patients (Roosenschoon, 1995). All the studies were conducted some time ago, sample sizes were small and costs were narrowly defined and measured. Although work about to be published or in progress may improve matters (see attached appendix), the current information base is limited and further research is needed to clarify these issues.

This report builds on our earlier review and provides advice on the content and structure of a programme of research on the economics of mental health.

2 Methods

The research included a number of activities.

2.1 Literature Overview

A brief overview of the international literature was conducted to identify broad types of research being conducted in this field. The purpose of the overview was not to provide an actual review of the literature but rather to identify the current themes and methods prevalent in economics research on mental health care. The following electronic databases were searched:

Medline (PubMed) 1990-2000
The key words employed were: "DEINSTITUTIONALIZATION", "COMMUNITY MENTAL HEALTH SERVICES", "COSTS AND COST ANALYSIS", "COST BENEFIT ANALYSIS" & "ECONOMICS".

Psychinfo (Psychlit) 1990-2000
The key words employed were: "DEINSTITUTIONALIZATION", "MAINSTREAMING", "COMMUNITY MENTAL HEALTH", "CASE MANAGEMENT", "COSTS AND COST ANALYSIS" "COST" & "ECONOMICS".

Current Opinion in Psychiatry 2000
The Social, Community and Public Health Psychiatry section was searched under the heading "ECONOMICS".

Information from the Cochrane Collaboration Library and the UK Health Technology Assessment Programme publication list were also reviewed. In addition, the *British Journal of Psychiatry* and the journal *Health Economics* were manually searched.

2.2 Interviews with International Experts

Telephone Interviews were conducted with a number of people in the international research community who are responsible for commissioning and/or conducting publicly funded research on the economics of mental health. The purpose was to identify further emerging research themes and to outline the structures within which economics research on mental health care is commissioned and conducted in the United Kingdom and the United States. Interviews were conducted with the following people.

- Dr. Daniel Chisholm is a senior researcher in mental health at the World Health Organisation, based in Geneva.
- Martin Knapp is professor of health economics and Director of the Personal Social Services Research Unit, London School of Economics and Director Centre for the Economics of Mental Health at the Institute of Psychiatry, London.
- Andrew Healey is research fellow at the Personal Social Services Research Unit, London School of Economics.

- Dr. Agnes Rupp is chief of the Financing and Managed Care research programme at the Division of Services and Intervention Research at the National Institute of Mental Health (NIMH), Bethesda, Maryland, United States.

- Dr. Nancy Wolff, is associate director of the NIMH-Center for Research on the Organization and Financing of Care for the Severely Mentally Ill in the Institute for Health, Health Care Policy and Aging Research at Rutgers University, New Brunswick New Jersey, United States.

2.3 Invitational Seminar

A special invitational seminar brought together researchers who are active in this area with policy workers. The seminar discussed issues around the content and structure of economics research. Unfortunately illness and other unforeseen events made it impossible for representatives of the research commissioning organisations Zorg Onderzoek Nederland (ZON), College voor Zorgverzekerars CVZ and the Nederlandse Organisatie voor Wetenschappelijk Onderzoek (NWO) to attend as planned.

3 Research themes identified in the literature

Research on mental health and economics/costs conducted during the last decade can be categorised in terms of both the general mode of research employed and the particular mental health services' issues that it addressed.

- Descriptive studies of where patients are resident, their service utilisation and costs taken from surveys and local studies;
- Studies that compare the relative costs of different ways of organising services, of which there are two broad categories:
  - Research examining the effects of changing the financing, reimbursement and commissioning processes for service provision;
  - Studies examining the costs and effects associated with particular treatments and service configurations. This second category can be further sub-categorised into studies which examine the costs and cost-effectiveness of:
    - Providing alternative care for former long-stay inpatients
    - Providing alternatives to short-stay acute inpatient admissions (hospital vs. community comparisons)
    - Providing alternative forms of community-based services (community vs. community comparisons)
- Finally, as the available information has grown there is increasing research on the costs and cost-effectiveness of care for sub-groups of patients who are heavy service users such as those with comorbid substance abuse problems.

3.1 Epidemiological Studies and Descriptive Studies of Services Use and Costs

An important area of research is the provision of descriptive information on the characteristics, degree of disability and use of services (costs) by people with mental illnesses. Although such research is not experimental in that it does not set out to provide an answer to which form of care is cost-effective, it can provide important insights into the patterns of service use (costs) for people in different residential settings with differing levels of need. This information can come from a variety of sources such as: epidemiological surveys, case registers and information collected on service users in a particular area.

Large-scale population-based epidemiological surveys, potentially provide information on all patients, non-users as well as users of services that is relevant at a national level. The Epidemiological Catchment Area (ECA) Study (Robins and Regier, 1991) and the National Comorbidity Survey (Kessler et al. 1996; Kessler, 2001) in the United States, the Surveys of Psychiatric Morbidity in the UK (Meltzer et al. 1995) and the NEMESIS study in the Netherlands (Bijl et al. 1998; Bijl et al. 1998) provide recent examples of studies producing information on needs and service utilisation. However, psychoses, the so-called severe mental illnesses, are difficult to capture in such surveys because of both the relative rarity of the conditions (5 per 1000 adults) and the increased likelihood of non-response to the initial postal screening by such individuals. Consequently in the case of the NEMESIS study there is limited information on people with psychoses living in households.

Traditionally case registers (based on a database of people who have been in contact with local psychiatric services) have been one of the most useful sources of service

utilisation information for people with severe mental illness. For example, case register data from a region of Scotland showed the high costs associated with care for around 200 people with schizophrenia(Lang et al. 1997). In Germany, a catchment area study of 66 patients with schizophrenia in community mental health care showed costs lower than that found in hospital (Salize and Roessler, 1996). In the Netherlands, information on the patterns of service contacts have also been published (Pijl et al. 2000b).

Information is also provided from local studies examining people in contact with a particular service. For example, as part of a project in five European countries (Becker et al. 1999) information is becoming available on the needs, service utilisation and costs for 61 patients with schizophrenia resident in Amsterdam. The patients have a wide variety of needs ranging from accommodation to personal safety. In most instances services had met these needs, but for a minority of patients unmet needs were reported for areas such as daytime activities (34%) and physical health care (15%) (McCrone et al. 2001). (Publication of the cost analyses are awaited).

Statistical analyses can be used to examine associations between individual characteristics and patterns of service use and costs. For example, personal characteristics such as male gender, the number of problems requiring rehabilitation, patients' previous history of service use, and diagnosis are all associated with costs of care (Salize and Roessler, 1996; Amaddeo et al. 2001) (McCrone et al. 1998). Such analyses can be used to identify the characteristics of patients who are likely to be heavy users of services and incur high costs.

Statistical methods can be further employed to construct predictive models that provide estimates of the costs of care for treatment in non-hospital settings of patients currently resident in hospital. For example, Knapp and colleagues' study of the costs of care in different residential settings used data on the associations between personal characteristics, characteristics of different types of non-hospital residential care (scale, etc.) to predict what the costs of treating inappropriately placed hospital inpatients in alternative settings would be (Knapp et al. 1997).

It is important when examining data on service use and costs from such sources to remember the data represent service use as it exists and not necessarily as it should be under ideal circumstances. The availability of services and the policies governing patient's access to them also play a key role in utilisation. For example, the availability of community-based services and the degree of service development were cited as the explanation for differences in treatment costs for patients with schizophrenia in three different areas in Spain (Haro et al. 1998).

Overall, although data from large national surveys may be more desirable, practical limitations mean that information from local studies of service users is a second best solution gained at the cost of degree of generalisability.

The most important point is that such studies describe either the current situation or trends in utilisation, but they rarely provide information on the relationship between costs and outcomes for patients and thus the most cost-effective manner to provide care. In subsequent sections we examine two broad categories of research: studies examining changes in the financing and management of care and studies which examine the cost-effectiveness of different service configurations and treatments.

3.2 Changing financing of services (managed care)

In the United States, the failed Clinton healthcare reforms were superceded by a range of changes introduced by state authorities, employers and private insurance companies which collectively became known as managed care. Consequently, recent literature relating to economics (costs) and mental illness is dominated by analyses of these changes to the financing and structures of services.

The driving force behind managed care was a desire to curb escalating costs associated with fee-for-service payments and to manage budgets appropriately. One of the main tools of managed care is utilisation management. This can, at basic level, begin with the funder of services employing retrospective audit of the treatments provided by services. Concurrent reviews, by the funder, of both the length and type of treatment during an episode of care and the potential use of second opinions can also be employed. More assertive forms of utilisation management, shifts the emphasis to the funder determining in advance what treatment is provided, through the use of pre-certification and strict protocols for treatment. Retrospective, concurrent and prospective forms of utilisation management can also be combined (Stone, 1995). Separate intermediate organisations known as managed care organisations (MCOs) can also be employed to conduct utilisation management and other activities. In the case of mental illness, where traditionally private insurance coverage has been less widespread, public sector agencies have also employed managed care techniques themselves or have involved an external MCO (Essock and Goldman, 1995).

In order to contain costs, changes can also be made to the financial incentives for providers of care. For example, capitated payments (a pre-determined payment per person for a fixed period) can be made directly by funders to providers or can be paid to MCOs who in turn contract with different providers of services. MCOs, often referred to as a Health Maintainence Organisation (HMOs), may in turn employ capitated payments and/or the utilisation management techniques outlined above. An increasing variety of organisational forms (Gold et al. 1995), using varying incentive structures are being employed (Frank et al. 1995).

A general point regarding the managed care literature is that information on outcomes is often lacking since research relies largely on insurance claims data. Consequently, a major concern is that the costs savings reported from managed care experiments (Christianson et al. 1995; Callahan et al. 1995) may be achieved at the cost of a worsening of patient outcomes. (For further information on managed care see for example: (Wells et al. 1995; Mechanic, 1996; Newhouse, 1993). Health Affairs and Psychiatric Services also contain regular coverage of these issues).

It is difficult to make generalisations to the Netherlands given the variety of mechanisms for financing care and particular local circumstances. However, utilisation management, although largely used in the United States to contain costs, also has potential for ensuring quality of care, in turn leading to greater cost-effectiveness of treatment.

More generally, managed care has lead to changes in service structures which have encouraged the use of more community-based services and less inpatient care and has therefore acted as a further spur to deinstitutionalisaton. Although it is difficult to translate findings from evaluations of large-scale changes in financing of care to a

European setting, more narrowly defined cost-effectiveness experiments with different forms of community care services (arising from wider managed care changes) can provide useful information. In addition, managed care has helped bring a research focus to groups of patients who are heavy service users and the care that they receive.

3.3 Longitudinal studies of (long-stay) patients discharged from hospital

Research from western countries, often using data from the late 1980s and 1990s, examined the costs of care for patients discharged from traditional long-stay psychiatric hospitals. In the United States, studies conducted in various states, reported that the closing of the state psychiatric hospitals led to reduced total costs of care for patients due to the increased use of ambulatory services (Wright, 1999). For example, analysis of insurance records for 321 patients discharged from the state hospital in Philadelphia in the United States found that costs in the three years following discharge were significantly lower for patients treated outside the hospital.(Rothbard et al. 1999). Similar findings have been reported in research from other countries, such as Australia, (Lapsley et al. 2000), Canada (Reinharz et al. 2000), and Northern Ireland (Donnelly et al. 1994)

Research from London demonstrates that it is important when considering these studies to look at the costs for an entire closure and not just at the costs for the early (less disabled) cohorts of patients discharged from the hospital. Results published in 1990 showed lower costs in community care for early cohorts of discharged patients and projected potential cost savings for the more disabled patients awaiting discharge (Knapp et al. 1990). However, when information for the entire hospital population became available, costs were much greater outside the hospital for the most disabled patients. Consequently average cost – for all patients – was greater for community care than for hospital care (Beecham et al. 1997). The study points to the difficulties of projections and planning.

The major policy issue arising in many of these studies was that the pattern of costs changed as a result of deinstitutionalisation with different funding agencies assuming new financial and organisational responsibilities. Studies that used a narrow definition of cost that focused only on mental health services and excluded other community care services failed to make explicit the true total costs associated with the policy change. Furthermore, such studies cannot provide information on the additional costs incurred by housing, social services and primary health care agencies. For example, Roosenschoon's study of 17 long-stay inpatients who received guided independent living in Utrecht failed to take account of costs for accommodation outside the hospital thus underestimating total costs and incorrectly suggesting cost savings for the guided living programme (Roosenschoon, 1995). In the absence of comprehensive information, the additional demand for community services may not be fully taken into consideration in planned changes for service structures and adjustments to budgets. This potentially leads to pressure on, or even the under-provision of, services with consequences for patients and their carers. In some cases, authors suggest that care outside the hospital for former long-stay residents led to patients having unmet needs for care and also greater out-of-pocket costs for patients and their families (Deb and Holmes, 1998). Even where particular costs components are small in the context of the overall costs of care, it is important to identify and estimate them. The costs of additional care by general practitioners may be a small part of the total cost for a particular patient but may be entail considerable extra workload for the general practitioner concerned.

Overall, the studies of discharged long-stay hospital patients provided the first pieces of information on the likely impact of deinstitutionalisation. The changes in service organisation, sometimes involving closures of wards or whole hospitals often imposed limitations on the types of study design that could be employed. Investigators were often able to employ only simple before-and-after comparisons.

Many of the long-stay patients had been resident in hospital for many years and had acquired secondary handicaps as a result of their long tenure in hospital(Goldberg, 1999) and had become "institutionalised". The data on the costs of care for these patients therefore reflects not only the effects of the patients' condition but also the effects of past treatment policies. It became increasingly important to have complementary information on the likely costs and outcomes for patients who had shorter prior experience of psychiatric care (new entrants to the system) - often with more acute episodes of illness - for whom the option of long-term hospitalisation would no longer be available.

3.4 Community versus hospital care

Pioneering experiments such as the model of assertive community based treatment employed by Stein and Test (Stein and Test, 1980) suggested a way of organising community care for acute patients that resulted in improved patient outcomes and a favourable balance between costs and benefits (Weisbrod et al. 1980). The service employed a case management system based upon the following factors: caseloads of 8-12 persons; interdisciplinary teams with at least 3 professional disciplines in team; no more than 20% of staff part time; 24 hour availability; team autonomy; and part-time psychiatrist input only (Stein and Santos, 1998). The model of care proved highly influential and there have been a large number of studies that attempted to replicate some or all of the service elements.

A variety of service models have developed with an increase in the number of differing labels used to describe them. The difference between service models is not always easy to ascertain and labels for services can be misleading with services having the same label employing differing methods and sometimes different labels being used to describes similar services (for example, intensive case management is often used interchangeably with assertive community treatment). The reviews contained within the Cochrane Collaboration Library illustrate the difficulties with four separate reviews for what could be described as community care for people with severe mental illness relating to: assertive community treatment (Marshall and Lockwood, 1998), case management (Marshall et al. 1997), community mental health teams (Tyrer et al. 1998) and crisis intervention(Joy et al. 1998). Poor descriptions of services meant that reviewers had to rely on the labels used by the authors of articles, sometimes resulting not only in overlap between the type of service model considered, but also in actual overlaps between the studies included in separate reviews. In order to bring the literature together in a more coherent manner Burns and co-authors used a broader definition of "home treatment" that included " a service that enables the patient to be treated outside hospital as far as possible and remain in their usual place of residence"(Burns et al. 2001).

The results of studies comparing home treatment with hospital inpatient care are mixed. In the three studies in the UK there was no evidence to suggest that the experimental

community based services were more cost-effective. However, in four studies conducted in North America, all the studies delivered evidence that favoured the experimental community-based services in cost-effectiveness terms (Burns et al. 2001).

3.5 Intensive case management versus standard case management

Given the range of organisational formats for community services, discussion has moved to the relative (cost) effectiveness of the differing structures and formats. For example, the work of Gardien and colleagues in Amsterdam, although not a costs study, suggested that assertive case management was more successful than standard case management in reducing hospitalisation(Gardien et al. 1999). In their review Burns et al. found no clear cost-effectiveness evidence to support one form of community care service over another (Burns et al. 2001). This was particularly the case in the UK where studies comparing case management with standard community psychiatric nursing services and assertive versus standard case management showed no differences in cost-effectiveness. In the US, more studies favoured assertive community treatment than standard services, but these results often related to special sub-groups such as the homeless or high cost users (Burns et al. 2001).

Most recently, thè cost-effectiveness gains from more intensive assertive community teams as opposed to standard case management has been questioned in a large scale study in the UK (Byford et al. 2000). The difficulties in identifying a clearly cost-effective model of community care has led to discussion on a variety of issues including:

- the absence of an effect from increasing contacts with patients (associated with smaller case loads and more assertive programs) and the possibility that some patients may find the extra visits intrusive and less acceptable(Burns et al. 2000; Tyrer, 2000; Tyrer, 2001).
- The potential confounding role played by differing types and administration strategies for anti-psychotic medication such as depot injections, which may also reduce the gains (in terms of compliance) associated with more frequent contacts.
- The usefulness of reducing hospitalisation in all circumstances is an appropriate aim for services; and
- the possibility that the much-reduced supply of hospital beds may have also reduced the scope for cost savings in such programmes.

Although the different forms of organising community services have received considerable attention, there is little cost-effectiveness evidence for the various elements of treatment and community services.

3.6 Day hospitals

Wiersma and colleagues' evaluation (Wiersma et al. 1991) is one of a relatively small number of studies that examined the potential cost-effectiveness of day hospital versus inpatient care (Creed et al. 1997; Sledge et al. 1996). Marshall et al.'s review found that there were cost reductions reported in four of the five studies including such information and that overall – depending on existing service conditions - day hospital may offer a useful addition to hospital and community services(Marshall et al. 2001).

3.7 Residential care

Research has examined the costs of different forms of residential care in the UK (Chisholm et al. 1997) (Knapp et al. 1997) and found that various personal characteristics were associated with the costs of providing residential care including: age, gender, ethnicity, history of admissions, diagnosis, daily living and social skills, aggression and co-morbid substance abuse. However, impact of the different types of residential care on patient outcomes and therefore the cost-effectiveness remains relatively under researched. Further information would be useful given the basic importance of accommodation within a patient's overall package of care and that residential care/housing often accounts for the majority of the care costs.

4 Research literature 1990-2000: emerging themes

4.1 Cost-effectiveness of new pharmaceutical treatments for schizophrenia

Pharmaceutical companies are increasingly being required to provide cost-effectiveness evidence for new treatments. As a result, the published literature on the costs for schizophrenia continues to grow. The costs of newer atypical anti-psychotics are relatively greater than older medicines and given the growing pressure on drug budgets, evidence is required for cost-effectiveness in terms of patients' quality of life and potential for cost offsets from reduced use of inpatient care (Rosenheck et al. 1997; Foster and Goa, 1999; Foster and Goa, 1998).

A further issue is that different types of medication and the way that they are administered (tablet or depot injection) potentially impact on treatment patterns and needs to be considered as a confounding factor when comparing different forms of community based treatment for people with schizophrenia.

4.2 First episode psychoses

Longitudinal studies following first-episode psychosis patients are increasing of interest to examine the potential treatment effects of early intervention. The profiles of costs for these new entrants to the system are also of interest as services move away from hospital based care. (Haro et al. 1998; Amaddeo et al. 1998). Goldberg suggests that the cost profiles may be lower because they have acquired fewer secondary handicaps as a result of long-stay hospital admissions (Goldberg, 1999). Several authors have examined the potential of early treatment programme for costs and patient outcomes (Mihalopoulos et al. 1999).

4.3 Comorbid substance abuse problems

The prevalence of co-morbid substance abuse problems among people with serious mental illness is high (Kessler et al. 1996), some commentators in the US go as far as to state that "dual-diagnosis is an expectation, not an exception for persons who present for treatment at a mental health facility" (Schneider, 2000). Furthermore many people with co-existing disorders do not receive appropriate treatment.

Various evidence from both the USA and Europe suggest that in addition to worse clinical and social outcomes, service use and costs are also greater among people with a 'dual diagnosis'. In a sample of 170 patients with psychosis in London, more than a third had substance abuse problems with the number of days spent in hospital amongst these patients being double that found in other patients without substance abuse problems(Menezes et al. 1996). Olfson and colleagues (Olfson et al. 1999) also found that inpatients with schizophrenia who were discharged from hospital had almost double the risk of readmission (60.3% vs 35.5%, p=0.0006) if comorbid substance abuse disorder was present. Further analyses by the same authors showed that these increased risks of admission may be caused by a higher rate of noncompliance with treatment among these patents (Olfson et al. 2000).

Bartels and colleagues found increased service use among schizophrenia patients who also were current substance abusers not only for hospital but also for emergency hospital use and prison (Bartels et al. 1993). Dual-diagnosis patients are a particularly difficult group for service providers dedicated to either mental illness or substance abuse services because of their multi-dimensional needs and potential treatment resistance. The cost-effectiveness of different treatments for this group are being investigated (Johnson, 2000; Jerrell, 2001)

4.4 High cost service users

As the available information on costs and cost-effectiveness has grown, increasing attention is being placed on patients who are heavy users of services incurring high costs for care. Community care based on assertive treatment in the US has been shown to be potentially cost-effective for high cost users (Rosenheck and Neale, 1998; Essock et al. 1998). Similarly, some US research suggests that it may be cost-effectiveness to apply assertive community treatment to sub-groups of homeless patients (Lehman et al. 1999; Wolff et al. 1997).

4.5 Summary of Literature Overview

Overall there has been an exponential growth in research on economic aspects of mental illness care. Current themes include:

- Cross-sectional studies of costs for service users show associations between patients' characteristics, disabilities, history of service use, and costs for care.
- The changing financing of services (managed care) has led to increasing use of less costly community-based alternatives, effects on patients not always fully investigated. Generalisation to the Netherlands is difficult.
- Longitudinal studies of long-stay patients discharged from hospital often report cost-savings for patient in community care but that results require careful interpretation.
- Community based care as an alternative to acute hospital care showed early promise in terms of costs and outcomes, but more recent evidence is mixed
- Evidence supporting the cost-effectiveness of intensive assertive community care as opposed to standard services is mixed with more positive results being reported in the US than in the UK. Overall the cost effectiveness of different forms of community care remains unclear.
- Residential care, housing and other elements of care for people in the community are in comparison relatively under-researched

Emerging research issues include:

- Cost-effectiveness of new pharmaceutical treatments for schizophrenia
- Longitudinal studies of first episode psychoses
- The costs and cost-effectiveness of care for special sub-groups of patients such as people with co-morbid substance abuse problems, the homeless, and high cost service users.

5 Themes identified by international experts

5.1 Reflection on past policies of deinstitutionalisation

The early stages of deinstitutionalisation were characterised by a backlog of patients deemed suitable for community care but basic information on their needs for care and were not readily available. This problem was compounded because secondary handicaps associated with long-term institutionalisation disguised patients abilities while staff's lack of experience with community based care made it difficult to plan the necessary services and estimate the likely costs. This lack of experience with planning in both the US and the UK led to an implicit hope that existing community services would be able to deal with the extra work within existing capacity, which in turn meant extra pressure on some services.

The experience of community care in England provided valuable lessons that were not fully foreseen 10 or 15 years ago when there was perhaps over-optimism of the potential cost consequences. First, care outside of old style hospitals for the people who were most disabled and treatment resistant was more costly than envisaged, second, the period required for the decommissioning or converting the old hospitals - and consequently the burden of parallel running costs - was much longer than expected.

The long-term parallel running costs suggests that planning is needed to predict the flow of funds released as a hospital closes or converts to other uses. The differing disabilities of patients and the important stages where savings are realised (e.g. where a ward or even a wing of the hospital can be closed or converted) are important for determining the pattern of investment required. The need to have bridging or double financing of two services was cited as being among the most important but most costly factor in developing new services.

For both the US and the UK, fragmentation of funding and organisation - where there is a movement away from a single organisation to a situation involving multiple organisations with separate budgets and differing eligibility criteria - was cited by all the people interviewed as a key factor inhibiting the success of community based care. A related area of concern centred on the leakage of funds given to outside agencies to provide community care for the mentally ill to some of their other activities. The desirability of ring-fencing the funds being transferred was therefore emphasised. Some of these issues can be summarised around the headings identified by Knapp and colleagues. Addressing the issues in a practical manner is of course more challenging.

5.2 Summary of Resource Issues

- Adequacy (are there enough resources?)
- Timeliness (Money is needed to start community services before discharges take place)
- Flexibility (hospitals have a fixed set of resources with lumpy capital assets while community services need to be more responsive to patient needs)
- Distribution (Money needs to go to all the services involved not just mental health care)

- Co-ordination (Agency strategies need to be co-ordinated at a strategic level as well as at a case-level)

With the progression of the policy of deinstitutionalisation two issues grew in importance: (i) the need to prevent the build up of long-stay patients and (ii) for some patients there is a continued need for asylum.

5.3 Current Concerns

Current debates about community care reflect the development of models for community services and their implementation into practice settings. For example, the discussion around home-based care provides a useful example of some of the difficulties facing the interface between policy and research. There is currently disagreement about the usefulness of Assertive Community Treatment models. At a basic level the usefulness of the approach itself is questioned. Even among proponents of such an approach there is considerable debate about what is the best model of care. Policy makers and researchers are finding it difficult to define a reproducible cost-effective model of community care. Problems include:

- Models reported in articles often reflect idealistic descriptions of what was desired as opposed to what actually happened in practice in the service being described.
- The comparison services are often inadequately described and so-called "usual care" varies widely between different localities.
- The processes of care in the "usual care" services can often be contaminated by the introduction of elements of the experimental service.
- Current "usual care" services are more developed than the "usual care" found in early studies, diminishing the potential gains from the introduction of new care processes.
- The reduction in the supply of hospital places has reduced the potential for cost-savings.
- The potential cost effects are often dependent on the supply of complementary and substitute services in particular areas.
- Community service organisation reflects a method of organisation and is not so easy to evaluate since there is an interaction between the services in question and other services, regulations, and the situational and organisational environment more generally.

Case management represents a philosophy of care rather than a tightly defined form of treatment. Consequently one of the emerging concerns is to more carefully examine the care and support (such as help with medication etc) that case managers provide rather than simply looking at the intensity of treatment provided through such measures as caseload or the number of visits per patient per week. The cost-effectiveness of case management is also dependent on the other services that it can draw upon, but these other service elements such as residential care and supported housing remain relatively under-researched. All those interviewed cited the issues around boundaries between services and the fragmentation of funding as an ongoing policy concern.

5.4 Summary of current research themes

- Difficult to define a cost-effective model of community care
- Costs and outcomes from a service evaluation in one area may associated with peculiar organisational factors in the area being studied rather than the form of care being evaluated.
- The elements of services and the actual activities of care need to be more tightly defined
- Residential care is costly but relatively little is known about its cost-effectiveness.
- Fragmentation of services (funding) is an ongoing concern

6 Invitational seminar – issues arising

6.1 Background

The seminar began with a discussion of the general policy background, focusing on the considerable numbers of patients who remain resident in long-term psychiatric hospital places, despite some researchers suggestions that the majority of these patients could receive alternative service placements (Borgesius and Bruenenberg, 1999). For example, independent living was suggested as a possibility for a significant minority of long-term care residents. Against this background, the lack of current information on the likely costs of placing long-stay patients in alternative community settings and the paucity of cost-effectiveness evidence for care of serious mental illness more generally was highlighted (Kavanagh and Steenbekkers, 2000).

6.2 Defining extramuralisation

In setting out possibilities for further studies three potential types of extramuralisation were suggested [see also, figure 1, page 19 (Kavanagh and Steenbekkers, 2000)].

- Diversion studies
- Rapid discharge studies
- Long-stay discharge studies

This typology of extramuralisation generated some discussions around the usefulness of the definitions and their applicability to the Dutch situation. It was suggested that unlike the UK and US where deinstitutionalisation was brought about by closing public psychiatric hospitals, in the Netherlands, the government provided encouragement to the private non-profit hospitals to innovate and provide a range of community services through policy initiatives such as "zorgvernieuwing" and "zorg op maat". Consequently it is neither easy nor useful to make clear distinctions between the use of hospital and community services, since the boundaries are themselves blurred within providers.

Instead it was suggested that research should not become pre-occupied with placing hospitals as the central comparator in studies, but instead should focus on service arrangements to meet various aspects of patients' needs such as rehabilitation, housing, etc. Furthermore, it was suggested that comparisons of the cost-effectiveness of different configurations of community-based services (community vs. community) would be more useful in informing long-term policy goals than studies comparing individual community based services with hospital care (community vs. hospital). A further related issue was the need to focus on final outcomes that are patient-based rather than concentrating on an intermediate measure of outcome - avoiding hospitalisation.

6.3 Data considerations

The difficulties of interpreting national statistics with respect to the changes in balance between hospital and community services were also discussed. Some of the participants pointed to recent research which shows increasing numbers of service users for

community-based services and data that patients remain longer under psychiatric care (Pijl et al. 2000b; Pijl et al. 2000a; Pijl et al. 2001).

Further data problems for cost-effectiveness studies were identified. Calculation of unit costs is difficult and often relies on existing tariffs for different care activities. However, it was suggested that in some cases the tariffs would be a poor proxy measure of cost because of the widespread variations between providers. A further divergence was brought about by the increasing flexibility and innovation of providers in using budgets for new and different activities. This can mean that the monies they received for activities covered by the tariff system providing an inpatient place may differ from how they are actually using the money and that cost structures are altered. This suggests that research should use tariff-based unit costs with caution or compute new unit costs on a bottom-up basis.

6.4 Complex Interventions

The complexity of mental health care, with different interacting elements of treatment and services was also recognised and discussed. The difficulty of trying to examine the cost-effectiveness of any individual service element and the need for research to take confounding factors into account was highlighted.

6.5 Quality of Life

As part of the discussion the need to look at outcomes as well as costs was highlighted and in particular to look at measures of patient's quality of life in addition to the usual symptom-based scales. It was suggested that the recent development of the Lancashire Quality of Life instrument in the Netherlands situation may provide promising possibilities (van Nieuwenhuizen et al. 2001; van Nieuwenhuizen et al. 1998). In addition quality of life for carers was also acknowledged.

6.6 Future Directions

Future directions for research were considered and the alternatives of a study collecting a very limited amount of information patients' characteristics for a large sample was compared with research examining a smaller number of patients, perhaps in given localities, in greater detail. It was suggested that an in-depth study of patients in several localities could be conducted as a sort of natural experiment. Given the complex nature of interventions by mental health services, data should be collected at the patient, the caseworker and the service level to allow appropriate comparisons.

6.7 Summary Points

- Potentially large numbers of current long-stay inpatients could be cared for in community settings – however, information on the costs and cost-effectiveness of care is limited.
- New research should also focus on comparisons of different strategies for community-based services rather than solely on comparisons of community services with hospital care.
- The complexity of mental health service interventions was acknowledged.
- There is a need to focus on patient outcomes such as quality of life.

- Future research could include natural experiments that compare services in different areas using both patient-level and service-level data.

7 Research concerns

The two most important issues for policy related research are timeliness and generalisability.

Typically politicians and policy makers need answers to inform decision that they are required to take in the short term with national, implemented at a national level, while researchers need time to establish the effects of a study often relying on an in-depth study in a particular area. In mental health there is the added need to look at the longer-term effects given the chronic nature of the conditions. There are therefore a number of trade-offs between timeliness and research quality.

Often in-depth research on community options for treatment of mental illness are conducted in particular localities. This can mean that service development in other areas may potentially have to wait for a long time for the results of the study. In the interim period, services in other localities may themselves evolve making the results of the evaluative study less valid in other parts of the country. This raises issues about the reproducibility of the results (see previous section). For example, will the estimates of the costs of care based on a sample in Groningen in 1996 translate well to the funding of a service in Limburg in 2001?

The table below shows the likely time scale for a number of different types of research.

Possible time scale for research

Type of research study	1 year<	2 years<	2-3 years	4-5 years
Expert panel on costs of care	X			
Decision tree model	X			
Re-analysis of existing case register data	X			
New Cross-sectional study		X		
Prospective study short-term results		X	X	
Prospective study medium-term results				X

- ***Expert Panel Study*** The first and perhaps quickest option would be to assemble a panel of staff and administrators from different types of community services and ask them to define potential packages of care (or the likely range of service used) for a limited number of patient categories. Using separate unit cost information it would then be possible to provide estimates of the costs of care. The approach has the advantage of speed and the fact that the current baseline of information is quite low. However, these advantages need to be considered against the idealised nature of the estimated service packages, the patient categories would be crude compared to the diversity and spectrum of care needs for patients, similarly various consequences such as readmission to hospital may be difficult to estimate.

- ***Decision modelling*** Decision modelling has the potentially to complement, or be distinct from, the expert panel study and also has the relative advantage of producing speedy results. An added advantage is that certain areas where there was uncertainty – such as the likelihood of readmission - can be explored using a range of values in a

sensitivity analysis. Also the approach can help people to conceptualise care as an ongoing process.

- ***Secondary Analysis of Existing Data*** Secondary analysis offers the advantages of relative speed together with the benefits of using actual data collected on patients in practice settings. For example one approach would be to take a samples from one or more of the three case registers in the Netherlands and construct variables on the intensity with which people used all the different services and their place of residence. It is then possible using estimates of unit costs to estimate the costs per patient and to examine the associations between patient characteristics (such as disability, previous service history, etc) and costs. Other possibilities would be analysis of the studies being conducted in Amsterdam and Groningen. Such analyses would be limited in terms of the original sampling of patients and the details on service use and accommodation that were collected.

- ***Cross-sectional Study*** A cross sectional study could be used to examine the costs of care for people with different characteristics in different care settings such as independent living, guided living or supported accommodation. Degree and type of disability is likely to differ between different settings and estimates of costs using prediction models can be used to provide estimates of the costs of care for people currently in hospital if the were placed in alternative care settings. This approach would take considerably longer in terms of setting up a sampling frame, contacting patients etc, but could collect information that can be more tailored to policy concerns. A further difficulty of using such an approach to estimate the future cost consequences of deinstitutionalisation is that the severity of disability of patients as well as costs is likely to differ between settings. Statistical models of costs provide only limited accuracy of prediction. A cross-sectional study could be employed as the first wave of data collection in a prospective study.

- ***Prospective studies*** Prospective studies can provide estimates not only of costs but also of the relative cost effectiveness of different treatments or service arrangements. However, the relative disadvantage is that the results are not available for a number of years. A consideration with such studies are the methodological trade-offs: Randomised Trials are often needed to establish (cost) effectiveness) but naturalistic studies are also important for showing how well scientific evidence translates into real world situations. However, it is also useful to bear in mind earlier discussion about issues around the generalisability of studies dealing with complex interventions such as community care conducted in a particular locality.

The possibilities for different forms of research set out above have been discussed in terms of the time needed before results are available. However, a further, important consideration is the relative costs of conducting the research. For example new field based studies are likely to require much more research funding compared with the options of expert panels, modelling and secondary analyses.

7.1 Summary of research concerns

- Timeliness and generalisability are key issues relating to policy research and are inter-linked
- Typically policy-makers require timely nationally applicable information, while researchers attempt to build arguments up from long-term local studies.
- A variety of research can be commissioned depending on the trade-offs between timeliness, cost and quality of research. Possibilities range from expert panels to long-term prospective research.
- The various research methods are not mutually exclusive and could be integrated into a complementary programme of research providing information at different stages of decision making, policy implementation and review.

8 Research organisation issues

8.1 Comparing results, the needs for transparency and comparability of studies

A persistent problem with research is the difficulty of comparing - or combining in a meta-analysis - the results produced by a study in one area with the results of a study conducted in another location by another research team. In mental health these problems are often compounded for a number of reasons.

8.2 Complex interventions

There are specific difficulties in defining, developing, documenting, and reproducing complex psychosocial interventions such as those in a mental health service where there is much more variation than in a study of drug versus placebo (Cambell et al. 2000). Ideally studies need to take account of a wide range of structure and process variables such as the expertise of professionals, investigations, drugs, arrangements for discharge and follow-up. For example community care such as case management is not a treatment but a philosophy for organising care. It is therefore important to look at the actual care being provided such as the type and frequency of medication, additional help with medication compliance, and/or behavioural therapy (Burns et al. 2000). In mental health care evaluations these problems are compounded since the comparator service is often not standard between areas and is liable to change over time and/or to quietly take on the good elements of fellow treatment approaches (Tyrer, 2000; Tyrer, 2001). Furthermore there is likely to be a relationship between the costs and outcomes of a service and the availability of other related services such as residential care.

8.3 Other methodological issues

Studies often chose inclusion and exclusion criteria that are based on local service definitions such as study only people who made contact with outpatients in the past month. Often the inclusion criteria or the logic behind them are not always explicitly stated.

Although the methods for economic studies are becoming increasingly well known, with a number of well-known published guidelines, there are still wide differences in the manner (quality) which studies are conducted. This applies to basic issues such as the comprehensive inclusion of different service and accommodation elements and the calculation of unit costs. The review of home-based care being conducted by Burns and colleagues provides a useful indication of the problems (Burns et al. 2001). In the first instance only 24 of the 80 studies identified by the reviewers included economic or costs information. Furthermore, the different studies used various standards for including services and calculating costs. For example, only 8 of the 24 studies with an economic component included outpatient care in their calculation of costs (Burns et al. 2001).

An additional problem found in mental health research is the large (and growing) number of instruments used to measure (changes in) patient's disability, symptoms and personal circumstances. For example, in their review of 2000 randomised controlled trials in schizophrenia, Thornley and Adams (Thornley and Adams, 1998) found that

510 studies did not use ratings scales but in the remaining 1490 trials, 640 different instruments were used (a list of the mostly commonly used is provided as an appendix). Most trials used between one and five instruments with some studies employing many more. Furthermore, results were often reported for sub-scales. The authors claim that in addition to the problems of comparability between studies, the interpretation of results is questionable since with the fine measures "it is often possible to achieve significance with small numbers". In addition, "the sheer quantity of data testing will result in misleading significant findings appearing by chance" (page 1183). There is an implicit warning that the use of particular scales can help results to favour the treatment or policy argument being championed by the investigator. Similar problems with non-comparable measures of outcome have been identified by recent systematic reviews in the area (Burns et al. 2001; Marshall et al. 1997; Marshall and Lockwood, 1998).

8.4 Quality of Reporting Methods and Results

Studies are also let down by basic problems in how results are reported. Often only total cost information is given without a breakdown of the component of costs and an indication of the distribution of costs in the group being studied (Barber and Thompson, 1998). As a minimum, studies in this area need to present basic information for each service included along the line of percentage using the service, mean number of contacts for those using the service, with an indication of the distribution and a separate report of the unit cost used and the source from which it was taken. When non-standard sources are used information is then also useful on the assumptions employed.

8.5 Potential Solutions

There are a number of potential ways to ensure the comparability of research that could be implemented during different stages in the research.

- Greater consideration of the complex intervention problems. Wider investigation and description of the processes and structure of care is needed. For example, a basic checklist for the care processes could be developed. For example, Burns et al employed a postal checklist on the structures and processes used by services contained in their review of home based care (Burns et al. 2001).
- Use of an agreed limited core set of disability outcome instruments for schizophrenia
- or psychoses patients
- Defining a set of guidelines for the conduct of economic evaluations applied to the particular issues in mental health care. For example a core set of services and resources to be included by investigators could be developed.
- Implementation of standard reporting guidelines for economic data.
- Use of steering committees or a specific co-ordinator responsible for the conduct of economic research within wider mental health programme.
- Archival of data as a condition of research funding. This allows greater return on the research investment through the potential for secondary analyses and acts to assure quality of research through outside scrutiny.

8.6 Composition of research teams

Successful research in this area requires a multidisciplinary approach consisting of the following elements:

- ***Economic expertise***
- ***Clinical Expertise*** is obviously important to define and evaluate the medical aspects of cost-effectiveness studies. Where possible this clinical expertise should be supplemented by a public health/epidemiological focus.
- ***Statistical support*** Analyses of cost effectiveness studies increasingly have to deal with a range of complex statistical issues including combining information from multi-centre studies, non-normal distribution of cost variables and issues around modelling for predicting costs.

A useful addition to these three core elements is a more general understanding of public administration issues which involves identifying, analysing and reporting the consequences for different parts of the public sector such as central and local government in the research process. More generally, research that is responsive to policy needs should be able to assemble available information, specify straightforward analyses and draw out policy and practice issues.

Good links with clinical researchers are important for assessing clinical outcomes and for making sure that practice implications are made clear. A further basic and practical issue is that such links are also important to ensure access to patient-level data. However, a number of issues need to be borne in mind. There is a danger that locating research at a teaching hospital or a clinical centre often means that much research is conducted on the same patients in the same area (often in an atypical setting). Furthermore some issues (such as primary care) can be potentially under-researched because they are not sufficiently glamorous or located conveniently to clinical researchers in teaching hospitals. There therefore a need to ensure that research follows the patients or funding.

The location of the team could take place in one organisation with an economist joining a largely clinical research team. A more common model is a consortium model where researchers from different organisations collaborate with each other.

There are a number of configurations for this type of research. One possibility would be to have a small group of economics/statistical researchers specialising in economics and mental health which various groups of clinical researchers could seek out for collaboration in the planning and analyses of economics/costs studies. Where the issue was primarily economic in nature the economic team could take the lead or where the intervention was a cost-effectiveness analysis component of a clinical intervention, then the clinical researchers could take the lead role.

8.7 Tendered research (HTA agencies) versus core funded centres

The manner in which research is commissioned is an area that influences the manner in which research is conducted along with the relationship between research and policy. The two main ways in which this is done is through direct financing from the ministry or indirect funding where government funding is channel through a (semi) independent health technology assessment agency (HTA) such as ZON or CVZ.

The obvious advantage of a HTA agency approach is that scientific quality is assured through the competitive, peer-review process. However, using HTA agencies to commission research also has drawbacks. For example, it is usual for HTA agencies to consult widely on priorities and approaches to research programmes. This could result

in a situation where by the time the tender is specified and commissioned the concerns of policy makers are diluted by other clinical or academic issues. Similarly, there is a danger that by the time that the research is reported and independently reviewed the research is no longer relevant to address the original policy question.

In comparison directly funded research tends is less exposed to external peer review and is open to criticism but has advantages that the researchers involved are closer and more responsive to the concerns of policy makers. It may also be possible to provide quality assurance by including elements of the peer review for research proposals and later for reports. A small steering group can also oversee the conduct of the research

8.8 Different models for commissioning research

Type of funding	Advantages	Disadvantages
Direct	Timely Close links between researcher and policy makers	Quality assurance more limited
HTA agency	Quality assurance through commissioning process	Slow? Transaction costs of specifying and reviewing proposals Research distant from policy

Different elements of research may be more amenable to different funding mechanisms with for example small focus-group or panel surveys being funded directly to inform larger field studies which are commissioned through a competitive tendering process by HTA agencies.

9 Summary

In this report information has been collated from a variety of sources to provide an overview of the research themes prevalent in the past decade, the themes currently emerging and the methodological and policy considerations arising. Currently there is a need for further research on the cost-effectivess of mental health care in the Netherlands. However, mental health is a challenging area for research and various considerations must be borne in mind to ensure that the research commissioned is relevant and generalisable.

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