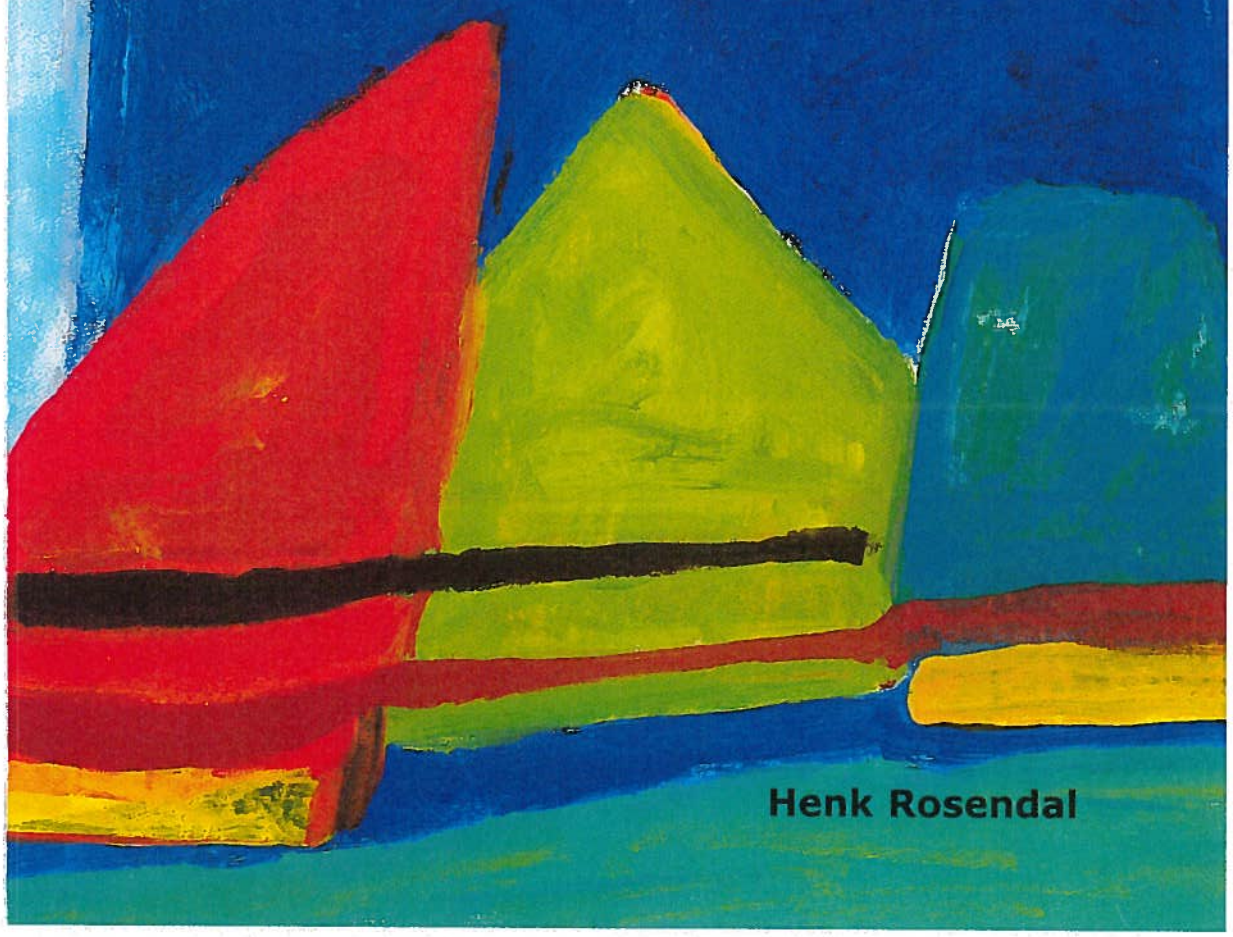
Comparative Cohort Studies in Transmural Care

Three cases of structurally embedded practice in The Netherlands



Henk Rosendal

STELLINGEN

behorend bij het proefschrift

'Comparative cohort studies in transmural care'

van Henk Rosendal

1. Transmurale zorg is niet per definitie beter dan gebruikelijke zorg. *(dit proefschrift)*
2. Observationeel vergelijkende cohortstudies zijn goed bruikbaar voor onderzoek naar de effecten van transmurale zorg in de dagelijkse praktijk. *(dit proefschrift)*
3. Het met de beste bedoelingen bieden van te veel nazorg leidt niet alleen tot afhankelijkheid van patiënten, maar ook tot kostenverhoging in de gezondheidszorg. *(dit proefschrift)*
4. Nu we gezien hebben waar 'het schip strandt', dient het gestrande schip 'een baken in zee' te zijn. *(dit proefschrift)*
5. 'Laat duizend bloemen bloeien' kan bij transmurale zorg slecht uitpakken voor patiënten. *(dit proefschrift)*
6. Transmurale zorg is slechts een eerste stap naar werkelijk geïntegreerde zorg.
7. You can integrate all of the services for some people, some of the services for all of the people, but you can't integrate all of the services for all of the people. (A. Lincoln)
8. Your integration is my fragmentation. (W.N. Leutz)
9. Zodra men de gebaande paden verlaat, liggen tal van wegen open. (W.T. van Beekum)
10. Het belang van evidence based medicine wordt inmiddels door iedereen onderkend, nu nog dat van evidence based policy.
11. De weg naar het succesvol volbrengen van een marathon is wetenschappelijk beter onderbouwd dan die naar het succesvol afronden van een wetenschappelijk proefschrift.

Comparative Cohort Studies in Transmural Care

Three cases of structurally embedded practice in The Netherlands

Henk Rosendal

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Comparative Cohort Studies in Transmural Care

Three cases of structurally embedded practice in The Netherlands

Vergelijkende cohortstudies in transmurale zorg

Drie cases van structureel ingebedde praktijk in Nederland

(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de Universiteit Utrecht op gezag van de Rector Magnificus, Prof. Dr. W.H. Gispen, ingevolge het besluit van het College voor Promoties in het openbaar te verdedigen op dinsdag 24 september 2002 des ochtends om 10.30 uur

door

Hendrik Rosendal

geboren op 11 juni 1961 te Ede

Promotor:	Prof.dr. A.J.P. Schrijvers
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Voor Vera

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Manuscripts on which this thesis is based

Chapter 3:

Rosendal H, Beekum WT van, Linden BA van der, Schrijvers AJP. The effectiveness of transmural care in The Netherlands, a review (in Dutch). Journal of Social Medicine (TSG) 2000:78:426-39.

Chapter 4:

Rosendal H, Vondeling H, Witte LP de, Hutubessy RCW, Heine RJ. Initiating insulin therapy in patients with diabetes mellitus type 2: in a transmural care form of care at least as effective as in an outpatient setting; a retrospective study with a 4 year follow-up. (in Dutch). Dutch Medical Journal (NTvG) 2002; 146(4):166-171.

Chapter 5:

Rosendal H, Nijhof P, Beekum WT van, Witte LP de, Schrijvers AJP. Can shared care deliver better outcomes for patients undergoing total hip replacement? International Journal of Integrated Care - Volume 1, issue 1, November 2000 - ISSN 1568-4156, www.ijic.org.

Chapter 6:

Rosendal H, Wolters CAM, Beusmans GHMI, Witte LP de, Boiten J, Crebolder HFJM. Stroke service in The Netherlands: an exploratory study on effectiveness, patient satisfaction and utilisation of healthcare. International Journal of Integrated Care - Volume 2; March 2002 - ISSN 1568-4156, www.ijic.org.

PREFACE

Introduction

At present, transmural care is popular in The Netherlands[1]. Considering the number of running transmural projects[2,3], this phenomenon has in a way been successful since its introduction in the early 1990s. Transmural care refers to care given 'through the (virtual) walls' of the existing healthcare system and is most often directed toward bridging the gap between different levels of care providers, for example between primary care and secondary care. More formally, transmural care has been defined as: *healthcare, geared to the needs of the patient, provided on the basis of co-operation and co-ordination between general and specialised caregivers, with shared responsibility and specification of delegated responsibilities*[4]. Considering this definition, it is no surprise that transmural care (in The Netherlands) is closely related, or even similar, to the concept of shared care[5] (in the United Kingdom). These concepts will be further elaborated in the next chapter. It is because of this similarity, and for the purpose of readability, that the terms shared care and transmural care are used interchangeable in this thesis.

Transmural care in The Netherlands comprises many different activities in which home-based and hospital-based healthcare providers, traditionally working apart, now join together in order to improve their performance. From this point of view, transmural care should not be considered as a specific medical intervention, but as an alternative way of organising healthcare, in which medical interventions are embedded. The main goals of transmural care are to improve the effectiveness, the quality and the efficiency of healthcare[6].

Although transmural care has become very popular in The Netherlands[3], not much is known about its effects[7]. This is rather surprising, considering the large number of running transmural care projects. In fact, it still is an assumption that transmural care has positive effects on the effectiveness, the quality and the efficiency of healthcare. Because of this lack of evidence, it is from a health policy point of view unclear whether transmural care should be promoted, or rather scaled down. In order to support decision making in a rational way, reliable and objective information about the effects of transmural care in daily practice is needed. The potential effects of transmural care are quite diverse: better patient outcome, higher satisfaction of patients and a more efficient healthcare. One could wonder why reliable studies on any of these effects of transmural care have hardly been performed until now. One possible argument is the absence of a proven, useful research design to answer questions concerning the effects of transmural care in daily practice. How to evaluate an organisational change that has already diffused widely? Which study design is useful in this situation? We have passed the academical stage, in which transmural care

as a concept might have been evaluated in randomised controlled trials. Also, pretest-posttest designs are probably less useful here, since we are not primarily interested in the initial stage of transmural care, but in the effects of structurally embedded transmural practice. For this purpose, other study designs have been suggested as valid and useful designs, such as comparative, non randomised cohort studies[8,9,10].

The central goal of this thesis is to increase the knowledge concerning the effects of transmural care in structurally, embedded practice. The most important effects of transmural care in this thesis concern patient outcome (as an indicator of effectiveness), the judgement of patients about the healthcare they have received (as an indicator of quality of care) and the utilisation of healthcare (as an indicator of efficiency). These three indicators (patient outcome, patient judgement and the utilisation of healthcare services) are considered as central healthcare performance indicators in this thesis. Amongst several others, these indicators have earlier been identified as potentially relevant for transmural care[11]. Concerning patient judgement, it should be noticed that in this thesis this indicator is considered to be a dependent variable, whereas co-ordination of care could be considered as an independent variable.

In 1991 a method was proposed to support the decisionmaking with respect to the coverage of basic healthcare provisions, the so called strainer, or filter of Dunning[12]. This committee proposed four criteria: 1) is this specific treatment necessary? 2) is evidence available with respect to its efficacy? 3) is it efficient (cost-effective)? and 4) can it be paid by patients themselves? The three outcome measures in this thesis can be considered as alternatives on the Dunning filter. From this perspective, the three criteria in this thesis could also be formulated as: 1) is this treatment effective? 2) do patients want it? and 3) is it efficient? The basic differences with Dunnings filter concern our main orientation on effectiveness in stead of efficacy (efficacy refers to the effects of a treatment modality under controlled circumstances, such as in controlled clinical trials, whereas the effectiveness is about its effects in real life situations) and the importance of patients' judgements.

In order to achieve our goal, we performed three different comparative cohort studies to evaluate transmural care in daily practice: one transmural care model for patients with diabetes mellitus, one model for patients undergoing total hip replacement and one model for stroke patients.

The research questions of this thesis are:

Compared to usual care, does transmural care result in:

1. **better patient outcome?**
2. **better patient judgement concerning the healthcare received?**
3. **different utilisation of healthcare services?**

Outline of this thesis

In the first chapter, the concept of transmural care in The Netherlands is elaborated. The second chapter deals with the study design of this thesis, the three specific cases of transmural care and the outcome measures used in this study. Chapter 3 presents the results of a review of Dutch literature on the effectiveness of transmural care. Then follow chapters on the assessments per patient category. Chapter 4 contains the assessment of transmural care for patients with diabetes mellitus type 2 who started with insulin therapy. Chapter 5 deals with transmural care for patients undergoing total hip replacement. Chapter 6 focuses on the long-term effects of this transmural healthcare model for stroke patients. Finally, in Chapter 7, the main results are synthesised and critically appraised.

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CHAPTER 1

Transmural care: concepts and theory

Transmural care

Healthcare always has been subject to change. During the 20th century, many of these changes were related to the development and introduction of new treatment modalities, such as surgical procedures and the application of pharmaceuticals. In recent years, more and more attention has been given to the organisational aspects of healthcare. This increase in attention to organisational aspects also illustrates a shift in the thinking about the management of healthcare: from a facilitator of healthcare providers to an important factor that also might have an effect on the effectiveness, the quality and the efficiency of healthcare. Thus its influence might be similar to the outcomes of prescribing pharmaceuticals, and of surgical procedures. It should be noted, however, that there is a difference between changes in medical interventions and changes in the organisation of healthcare. Drugs and surgical procedures are medical provisions delivered to individual patients. For every patient, the physician has the possibility of choosing between different treatment modalities. So, medical treatment can vary from one patient to another. The organisational setting in which this treatment modality is delivered to the patient is, contrarily, not so easily changed from one case to the other. Healthcare is delivered in an organisational setting, which as a rule can not be greatly changed by one individual provider. This principal difference is also of importance for the assessment of such organisational changes, as will be described in the next chapter. In this chapter first the concept of transmural care is elaborated. This is done with this thesis' purpose in mind, the intention was not to develop a complete taxonomy of the concept of transmural care.

What is transmural care?

As mentioned in the Preface, transmural care is defined in this thesis as: *healthcare, geared to the needs of the patient, provided on the basis of co-operation and co-ordination between general and specialised caregivers, with shared responsibility and specification of delegated responsibilities*[1]. In practice, transmural care exists of many different activities where home-based and hospital-based care providers, traditionally working independently, join their activities in order to improve the effectiveness, the quality and/or the efficiency of healthcare[2,3]. Transmural care was born as a reaction to perceived deficits in the organisation of healthcare: patients as well as care providers felt there was not enough continuity, caused by deficient co-ordination between primary and secondary healthcare. The care process patients were following was interrupted when they moved from one healthcare provider to the other. It was argued that this situation resulted in an ineffective, and inefficient healthcare[4]. Based on this presumption, the concept of transmural care was introduced as an answer to this fragmentation of care. By bridging

the gap between different healthcare providers, the effectiveness, the quality and the efficiency of healthcare could be improved. Although most transmural care projects deal with the co-ordination between primary and secondary care, the concept is not limited to these two types of healthcare providers. Projects have emerged concerning the co-ordination between hospitals and nursing homes, between hospitals and mental healthcare providers, between nursing homes and primary care, and so forth[2,3]. This thesis deals with the most common examples of transmural care, which focus on bridging the gap between primary and secondary care.

Transmural care and related concepts

In connection with transmural care, several terms, or concepts, are used to describe organisational changes in healthcare. In order to give a better idea of these concepts, some of the best known are described. Attention is given to both overlaps and differences with the concept of transmural care.

Transmural care has its own specific origins in the Dutch healthcare system, which traditionally has a distinct division between primary care and secondary, hospital based care on both organisational and financing levels. Notwithstanding this specific origin, there certainly are overlaps with concepts such as 'shared care' (United Kingdom) and 'integrated care' (United States). Transmural care is most similar to the British concept of shared care[5]. Some authors[6] obviously consider these concepts as equivalent, since they translate the Dutch phrase 'transmurale zorg' into English as shared care. In this thesis we also use 'shared care' and 'transmural care' as synonymes.

Although the term integrated care seems to refer to similar objectives as shared care, or transmural care, it is clearly different. Integrated care, which emerged in the United States in the 1990s, deals with the integration of healthcare, social care and related services. A useful definition of the term integrated care, which in fact has many meanings[7,8], is given by Kodner and Kyriacou[9]. They define integrated care as *'a discrete set of techniques and organisational models designed to create connectivity, alignment and collaboration within and between the cure and care sectors at the funding, administrative and/or policy levels'*. It is not surprising that these authors think of integrated care as a variant of managed care. Considering this definition, we conclude in this thesis that the concept of integrated care is more comprehensive than transmural care since transmural care generally does not include the whole care-process of patients. Transmural care on the other hand tends to focus on one or two crucial transition-steps between different types of healthcare providers.

Managed care, with well known examples in the form of health maintenance organisations (HMO), combines both the financing and delivery systems of healthcare. It nowadays is one of the predominant forms of healthcare coverage in the United States. Managed care allows employers and public health programmes to purchase services for their clients at lower costs than traditional insurance. This is done by negotiating aggressively with hospitals and providers groups on rates and use of expensive resources such as inpatient care[10]. In contrast with transmural care, managed care is in many cases a commercial activity initiated by entrepeneurs, very often mainly directed at cost-containment. It is never developed 'bottom-up' by healthcare providers. Managed care is not directed at one patient-group, but aims to cover a complete healthcare package.

Another term that often is mentioned in relation with transmural care, is disease management. Here, as with transmural care, patients are the pivot around which healthcare is organised. Disease management is considered internationally as an optimal approach to the planning and delivery of healthcare[11,12]. Disease management was introduced in the United States in the 1990s as an attempt to improve the quality of healthcare and to reduce the cost of caring for people with chronic diseases[13,14]. Commercial firms who sell their programmes to employers, health maintenance organisations and hospitals, run most of the disease management programmes. The difference with transmural care is that in case of disease management one single, often commercial, organisation conducts the prevention, health screening, diagnosis, treatment, including the supply of drugs, and follow-up of a patient with a particular disease. Although transmural care and disease management are answers to the same problems, disease management is more robust, and is applied on a larger scale[6]. Also, the programmes are run by specialised, one disease oriented staff, who are given intensive training and support, whereas transmural care is mostly realised by non-specialised healthcare providers themselves, often with the assistance of a co-ordinator.

One can conclude from this that the most robust and comprehensive organisational changes (managed care, disease management, integrated care) have emerged in the United States, while other, less rigorous approaches such as shared care and transmural care, have their roots in Europe. This can be understood if one considers that clinical behaviour at the micro-level until now has not been managed so closely in Europe as is the case in the United States.

Categories of transmural care

Transmural care in The Netherlands, which is not aimed at integrating healthcare and social care, but at co-ordinating the activities of various healthcare providers, is especially suitable for patients who need primary and secondary healthcare simultaneously or in a tight sequence. Very often, these are chronically ill patients (for example patients with diabetes mellitus, with a stroke, or with severe arthritis). Innovative, transmural projects for these patients are initiated for various reasons[3]: to improve the effectiveness of healthcare, to improve its quality and/or its efficiency. In practice, this is realised by better synergy between primary and secondary care, by improving hospital-admission and -discharge procedures and by providing tailor-made healthcare.

As a consequence, there is a great variety in transmural care projects. For this thesis, a clear categorisation of transmural care would be useful. Recently, an inventory was made of all running transmural projects in The Netherlands. Based on the questionnaires returned, the authors grouped transmural care into seven categories, illustrating the variety with which the concept is realised in practice[3,15]. These categories are: specialised transmural nurses, guideline development, home care technology, discharge planning, consultation of medical specialists in a primary care setting, rehabilitation wards, and pharmacological transmural care. It should be noted that these seven categories are of a different kind, varying form introducing a new type of professional (transmural nurse) and focussing on the care-process (discharge planning) to the introduction a new type of site (rehabilitation wards). Furthermore, these categories are not mutually exclusive. For example, focussing on discharge planning and introducing home care technology will very often require a specialised transmural nurse, which was identified as a separate category by the authors.

Subsequently, the authors made an inventory of the patient categories involved in transmural care: cancer (12%), COPD (7%), diabetes mellitus (7%), rheumatoid arthritis (4%), stroke (4%), cardio-vascular diseases (4%), orthopedic diseases (3%), at-risk pregnancies (2%), more than 1 patient-group (26%), all patients (13%) and other categories (18%). This inventory illustrates the great variety in existing transmural care projects.

Another, more theoretical approach is to consider transmural care in terms of its goals and the instruments used to realise these goals. As a rule, transmural care starts bottom-up: healthcare providers trying to find a way out of the problems experienced in daily practice. The starting point for transmural care is often when several different healthcare providers, traditionally working independently, acknowledge these problems and decide to join together in order to improve the effectiveness, the quality and/or the efficiency of

healthcare. These three goals can be considered as the ultimate goals of transmural care[1]. To achieve these goals, several different organisational measures can be taken. Examples of such measures are: improving the exchange of information, co-ordination of activities of primary and secondary healthcare providers, substitution of secondary healthcare with primary health care, and the integration of the complete care-process. Such organisational changes can be considered as intermediate goals, since they are implemented to realise one or more of the ultimate goals of transmural care.
Taking this one step further, one may argue that these changes represent a step-scale. Improving the exchange of information is a relatively 'light' instrument, but also a condition for co-ordination. Co-ordination of activities in its turn, is crucial for realising substitution of healthcare, for example in case of the substitution of outpatient care with primary healthcare. And substitution of healthcare is one of the elements of full integration of care. Integration of care is broader and has the deepest impact, since it implies the creation of new programmes pooling the resources from multiple systems[16]. From this perspective, fully integrated care could be considered as an ultimate form of transmural care. In practice, these organisational changes are often supported by guidelines and protocols.

Compared to unco-ordinated, usual care, transmural care is not very different with respect to its goals and its medical interventions. The main difference is visualised in the use of co-ordinating measures, such as the ones described above. Elsewhere several co-ordinating mechanisms were identified[17] as possible answers to the fragmentation of healthcare: central front-office for healthcare providers, central referral authority, case management, protocols, integrated patient files, healthcare circuits and tailor-made healthcare. These mechanisms can also be considered as organisational measures that can be taken to realise one, or more goals of transmural care.

Besides these co-ordinating mechanisms, there is another important dimension of transmural care, which is the complexity of the organisational change. A useful indication for this complexity could be the number of actors involved. Implementing a change between only two different healthcare providers, for example between some general practitioners and the outpatient clinic of a hospital differs fundamentally from implementing an initiative that involves all regional healthcare providers. The complexity of the evaluation of such programmes will vary accordingly.

In this way, transmural care projects can be categorised in two different dimensions: organisational measures ('intermediate goals') and complexity. Based on this distinction,

and on the incidence and prevalence rates of the disease categories involved, three transmural care models were chosen for the evaluation reported in this thesis.

Phases of transmural care

With respect to the purpose of this thesis, the different phases of transmural care need some considerations.

Elsewhere, a distinction in the innovation process was made between the development phase and the implementation phase[18]. In theory, the first phase concerns the discovery of a new idea, which later is operationalised into concrete innovations, tested and incorporated in a local setting. The (widespread) implementation phase starts with the introduction of a proven effective innovation, the adaptation, further testing and ends when it is structurally incorporated in a definite organisational configuration. The innovation of transmural care did not follow this theoretical pattern at all, since it has diffused widely, virtually without any kind of formal testing. Because of this, transmural care is evaluated in structurally, embedded practice in this thesis.

Finally some remarks concerning the implementation of transmural care, which differs considerably from the introduction of, for example, a new drug. Transmural care is a complex phenomenon and the difficulties in implementing it have been summarised elsewhere[19]:

- First, primary and secondary healthcare programmes have been separated since the 1970s in The Netherlands. Treatment modalities, the organisation of healthcare, cultures and goals were quite diverse in the different levels of healthcare. In fact: the various, different healthcare providers were hardly informed about each others' methods and approaches.
- Second, healthcare providers are not trained to co-operate with other disciplines.
- Furthermore, in many cases the implementation of transmural care implies a heavier workload for primary, as well as secondary healthcare because of substitution-effects. As a result, the higher turnover of patients that can be realised in hospitals, implies an increase of the mean burden of healthcare. So, transmural care puts pressure on healthcare capacity. It should be kept in mind that the realisation of transmural care often has serious consequences for general practitioners[20]. Without extra capacity to meet this growing workload, it was expected that general practitioners would face their limits soon. It is not surprising that general practitioners are not over-enthusiastic about involvement in transmural care projects.

- Finally, the financing system of Dutch healthcare does not encourage transmural initiatives: hospitals, general practitioners and home care organisations are paid in different ways. Their budgets are determined based on the estimated yearly productivity. In the short term, a raise in the workload will not result in a similar rise in the budget. This is of importance, since in case of substitution effects of transmural care, for example patients leaving hospital earlier, primary healthcare providers are confronted with a heavier workload, without getting extra money. On the other hand, hospitals lose relatively healthy patients and get more seriously ill patients in return (higher turnover), also without getting extra budget. Because of this, most transmural projects are financed based on temporary project-budgets since the regular method of financing healthcare does not encourage such initiatives. As a consequence transmural projects seldomly survive long after the experimental project status has ended.

Despite these difficulties in implementation, many transmural care projects have started in The Netherlands[3], illustrating the general belief in its positive effects. This thesis explores the extent to which this belief is justified.

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CHAPTER 2

Research methodology for evaluation of embedded transmural care

Introduction

This chapter deals with the methodology we used to evaluate transmural care. After a brief discussion concerning some central issues in the assessment of healthcare in general, a description of health technology assessment is given. Then follow the study population of this assessment, the chosen design, the outcome measures and the statistical methods used in the projects this thesis was based upon.

Central issues in healthcare

Mainly because of concerns regarding the continuously rising costs of healthcare together with the pursuit of quality improvement, the efficiency of healthcare-delivery has received much attention in the last decades. Efficient healthcare can be defined as healthcare with a proven effectiveness that is delivered at reasonable costs. In other words: efficient healthcare implies value for money. Both cost containment and quality improvement underline the necessity of efficient healthcare. In practice, however, these goals can be in conflict since many medical innovations which have been developed to improve the effectiveness of healthcare resulted in higher costs, at least in the short term. The issue then is whether higher costs are balanced by higher (future) effectiveness.

Answers to the question whether or not to adopt an emerging technology, are summarised in the simple table below. This is an adapted version of a figure by Sculpher and Buxton[1], concerning the decision whether to encourage diffusion of an innovation. In case of this thesis, the word 'technology' can also be read as 'transmural care'.

Table 2.1: When to encourage diffusion of a new technology

Compared to alternative	Lower costs	Higher costs
lower effectiveness	?	do not adopt
higher effectiveness	adopt	?

Whenever higher, or equal effectiveness can be realised at lower costs, it will be clear that adoption and diffusion of a technology should be strongly promoted. On the other hand, in case a technology results in lower, or equal effectiveness at higher costs, its spread should be prevented by all means. It is obvious that most discussion is needed in case of 'contrasting' effects: the question-marks in the table. How much are we willing to pay extra for a certain gain in effectiveness? Moreover, perhaps more theoretically, how much money saved justifies a certain reduction of effectiveness? There are no easy answers to these questions, which in reality are even far more difficult since effectiveness and efficiency, although crucial, are only two criteria. Including, for example, patient judgement as another criterion will complicate this decision-making: should the adoption

and diffusion be promoted in case an innovation is proven (cost-) effective, but rejected by patients?

One of the complicating factors here is the difference in origin of these concepts: quality improvement and the search for higher effectiveness have always been more or less central issues in the field of medicine. Cost containment on the other hand, at least in the last decades, has been mainly a concern of policymakers. Although the relationship between these two actors has improved in the last decades, the basic differences in language, interests and goals still exist. Despite these differences, most actors involved agree in general on the crucial role of proper assessment of emerging as well as mature treatment modalities in order to gain information about the effectiveness, the quality and the efficiency of healthcare to support rational decision-making. Considering the several national and international assessment programs, one could conclude that there is consensus about the importance of assessment to support decision-making about employment of new treatment modalities. This particularly holds truth in case of new pharmaceuticals and in case of new, expensive treatment modalities. Contrary to these now well established subjects of assessment, evaluation of the effects of changes in the organisation of healthcare up to now has had no priority in assessment programmes. This is remarkable, since these changes are in most cases not only implemented to improve the effectiveness of healthcare, but are also meant to have an impact on the quality of care and to reduce its costs. Despite this, little is known about the effects of organisational changes such as managed care and disease management[2,3,4,5]. Also concerning transmural care, little evidence is available about its effectiveness and its efficiency[6] as we will discuss in Chapter 3.

It should be borne in mind that also in case of transmural care, the issue whether or not to promote this innovation is more complex than 'only' weighing effectiveness against costs. As mentioned in the Preface, a number of health performance indicators have been identified as potentially relevant for transmural care[7]. Besides patient outcome (as an indicator of effectiveness), patient judgements about the healthcare they have received (as an indicator of quality of care) and utilisation of healthcare (as an indicator of efficiency), other indicators were identified which decision-makers should take into consideration also. Examples mentioned are the waiting times during treatment, the availability of information on care given by other providers (as indicators for continuity of care), and waiting times for access to healthcare, and for after care (as indicators for availability). This thesis is concentrated on three indicators because of the financial limitations of this study.

Balanced, and evidence-based decision making with respect to promoting or scaling down transmural care, requires valid information about these performance indicators. Such information is generated by health technology assessment, which is the object of the next paragraph.

Health technology assessment and study designs

Health technology assessment (HTA) has a broad meaning. First of all, it must be emphasised that the term 'technology' in HTA does not refer to a machine, or high-tech equipment only, but to *the drugs, devices, and medical and surgical procedures used in medical care, and the organisational and support systems within which such care is delivered*[8]. HTA can be defined as *the systematic process by which the direct and indirect consequences of a particular technology are assessed; it is concerned with evaluating the safety, effectiveness, and cost-effectiveness and (where appropriate) the social, ethical and legal impact of a technology*[9].

So, HTA is about the assessment of many different aspects of healthcare, which implies that researchers in HTA represent a great variety of disciplines. In practice, however, in most assessments the effectiveness and/or costs of a health technology play dominant roles. To some extent this is understandable, as HTA was initiated in order to support policymakers and healthcare providers in deciding whether or not to employ a new technology. And, as mentioned above, these two types of actors have been mainly interested in cost-containment and in the effectiveness of healthcare, respectively. It is not surprising that the methodologies of assessing these two aspects have developed rapidly in the last decades, a development that was described more elaborately elsewhere[10]. Concerning the effectiveness of healthcare a distinction can be made between the effectiveness under fully controlled circumstances, the so-called 'efficacy', and the effectiveness in daily practice. Ideally, after having established the efficacy of a drug, or a medical procedure in a controlled situation, its effectiveness in daily practice should be assessed subsequently. This study is an example of the latter type: evaluating the effects in daily practice.

In general, there is no one single, always-best design for a health technology assessment[11]. Each research question has its own optimal design, which depends on the available budget, and the ethical, legal and organisational limitations. In order to generate the best information about the efficacy of a medical intervention, such as a new drug or surgical procedure, it is recommended to control for all possible confounders in the assessment. In such cases, the organisation of healthcare in which the delivery of the treatment modalities is embedded can be considered as a potential confounder. To control

for this, the organisation is kept constant. To control for other confounders, patients usually are randomly divided between those receiving the new treatment modality and those receiving an alternative. Furthermore, patients in both groups should be as similar as possible, which implies a well-defined, and limited study population with no, or exactly the same kind of co-morbidity. And ideally, during the treatment process, neither patients nor healthcare providers nor researchers should know which patients receive which treatment modality. The design for this type of studies is known as the randomised controlled trial (RCT) and has become the golden standard for the assessment of the efficacy of a medical intervention[12].

In case of evaluating the effectiveness in daily practice, RCT's are often less suitable. Here, circumstances are not fully controlled, patient mixes differ all the time, and variety in co-morbidity is no exception but the rule. Furthermore, the effects detected under fully controlled circumstances may very well disappear in daily practice. In these situations, and not only because of organisational or ethical reasons, other study designs such as observational cohort studies should be considered[13]. Or, as elswhere[14] asserted: *less rigorous impact assessment designs of high generalisability are more relevant for policy purposes than very rigorous designs with low generalisability*. Despite this, it should be borne in mind that different types of study designs produce different quality of evidence. Based on elsewhere formulated rules of evidence[15], a categorisation by declining robustness can be made:

- Meta-analysis;
- Randomised controlled trial (RCT);
- Non-randomised (observational) comparative cohort study;
- Non-randomised historical cohort study;
- Case series.

Meta-analysis includes the pooling of the results of several RCT's. As mentioned earlier, RCT's are, all other things being equal, best able to attribute effects to causes[16]. The main problem with observational cohort studies is that their internal validity may be undermined by previously unrecognised confounding factors that may not be evenly distributed between the intervention groups[13]. On the other hand, this type of study design offers the opportunity to establish a high external validity, something that is difficult to achieve in RCT's[13].

Study population in this thesis

The research question of this thesis concerns the extent to which transmural care compared to usual care results in better patient outcome, in better patient judgement with

respect to the healthcare received and in a different utilisation of healthcare services. In order to generate empirical evidence for answering these research questions, a first important choice had to be made: should we limit ourselves to only one cohort study of transmural care, or should we try to perform several different assessments? In case of performing only one study, this could probably be done more thoroughly within the (budgettary) limitations. A disadvantage of such a choice would be the limited possibilities for generalising the results afterwards, especially because of the great variety in transmural care (see Chapter 1). On the other hand, including a high number of cohort studies, in order to enlarge the external validity, would surely endanger the internal validity of the assessments, since time and money were limited. After careful consideration, it was decided to perform three different comparative cohort studies. This would enable us to carry out several proper assessments, at the same time offering better possibilities for generalising our results afterwards. Three transmural care projects were selected: one for patients with diabetes mellitus type 2, one for patients undergoing total hip replacement and one for stroke patients. For each category a reference group was included in order to compare results. We tried to select reference groups that were similar to the transmural care group, with the exception of transmural activities.

These three examples of transmural care were chosen for different reasons.

- First, all three the examples chosen concern patient categories belonging to the group of chronic diseases with relatively high incidence and prevalence rates. The estimated number of persons with diabetes mellitus in The Netherlands is about 500.000, representing 3% of the population[17,18,19]. Of these patients, 80-90% have diabetes mellitus type 2. Concerning total hip replacement, yearly about 14.000 people undergo this surgical procedure, which is almost 1‰ of the Dutch population. And the yearly incidence of stroke in The Netherlands is estimated between 1.7 (man) and 2.0 (women) / 1.000 inhabitants, its prevalence between 5.6 (man) and 5.4 (women) / 1.000 inhabitants[20]. Because of these rates, potentially many people could profit from the results after our study.
- Second, the projects in our study should concern patient categories that are not unique in transmural care. As mentioned in Chapter 1, 7% of the transmural care projects in The Netherlands concerns patients with diabetes mellitus, 4% concerns stroke patients and 3% concerns orthopaedic patients.
- Third, the projects to be included in this study should represent different examples of transmural care. In terms of the classification in Chapter 1, we tried to include projects of different complexity, and with different organisational measures. In table 2.2 the three selected transmural projects are categorised.

Table 2.2: A categorisation of the three transmural care projects by complexity and organisational measures.

	Information exchange	**Co-ordination**	**Substitution of care**	**Integration of care**
two different healthcare providers		total hip replacement	diabetes mellitus	
multiple healthcare providers			stroke	

At the time our study started, we could not find any projects that represented fully integrated care. Concerning the classification of the project on diabetes mellitus, it could be argued that more than two different healthcare providers were involved. However, since the main organisational change concerns (only) two types of healthcare providers: general practitioners and the outpatient clinic, we classified this model as shown in the table above. The characteristics of this specific transmural care model are further elaborated in Chapter 4.

Study design in this thesis

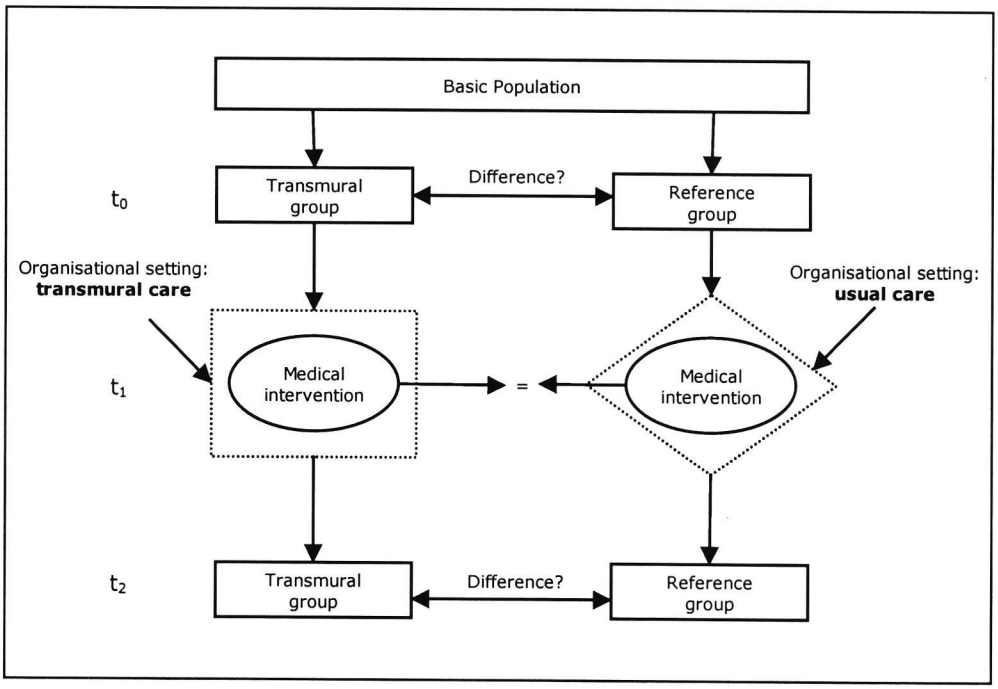
In this thesis three separate observational comparative cohort studies were carried out. This type of study design was the most suitable for our purpose because of several reasons.

- First, transmural care has already diffused in healthcare practice. In fact, we have passed the phase that transmural care might have been evaluated as a concept (for example in a randomised trial), before dissemination. The purpose of our study is to evaluate transmural care in structurally embedded practice.
- Second, as described earlier, transmural care is a complex, comprehensive and multi-component organisational change in the delivery of healthcare. A change which involves various actors, and which has an impact on the total institution, or site in which healthcare is delivered. This makes the evaluation of transmural care different from that of new drugs, or surgical procedures: the latter interventions are delivered within an organisational setting that is (should be!) similar for both the experimental and the control group. In case of transmural care, it is the other way around, since the medical intervention, for example total hip replacement or initiating of insulin therapy, is (should be!) similar in both groups. Here, differences in the organisational setting in which the delivery of these medical interventions is embedded, are the subject of evaluation. It is not only because of the phase of development of transmural care, but also because of its characteristics that we evaluated transmural care in running, daily practice.

- Third, we considered carrying out a survey amongst healthcare providers and patients. However, since this approach would not provide us with information about changes in time, we preferred another study-design.
- Fourth, randomisation of patients to either one of the settings was considered. However, this was hardly possible because a transmural care model and a usual care model are mutually exclusive, they can not be located in the same site, with the same healthcare providers. Therefore, evaluating the effects of transmural care inevitably implies the comparison of at least two geographically different settings: a transmural care setting and a reference setting (unco-ordinated, usual care).

Considering this, conducting observational, comparative cohort studies seemed optimal for answering the present research questions. In this way we could conduct three separate assessments in daily practice on three different patient-categories, in which transmural care was compared to usual care. This study design is illustrated in Figure 2.1.

Figure 2.1: The design of the evaluation of transmural care in this thesis.



As described earlier, observational cohort studies are useful, but not without problems. The principal shortcoming of this type of design is that its internal validity may be undermined by unrecognised confounding factors that may not be evenly distributed between the intervention groups. Although it is currently unclear how serious and how insurmountable a methodological problem this is in practice[12], extra attention to this is paid in our analyses.

Data collection and analysis

In all three case studies, patient files served as the main source for socio-demographic patient characteristics, clinical data and information about the proceedings of the treatment-process. All other data were collected by way of face to face interviews (stroke, diabetes mellitus) or by using questionnaires which were sent by mail (total hip replacement).

We used standard methods[21] to determine sample sizes. With an α value of 0.05 and power of 0.80, the total sample size (number of subjects in both groups) for studies with expected medium (γ = 0.50) and large (γ = 0.80) effects would be 126, and 50, respectively. The estimated effect size γ is calculated as $\gamma = (\mu 1 - \mu 2) / \sigma$.

Baseline clinical and socio-demographic characteristics and outcome measures were analysed using chi-square or Fisher Exact test and unpaired T- or Mann-Whitney tests when appropriate. A p-value equal to or less than 0.05 was considered statistically significant. The test-hypothesis for all the analyses performed was that there would be no difference between the two settings. Further details on applied statistical methods are given in the following chapters.

Outcome measures

The most important effects of transmural care in this thesis concern patient outcome (as an indicator of effectiveness), patient judgements about the healthcare they have received (as an indicator of quality of care) and utilisation of healthcare (as an indicator of efficiency).

In order to establish patient outcome, we measured both generic and disease specific health status. For this, we used various validated instruments. Costs are approached by an inventory of the volume of healthcare services that was brought into action in the various healthcare settings. With respect to the judgement of patients, however, no validated instrument was available at the time we started our study. Therefore, we developed a questionnaire with several items concerning patient judgements with respect to several aspects of the healthcare they received. Some special attention to this particular

instrument is given in the next section, since this specially developed instrument is a common issue in the three case studies in this thesis.
Together with the statistical methods, the design and methods are, per patient category, further elaborated and discussed in the Chapters 4, 5 and 6.

Patient judgement

Measuring patient satisfaction is of importance, since patients are pivotal in healthcare. When changing the organisation of healthcare, it seems logical to assess whether or not this will affect their opinion. This, however, is easier said than done. For example, there is no clear definition of the concept of patient satisfaction[22], and about the way it should be measured. As others[23] have put it: "*Studies of customer satisfaction are perhaps best characterized by their lack of definitional and methodological standardization*". Besides that, the relationship between satisfaction gradings and the healthcare received is not clear[24].
Despite these (methodological) difficulties it is important to measure patient satisfaction, since patients should have the best overview of the complete care-process and healthcare providers could benefit from their experiences[25]. The importance of patient satisfaction is acknowledged internationally[26,27]. Patient satisfaction can be considered as an indicator for the quality of care. This time not from a healthcare provider's point of view, but from the perspective of patients.
In order to measure patient satisfaction, we first screened the existing literature using Medline and Dutch databases (VWS, SWIDOC) on the keywords 'patient' in combination with 'satisfaction'. This resulted in many published studies in which patient satisfaction was one of the outcome measures. However, amongst them we found no articles in which the methodology of measuring satisfaction was elaborated. In most cases, patient satisfaction was measured with a few global questions such as: "*Are you satisfied with the healthcare you have received?*", and so forth. Also, we found no manuscripts of studies in which differences in patient satisfaction between two different organisational models was measured.
In several studies, important factors related to the outcomes of patient satisfaction were identified. Not as a result of specific research, but afterwards ('data-driven'), in the period of analysing the outcomes of patient satisfaction. These factors included age[28,29,30], education[31], expectations[32], and health status[33]. Futhermore, some methodological choices appear to have an impact on the final outcome: face to face interviews result in higher outcomes compared to written questionnaires sent by mail[34], similar to questions that are positively formulated[35].

Based on these findings we concluded a) that the concept of patient satisfaction is still unclear, and b) that there was no validated instrument available to measure it. With respect to this outcome measure of transmural care we decided to focus specifically on the judgement of patients about the healthcare they have received.

In order to do so, we developed a questionnaire which contained items concerning:

- the information that was provided to patients;
- the way healthcare was organised;
- the extent to which patients are satisfied with several specific aspects of healthcare and
- the extent to which they judge improvements desirable.

We developed three different questionnaires, one for each patient-category in this study. This is elaborated further in the Chapters 4, 5 and 6.

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CHAPTER 3

The effects of transmural care – a review

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Abstract

Objective: To gain more insight in the available knowledge concerning the effectiveness of transmural care in The Netherlands.

Design: A review of Dutch literature.

Methods: The annual volumes of all important Dutch journals were scanned on the keywords 'transmural' and 'transmural care'. Also, the databases of Dutch Medical Dissertations and of the Dutch Institute for Scientific Information Services were scanned on recent dissertations that could possibly provide information on the effectiveness of transmural care. Finally, the enclosed material in a recently held inventory of transmural projects was reviewed. Subsequently, all material was assessed on the quality of evidence.

Results: In total, 17 publications on the effectiveness of transmural care were found. Strongest evidence was found in case of the integrated treatment of risk-pregnancy at home, transmural care for end-stage cancer patients, intravenous antimicrobial treatment at home and structured care for patients with diabetes mellitus type 2.

Conclusions: There is little evidence regarding the effectiveness of transmural care in The Netherlands. Taking the great number of running projects into account, this finding is striking.

Introduction

Transmural care is a relatively new phenomenon in Dutch healthcare. Transmural care was introduced in 1994 by the Committee for Modernisation of Healthcare[1]. Transmural care has diffused rapidly since then. A recently held inventory by the Dutch Institute for Health Care Research (NIVEL) showed that between 1990 and 1996 in total 353 transmural projects had been initiated in The Netherlands[2]. Most of these projects concerned somatic healthcare, involving both primary and secondary healthcare providers. The authors assumed not every transmural project was registered in the databases used in the inventory and the actual number of projects is even higher.

The concept of transmural care is rather ambiguous. The most commonly accepted definition[3] describes transmural care as tailor-made healthcare, delivered on the basis of agreements about co-operation, attunement and direction between general (primary) and specialist (secondary) healthcare providers, with shared and explicit responsibilities. The main goals of transmural care are to improve effectiveness, efficiency and continuity of care[3].

Despite the many transmural care projects in The Netherlands, little or no information regarding the effectiveness and quality of transmural care appears readily available. This information can be obtained in two ways: by critical literature review, or by empirical study. The latter is very costly, and should only be performed in case the existing literature provides little valid information.

The NIVEL-inventory[2] showed that almost 25% of the 353 identified transmural projects were assessed. The reported, mainly positive, effects were improvement of co-operation between different healthcare providers, substitution of secondary for primary healthcare and cost containment. However, as the quality of these assessments appeared to be rather poor, little can be concluded about the effects of transmural care. Effectiveness, which can be considered as the basic criterion for healthcare, appeared not to be an essential subject in these assessments. In order to gain more insight in this important aspect, a review was performed.

It was decided to limit the scope of the review to the Dutch literature on the assessment of transmural care for several reasons:

- Implementation of transmural care is closely related to the way healthcare is organised in The Netherlands.
- A large number of experimental, transmural projects were initiated in The Netherlands in the last decade.

- Considering the importance of determining the effectiveness of transmural care for its implementation it seems likely, that if effectiveness was assessed in any of the evaluations, the results would be reported in Dutch literature.
- A quick literature scan of English literature on the keyword 'transmural care' resulted in no valuable references.
- A search on related concepts, such as 'shared care' and 'integrated care' resulted in an enormous amount of literature, but it is unclear to what extent foreign results can be extrapolated to the typical Dutch situation.

Methods

The literature search was performed in three stages:

1. A search on keywords in automated journals' annuals and other databases;
2. The scanning of recent dissertations on relevant information;
3. Analysis of the material enclosed by respondents in a recent inventory of Dutch transmural projects.

1) Journals and databases

Journals and databases included in the search were the Index of the Dutch Journal of Medicine (INTVG), the Informed General Practitioner (GH), the Dutch Medical Dissertations (DMD), the Dutch Research Database (NOD) and Grey Literature in The Netherlands (GLIN).

Since the first search on the keywords 'transmural' and 'transmural care' provided unsatisfactory results, it was decided to expand our search with other, related keywords. The GLIN as well as the INTVG were scanned for a second time, now on the keywords 'homecare' and 'home based hospital care', as they appeared several times in the first literature scan. In addition, we asked the editorial board of the journal Medical Contact (Medisch Contact) for all articles that were published from 1994 up to 2000 with the keyword 'transmural care'. We also scanned the Journal of Social Health Care (TSG) and the Journal of Nursing (TVZ) from the period 1994 to 2000.

2) Recent dissertations

The titles of recent articles in the DMD and the database of the Dutch Institute for Scientific Information-services (NIWI) were scanned on words related to transmural care and its effectiveness. In case the relevant material was published both in a dissertation and a peer-reviewed journal, the latter prevailed over the first.

3) Reports

Recently, an inventory was carried out concerning the number and type of transmural initiatives in The Netherlands[4]. Respondents were asked whether their activities were evaluated and, if so, if they could enclose the results, or published reports. Subsequently, this material was scanned on relevant information.

This review was performed in July, August and September 1999. Two researchers were appointed to independently determine which of the received material to include in our review. The only selection criterion employed was the impression that these articles and reports may contain empirical evidence on the effectiveness of transmural care. In case of disagreement between the two researchers, the material was included to avoid the exclusion of important information. Specific attention was paid to the effect measures used and on the quality of evidence, which were both subdivided in categories.

The categories of effect measures:

- cost-effectiveness;
- effectiveness (gain of health status, or quality of life);
- costs;
- patient satisfaction and
- satisfaction of care providers.

The quality of evidence was categorised by declining robustness based on the rules of evidence by Cook et al.[5]:

- meta-analysis;
- randomised controlled trial (RCT);
- non-randomised comparative cohort study;
- non-randomised historical cohort study;
- case series.

Results

1. Journals and databases

Scanning on the keywords 'transmural' and 'transmural care' resulted in 17 hits. However, 14 of these appeared not to contain any empirical data on the effectiveness of transmural care. The other three hits[6,7,8] were included in this review and were subsequently assessed (see table 1). The second search, in GLIN and INTVG on the keywords 'homecare' and 'home based hospital care', resulted in 77 hits. A critical review of the abstracts and

descriptions of these articles and reports reduced the number of valuable references to two. These two articles concerned the intravenous treatment of airway-infections of patients with cystic fibrosis at home[9,10]. Both articles were included in this review.
The editorial board of Medical Contact listed 36 articles published in her journal relating to transmural care. However, none of these contained empirical data on the effectiveness of transmural care. The scanning of the annuals of TSG did not result in any hit either. In the TVZ a summary was published of the results of an empirical study. The original study[15] is included (see section 3: Reports).

2. Dissertations

Our search of dissertations resulted in 21 hits of which 17 did not concern transmural care. The remaining 4 dealt with costs and effects of home based hospital care for patients with cancer and AIDS[11], the effects of transmural care for patients with type 2 diabetes mellitus[12], integrated home care in case of high-risk pregnancy[13] and the assessment of intravenous therapy at home[14]. All 4 dissertations were included in this review.

3. Reports

A recent inventory on transmural care in The Netherlands resulted in a description of 271 initiatives. As not all Dutch hospitals participated in the study, the actual number of transmural projects in The Netherlands is estimated to be higher: about 500[4]. Only 18 of 271 respondents included assessments, of which 7 contained empirical evidence, and were included for further assessment[15,16,17,18,19,20,21]. The results of the assessment are summarised in table 3.1.

Table 3.1: Effectiveness of transmural care: evidence per application.

Aspect→ Quality of evidence↓	Cost-effectiveness	Effectiveness	Costs	Patient satisfaction	Satisfaction healthcare providers
meta analysis	-	-	-	-	-
randomised controlled trial	- home care for high risk-pregnancy[13]	-	-	- home care for high risk-pregnancy[13]	-
non-randomised comparative cohort study	-	- patients with end-stage cancer[6] - intravenous infusion of antibiotics at home[20]	- patients with end-stage cancer[6] - intravenous infusion of antibiotics at home[20]	-	-
non-randomised historical cohort study	-	-	- diabetes mellitus type 2[12]	-	-
case series	-	- intrathecal treatment of pain[7] - diabetes mellitus type 2[12] - patients with end-stage cancer/AIDS[11] - intravenous infusion at home[14] - intravenous treatment of cystis fibrosis at home[9,10] - diabetes mellitus[18]	- intravenous treatment of cystic fibrosis at home[9] - ultrasound in primary care[19] - patients with end-stage cancer/AIDS[11]	- patients with cancer[8] - intravenous infusion at home[14] - liaison-nurse[15] - transmural nursing consultant[16] - patients with RA[17] - diabetes mellitus[18] - ultrasound in primary care[19] - patients with breastcancer[21]	- patients with cancer[8] - liaison-nurse[15] - transmural nursing consultant[16]

Altogether 17 publications on empirical studies on the effectiveness of transmural care were found, comprising a variety of patient categories. The results of these studies are listed below, ranging from strong to weak(er) evidence:

- integrated treatment of risk-pregnancy at home is cost-effective compared to hospital care, and results in higher patient satisfaction[13];
- transmural care for end-stage cancer patients results in shorter length of hospital stay, and higher quality of life of patients[6];
- intravenous anti-microbial treatment at home is feasible, cheaper and is positively assessed by patients[20];
- structured care for patients with type 2 diabetes mellitus starting with insulin therapy is not more expensive than outpatient care[12].

All other studies included in our review were designed without any control group, often consisting of a post-measurement only. Obviously, the evidence of those studies is very weak.

Conclusion

Our conclusion is that at the time of this study relatively little has been published in The Netherlands with respect to the effectiveness of transmural care. Considering the large number of transmural initiatives this observation is striking. The few studies published are in favour of transmural care. However, the evidence is not very strong due to the small number of studies published and the poor quality of the study designs. The latter is illustrated by several studies to assess patient satisfaction after the intervention (which is the implementation of a transmural care model). Considering that patients always rate their satisfaction with healthcare as relatively high[22,23] and that the studies were carried out without adequate control groups, these results are not inconclusive.

Discussion

The observation that little robust information on the effectiveness of transmural care is available is remarkable. An explanation for this observation could be the employed search strategy. This would imply that, despite the availability of evidence, methodological errors prevented their detection because of:

- Inadequate (or incomplete) choice of sources and databases. Sufficient evidence is published, but not in the included journals and databases. We consider this unlikely as all essential Dutch journals and databases on healthcare were included in our search;
- Inadequate keywords. One could argue that the keywords were not the best for our purpose. To correct for this, we scanned the GLIN and the INTVG on two other keywords: 'home care' and 'home based hospital care'. Although inclusion of these additional keywords did not uncover more literature, it can not be ruled out that searching on other keywords could possibly lead to more hits;
- Publication-bias. More studies may have been carried out, but their results did not correspond to the interests of researchers, or of any of the established journals, and consequently were not published in any of these. We therefore scanned the 'grey literature' as well. Since we found no indication for other empirical studies, we consider this is improbable.

Another explanation is that only a few, reliable studies on the effectiveness of transmural care have been performed. The observations of other authors[2] support this.

Possible arguments for this explanation of this are:

- Transmural care is such a recent phenomenon that proper studies have been initiated but are still in progress and, therefore, not yet published;
- As most transmural projects start bottom up[4], assessment has seldom priority;
- Transmural projects are usually implemented step-by-step, and not from one day to another. This long process complicates detection of changes arising from transmural care and adequate pre-tests are difficult to realise;
- Because of the perceived methodological difficulties only few assessments of transmural care have been initiated;
- Initiating transmural care is mainly an organisational matter, and is therefore not seen as an intervention effecting patient outcome. From that point of view, assessment is redundant.

We consider these, and in particular the last two, arguments critical in explaining the small number of publications. A quote in one of the reports[24] studied supports this: '*In this study we do not deal with the assumption that a better organised healthcare results in higher quality of life of chronically ill. We assume that this is the case'*. The contemplated Transmural Care programme of ZorgOnderzoek Nederland (ZON), the governmental intermediate organisation for health service research and development, may change this. Because we think that the methodological difficulties are an important obstacle to the assessment of transmural care, this aspect will be discussed in more detail below.

In health technology assessment the standard procedure for assessment is the randomised controlled trial (RCT). This study design enables measurement of the effects of an intervention without confounding. However, there are also some drawbacks related to this approach: besides the relatively high costs it is often impossible to realise a RCT because of ethical, or practical reasons[25]. RCT's are less suitable for the assessment of complex, multi-component interventions such as transmural care[26]. Observational cohort studies, in which two (or more) different interventions (i.e. healthcare models) are compared with each other, can be considered a valid and feasible alternative for RCT's. This approach, however, implicitly introduces confounding, which can be corrected for only to some extent. A disadvantage of this approach, shared with the RCT approach, is the relatively high costs. When neither one of these options is feasible, pre-post-test designs without external control group are used in practice, but these studies are more indicative than conclusive. Because of the complexity of the RCT approach the best, and most feasible, option for assessment of transmural care is probably the observational cohort type of design.

The assessment of transmural care is in our opinion more complex relative to conventional assessments, for example of the efficacy of a new drug. These assessments are conducted in a fully controlled situation. The intervention, the drug, is the only thing that differs between two or more groups. In case of transmural care, it is simply impossible to conduct such a comparison of two different types of care, transmural and usual care. The reason for this is obvious: the intervention (implementation of transmural care) exists of several components, covering the total treatment- and careprocess of patients. It affects the complete organisation, which can not be divided in two halves, relating to transmural care and usual care respectively, for comparison reasons only.

Another important and difficult issue is the determination of effects. Transmural care is not an unambiguous entity, but a collection of many diverse initiatives, with different goals and designs. This implies that factors that are important for one specific transmural initiative might be unimportant for another. Furthermore, our survey indicates that there is no consensus about the way effects of transmural care should be measured. An exception to this observation is the assessment of clinical effectiveness, using the same measures as those used in clinical trials, for example the HbA1c-percentage of patients with diabetes mellitus. All other effect measures reported, however, differ between the reported assessments. Cost-assessments are illustrative, in which the effect measures applied are so diverse that a mutual comparison is difficult. The reports on patient- and care provider satisfaction show even greater discrepancy: in most cases this is measured by a few, separately developed, questions only.

The large amount of energy and other resources necessary to implement transmural care, together with potential, dangerous side effects (like calamities in home situations) justify equally big efforts to assess the effects of these organisational changes on patient outcomes and costs. Hence, despite the many difficulties of such assessments, it is vital to conduct thorough analyses of the effects of transmural care to generate valid information upon which to base the decision of its implementation. We propose that in The Netherlands, at this time, these assessments can best be conducted through observational cohort studies with clear and unambiguous measuring of the effects. For example, a standardised cost calculation[27] could be very valuable, as well as standardised measure of patient satisfaction, which enables better comparison of different studies.

An alternative for these types of assessments would be 'audit-type-constructions' for the evaluation of running projects. With the use of available parameters from 'usual care ' (for example patient-logistics, various types of costs) and comparison to transmural projects, it might be relatively simple to generate practical information about various effects. Moreover, this option would enable comparison of different transmural care models for identical patient categories. Finally, it might be worthwhile to gather expertise and

relevant information in some kind of a knowledge-centre, or expertise-panel. Healthcare providers, planning to start with transmural care, could discuss their initiatives with these expert-panels prior to actually implementation. In this way, the available knowledge of barriers to as well as factors promoting successful implementation can be used in an efficient way.

We think that the collection of knowledge through evaluations and making this knowledge readily available is more efficient than initiating new transmural projects, without any clear evidence to what extent they are feasible, and what the (side)effects will be.

Postscript

In the period after publication of this article, some more relevant material with respect to transmural care was published. In total three theses were published in this period: one exploring the quality and continuity of care in transmural nurse clinics[28], one evaluating the effectiveness of several structured diabetes care and education programmes[29] and one exploring the development and implementation of transmural care in The Netherlands[30].

In the first thesis it was demonstrated that both patients and professionals assessed the quality and continuity of care in transmural rheumatology nurse clinics positively (no control group). In case of asthma, no differences were found between transmural and extramural nurse clinics with respect to the information needs and the use of healthcare services. The second thesis indicates that primary care programmes which integrated education into structured care are able to improve disease knowledge and self-care behaviour as well as glycemic control and metabolic risk in diabetes type 2 patients. The third thesis contains no emperical data concerning the effects of transmural care, but explores the develoment and implementation of this healthcare innovation in The Netherlands, demonstrating its variety as well as its popularity.

Furthermore, evaluations of transmural care for patients undergoing total hip replacement[31] and for patients with diabetes mellitus type 2[32] were published, see Chapters 4 and 5.

And finally, the results of the evaluation of three transmural stroke services in The Netherlands were published recently[33]. It was concluded that (only) one of these three stroke services was cost-effective compared to the reference groups.

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CHAPTER 4

The case of patients with diabetes mellitus

Published as:

Rosendal H, Vondeling H, Witte LP de, Hutubessy RCW, Heine RJ. Initiating insulin therapy in patients with diabetes mellitus type 2: in a transmural care form of care at least as effective as in an outpatient setting; a retrospective study with a 4 year follow-up. (in Dutch). Dutch Medical Journal (NTvG) 2002; 146(4):166-171.

Abstract

Objective: To assess whether or not insulin therapy in patients with type 2 diabetes mellitus can be delivered as effectively in a transmural care setting as in secondary, outpatient care in the long run.

Design: Retrospective comparative cohort study.

Setting: A transmural care setting and an outpatient setting of a university hospital. Both settings are located in Amsterdam, The Netherlands.

Patients: All type 2 diabetes patients above 40 years of age who started with insulin therapy in 1993 in both settings and who were monitored for 4 years.

Main outcome measures: Baseline and glycated haemoglobin (HbA1c) for a period of 4 years; health status, self care behaviour and patient satisfaction 4 years after initiation of insulin therapy.

Results: In the period 1993 - 1997 the mean glycated haemoglobin fell from 9.1% to 7.2% in the transmural care group (n=25, p=0.000) and from 9.3% to 7.6% in the outpatient group (n=27, p=0.000). In this period the percentage of patients with poor glycemic control (glycated haemoglobin>8.5%) decreased from 60% to 8% in the transmural care group, compared to 59% to 15% in the outpatient group. The percentage of patients with good glycemic control (glycated haemoglobin<7%) increased between 1993 and 1997 from 4% to 52% in the transmural care group and from 11% to 30% in the outpatient care group. No statistically significant differences were found between the patient groups with respect to health status, self care behaviour and patient satisfaction.

Conclusions: Long term outcomes of insulin therapy in patients with diabetes mellitus type 2 are at least as good in transmural care as in secondary, outpatient care.

Introduction

In The Netherlands, a 40-50% increase of patients with diabetes mellitus type 2 has been predicted between 1990 and 2005[1]. As about 50% of persons with diabetes mellitus is still undiagnosed[2,3], the estimated number of persons with diabetes mellitus in The Netherlands is about 500.000, representing 3% of the population. Of these patients, 80-90% have diabetes mellitus type 2. Patients with diabetes mellitus type 2 are treated according to (inter)national guidelines in order to improve well-being and reduce the incidence of chronic complications[4]. Treatment strategies for patients with diabetes mellitus type 2 basically include three steps: dietary advice, oral medication and insulin therapy. Insulin therapy is increasingly applied when oral medication and dietary advice fail[5]. For this purpose, general practitioners in The Netherlands usually refer their patients to secondary, outpatient hospital care. Recently, the Dutch College of General Practitioners published a new guideline for the management of diabetes mellitus type 2, which includes steps for insulin therapy in primary care[6].

As demonstrated by the Diabetes Control and Complication Trial[7], strict glycemic control can reduce chronic complications in patients with diabetes mellitus type 1. More recently, the United Kingdom Prospective Diabetes Study[8] demonstrated similar effects in patients with diabetes mellitus type 2. Now that treatment targets and treatment strategies have been defined, it is an important next step to find out which organisational setting is most suitable to deliver care for patients with diabetes mellitus type 2: transmural care or secondary, outpatient care? There is some evidence that for patients with diabetes mellitus, shared care (which is equivalent to transmural care) performs at least as well as secondary care[9,10,11,12,13,14]. However, none of these studies focused specifically on patients diabetes mellitus type 2 starting with insulin therapy. Or, if these patients were included, the results can not be desegregated for this group. We therefore initiated a study in a Dutch city, comparing a transmural care setting and an outpatient care setting with respect to the transfer of diabetes type 2 patients to insulin therapy. Earlier it was demonstrated that short term costs and effects of initiating insulin therapy were comparable in both settings[15]. However, as diabetes mellitus is a chronic disease, it is also important to investigate patient outcomes over a longer period of time. To address this issue, we performed a retrospective comparative study on the same cohort of patients[15], extending the follow up to 4 years after initiation of insulin therapy, in order to asses whether or not insulin therapy in patients with diabetes mellitus type 2 can be delivered as effectively in transmural care as in outpatient care in the long run.

Patients and methods

Patients

This study was approved by the medical-ethical committees of TNO-Prevention and Health and of the Academic Hospital Vrije Universiteit Amsterdam. Patients with diabetes mellitus type 2 were eligible if they were transferred from oral hypoglycemic agents to insulin therapy in 1993 and if they were above 40 years of age in 1993. Only patients that could be traced in 1997, 4 years after starting with insulin therapy, were included in the study. Patients were excluded if they were temporarily transferred to insulin therapy during hospital admission or because of intercurrent illness. Patients were informed about the study, and gave informed consent when they were interviewed in 1997.

Transmural care setting

Since 1992, 22 general practitioners in Amsterdam treat their patients with diabetes mellitus type 2 with support of a 'diabetes service system'. This care system consists of a patient registration system, a recall system and a laboratory. Patients visit the diabetes service to have their blood samples taken and to receive diabetes education from a dietician and a diabetes educator. By protocol, all patients have glycemic control assessed at least every 3 months. Annually a review of complications and cardiovascular risk factors is performed in this clinic. Fundus photography is performed by a trained diabetes nurse. After patients' visit to the clinic, their general practitioners receive the results within two weeks, together with a protocollised therapy advice approved by the supervising diabetologist from the Academic Hospital Vrije Universiteit Amsterdam. This diabetologist can easily be consulted by phone, 24 hours a day. In this model, the general practitioners remain responsible for the treatment of these patients.

Secondary care setting

The control-group included patients with diabetes mellitus type 2 receiving conventional, outpatient care (usual care). In this model, the general practitioners refer their patients eligible for insulin therapy to the outpatient clinic. If the diabetologist at the outpatient department, in this study the diabetologist of the Academic Hospital Vrije Universiteit Amsterdam, decides to initiate insulin therapy, a diabetes nurse educator performs diabetes education, especially for instruction of self monitoring of blood glucose and insulin injection technique. In general, the patient also visits a dietician for nutritional advice and information to adequately correct hypoglycaemia. These health care providers are situated in the outpatient department of the hospital. In this care setting, the diabetologist is responsible for the insulin therapy given to the patient.

Assignment of patients

Patients' assignment to either one of the settings is dependent on their general practitioner. In The Netherlands, patients are free to choose their own general practitioner who is a gatekeeper to hospital or specialist care. General practitioners who are associated with the diabetes service system keep their patients in primary care, whereas others refer their patients to secondary, outpatient care. There are no general practitioners who have patients in both care settings.

Treatment regimen

The step-up regimen for insulin therapy is similar in both care settings. If target glycated haemoglobin level is not met on maximal doses of oral therapy, self-monitoring of blood glucose and insulin injection technique are instructed in individual sessions with the diabetes educator. At first, sulphonylurea at daytime is combined with NPH-insulin at bedtime. Twice weekly telephone appointments are made to adjust insulin dose on the basis of fasting blood glucose values. Measurement of fasting and pre-dinner glucose levels is requested in patients on a twice daily NPH-insulin regimen, which is the next step in therapy. If short-acting insulin is applied, more frequent blood glucose measurements are required.

Outcome Measures

The primary outcome measure was glycated haemoglobin (HbA1c) determined by ion-exchange high performance liquid chromatography. Patients were categorised according to HbA1c-values less than 7% as good glycemic control, values between 7% and 8.5% as acceptable control and values higher than 8.5% as poor control. These levels were measured at baseline and 1, 2, 3 and 4 years after initiation of insulin therapy. Disease specific quality of life was assessed using the Diabetes Health Profile[16,17]. Generic health status was assessed using COOP/WONCA charts and the RAND-36. COOP/WONCA charts are simple, easy to understand instruments that are frequently used in general practice[18,19]. The RAND-36 is a more elaborate questionnaire, allowing the comparison of the results of this study with both Dutch national age- and gender specific norm scores and a variety of results across patient groups and interventions[20,21]. To measure self care behaviour we used a questionnaire, developed and validated by Pennings-van der Eerden[22,23]. Patient satisfaction was measured with the Diabetes Treatment Satisfaction Questionnaire[24]. To assess more aspects of satisfaction besides patient satisfaction with care, a TNO devised list of complementary questions was added. These questions concerned the way health care is organised, the way patients are met by the professionals and how they were informed about their disease, and self control. The argument for using

more measures than glycemic control only, is that good glycemic control does not necessarily correlate with high scores on health status and patient satisfaction[25,26].

Data collection and statistical analysis

Patient records served as the most important source for HbA1c-values and patient characteristics. All other data were collected during a face to face interview held in 1997. Clinical and demographic characteristics and data were analysed using chi-square, and unpaired T- or Mann-Witney U tests (two tailed). A p-value equal to or less than 0.05 was considered statistically significant.

Results

Patients

In total 57 patients with diabetes mellitus type 2 met the inclusion criteria in the transmural care setting and 45 patients in the outpatient care setting. Of these, 25 patients in the transmural care group and 27 patients in the outpatient care group could be traced in 1997 and were willing to participate in this study.

Reasons for this loss to follow-up (transmural care/outpatient care) were: no patient records available after 1995 (13/6), non-Dutch speaking (1/1), change of address (1/2), mortality (0/2), no reaction on our invitation for an interview in 1997 (7/5) and refusal to participate in this study (10/2).

The baseline characteristics of the study population are outlined in table 4.1.

Table 4.1: Baseline clinical characteristics of patients in the transmural care and the outpatient care population in 1993.

Patient characteristics	Transmural care (n=25)	Outpatient care (n=27)	p-value
mean age (sd)	67.5 (±11.7)	65.3 (±11.3)	>0.05
no. males (%)	8 (32)	13 (48)	>0.05
no. dutch origin (%)	20 (80)	21 (78)	>0.05
mean HbA1c-% (sd)	9.1 (±1.7)	9.3 (±2.2)	>0.05
mean diabetes duration in years (sd)	7.3 (±6.7)	10.6 (±7.8)	>0.05
mean body mass index (sd)	27.4 (±5.4)	29.1 (±6.6)	>0.05

There was no statistically significant difference in these characteristics between the two patient groups.

Glycemic control

In the period 1993 - 1997 the mean HbA1c-values fell from 9.1% to 7.2% in the transmural care group and from 9.3% to 7.6% in the outpatient group. Both decreases were significant (p=0.000). There was no statistically significant difference between the two settings in the decrease of HbA1c-values in this period. In both settings, the percentage of patients with good control (HbA1c<7%) increased significantly (p<0.05) and the percentage of patients with poor control (HbA1c>8.5%) decreased significantly (p<0.05) in the period 1993 - 1997, see table 4.2.

Table 4.2: Number (%) of patients with good, moderate and poor glycemic control in the period 1993 - 1997, in the transmural care and outpatient care population.

		1993	1994	1995	1996	1997
transmural care (n=25)	good control	1 (4)	3 (12)	6 (24)	13 (52)	13 (52)
	moderate control	9 (36)	12 (48)	16 (64)	9 (36)	10 (40)
	poor control	15 (60)	10 (40)	3 (12)	3 (12)	2 (8)
outpatient care (n=27)	good control	3 (11)	3 (11)	1 (4)	2 (7)	8 (30)
	moderate control	8 (30)	15 (56)	15 (56)	22 (82)	15 (56)
	poor control	16 (59)	9 (33)	11 (41)	3 (11)	4 (15)

In 1997, the percentage of patients with good glycemic control was higher (p<0.05) in the transmural care group than in the outpatient group. This difference is established after 2 years after initiation of insulin therapy. In 1997, there is no significant difference in the percentage of patients with poor glycemic control between the two patient groups.

Disease specific quality of life

Table 4.3 represents the results for each dimension of the Diabetes Health Profile.

Table 4.3: Diabetes Health Profile subscale mean scores (sd) in the transmural care and outpatient care population in 1997.

Diabetes health profile	Transmural care (n=25)	Outpatient care (n=27)	p-value
psychological distress	84.3 (±14.8)	87.9 (±9.4)	>0.05
barriers to activity	77.2 (±20.5)	81.0 (±13.9)	>0.05
disinhibited eating	68.1 (±20.1)	69.3 (±25.8)	>0.05

There was no significant difference in any of the scales of the Diabetes Health Profile between the two settings. Overall, these scores are similar to those reported by Goddijn[26].

Generic Health Status

The generic health status, as measured with the COOP/WONCA-charts and the RAND-36, is visualised in tables 4.4 and 4.5.

Table 4.4: COOP/WONCA subscale mean scores (sd) in the transmural care and outpatient care group in 1997.

COOP/WONCA charts	Transmural care (n=25)	Outpatient care (n=27)	p-value
physical fitness	3.0 (±1.2)	3.0 (±1.3)	>0.05
feelings	1.6 (±1.0)	1.6 (±0.8)	>0.05
daily activities	2.3 (±1.5)	2.0 (±1.1)	>0.05
social activities	1.9 (±1.4)	1.4 (±0.7)	>0.05
change in health	2.9 (±0.6)	2.9 (±0.6)	>0.05
overall health	3.3 (±0.6)	3.2 (±0.9)	>0.05

On neither one of the subscales of the COOP/WONCA charts we found any statistically significant difference between the two groups.

Table 4.5: RAND-36 subscale mean scores (sd) in the transmural care and outpatient care group in 1997.

RAND-36	Transmural care (n=25)	Outpatient care (n=27)	p-value
physical functioning	63.9 (±25.4)	62.8 (±27.5)	>0.05
social functioning	73.9 (±32.4)	81.9 (±21.7)	>0.05
functional role impairment	58.7 (±42.4)	55.8 (±43.2)	>0.05
emotional role impairment	72.2 (±42.5)	84.6 (±34.2)	>0.05
mental state	72.8 (±19.9)	84.6 (±30.2)	>0.05
pain	70.2 (±27.3)	75.9 (±27.1)	>0.05
vitality	56.5 (±23.9)	56.3 (±22.8)	>0.05
general health perception	50.6 (±18.9)	47.1 (±25.5)	>0.05
health change	46.9 (±16.9)	46.2 (±20.8)	>0.05

There was no statistical significant difference in any of the scales of the RAND-36 between the two different settings. Overall, these scores indicate that, compared to measurements in a general population[19,20,21], the study population scores lower on both generic health status measures.

Self care behaviour

The results of measuring patients self care behaviour in 1997 are summarised in table 4.6.

Table 4.6: Self care behaviour mean scores (sd) in the transmural care and the outpatient care population in 1997.

Self care behaviour	Transmural care (n=25)	Outpatient care (n=27)	p-value
extra physical activity	4.9 (±2.5)	2.5 (±2.6)	0.006
feet self-check	6.8 (±2.7)	5.2 (±3.9)	>0.05
diet compliance	6.4 (±1.8)	6.6 (±2.2)	>0.05
glucose self-regulation	6.9 (±2.2)	7.4 (±2.2)	>0.05

The only statistically significant difference ($p<0.05$) between the two groups was found for the subscale extra physical activity. This difference concerns two topics of this subscale: patients in the transmural care group tend to do more extra exercise when the weather is good and at times when they feel not well, compared to the outpatient group.

Patient satisfaction

Patient satisfaction, as measured with the Diabetes Treatment Satisfaction Questionnaire, resulted in a total score of 8.1 (sd 1.6) in the transmural care group, compared to 8.2 (sd 1.9) in the outpatient group. In addition, several questions were asked about the healthcare patients had received. Patients were asked to grade the overall care as well as the way that healthcare was organised with a mark from 0 to 10. This resulted in a score of 7.5 (sd 1.8) in the transmural care group, and 7.9 (sd 1.1) in the outpatient group. Again, no statistically significant difference.

Besides these gradings, patients were also asked whether or not they found improvements desirable on different aspects of their care. The results are visualised in table 4.7.

Table 4.7: Number of patients (%) that find improvements desirable on several aspects of care in the transmural care setting versus an outpatient care setting.

Number of patients (%) that find improvements desirable on:	Transmural care (n=25)	Outpatient care (n=27)	p-value
general information	9 (36)	7 (26)	>0.05
listening to patients	8 (32)	4 (15)	>0.05
information about feet self-check	13 (52)	20 (74)	>0.05
taking their wishes into account	8 (32)	2 (7)	>0.05

It seems that patients in the outpatient group tend to be somewhat more satisfied with several aspects of the care they have received. Patients in the outpatient group felt that professionals listened better to them, compared to patients in the transmural care setting.

Conclusion

The results of this study indicate that, also in the long run, the initiation of insulin therapy in patients with diabetes mellitus type 2 can be delivered as effectively in a structured, transmural care setting as in a secondary, outpatient setting. Good, or at least acceptable, glycemic control can be achieved in the vast majority of patients in both settings. However, there are some differences between the two settings. The decrease of HbA1c-values seems to be realised faster in the transmural care group compared to the outpatient group and it is also more stable over time. The results of both disease specific and generic quality of life questionnaires demonstrate comparable long term outcome of initiation of insulin therapy in patients with diabetes mellitus type 2.

Discussion

The conclusion that in the long run good, or at least acceptable glycemic control can be achieved in the vast majority of patients in both settings is of major concern as the importance of good glycemic control can hardly be overestimated[7,8]. Earlier it was documented that in both settings effectiveness and costs were comparable the first year after initiation of insulin therapy[15]. In addition, we now conclude that transmural care in this particular setting is at least as effective in the longer run, compared to outpatient care. The conclusions of this study, however, should be interpreted with some caution, as, due to the retrospective design, selection bias can not be ruled out completely. This can be illustrated by the fact that the extension of the follow-up period to 4 years resulted in a somewhat different study population.

The finding that, compared to usual care, patients in the transmural care group scored higher on extra physical activity and feet self check could very well be a result of the more strict education program in this setting. Although this was not reflected in differences in health status, it cannot be ruled out that this might have a beneficial effect in the long run. Finally, there is another aspect that might be important in weighing the advantages of this type of transmural care in this field. This is the well known fact that a high percentage of patients with diabetes mellitus type 2 is not yet diagnosed as such. It can been argued that a transmural care setting has a lower threshold for these patients[27], so they can be detected and treated in an earlier stage of their disease. As the importance of early detection of patients with diabetes mellitus type 2 can hardly be overestimated, evaluation of this potential advantage of transmural care deserves priority for future research.

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CHAPTER 5

The case of patients undergoing total hip replacement

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Abstract

Objective: To assess whether shared care for patients undergoing total hip replacement results in better patient outcome, higher patient satisfaction and different use of healthcare services compared to usual care.

Design: Prospective comparative cohort study.

Setting: Two regions in The Netherlands where different organisational health care models have been implemented: a shared care setting (experimental group) and a usual care setting (control group).

Patients: 115 patients undergoing total hip replacement: 56 in the experimental group and 59 in the control group.

Main outcome measures: Functional health status according to the SIP-68, hip function, patient satisfaction and use of health care services.

Results: Two weeks before hip replacement both groups were comparable concerning patient characteristics, hip function and health status. The mean improvement of the total sickness impact profile score between two weeks before hip replacement and six months after was -1.92 in the shared care group, compared to -5.11 in the usual care group, a difference in favour ($p=0.001$) of usual care. Length of hospital stay was comparable in both settings: 12.8 days in the shared care group and 13.2 days in the usual care group. After hip replacement, compared to usual care, patients in the shared care group received more homecare, with a higher frequency, and for a longer period of time. No differences in patient satisfaction between the two groups were found.

Conclusions: Six months after hip replacement, the health status of patients in the usual care group, using significantly less home care, was better than the status of patients in the shared care group. The utilisation of home care after hip replacement should be critically appraised in view of the need to stimulate patients' independence.

Introduction

Total hip replacement is widely regarded as a very effective treatment for patients with hip joint failure. The aims of total hip replacement[1], which is mainly delivered to patients with osteo-arthritis, are relief of pain and improvement in function. Yearly, about 14.000 people, which is almost 1‰ of the Dutch population, undergo total hip replacement in The Netherlands. Although there is no doubt about its positive effects, there is variability in the outcomes of total hip replacement[2,3]. One of the aspects which possibly might have an impact on the outcome of total hip replacement could be the way that health care for these patients is organised.

Patients receive health care on different levels, or stages, varying from informal home care by partners and family to (super-) specialised (university) hospital care. One of the present tendencies in Dutch health care is to try to provide care at the 'lowest' level where it can be delivered adequately. It is generally believed that it is better to deliver health care as close as possible to the patients' own living situation. Another factor is the widely spread belief that primary care, compared to secondary care, is less expensive and not per se less effective. In the treatment of some diseases, for example diabetes mellitus, it is possible to change the site of care-delivery in toto from a secondary to a primary care setting without loss of quality. In many other cases, such as total hip replacement, there is no doubt that the surgical procedure itself has to be carried out in a well-equipped hospital.

In such cases a stronger role of primary care during the recovery phase can be realised by intensifying collaboration and communication between primary and secondary care. This alternative way of organising health care in The Netherlands is called transmural care. In other countries, more or less equivalent phenomena are known as shared care. The aims of shared care are an earlier and safer discharge from hospital, more support to frail and elderly people in their own homes, a better co-ordinated and more flexible community care, an efficient use of acute hospital services and greater responsiveness to the needs of patients[4].

That shared care is beneficial for patients is merely an assumption. In case of diabetes[5] and hypertension[6] there is some evidence that shared care is as cost-effective as conventional secondary care. About the effects of shared care on patients undergoing total hip replacement, no information is available in literature. This paper presents the results of a prospective comparative cohort study that was carried out to evaluate the effects of shared care for patients undergoing total hip replacement.

Patients and methods

Patients

Patients were selected based on the decision, made by the orthopaedic surgeon together with the patient, to do a total hip replacement. After this, patients were informed about the study and were subsequently asked to participate. They did not know whether their setting was considered as the experimental or the control setting in this study. Patients who were not able to complete the questionnaires used in this study, for example non-Dutch speaking patients, or patients with severe illnesses like dementia, were excluded from the study. The study was approved of by the Medical-Ethical Committee of TNO-Prevention and Health.

Intervention

Patients were selected from two different hospitals. In one of them, the experimental setting, a form of shared care had been implemented for a number of years. In the other hospital, that was considered to be the reference site, care was given in the usual, conventional way. These equally sized hospitals are located in two regions in The Netherlands with comparable social and cultural circumstances. Surgical procedures and post hospital care are comparable in these hospitals. The only significant difference is the way in which health care for patients undergoing total hip replacement has been organised, which is the intervention under study.

Shared care (experimental) setting

Primary and secondary health care professionals have attuned their activities in such a way that the healthcare patients receive before, during and after their admission to the hospital has a high degree of continuity. This has been laid down in a protocol, which serves as a guideline for all health care providers involved. A few weeks before their admission, patients are visited by a home care co-ordinator, who informs patients and their family about things to happen, meanwhile assessing their home situation. Also assessed are the extent to which the family is able to take care of the patient after discharge from hospital and whether or not any adjustments are needed in the house, such as bed-heighteners, toilet-heighteners, and so forth. Subsequently, the co-ordinator takes care of organising whatever is needed to guarantee a well-prepared and safe home-situation once the patient returns home from the hospital after the operation. During the hospital-admission-period, this co-ordinator visits the patients and makes sure that everything goes as planned. By the time the patients are discharged from hospital,

adjustments in the house have been arranged and the home care that is needed can start immediately. In this way, hospital-stay should be reduced to a minimum, for patients can return home as quickly as possible. It is believed that this has not only a positive effect on costs (reduced length of hospital stay), but also on the effectiveness of care, since patients can start earlier with their rehabilitation. Furthermore, it is assumed that patients in this setting are better informed about their healthcare.

Usual care (control) setting

The control group consists of patients, whose health care is organised as usual, implying no visit from home care before hospital admission. Furthermore, their needs for 'post-discharge-care' and home adjustments are assessed not before, but during their stay in hospital, or sometimes not before they have returned home after discharge from the hospital. In this model, there are no special workers to support patients' transition before, during and after their hospital admission period.

Assignment of patients

The assignment to either one of the settings is dependent on the place of residence of patients. The organisational settings in this study are located in two different cities in The Netherlands, about 30 miles apart.

Outcome measures

- General health status was measured with the SIP-68. The SIP-68[7,8] is a short version of the Sickness Impact Profile, which originally consisted of 136 questions. The SIP-136, as well as its short version, is considered as a reliable and valid instrument for measuring functional status[9]. The questionnaire has six dimensions: somatic autonomy, motor control, psychological autonomy and communication, social behaviour, emotional stability and mobility range. For each dimension the scores are straightforwardly added up, a higher score indicating a higher impact on health, implying a lower health status.
- Hip function, a disease-specific measure, was assessed with a translation of the Hip-Rating-Questionnaire[10]. This 14-item questionnaire uses a 100-point scale in which equal weight is given to the domains of overall impact of arthritis, pain, walking and function. Here, in contrast to the SIP, a higher score indicates a better health status.
- Patient satisfaction was measured with a questionnaire developed especially for this study since no validated instrument for measuring patient satisfaction, which is also sensitive enough to detect any differences in patients who need total hip replacement, is available. The questionnaire focuses on the way patients are met by professionals,

on the information that was given to them (about their disease, treatment-modalities, home care, adjustments, and so forth) and on the way health care is organised.

- Costs were approximated by an inventory of the type and number of adjustments realised in patients homes, the amount and type of home care after discharge from hospital and the length of stay in the hospital.

Data collection and statistical analysis

All patients who entered the study were asked to complete the SIP and hip-function questionnaires two times: two weeks before their admission to the hospital and six months after total hip replacement. Patient satisfaction was measured only six months after hip replacement. Beside the completed questionnaires, we used patient-records as important source of information about the length of hospital stay, the technique and material used by the orthopaedic surgeon, co-morbidity and complications.

Baseline clinical characteristics and outcome measures were analysed and tested (two-tailed) using chi-square or Fisher Exact test and unpaired T- or Mann-Witney tests when appropriate. A p-value equal to or less than 0.05 was considered statistically significant[11,12].

Results

Patients

All patients, who were to have a total hip replacement in either one of the hospitals in the period from December 1996 to June 1998 were informed about the study and were asked to participate. Patients who only completed the questionnaire once were excluded from the study. This resulted in a total of 115 patients entering the study, 56 in the shared care setting and 59 in the usual care setting. The baseline characteristics of these patients are depicted in table 5.1.

Table 5.1: Baseline patient characteristics.

Patient characteristics	**Shared care (n=56)**	**Usual care (n=59)**	**p-value**	**p-value (95% CI of the difference)**
mean age (sd)	69.8 (±10.1)	67.2 (±11.2)	0.19*	n.s.* (-1.29 to 6.59)
no. males (%)	11 (20)	10(17)	0.71**	n.s.**
no. primary THR (%)	37 (66)	44 (75)	0.19**	n.s.**
no. living alone (%)	25 (45)	19 (32)	0.17**	n.s.**
no. waiting-days before admission (sd)	70.9 (±32.2)	64.7 (±11.2)	0.38*	n.s.* (-7.68 to 20.0)

* t-test
** Chi-square test

There was no statistically significant difference in any of these characteristics between the two patient groups. Also, concerning generic health status as measured at baseline by the SIP, both groups were comparable, see table 5.2.

Health status

In general, the differences in scores on health status showed the same pattern in both settings in the period from two weeks before their hip replacement to six months afterwards. In short, there was a significant improvement in both groups on most of the sub-scales of the instruments used. Beside many similarities, there are also some differences between the two groups, as is shown in table 5.2.

Table 5.2: Mean scores on generic and disease specific health status at baseline (t0) and at six months after hip replacement (t1).

Measure	Shared care (n=56) t0	Usual care (n=59) t0	p-value* t0	Shared care (n=56) Δscore**	Usual care (n=59) Δscore**	p-value* t1
SIP-68						
- somatic autonomy	1.00	0.80	0.48	+0.18	-0.30	0.04
- motor control	5.03	5.52	0.30	-1.26	-2.21	0.49
- psychological autonomy and communication	0.79	0.37	0.14	-0.07	-0.11	0.07
- social behaviour	3.76	3.50	0.61	-0.70	-1.38	0.07
- emotional stability	0.41	0.54	0.43	-0.12	-0.38	0.30
- mobility range	1.68	1.71	0.94	-0.18	-0.76	0.03
Total SIP	12.7	12.4	0.88	-1.92	-5.11	0.03
Hip Rating Questionnaire						
- overall impact	9.2	10.0	0.40	+7.9	+7.8	0.52
- pain	12.5	11.4	0.19	+7.8	+9.2	0.76
- walking	15.7	15.5	0.84	+3.0	+3.8	0.50
- function	19.1	19.5	0.56	+1.2	+2.1	0.07
Total HRQ	56.7	56.4	0.92	+18.9	+24.3	0.14

* t-test, shared care group versus usual care
** Δscore = score t1 – score t0

It appears that the usual care group scored better on several sub-scales of the measures used at six months after hip replacement. For example, the mean improvement on the total SIP-score between two weeks before hip replacement and six months after, was -1.92 (±7.39) in the shared care group compared to -5.11 (±6.19) in the usual care group, a difference in favour of the latter (p=0.01). Stratification for patients with a first ever hip replacement resulted in a similar difference in favour of usual care (p=0.05) in the total SIP-score: -9.73 versus -6.65.

Costs/Use of service

There appeared to be no significant difference in the mean length of hospital stay between the two groups: 12.8 (±7.4) days in the shared care group versus 13.2 (±3.5) in the usual care group. All patients were asked whether they judged the hospital admission period too long, just good, or too short. Compared to usual care, somewhat more patients in the shared care group judged this period either too short or too long, whereas a greater

percentage of patients in the usual care group judged this period as just good. This difference however, is not statistically significant (Mann Whitney test, p=0.08).

After discharge from hospital, patients can be supported by having different kinds of adjustments installed in their houses or by receiving home care. Examples of these adjustments are bed- and toilet heighteners, handgrips and shower-chairs. The number of patients in both settings that received adjustments and home care is given in table 5.3.

Table 5.3: Number (%) of patients that received adjustments in their home and home care.

	Shared care (n=56)	**Usual care (n=59)**	**p-value***	**95% CI**
adjustments present at:				
- one month after hip replacement	42 (75)	39 (66)	0.32	-0.08 to 2.5
- six months after hip replacement	35 (64)	24 (41)	0.02	0.04 to 0.40
home care at:				
- one month after hip replacement	30(54)	19(32)	0.03	0.04 to 0.39
- six months after hip replacement	11(20)	11 (19)	0.89	-0.13 to 0.15

* Chi-square test

This indicates that adjustments remain longer in the houses of patients in the shared care group. With respect to home care, it appears that, compared to usual care, this was received by more patients in the shared care group in the first period after discharge from hospital. Six months later this difference has disappeared. Not only did patients in the shared care group receive more home care, but this care started earlier compared to the usual care group also (Mann-Whitney test, p=0.002). This difference is illustrated table 5.4.

Table 5.4: Time needed for home care to start for patients (%) in both settings.

Time before home care started after discharge	**Shared care (n=30)**	**Usual care (n=19)**	**95% CI**
same day	11 (37)	1 (5)	0.11 to 0.51
next day	13 (43)	6 (32)	-0.16 to 0.39
a few days	4 (13)	6 (32)	-0.42 to 0.06
a week	1 (3)	5 (26)	-0.44 to 0.02
more than a week	1 (3)	1 (5)	-0.14 to 0.10

This difference was not reflected in differences between the two groups in the way they felt about the time needed for home care to start after discharge: about 90% in both groups said this was all right, whereas 5% - 10% felt that this period was too long.

Patients in the shared care group were informed earlier (p=0.001) about receiving home care after discharge from hospital compared to patients in the usual care group: 87% of patients in the shared care group were informed before hospital admission, compared to 26% in the usual care group. Almost half of the patients (47%) in the usual care group were informed during their hospital stay, compared to 10% in the shared care group. Only 3% of patients in the shared care group was informed after discharge, compared to 10% in usual care.

The type of home care that patients received after discharge from hospital is summarised in table 5.5. The totals do not necessarily sum up to 100% here because many patients received different types of care.

Table 5.5: Type of home care delivered to patients (%) in both settings at one month after total hip replacement.

Type of home care	Shared care (n=30)	Usual care (n=19)	p-value*
household	21 (70)	14 (74)	0.12
body care (bathing, clothing)	28 (93)	8 (42)	0.000
nursing (wound)	18 (60)	3 (16)	0.000

* Chi-square test

Not only did patients in the shared care group receive more home care, they also received more different types of care. Furthermore, there was also a difference between the two groups in the frequency of home care, see table 5.6.

Table 5.6: The frequency of patients (%) receiving home care in both settings at one month after total hip replacement.

Frequency of home care	Shared care (n=30)	Usual care (n=19)	95% CI
twice a day	10 (33)	1 (5)	0.08 to 0.45
once a day	12 (40)	4 (21)	-0.06 to 0.44
a few times a week	5 (17)	3 (16)	-0.20 to 0.22
once a week	3 (10)	10 (53)	-0.67 to -0.18
other	-	1 (5)	-

Obviously, compared to usual care, the frequency of home care in the shared care group was significantly higher (Mann-Whitney test, p=0.000). Besides the type of care and its frequency, the total period that patients received home care after hip replacement was inventarised also. It appeared that in both settings, whenever home care continued to be delivered until three months after hip replacement, this was retained up to six months. At that time, the type of care did not differ between the two groups: about 65% consisted of

household care and about 35% of household care together with body care, for example help with bathing. Overall, patients in the shared care group received home care for a longer period of time compared to usual care (Mann-Whitney test, p=0.037).

Patient satisfaction

On both measuring-moments patients were asked to grade the overall care they received with a mark from 0 (very bad) to 10 (excellent). There was no significant difference between the two groups. Furthermore, patients were also asked whether or not they judged improvements desirable on the various aspects of the healthcare they had received. The results are visualised in table 5.7.

Table 5.7: Number of patients (%) judging improvements desirable on several aspects of care at six months after total hip replacement.

Improvements desirable on:	Shared care (n=56)	Usual care (n=59)	p-value*
information about things to happen	5 (9)	11 (19)	0.12
information about behaviour after discharge	5 (9)	12 (20)	0.06
listening to patients	6 (11)	8 (14)	0.59
organising adjustments	2 (4)	5 (8)	0.31
organising home care	6 (11)	8 (14)	0.65
deliberation between different care providers	5 (9)	12 (20)	0.08
taking their wishes into account	4 (7)	7 (12)	0.43

* Chi-square test

Although patients in the shared care group tended to be somewhat more satisfied on every aspect we measured, this difference was never significant.

Conclusions

The results of this study indicate that shared care for patients undergoing total hip replacement, as organised in the experimental setting studied, compared to usual care does not perform better. In fact, the health status of patients in the usual care group was better compared to that of patients in the shared care group. Also, the patients in the usual care group used significantly less home care. This indicates that this particular form of shared care, which was originally implemented to reduce the length of hospital stay and to improve the quality of care, is not cost-effective.

Discussion

Total hip replacement can be considered as a highly effective medical treatment. Most patients in both organisational settings improved significantly on health status after six months. This finding is coherent with other findings in literature. However, this study was not carried out to assess the effects of the surgical procedure, but to find out whether another way of organising health care for these patients would have positive effects on patient outcomes. For this purpose, we compared the effectiveness between a shared care setting with usual care. As our study did not primarily intend to measure the effects of the clinical intervention as such, but the way that health care was organised, we supplemented the measurement of clinical outcomes with measurement of other outcomes such as health status, patient satisfaction and efficiency.

Assessing the organisation of care is complicated because the intervention to be evaluated is a complex change in the delivering of health care, with many different actors involved. To address this issue, it was for practical reasons hardly feasible to carry out a randomised trial. Randomisation of patients in order to eliminate selection bias within one setting was difficult since two different ways of organisation within one setting is not workable in daily practice. Randomisation between both hospitals in two different cities was hardly feasible either, because this would imply long(er) travels for patients and their relatives during the hospital stay, as well as for providers of home care after discharge. Because of these reasons, we designed a prospective observational study to assess the effects of shared care by comparing the outcomes of usual care with the outcomes of this new shared care model for patients undergoing total hip replacement. We concluded that usual care compared to shared care performed better: six months after hip replacement, patients in the usual care group scored better on several SIP-68 items. As this instrument measures the impact of health problems on the actual behaviour of patients, a better (lower) score implies less restriction in daily activities. Patients with lower scores develop more daily activities compared to patients with higher scores.

Concerning costs that are associated with both models of health care, we concluded that shared care was more expensive compared to care as usual. Firstly, despite the original goals of shared care, the length of hospital stay appeared to be comparable in both settings. Secondly, in the shared care model significantly more home care was brought into service to reach equal (patient satisfaction) or even lower (health status) results. The latter finding brings the cost-effectiveness of home care after total hip replacement under discussion. Our results suggest that the greater amount of home care in the shared care setting did not stimulate the independence of patients, but on the contrary may have prevented them from developing more independent daily activities.

Do these findings lead to the recommendation to abandon shared care totally and stick to usual care in case of total hip replacement? No, we think it is far too early for that. In fact, the study reported upon here should be seen as merely a study of just a single case of shared care. In order to come to a conclusion about shared care for this group of patients in general, many more of these cases should be studied. Nevertheless, we think this particular case can teach us some lessons. First of all, we would suggest carrying out more trials such as the one reported upon here, with larger numbers of patients and whenever possible, a stronger design than the one we were restricted to. Further, there might be other advantages of shared care that were not subject of our study, such as satisfaction of health care providers. We suggest including assessment of these aspects of care in future studies also. Finally, and maybe even more important, we recommend strongly to critically appraise the targets and utilisation of home care after total hip replacement. It seems obvious from our results that optimisation of the effectiveness of home care could be of decisive importance in the ever continuing striving to improve the quality of care and to reduce its costs.

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CHAPTER 6

The case of patients with a stroke

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Abstract

Objective: To assess whether shared care for stroke patients results in better patient outcome, higher patient satisfaction and different use of healthcare services.

Design: Prospective, comparative cohort study.

Setting: Two regions in The Netherlands with different healthcare models for stroke patients: a shared care model (stroke service) and a usual care setting.

Patients: Stroke patients with a survival rate of more than six months, who initially were admitted to the Stroke Service of the University Hospital Maastricht (experimental group) in the second half of 1997 and to a middle sized hospital in the western part of The Netherlands between March 1997 and March 1999 (control group).

Main outcome measures: Functional health status according to the SIP-68, EuroQol, Barthel Index and Rankin Scale, patient satisfaction and use of healthcare services.

Results: In total 103 patients were included in this study: 58 in the experimental group and 45 in the control group. Six months after stroke, 64% of the surviving patients in the experimental group had returned home, compared to 42% in the control group ($p<0.05$). This difference could not be explained by differences in health status, which was comparable at that time. Patients in the shared care model scored higher on patient satisfaction, whereas patients in the usual care group received a higher volume of homecare.

Conclusions: The Stroke Service Maastricht resulted in a higher number of patients who returned home after stroke, but not in a better health status. Since patients in the usual care group received a higher volume of healthcare in the period of rehabilitation, the Stroke Service Maastricht might be more efficient.

Introduction

Stroke is a major healthcare problem because of its devastating effects on patients' life in combination with high incidence and prevalence. In The Netherlands, the yearly incidence of stroke is estimated between 1.7 (man) and 2.0 (women) / 1.000 inhabitants, its prevalence between 5.6 (man) and 5.4 (women) / 1.000 inhabitants[1].

Some years ago, the Dutch Heart Foundation identified several bottlenecks in healthcare for stroke patients in The Netherlands[2]. These bottlenecks concern actual patient care and patient education as well as basic and applied research. Some examples: a) it is still unclear what is the most adequate site of treatment in the acute phase of stroke, b) there is lack of sufficient capacity in nursing homes and home care, and c) there is not enough co-operation between primary and secondary healthcare providers. On the other hand, healthcare for stroke patients is continuously in progress. New treatment modalities are emerging and the organisation of care for stroke patients is constantly being modified in order to improve the quality of care[3]. Well known are two meta-analyses on the effectiveness of stroke units[4,5]. Although the control groups in these analyses were not comparable to the neurological wards in Dutch hospitals, it is generally believed that structured care for stroke patients will have positive effects on the quality of care[6]. This structured care usually implies a multidisciplinary approach, continuity of care, and support by protocols.

In The Netherlands, an alternative way of organising healthcare, called transmural care, has received a great deal of attention recently. Transmural care is usually[7] defined as: *'tailor made healthcare that is delivered on the basis of co-operation and direction between primary and secondary healthcare providers, with shared responsibilities and explicit sub-responsibilities'*. Transmural care encompasses many different forms of healthcare directed toward bridging the gap between general primary care and specialised hospital care. The concept of transmural care overlaps with that of 'shared care'[8]. With the definition of transmural care in mind, structured care for stroke patients in The Netherlands can be considered as an example of transmural care.

In spite of the popularity of transmural care in The Netherlands, there is hardly any evidence for its effectiveness or efficiency[9]. In Chapter 3 it was suggested that one of the causes for this lack of evidence could be the methodological difficulties inherent to this type of assessment. For example, the randomisation of patients to different healthcare models is difficult in case of transmural care because of practical reasons.

A recent inventory of transmural care projects in The Netherlands demonstrated that in total over 300 transmural projects were initiated, of which 12 concerned care for stroke patients[10]. These 12 projects are situated in 8 hospitals and comprise many different

activities in order to improve the 'care chain', varying from early diagnosis to fast transitions and adequate rehabilitation sites. Most of these projects have not yet reached maturity. To illustrate this, none of these initiatives is structurally financed and insurance companies are involved in only one of these projects. Furthermore, only 4 of these 12 projects are being evaluated, information about the quality of these assessments is lacking.

One of the transmural care projects for stroke patients in The Netherlands that have reached maturity is the Stroke Service Maastricht (SSM). The primary goals of this healthcare model are to admit all patients suspected of having a stroke to the (university) hospital for diagnosis, followed by fast transition to, preferably, home, and otherwise to a rehabilitation centre or a specialised nursing home. The basic assumption behind this stroke service is that this model will result in a more effective as well as in a more efficient healthcare for patients with stroke. To assess the extent to which these goals are realised in practice, we performed an exploratory cohort study, in which the SSM as an example of shared care, is compared with usual care.

The research questions for this study were whether this example of transmural care for stroke patients with a survival rate of more than 6 months, results in:

- a higher health status and functioning of patients;
- a higher patient satisfaction and in;
- a different use of healthcare services after discharge from hospital.

Methods

Patients

The patients in this prospective study were recruited from all patients with a stroke who were admitted to either one of the two hospitals. Patients with a stroke who were not admitted, but stayed home, were not included in this study. The inclusion period for patients in the SSM group was the second half of 1997. Since the hospital in the reference group is of a smaller size, and has a smaller referral area, we extended the inclusion period in this group with another year. In this way, we were able to create equal sample-sizes. The choice of the reference group was based on the fact that at the time of the study no elements of stroke service were present in this hospital. The medical treatment was comparable in both models. Both hospitals had education facilities for neurologists. In this way, we tried to organise two patient groups that were as similar as possible, with the exception of the way that healthcare has been organised. However, because of the chosen

design (no randomisation of patients) a complete similarity of both patient-groups could not be 'garanteed'.

The inclusion of patients and data-collection in both groups was organised in a similar, prospective way. Patients were considered to have suffered a stroke if there was a sudden focal neurological deficit with no other known cause. Patients with first ever as well as with recurrent strokes were included in this study. Whenever symptoms disappeared within 24 hours, patients were considered to have suffered a transient ischaemic attack (TIA), and were subsequently excluded from this study. Patients with a subarachnoid hemorrhage were excluded also. All other stroke-patients admitted to the neurological wards in both hospitals were informed about the study during their hospital stay and gave informed consent to use their medical records in order to collect data about socio-demographic aspects and about the care-process. About six months after the onset of stroke, all surviving patients were sent a letter, in which they were informed about this study and invited to participate in an interview. Patients who were willing and able to participate, were subsequently visited and interviewed by a trained researcher. The medical-ethical committee of TNO Prevention and Health approved the study.

Stroke service group

SSM is a co-operative healthcare model of general practitioners, neurologists, care co-ordinators, nurses, the hospital rehabilitation team, liaison-nurses, homecare, physical therapists, speech therapists, the regional rehabilitation centre and nursing- and residential homes. The treatment of stroke in the SSM is given under set protocol[11,12]. The key-characteristics of this model are:

- all stroke patients are referred to the hospital accompanied by a structured referral-letter from the general practitioner. This letter also contains a first estimation of the possibilities for home support after discharge;
- patients are admitted to the stroke unit for diagnosis and treatment;
- nursing care co-ordinators are brought into action on the stroke unit as well as in primary care in order to facilitate the returning home of patients;
- patients are accompanied by a transmural patient-record throughout the whole care-process.

In the weekly multidisciplinary meetings in the hospital, the progress of all stroke patients is assessed. Whenever prolongation of medical treatment is judged to be unnecessary, the care co-ordinators start preparing a patient's discharge. These care co-ordinators have an important role in the collaboration between primary and secondary care and can be considered as central actors throughout the whole care process.

Reference group

In contrast with the SSM, healthcare in the reference group ('usual care') is not structurally embedded in a co-operation model of various care providers involved in the healthcare for stroke patients. To illustrate this, there is no explicit guideline to admit all patients suspected of having a stroke to the hospital. The assessment of discharge possibilities can be characterised as ad-hoc, since it is based on the progress of rehabilitation and does not happen at set times. Whenever it is expected that homecare will be needed after discharge, this is organised by a liaison nurse.

Outcome measures

- Generic health status of patients was measured using the SIP-68 and the EuroQol. Both instruments are considered to measure the so called 'health related quality of life'. The SIP-68 contains 68 items, covering 6 dimensions of health: somatic autonomy, motor control, psychological autonomy and communication, social behaviour, emotional stability and mobility range. For each dimension the scores are straightforwardly added up, a higher score indicates a higher impact on health, implying a lower health status[13,14]. The EuroQol is a generic instrument with 5 questions about subjective health together with a so called 'health thermometer'[15]. To measure the disease specific health status we used the Barthel Index and the Modified Rankin Scale (Oxford Handicap Scale). The Barthel Index exists of 10 items concerning daily functioning and limitations of mobility[16,17] and is considered as a standard measure of disability[18]. The Modified Rankin Scale (to be called the Rankin Scale from here) is a more global measure of disability and consists of 6 scoring options, varying from 'no complaints' to 'severe limitations', with a constant need of support[19,20,21,22]. The cognitive functioning of patients was measured using the Mini Mental State Examination[23].
- To measure patient satisfaction we used several questions that were previously used in another project on stroke, the 'Research On Stroke Amsterdam'[24]. In order to measure more specifically patients' judgement about the healthcare that was delivered, we added some questions developed especially for this study about the length of hospital stay, the way patients were treated by healthcare providers and the organisation of care.
- The use of healthcare services after discharge from hospital was estimated by an inventory of the (para)medical and nursing care that patients received the first half-year after stroke.
- The place of residence and patients' living situation were documented during an interview, six months after the onset of stroke.

Data collection and statistical analyses

Patients' records served as the main source for socio-demographic characteristics, clinical data and information about the proceedings of the treatment-process. All other data were collected during an interview, six months after stroke. Since there was no prior relevant research on which our estimations of the expected effects could be based we used standardised effect sizes ($\gamma = (\mu 1 - \mu 2) / \sigma$)[25] to estimate the necessary sample sizes. With an α value of 0.05 and power of 0.70, the total sample size (number of subjects in both groups) for this study, with expected medium ($\gamma = 0.50$) effects, would be 98. Baseline clinical and socio-demographic characteristics and outcome measures were analysed using chi-square or Fisher Exact test and unpaired T- or Mann-Whitney tests when appropriate. A p-value equal to or less than 0.05 was considered statistically significant. The test-hypothesis for all the analyses performed was that there would be no difference between the two settings. Data were processed and analysed using SPSSWIN.

Results

Patients

During the period of inclusion, in total 417 patients were admitted to the hospital: 287 in the SSM group and 130 in the control group. The baseline characteristics of this initial study population are depicted in table 6.1.

Table 6.1: Baseline characteristics of stroke patients in the initial study population.

Patient characteristics	**SSM (n=287)**	**Usual care (n=130)**	**p-value**
- mean age ± sd	72 ± 12	76 ± 12	ns*
- % male/female	48/52	43/57	ns**
- % haemorrhage/infarction	21/79	15/85	ns**
Severity of stroke, affected side			
- *arm (%):*			<0.05**
no problem	7.2	20.3	
paresis	64.4	62.5	
paralysis	28.3	17.2	
- *leg (%):*			<0.05**
no problem	7.7	21.1	
paresis	78.6	69.5	
paralysis	13.7	9.4	
Co-morbidity / risk factors:			
- % previous stroke	30	20	<0.05**
- % previous TIA	19	14	ns**
- % high blood pressure	50	36	<0.05**
- % angina pectoris	24	9	<0.05**
- % myocard infarction	18	8	<0.05**
- % cabg / ptca	10	7	<0.05**
- % high cholesterol	13	5	<0.05**
- % diabetes	20	25	ns**
- % copd	14	4	<0.05**
- % smoking	35	40	ns**
- % alcohol (>10 glass/week)	16	24	ns**

* t-test
** Chi-square test

The patients who were admitted to the SSM were more seriously affected by the stroke compared to patients in the usual care group. More patients in the SSM group had suffered a previous stroke and were known with some kind of co-morbidity. Of all patients, 31% in the SSM group, and 25% in the control group had died six months after stroke. From the remaining cohorts, we managed to include 58 patients in the SSM group and 45 in the control group. All other patients, who in fact can be considered as lost to follow up, were not able or willing to participate in this interview. They represent a high number of patients which, considering the severity of this disease and its many complications (for example aphasia) is not too surprising.

The baseline characteristics of all patients who were included in this study are summarised in table 6.2. It appears that both groups did not differ concerning these characteristics with the exception of the higher number of patients in the SSM group that had previously

suffered a TIA. We also tested whether or not the interviewed patients differed from the original, larger cohorts[26]. On neither aspect were any statistically significant differences found, implying that our study group can be considered as representative for all patients with a stroke in both hospitals.

Table 6.2: Patient characteristics at the time of admission to the hospital in both groups.

Patient characteristics	**SSM group (n=58)**	**Usual care (n=45)**	**p-value**
mean age ± sd	72 ± 13	72 ± 12	ns*
% male/female	48/52	43/57	ns**
% haemorrhage/infarction	17/83	18/82	ns**
Severity of stroke, affected side			
- *arm (%):*			ns**
no problem	22	27	
paresis	47	58	
paralysis	26	16	
missing data	5	-	
- *leg (%):*			ns**
no problem	21	24	
paresis	66	60	
paralysis	7	16	
missing data	7	-	
Co-morbidity / risk factors:			
- % previous stroke	32	22	ns**
- % previous TIA	33	13	<0.05**
- % high blood pressure	47	38	ns**
- % angina pectoris	26	11	ns**
- % myocard infarction	19	7	ns**
- % cabg / ptca	14	7	ns**
- % high cholesterol	11	7	ns**
- % diabetes mellitus	19	27	ns**
- % copd	9	4	ns**
- % smoking	42	49	ns**
- % alcohol (>10 glass/week)	16	22	ns**

* t-test
** Chi-square test

Living situation

The living situation of patients during the interview, six months after the stroke, is given in table 6.3.

Table 6.3: Living situation of patients in both groups, six months after stroke.

Living situation (%)	SSM group	Usual care	p-value**
home	64	42	<0.05
sheltered living*	12	7	ns
nursing home	22	38	ns
rehabilitation centre	2	13	<0.05

* Sheltered living: residential home, living in with their children or with other family
** Chi-square test

The results show that, six months after stroke, relatively more patients in the SSM group lived in their own houses again. On the other hand, more patients in the usual care group stayed in a rehabilitation centre at that time.

Health status

The generic and disease specific health status of patients at the time of the interview is summarised in table 6.4.

Table 6.4: Health status of patients in both groups, six months after stroke.

Measure	SSM group	Usual care	p-value
- SIP-68			
mean total score (± sd)	34 ± 30	30 ± 20	ns*
- EUROQOL (% without problems)			
walking	52	31	ns*
bathing	43	44	ns*
daily activities	27	41	ns*
pain / other complaints	43	42	ns*
fear or depression	47	51	ns*
health thermometer (± sd)	65 ± 18	63 ±17	ns*
- BARTHEL Index			
mean total score (± sd)	15 ± 6	14 ± 5	ns*
- RANKIN-scale (%)			ns**
0	4	2	
1	14	16	
2	37	37	
3	11	20	
4	18	14	
5	18	10	
- Mini Mental State Examination			
mean total score (± sd)	24 ± 4.5	25 ± 5.2	ns*

* t-test
** Chi-square test

Concerning health status, both groups appear to be quite comparable six months after stroke. Some differences were detected in favour of the SSM group on three sub-scores of the Barthel Index: personal care, transport and walking stairs. This, however, was not reflected in the total score.

Patient satisfaction

The length of hospital stay of patients in the SSM group was 27 ± 19 days compared to 37 ± 37 in the reference group (ns). We asked patients how they judged this length of stay: 26% of the patients in the SSM group judged this as 'too long', compared to 53% of the patients in the reference group ($p<0.05$). Patients in the SSM group graded the quality of hospital care with 7.7 ± 0.9, patients in the control group with 7.1 ± 1.8. After dichotomising these gradings in 'sufficient' (>6) versus 'not sufficient' (<6), significantly more patients in the SSM group graded the hospital care as 'sufficient'.
Furthermore, patients were asked to judge healthcare and information, as delivered by several in-hospital care providers, see table 6.5.

Table 6.5: Patient satisfaction: healthcare providers and information in the hospital.

Patient judgement (%) with respect to:	**SSM group**			**Usual care**		
	good*	not good/ not bad	bad*	good	not good/ not bad	bad
nurses	82	16	2	71	16	13
physicians	75	22	2	74	15	12
information about disease/ treatment	37	46	17	42	10	48
information about self care	49	49	0	27	30	42

* In this table the answering modalities 'excellent' and 'good', as well as 'bad' and 'very bad' were put together in 'good', respectively 'bad'.

These results show that relatively more patients in the reference group judged the information they received about their disease as well as the information about self care as 'insufficient' ($p<0.05$).

Also, we inventorised the type and volume of healthcare that patients received in the period after discharge from hospital. We also asked whether or not patients judged this as sufficient, see table 6.6.

Table 6.6: Use of health services after discharge from hospital.

Patients (%) having received healthcare from:	SSM group			Usual care		
	received care in the past*	still receiving care	wants more care	received care in the past*	still receiving care	wants more care
physical therapy	35	38	6	26	62	56
occupational therapy	48	9	4	45	29	27
speech therapy	35	28	0	42	15	27
day care	14	14	4	15	54	50
primary nursing care	14	23	19	0	25	6
home help	9	36	23	5	37	0
social care	22	6	4	24	44	12

* 'The past' refers to the period of six months after the onset of stroke.

Compared to the SSM group, more patients in the usual care group group received physical- and occupational therapy, day care and social care six months after stroke. The SSM group, on the other hand, received a higher volume of speech therapy and primary nursing care. It is striking that patients in the usual care group group, despite the fact that they received a higher volume of healthcare, more often judged this as 'not enough', compared to patients in the SSM group. The patients in the SSM group, on the other hand, more often judged the volume of home help and primary nursing care as 'not enough'.
Finally, an inventory was made of the extent to which patients considered improvements desirable on various aspects of the healthcare they received after discharge from hospital. The results are depicted in table 6.7.

Table 6.7: Patients' judgements on aspects of healthcare that need improvement.

Number of patients (%) that consider improvement desirable on:	SSM group	Usual care	p-value*
information about whom to ask for information	65	71	ns
information about stroke	57	89	$p<0.05$
information about things to happen	45	72	$p<0.05$
listening to patients	71	68	ns
taking patients' wishes into account	70	64	ns
deliberation between healthcare providers	27	55	$p<0.05$
organising healthcare	24	60	$p<0.05$
organising adaptations in their houses	65	73	ns
healthcare as a whole	73	71	ns

* Chi-square test

It appears that patients from the reference group more often felt that various aspects could be improved, specifically, the provision of information about stroke and its consequences and the co-ordination and organisation of healthcare.

Discussion

On the basis of the results of this exploratory study, we conclude that changing the organisation of healthcare towards a stroke service can probably result in a higher number of patients who return home after stroke. We could, however, not detect any effect on the health status of patients. Together with the finding that the patients in the stroke service model consumed less healthcare after discharge from hospital, we conclude that this transmural stroke service is more efficient compared to usual care.

Our results, however, need cautious interpretation and should be considered as tentative. To begin with, despite the fact that patients in both groups were comparable concerning most relevant characteristics at baseline, selection bias can not be completely ruled out, since randomisation of patients to either one of the two models involved was not feasible. Assessing the organisation of care is complicated because the intervention to be evaluated is a complex change in the delivery of healthcare, with many different actors involved. This made randomisation very difficult because of practical reasons. Randomisation of patients within one setting was not possible since two different ways of organisation within one setting is not workable in daily practice. The randomisation of patients between both hospitals in different cities was not feasible, since this would imply long travels for patients and their relatives during the hospital stay, as well as for providers of home care after discharge. Another option would have been a pretest-posttest design, which was not possible because the transmural care model had already been implemented when it was decided to do an evaluation study. For these reasons, we designed a prospective observational comparative study to evaluate the effects of transmural care by comparing the outcomes of usual care with the outcomes of this new transmural stroke service. Another limitation of this study is the relatively small number of patients that could be included in this study. Because of these sample sizes, we were not able to detect smaller differences ($\gamma < 0.50$) between the two groups should they exist.

Furthermore, it should also be kept in mind that, because patients were recruited from two different regions, it can not be ruled out that there were more differences besides the healthcare model only. For example, social characteristics or common, regional types of housing could have had an impact on the results also.

Despite these considerations, it can be argued that our study population was representative for all Dutch stroke patients. We compared our study population with patients from a recent, large study on stroke in The Netherlands, which included 738

patients[27]. It appeared that, concerning the main baseline patient characteristics, our study population was quite similar. Therefore, we think that this study has produced some useful results that are relevant for the organisation of healthcare for stroke patients.
During the inclusion period a higher percentage of all patients who were admitted to the hospital died in the SSM-group. This is related to the finding that patients in this original cohort were more seriously affected by the stroke[26]. It can be concluded from this that SSM reached one of its goals: to have as much patients with stroke as possible admitted to hospital for diagnosis and treatment. As there is no protocol in the control group about the admission of all stroke patients to hospital, relatively more patients with a severe stroke were kept at home in this group, instead of being admitted to the hospital. A reason for this might be the wide-spread belief that for these patients, hospital admission will not be profitable[28].
One of the results of this study was that six months after stroke more patients in the SSM group lived in their own houses again. This difference is in accordance with the discharge destinations in both healthcare models[26]. Recently, another study in The Netherlands, including 760 patients with stroke, showed that almost 50% of all patients was living at home again, six month after stroke[29], which is 'just in between' the two models in our study.
A striking finding is that this difference in living situations is not reflected in differences in health status. Apparently, health status and patients' functioning are not the only criteria in determining the discharge destination. Earlier we found that the severity of stroke was not decisive in determining the discharge destination[26], now we conclude that patients' health status and functioning is not either. This could very well be one of the effects of the SSM, which was initiated to discharge as many patients home as possible. In general, our study indicates that changing the organisation of care can have an effect on patients' living situations, while not improving their health status.
Another important result concerns the difference between the two groups in the use of healthcare services after discharge from hospital, indicating that the SSM is more efficient compared to usual care. Moreover, this difference cannot be explained by differences in health status or the functioning of patients. In order to gain more insight into the real differences in costs, a thorough cost analysis would be needed, in which the costs associated with the maintenance of a stroke unit, and the personnel costs of care co-ordinators should be included. Nonetheless, one could question whether the (para)medical care after discharge from hospital, at least in the control group, was correctly brought into action. Also striking is the finding that patients in the usual care group wanted more healthcare services, despite the fact that they had already received more healthcare compared to the SSM group. Notwithstanding these differences between the two groups,

our study shows that an impressive number of patients feel the need for more healthcare service. Since there is some evidence that patients who perceive an unmet care demand do appear genuinely to have an unmet need for care[30], it can be tentatively concluded that healthcare for stroke patients still needs to be improved in The Netherlands.

Compared to patients in the usual care group, the patients in the SSM group scored higher on patient satisfaction. This could be explained by the fact that healthcare providers in the SSM have reached a higher degree of attunement and co-ordination of their actions, with explicit feedback moments, allowing them to improve their performance. Although our results with respect to patient satisfaction are coherent with other findings[31], it can not be ruled out that cultural differences between the two groups could also have played in role here. Nonetheless, our results show that patient satisfaction in both groups can still be significantly improved.

Finally, the study reported on here should be seen as merely a study of just one single case of transmural care. In order to formulate a general conclusion about transmural care for this group of patients, more cases of transmural care should be evaluated. Our study has produced some first tentative results, which can be considered as a first step. Since randomisation in case of transmural care is difficult, we believe that the most possible path will be replications of our study. We demonstrated that for this purpose, this design is feasible. To aggregate the results in a databank or knowledge-centre could be very helpful as a next step. In this way, evaluation could become part of the ongoing development of transmural care in The Netherlands.

Postscript

Very recent, the results of an evaluation of three stroke services in The Netherlands were published[32]. These three stroke services were compared with three usual care models. It appeared that (only) one of these stroke services could be considered as cost-effective, compared to usual care. The main characteristics of that particular model are to a large extent similar to that of SSM, which we have evaluated in this current study. Also, one of the reference groups in that study was the same hospital as the control group in the study described above.

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CHAPTER 7

General discussion

Introduction

The aim of this thesis was to evaluate structurally embedded transmural care. Performance indicators for the evaluation were the extent to which embedded transmural care, as compared to usual care, results in better patient outcome, in better patient judgement with respect to the healthcare received and in different utilisation of healthcare services. In order to answer these research questions, three case studies of structurally embedded practice were carried out in a comparative cohort approach. In this final chapter, the results of these different evaluations of transmural care are appraised and synthesised. After answering the research questions, attention is given to the methodology of this study. Then implications for further research are presented, followed by implications for clinicians and healthcare managers. Finally, recommendations for policymakers are formulated.

Research findings

Based on the results of the three case assessments of transmural care, the answers on the research questions of this thesis are summarised per patient-category below.

Research question 1:
Does transmural care result in better patient outcome compared to usual care?

- *diabetes mellitus*

We concluded that good, or at least acceptable, glycaemic control can be achieved by the majority of patients in both settings involved in this study. This conclusion is of major concern, as the importance of good glycaemic control can hardly be overestimated. With respect to glycaemic control in the long run, the transmural care model performed better than usual care since two years after initiating insulin therapy, the percentage of patients with good glycaemic control was higher in the transmural care group. This difference was still present after 3 and 4 years. The differences between the two care models as found in glycaemic control were not reflected in differences in health status. Considering these results and the other potential long term advantages (early detection) of the transmural care model, we concluded that this design is at least as effective as usual care.

- *total hip replacement*

Both patient groups improved significantly with respect to their health status in the period between two weeks before total hip replacement and six months after the replacement, confirming that this surgical intervention is highly effective in itself. However, the results

of rehabilitation of patients in the usual care group were significantly better than those in the transmural care group.

- *stroke*

In case of stroke, no differences were found between the two models with respect to the health status of patients and their functioning six months after stroke. This implies that the change in the organisation of healthcare did not have any effect on the health status of patients.

Research question 2:
Does transmural care compared to usual care result in better patient judgement concerning the healthcare received?

- *diabetes mellitus*

We could not detect any differences in patient judgements between the two models. Both the results on the Diabetes Treatment Satisfaction Questionnaire and the patients' gradings with respect to the healthcare they received were comparable. Also, the percentage of patients that judged improvements desirable on various aspects of healthcare did not differ between the two models.

- *total hip replacement*

Likewise, no differences in patient judgements were detected between transmural care and usual care in this patient category. The gradings of patients in both groups were similar, just as were their judgements about the information they received, the organisation of home care and the deliberation between the various healthcare providers involved.

- *stroke*

Stroke patients in the transmural care setting judged the healthcare they received better than the patients in the usual care model did. Significantly more patients in the transmural care group were satisfied with the limited length of hospital stay. Also, compared to usual care, more patients in the transmural care group graded the hospital care they received as 'sufficient'. Finally, patients in the transmural care group judged the information they received about their disease and the training on self-care better compared to patients in the usual care setting.

Research question 3:
Does transmural care result in different utilisation of healthcare services compared to usual care?

Per patient category the utilisation of healthcare services is summarised. This is considered as a rough estimate of costs. Using this, a global conclusion concerning the trade off between patient outcome (research question 1) and the utilisation of healthcare (research question 3) is used to indicate the efficiency of healthcare.

- *diabetes mellitus*

Earlier it was demonstrated that the first year after initiation of insulin therapy, transmural care and usual care are quite comparable with respect to both costs and effectiveness[1]. In addition, we now concluded that in the longer run the transmural care model results in a higher percentage of patients with good glycaemic control. This probably has a positive effect on future health status and (thus) will reduce future care utilisation and expenditures. Based on these findings we conclude that, compared to usual care, this model is at least as efficient.

- *total hip replacement*

No differences were found in the length of hospital stay. In the period of rehabilitation, however, patients in the transmural care group received more homecare, with a higher frequency and for a longer period of time. It was argued that this higher volume of after-care in the transmural care model could very well have prevented these patients from functioning independently, resulting in a lower health status. Our results indicate that this particular form of transmural care for patients undergoing total hip replacement is not efficient.

- *stroke*

We demonstrated that a) relatively more patients in the transmural care model returned home after their stroke and b) less healthcare in the period of rehabilitation was brought into service in this model. These differences could not be explained by differences in the severity of stroke, in health status, or in functioning of patients. Based on these findings we conclude that this model for patients with a stroke is probably more efficient than usual care. On the other hand, it can not be ruled out that in the beginning of the care-process, during the hospital admission period, this particular form of transmural care will turn out to be more expensive because of the maintenance of a stroke unit and the higher personnel costs (transfer nurses).

The answers on the three research questions are summarised in table 7.1.

Table 7.1: Effects of transmural care compared to usual care in three different patient-categories

Performance indicator→ / Patient category↓	Generic health status	Disease specific health status	Patient judgement	Use of healthcare services
diabetes mellitus	similar	higher	similar	similar
total hip replacement	lower	similar	similar	higher
stroke	similar	similar	better	lower

The results in this thesis demonstrate that transmural care can indeed have an effect on patient outcome, on patient judgement and on the use of healthcare services, but that these effects are not impressive and not unambiguous. When we started this study, not much was known about the effects of transmural care. After having finished our study, information about the effects of three particular forms of transmural care is added to the available body of knowledge. The present, general conclusion is that no conclusive, unambiguous answer can be given to the question whether to promote or scale down transmural care (see table 2.1.). In line with this, and with respect to the performance indicators in this study, there also is no unambiguous justification for the general faith in the positive effects of transmural care. The positive (and negative) effects are most probably determined primarily by the specific design of every single transmural care project.

These conclusions have implications for the recommendations for researchers, clinicians and policymakers, given after discussing the strengths and limitations of this study in the next section.

Methodological considerations

The methodology of this assessment deserves some more attention, as there are factors that can be considered as a potential threat to the validity of this study.

- First, because only three examples of transmural care out of a range of many more were involved in this assessment, one could argue that the outcomes do not necessarily hold truth for other transmural care projects. Because of this, the results should be interpreted cautiously. However, the included projects are, compared to most other transmural care initiatives in The Netherlands, relatively mature. They can be considered as typical examples of how transmural care can work out in daily practice.

- Second, the relatively small sample sizes in the three assessments can be considered as a threat to the validity of their results. The sample sizes were relatively small because of several reasons. As argued in Chapter 2, it was decided to include several patient-categories in this study to answer the research questions. This resulted in fewer patients to be included in the different assessments. Furthermore, about halfway through the study it became clear that, for various reasons, the number of patients who could be included turned out to be lower than the number estimated in advance. Per patient category this had a negative effect on the power of the statistical tests. Therefore, it can not be ruled out that we were not able to detect existing smaller differences between the various groups. In Chapter 2 a general rule of thumb for the sample size in relation to the expected effects was given. Based on this we conclude that the sample size in case of patients with diabetes mellitus turned out to be large enough to detect existing large effects ($\gamma = 0.80$), whereas the sample sizes in both other cases were almost large enough to detect existing medium sized differences ($\gamma = 0.50$) between the groups.
- Another issue concerns the extent to which the chosen design has been adequate for answering the research questions. In Chapter 2 it was argued that, considering the stage of diffusion and the characteristics of transmural care, an observational cohort study was the optimal design for answering the research questions under the given circumstances. We demonstrated that this design is indeed useful to detect differences between healthcare models in daily practice. Within the limited timeframe of a few years such a study design is feasible, and useful to answer questions with respect to the effects of organisational changes in embedded practice. On the other hand, it should be noted that this design implies the risk of introducing (unknown) confounding factors[2]. To address this issue, we carried out (multiple) regression analyses afterwards in order to determine whether adjustment for confounding would have significant consequences for the conclusions. In all three studies we tested the extent to which the main outcome measure, i.e. generic or disease specific health status, was influenced by other factors than the difference in health care setting, such as the patient characteristics registered at baseline. In case of patients with diabetes mellitus we tested the influence of gender, origin, BMI (Body Mass Index), age and duration of diabetes on the HbA1c-percentage in 1997 and on the total decrease in the period 1993 - 1997. Multiple regression analysis (stepwise method) showed that none of these confounders had a significant influence on the HbA1c-percentage in 1997, nor on the total decrease during the period of our study. The confounder with the strongest influence with respect to the HbA1c-percentage in 1997 appeared to be patients' BMI ($p=0.071$). At baseline, both groups were comparable with respect to

the mean BMI (27.4 vs 29.1, see table 4.1), implying that the effects of the BMI of patients were equally distributed among both groups. Not surprisingly, adjusting for this confounder consequently did not change the outcome of the analysis in any significant way. In case of patients undergoing total hip replacement we tested in a similar way (stepwise method) to what extent patients characteristics were significantly associated with the main outcome measure, the (SIP) Sickness Impact Profile. The age of patients appeared to be a significant predictor for the total SIP scores 6 months after the hip replacement (p=0.001). The mean age of patients in both groups, however, was comparable (69.8 years vs 67.2 years, p=0.19, see table 5.1). Adjusting for this potential confounder again did not result in different outcomes of our study. We also tested the effects of these potential confounders on the total decrease in SIP-scores between 2 weeks before, and 6 months after the hip replacement. The only factor contributing significantly (p=0.02) to this decrease was the study group to which patients belonged, which confirms the conclusions of our study. In case of patients with a stroke, we tested the influence of patient characteristics such as age, gender, type of stroke, severity of stroke, co-morbidity and lifestyle (smoking, drinking alcohol) on one of the main outcome measures, the SIP. With respect to SIP-scores, two factors were identified (stepwise-method) as significant predictors for the total SIP-score: the age of patients (p=0.016) and the presence of diabetes mellitus (p=0.024). There was, however, no significant difference between the two groups with respect to these two factors, see table 6.2. Subsequently, we nevertheless adjusted the outcomes for these confounders, which in this case again did not change the results of the study. Still, and despite these analyses, it can not be ruled out that somehow we missed unknown confounders we did not measure. However, such disadvantages, which are inherent to this type of study, in this case easily are outweighed by its merits. To our opinion it is better to have possibly inaccurate information than no information at all, however accurate the latter could have been. In conclusion, transmural care in structurally, embedded practice can be considered as a typical example of an area in which observational studies are very useful for evaluation[3,4].

- With respect to the three outcome measures in this thesis: patient outcome, patient judgement and the utilisation of healthcare services, it should be noted that the first two were elaborated more extensively than the last indicator in this thesis. As described in Chapter 2, the costs were approached by an inventory of the volume of healthcare services that was brought into action in the various healthcare settings. This approach results in an indication of the real costs; in order to generate more valid information concerning this issue, more thorough cost-analyses are needed.

Summarising, these methodological considerations on the one hand underline the necessity of handling our results with a certain reserve. On the other hand we conclude that our study has brought up important findings that can be useful for the organisation of healthcare as well as for research in this field.

Implications for further research

When we started our study in 1996, not much was known about the effects of transmural care in The Netherlands and about the way this could, or should, be evaluated. Despite this lack of knowledge, hundreds of transmural projects had already been initiated in The Netherlands. In this thesis, we assessed three models that were regarded to be representative. As mentioned before, we did not evaluate the concept of transmural care as such, but three running examples. We have concluded that findings about the effects of transmural care are not unambiguous. Subsequently, we argued that the particular design of every transmural care project is of extreme importance, which therefore justifies close monitoring and further research.

An optimal evaluation strategy, starting from where we are in The Netherlands today, might be to carry out several more evaluations. These evaluations should be accompanied by critical examinations of the models themselves, and the factors that are important in the success of transmural care should be identified. On the basis of these results, an 'optimal' model could be designed, implemented and tested in a randomised trial. Such a path is probably feasible, be it complicated, but it would be quite expensive and difficult to organise. One might ask whether the expenses and efforts would be worth the outcome, and whether there are no reasonable alternatives.

Evaluating existing models is easier and less expensive. The assessments in this thesis show that this is indeed feasible. The weaknesses in the design of this study are, to an extent, obvious. But the alternative presented above is not very attractive either. It is questionable, among other problems, that the resources for carrying out a large effort at design and evaluation of an ideal model of transmural care will be available. Along with other factors discussed throughout this thesis, this indicates serious problems of feasibility of randomised trials in this field in The Netherlands today.

Therefore, we believe that the most practical and efficient path would be to organise replications of our studies and similar evaluations of other models of transmural care. Aggregating the results in a databank or knowledge-centre could be a help. Also, the categorisation of transmural care as proposed in table 2.2 might be useful here. In this way, evaluation can be made part of the ongoing development of transmural care in The

Netherlands. Because this strategy has now been proven feasible and probably satisfies the need of evidence in the most cost-effective way, it is this path we recommend.

In order to realise such evaluations of transmural care, some practical considerations for (future) researchers following from our experiences are given below.

- Concerning the study design, we conclude that a workable and even sufficiently robust design for this purpose is the observational, comparative cohort study. Earlier in this chapter, we discussed the methodological strengths and limitations of this design.
- In addition, it should be noted that in case of the assessment of transmural care, the application of this design requires the involvement of (at least) two geographically separated healthcare settings. Researchers should not only realise that this implies extra deliberations with the healthcare providers involved, but that it also complicates the data-collection. More and different staff is needed to co-operate, medical records can vary between different healthcare organisations, data collection consumes more time, and so forth. Including two geographically separated healthcare settings, on the other hand, has one important advantage, which is the prevention of 'cross study-group contamination'. This contamination happens easier when patients, as well as healthcare providers work and live close(r) together. They meet each other, and the exchange of information about the different organisational aspects, or even the evaluation, becomes highly probable. Such exchanges of information could easily influence results.
- Finding an adequate control setting that is similar to the transmural care model with respect to (other) cultural aspects is not easy. Also, there has to be an incentive to co-operate: *"What's in it for me?"*. These are important aspects for researchers to keep in mind when organising an assessment following the design outlined in this thesis. A major advantage of this type of study design on the other hand is the fact that it gives a valid picture of the effects of the intervention in daily practice. No translation of the results to 'the real world' is needed.

The experiences from our evaluation might help other researchers to continue on this relatively new path by using similar methodology, instruments and questionnaires. By doing this, a future comparison with our results would become feasible, which would also contribute to the body of knowledge about the effects of transmural care.

Implications for clinicians and healthcare managers

Until now the assessment of the effects for patients of changing the organisation of healthcare has not received much attention (see Chapters 1, 2 and 3). This is unfortunate.

The general assumption seems to be that 'improvements' of the organisation of healthcare automatically result in other improvements, such as patient outcome, patient judgement or the utilisation of healthcare services. We demonstrated that in case of transmural care, practice does not confirm justification of this assumption. Because of this, evaluation of such organisational changes deserves higher priority, especially because the expected improvements of such changes could just as well turn out quite adversive in practice (Chapter 5). The general conclusion that transmural care can indeed have an impact on several major outcomes is relevant for clinical practice. Since we demonstrated that these effects are quite diverse, this will be discussed per patient category.

- First of all, we concluded that in case of patients with diabetes mellitus type 2 starting with insulin therapy, a higher percentage of patients with good glycaemic control was realised in the transmural care setting. This finding is important, since the relevance of good glyceamic control for future health status and healthcare expenditures can hardly be overestimated. Furthermore, it was argued that because of the lower threshold in the transmural care model, more patients with (undiagnosed) diabetes mellitus could potentially be detected. In the longer run, this could result in an overall gain in population health status, given the number of undiagnosed patients, the severe late complications of this disease, and the availability of good treatment modalities. Also, until now there was hardly any solid evidence available to support the delivery of insulin therapy in primary care. Our study demonstrated that initiating insulin therapy in patients with diabetes mellitus type 2 in a transmural care model is certainly not inferior to a secondary, outpatient model, provided that several conditions to assure the quality of care are met.
- In the case of total hip replacement, we confirmed that this surgical intervention is a highly effective one, since the health status of patients in both groups improved significantly. Comparing the transmural care model with usual care resulted in differences in patient outcome as well as in costs, both in favour of usual care. We argued that the higher volume of after-care in the period of rehabilitation could very well have an adverse outcome on the independence of patients, resulting in lower overall health status. This is highly important as it demonstrates that an 'improvement' in the organisation of healthcare can work out to be harmful. In this particular case, reconsideration of the use of after-care in the rehabilitation period is needed, and it should be aimed more explicitly at improving the patients' independence.
- With respect to patients with a stroke, no evidence was found for a better recovery in the transmural care model. It was argued that changing the organisation of healthcare has a marginal effect on patient outcome because, in this case, the severity of stroke

is by far the most dominant predictive component. On the other hand, significantly more patients in the transmural care model returned home after stroke, which is probably the result of a better co-ordination between the various healthcare providers involved in this model. Also, patient judgements were better in this transmural care model. Since both differences are in favour of transmural care, it justifies making efforts to realise such organisational changes.

We demonstrated that transmural care can have an effect on the performance of clinicians and managers in healthcare. Proper evaluation, or at least monitoring, is very important, since the effects of implementing transmural care are ambiguous and not necessarily always positive. Based upon valid information generated by suitable evaluations, both clinicians and managers will be able to adjust their policies and actions.

Implications for policymakers

Effective, and efficient healthcare is of major concern also for policymakers. Innovations that can contribute to this major target should be encouraged and facilitated. Innovations that are a (potential) threat, on the other hand, should be discouraged, see table 2.1. Whenever the effects of such innovations are unknown, assessment is justified. In the case of transmural care, however, reality proved to be quite different: hundreds of projects were initiated with very little or no evidence with respect to its (assumed) effects. Therefore it can be argued that the Dutch approach towards initiating transmural care has been not well thought over. It would have been preferable to test some well designed model programmes on efficacy before starting widespread implementation. Afterwards, diffusion could have been promoted on the basis of the proven results.

Apparently, research on the effects of organisational changes has not had a high priority up to now. It was argued in Chapter 3 that this is not only because of methodological difficulties. Also the interest of clinicians lies primarily in improving the effectiveness of medical interventions, and not of the organisational settings in which they are embedded. In fact, organisational aspects are not perceived as potential 'study-objects'. Policymakers, on the other hand, think of organisational changes like transmural care and its assessment, as a responsibility of healthcare providers. Because of this, research on transmural care has had little attention, up to now. This is unfortunate, as demonstrated in this thesis: transmural care can have positive as well as negative effects on patient outcome, on patients' judgement with respect to the healthcare received and on the utilisation of healthcare services.

The effects of transmural care as demonstrated in this thesis are modest. One could even question whether, taken the amount of effort put into these projects, transmural care should better be scaled down. We think this would not be the right thing to do for several reasons.

- First, we demonstrated that transmural care can indeed have positive effects, of which (many) patients as well as society should benefit. The finding that transmural care can have negative effects as well, is an important warning and underlines the importance of, at least, monitoring the effects of this organisational change. In this way, adverse effects could be minimised since it enables clinicians to adjust their actions in time.
- Second, in this thesis three performance indicators of transmural care were measured. It can not be ruled out that transmural care performs significantly better (or worse) with respect to other performance indicators[5]. Besides these indicators identified earlier, transmural care might also have a positive effect on the satisfaction of healthcare providers. This outcome measure was not included in our study, but it could very well be one of the main reasons for the present success of transmural care. Although healthcare-provider satisfaction is not a 'formal' goal of transmural care[6], it could in itself be sufficient reason to initiate transmural projects, provided no adverse effects to patients or society occur (for example with respect to patient outcome). This also underlines the importance of close monitoring.
- Third, it can be argued that transmural care should be considered as a first, cautious step towards more comprehensive approaches such as disease management, or integrated care. And if modest effects can be attained with transmural care, it is plausible (but not proven!) that a more comprehensive approach could lead to larger effects. From this perspective transmural care should certainly not be scaled down, or, in other words: one should not throw away the child together with the bath-water. Also from this point of view the monitoring of (side-)effects is very important. It has been stressed elsewhere that measuring health outcomes are crucial for the success of disease management programmes[7].

Whatever the outcome of the decision-making towards the future of transmural care might be, and whether or not transmural care will be further developed towards more comprehensive models, the importance of close monitoring of (side-) effects remains highly important. On the basis of the results of this thesis, we strongly recommend the evaluation and monitoring of new (and existing) initiatives, and to make this knowledge readily available. As argued in Chapter 3 and in this chapter, it might be worthwhile to gather expertise and relevant information with respect to the effects of transmural care in some kind of knowledge-centre, or expert-panel. This would also enable healthcare

providers planning to start with new initiatives, to discuss their plans with these expert-panels prior to actual implementation. In this way, the available knowledge of barriers to, as well as factors promoting successful implementation of transmural care, can be used in an efficient way.

In case transmural care is to be further developed towards disease management or integrated care, one should realise that this will result in resistance amongst healthcare providers, since it inevitably implies a reduction of their professional autonomy. This is what can be learned from the experiences in the United States[8,9,10,11,12]. In order to succeed, incentives for healthcare professionals have to be created. Without their active involvement in such changes, things will not work out in The Netherlands.

In this thesis we evaluated the effects of embedded transmural care in comparative cohort studies. We demonstrated that these effects are modest, and not unambiguous. No justification for the enthusiasm for transmural care in The Netherlands was found. In order to improve the outcomes of healthcare, reliable information about activities and results is needed. Surprisingly, the monitoring of such crucial parameters is still not part of regular healthcare today.

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SUMMARY

The preface describes that transmural care refers to care given 'through the (virtual) walls' of the existing healthcare system. It aims to bridge the gap between different levels of healthcare providers, most often that which exists between primary and secondary care. Transmural care should not be considered as a specific medical intervention, but as an alternative way of organising healthcare and the medical interventions embedded therein. The main goals of transmural care are to improve the effectiveness, quality and efficiency of healthcare.

In spite of its widespread application in The Netherlands, little is known about the effects of transmural care in practice. That transmural care has positive effects on effectiveness, quality and efficiency of healthcare is not much more than an assumption. In order to increase knowledge about the effects of transmural care in structurally embedded practice, we carried out three different observational, comparative cohort studies. In all three studies, transmural care is compared with usual care. The main outcome measures are patient outcome (as an indicator of effectiveness), the judgement of patients about the healthcare they have received (as an indicator of quality of care) and the utilisation of healthcare (as an indicator of efficiency).

Chapter 1 describes the concept of transmural care in The Netherlands. The differences and similarities with related concepts such as shared care, disease management and integrated care are discussed. It appears that transmural care is to a large extent equivalent to the concept of shared care, which has emerged in the United Kingdom. To obtain a better understanding of transmural care, projects can be categorised in terms of organisational measures ('intermediate goals') and complexity. Based on this categorisation and the availability of mature, representative transmural care projects in daily practice, three transmural care models were selected for this evaluation: one concerning patients with diabetes mellitus, one for patients undergoing total hip replacement and one for patients with a stroke.

The research methodology used to evaluate transmural care is described in **Chapter 2**. Observational comparative cohort studies are demonstrated to be useful in answering research-questions concerning the effects of transmural care in structurally embedded practice. The most important argument here is the fact that transmural care has already widely diffused in healthcare practice. The phase in which transmural care might have been evaluated as a concept has long since passed. Furthermore, and related to this, we were mainly interested in the effects of transmural care in daily practice, and not under

controlled circumstances. Because of these considerations, an observational, comparative cohort design was both suitable and feasible for our purpose.

Chapter 3 describes a review of available Dutch literature with respect to the effectiveness of transmural care. The annual volumes of all relevant Dutch journals were scanned on the keywords: 'transmural' and 'transmural care'. Also, several databases were scanned on recent dissertations that could possibly provide information on the effects of transmural care. Subsequently, the quality of the evidence found was categorised by declining robustness based on accepted rules of evidence varying from meta-analyses to case series. In total 17 useful publications were found. Strongest evidence (in favour of transmural care) was found concerning integrated treatment of risk-pregnancy at home, end-stage cancer patients, intravenous ant microbial treatment at home and structured care for patients with diabetes mellitus type two. Taking the great number of running projects into account we concluded that there is little reliable evidence available with respect to the effects of transmural care in healthcare practice.

Chapters 4, 5 and 6 describe the three different comparative cohort studies used to evaluate transmural care in structurally embedded practice.

The case of patients with diabetes mellitus is the subject of **Chapter 4**. We carried out a retrospective comparative cohort study to evaluate the initiation of insulin therapy in patients with diabetes mellitus type 2. All patients in both settings who started with insulin therapy in 1993 were followed up 4 years later. Subsequently, all patients who could be traced, and who were willing to participate in this study, were interviewed in 1997. It appeared that, in the period 1993 - 1997, the mean glycated haemoglobin fell from 9.1% to 7.2% in the transmural care group ($p=0.000$) and from 9.3% to 7.6% in the outpatient group ($p=0.000$). In this period the percentage of patients with poor glycemic control (glycated haemoglobin>8.5%) decreased from 60% to 8% in the transmural care group, compared to a decrease from 59% to 15% in the outpatient group. The percentage of patients with good glycemic control (glycated haemoglobin<7%) between 1993 and 1997 increased from 4% to 52% in the transmural care group and from 11% to 30% in the outpatient care group. No statistically significant differences were found between the patient groups with respect to health status, self-care behaviour and patient satisfaction. We concluded that insulin therapy in patients with diabetes mellitus type two can at least be as effectively delivered in a structured, transmural care setting as in conventional secondary, outpatient care.

The second case concerns patients undergoing total hip replacement. This study is described in **Chapter 5**. All patients in both participating hospitals were monitored in the period from two weeks before total hip replacement to six months after the operation. At baseline, both patient groups were comparable with respect to patient characteristics, hip function and health status. The mean improvement in the total Sickness Impact Profile score between two weeks before hip replacement and six months after was -1.92 in the transmural care group, compared to -5.11 in the usual care group. This difference is in favour ($p=0.001$) of usual care. No differences were found between the two groups in the judgements of patients with respect to the healthcare received. The length of hospital stay was comparable in both settings: 12.8 days in the transmural care group and 13.2 days in the usual care group. After hip replacement, compared to usual care, patients in the transmural care group received more home care in terms of higher frequency and length of time. On the basis of these results, we concluded that the cost-effectiveness of this specific form of transmural care is inferior compared to usual care. We strongly recommended a critical appraisal of the utilisation of home care after hip replacement in view of the need to stimulate patient independence.

The third case study is about patients with a stroke. This prospective, comparative cohort study is the subject of **Chapter 6**. All stroke patients admitted to both the participating hospitals in the inclusion period were monitored. Six months after the onset of stroke, all patients who were willing and able to answer the questions about their health status and the healthcare they received, were interviewed. At that time, 64% of the surviving patients in the transmural care group had returned home, compared to 42% in the reference group ($p<0.05$). This difference could not be explained by differences in health status between both groups, which was comparable at that time. The transmural care model scored better on patient judgements. Furthermore it appeared that patients in the usual care group received a higher volume of home care. These results indicate that this specific form of transmural care for stroke patients might be cost-effective compared to usual care.

In the last chapter (**Chapter 7**) the three case studies are appraised critically. While the results should be interpreted with caution, the observational, comparative cohort study design is nevertheless feasible and sensitive.
The results of this thesis demonstrate that transmural care can indeed have an effect on patient outcome, patient judgement and the use of healthcare services. These effects however, are modest and not unambiguously in favour of transmural care. On the basis of these results, we conclude that there is no clear justification for the general belief in the

positive effects of transmural care. Instead, it is the specific design of every transmural care project that is decisive for actual improvements.

The issue thus emerging from a health policy point of view is whether transmural care should be further promoted, or rather scaled down. It is argued that scaling down would be incorrect. First, this is so because patients and society should not be denied the possible benefits from transmural care. Second, we only measured three performance indicators, whereas other outcomes might also be of importance. Third, it can be argued that transmural care is a first, cautious step to a more comprehensive approach, such as disease management or integrated care. If so, then this could possibly lead to more decisive results.

But, whatever the outcome of future decision-making concerning transmural care, the importance of close monitoring of (side) effects can hardly be overestimated. On the basis of the results of this thesis, we strongly recommend a) the evaluation and monitoring of new (and existing) initiatives, and b) making the resulting knowledge readily available. Gathering expertise and relevant information with respect to the effects of transmural care in some kind of knowledge-centre, or expert-panel, might be worthwhile. This would also enable healthcare providers who intend to start with new initiatives, to discuss their plans with these expert-panels prior to actual implementation. In this way, the available knowledge of barriers to, as well as factors promoting successful implementation of transmural care, can be applied in an efficient way.

SAMENVATTING

Het concept transmurale zorg werd in 1994 in de Nederlandse gezondheidszorg geïntroduceerd. Gezien de grote hoeveelheid projecten die inmiddels onder deze noemer van start zijn gegaan, kan het een groot succes worden genoemd. Transmurale zorg is omschreven als *zorg die, toegesneden op de behoefte van de patiënt, wordt verleend op basis van afspraken over samenwerking, afstemming en regie tussen generalistische en specialistische zorgverleners, waarbij sprake is van een gemeenschappelijk gedragen verantwoordelijkheid met expliciete deelverantwoordelijkheden*. De term refereert naar zorg 'door de (virtuele) muren' van de huidige gezondheidszorg, en is in de meeste gevallen gericht op coördinatie van eerste- en tweedelijnsactiviteiten. Bijvoorbeeld tussen ziekenhuizen en thuiszorg. Transmurale zorg is geen medische interventie, maar een alternatieve wijze van de organisatie van zorg, waarin medische interventies zijn ingebed. De beoogde doelen van transmurale zorg zijn een verbetering van de effectiviteit, van de kwaliteit van zorg en van de doelmatigheid ervan.

Ondanks het grote aantal lopende projecten is er nog maar weinig bekend over de effecten van transmurale zorg in de praktijk. Goed beschouwd is het op dit moment niet meer dan een aanname dat transmurale zorg resulteert in de beoogde, positieve effecten. Teneinde de kennis omtrent de effecten van structureel ingebedde transmurale zorg te vergroten hebben wij drie vergelijkende cohortstudies uitgevoerd. Deze casestudies, die zijn beschreven in dit proefschrift, betreffen een vergelijking tussen transmurale zorg en gebruikelijke zorg. De belangrijkste uitkomstmaten zijn de gezondheidstoestand van patiënten (als een indicator voor de effectiviteit van zorg), de mening van patiënten over de ontvangen zorg (als een indicator voor de kwaliteit van zorg) en de zorgconsumptie (als een indicator voor doelmatigheid).

In **hoofdstuk 1** wordt verder ingegaan op het concept transmurale zorg. Overeenkomsten en verschillen met termen die vaak in verband worden gebracht met transmurale zorg worden hier beschreven. Voorbeelden zijn 'shared care', 'disease management' en 'integrated care'. Geconcludeerd wordt dat vooral het concept 'shared care', afkomstig uit het Verenigd Koninkrijk, ongeveer gelijk is aan het Nederlandse begrip transmurale zorg. In dit proefschrift zijn beide termen dan ook onderling uitwisselbaar.
Teneinde meer vat te krijgen op het verschijnsel transmurale zorg, wordt een categorisering voorgesteld in enerzijds de in het kader van transmurale zorg genomen maatregelen (ook wel te beschouwen als tussendoelen) en anderzijds in de complexiteit van het betreffende transmurale project. Op basis van dit onderscheid, en de beschikbaarheid van volgroeide, representatieve vormen van transmurale zorg, werden drie zorgmodellen in deze studie geïncludeerd. Eén voor patiënten met diabetes mellitus,

één voor patiënten die een totale heup vervanging ondergaan en één voor patiënten met een beroerte.

De methodologie van het uitgevoerde onderzoek is beschreven in **hoofdstuk 2**. Beargumenteerd wordt dat observationeel vergelijkend cohort onderzoek een bruikbaar design is voor het beantwoorden van vragen over de effecten van transmurale zorg in de dagelijkse praktijk. Dit vooral vanwege het feit dat transmurale zorg inmiddels al wijd verspreid is in onze gezondheidszorg. De (academische) fase waarin transmurale zorg mogelijk als concept kon worden geëvalueerd is reeds voorbij. Bovendien waren wij met name geïnteresseerd in de effecten van structureel ingebedde transmurale zorg.

Om na te gaan wat er in de literatuur bekend was over de effecten van transmurale zorg in Nederland is een literatuurstudie verricht. Deze studie is beschreven in **hoofdstuk 3**. Van alle belangrijke Nederlandse tijdschriften werden de beschikbare jaargangen nagezocht op de trefwoorden 'transmuraal' en 'transmurale zorg'. Voorts werden de databanken Dutch Medical Dissertations en die van het Nederlands Instituut voor Wetenschappelijke Informatiediensten nagezocht op mogelijk relevante proefschriften. Alle zo gevonden publicaties werden vervolgens beoordeeld op de kwaliteit van bewijs. In totaal werden 17 publicaties van effectevaluaties gevonden met een grote variëteit aan diagnosegroepen. Het sterkste bewijs dat transmurale zorg positieve effecten sorteert werd gevonden bij geïntegreerde thuisbehandeling van risicozwangeren, bij transmurale zorg voor terminale kankerpatiënten, bij intraveneuze behandeling met antimicrobiële middelen thuis en bij gestructureerde transmurale zorg voor patiënten met diabetes mellitus type 2. Afgezet tegen het grote aantal lopende transmurale projecten (enige honderden) concluderen wij dat er opvallend weinig is gepubliceerd over de effecten daarvan.

De hoofdstukken 4, 5 en 6 beschrijven de drie vergelijkende cohortstudies die wij hebben uitgevoerd naar de effecten van transmurale zorg in de dagelijkse praktijk.

Hoofdstuk 4 beschrijft een retrospectief, vergelijkend cohortonderzoek naar transmurale zorg voor patiënten met diabetes mellitus type 2. Het betreft twee groepen van patiënten die in 1993 zijn gestart met insulinetherapie: één in een gestructureerd, transmuraal zorgmodel, en één in de gebruikelijke poliklinische structuur. Allen werden vier jaar gevolgd en uiteindelijk in 1997 geïnterviewd. Tussen 1993 en 1997 daalde de gemiddelde HbA1c-waarde van 9,1% naar 7,2% bij de patiënten in de transmurale groep (p=0,000) en van 9,3% naar 7,6% in de poliklinische groep (p=0,000). Het percentage slecht

ingestelde patiënten (HbA1c>8%) daalde van 60% naar 8% in de transmurale groep en van 59% naar 15% in de poliklinische groep. Het percentage goed ingestelde patiënten (HbA1c<7%) steeg van 4% naar 52% in de transmurale groep en van 11% naar 30% in de poliklinische groep. Er werd vier jaar na het starten met insuline geen statistisch significant verschil tussen beide groepen gevonden aangaande generieke gezondheidstoestand, zelfzorggedrag en tevredenheid. Op basis hiervan concluderen wij dat het instellen op insuline van patiënten met diabetes mellitus type 2 in een gestructureerde, transmurale organisatievorm minstens even effectief is als in een poliklinische setting.

Hoofdstuk 5 beschrijft een prospectief vergelijkend cohortonderzoek naar transmurale zorg voor patiënten die een totale heupvervanging ondergaan. Ook hier werd een transmurale setting vergeleken met een gebruikelijke zorgvorm. Alle patiënten die in beide deelnemende ziekenhuizen werden opgenomen voor een totale heupvervanging werden gevolgd van twee weken voor de ingreep tot zes maanden erna. Voor de operatie waren beide groepen vergelijkbaar qua algemene kenmerken, heupfunctie en gezondheidstoestand. In de periode van twee weken voor de operatie tot zes maanden erna verbeterde de gezondheid volgens de 'Sickness Impact Profile' met -1.92 in de transmurale groep en met -5.11 in de referentiegroep. Dit verschil is in het voordeel van de referentiegroep (p=0.001). Er werden geen verschillen gevonden aangaande de tevredenheid over de ontvangen zorg. De gemiddelde opnameduur in het ziekenhuis was vergelijkbaar tussen beide groepen: 12.8 dagen in de transmurale groep, en 13.2 dagen in de referentiegroep. Voorts bleek dat in de periode na de ingreep de transmurale groep meer thuiszorg, met een hogere frequentie en voor een langere periode ontving. Op basis hiervan concluderen wij dat deze vorm van transmurale zorg niet kosteneffectief is. Teneinde de onafhankelijkheid van patiënten zoveel mogelijk te stimuleren, is aanbevolen de inzet van thuiszorg tijdens de revalidatieperiode kritisch onder de loep te nemen.

Het derde vergelijkend cohortonderzoek betreft patiënten met een beroerte en is onderwerp van **hoofdstuk 6**. Ook in dit prospectieve onderzoek werd een transmurale setting met een gebruikelijke zorgvorm vergeleken. Alle patiënten die in de inclusieperiode met een beroerte in de twee deelnemende ziekenhuizen werden opgenomen, werden zes maanden gevolgd. Vervolgens werden alle patiënten die in staat, en bereid waren mee te werken aan dit onderzoek, geïnterviewd. Zes maanden na ziekenhuisopname woonde 64% van de overlevenden in de transmurale groep weer thuis, in vergelijking met 42% van de overlevenden in de referentiegroep (p<0.05). Dit verschil kon niet worden verklaard door verschillen tussen beide groepen in gezondheidstoestand, die op dat moment vergelijkbaar

was. De patiënten in de transmurale groep bleken meer tevreden te zijn over de ontvangen zorg, terwijl zij in vergelijking met de referentiegroep minder (thuis)zorg kregen. Deze resultaten geven aan dat deze vorm van transmurale zorg waarschijnlijk kosteneffectief is in vergelijking met gebruikelijke zorg.

Hoofdstuk 7, tenslotte, bevat een kritische beschouwing van het uitgevoerde onderzoek. Allereerst wordt benadrukt dat de resultaten voorzichtig dienen te worden geïnterpreteerd aangezien door de gekozen onderzoeksopzet selectiebias niet kan worden uitgesloten. Desondanks is hiermee aangetoond dat observationeel vergelijkend cohortonderzoek haalbaar en zinvol is bij het beantwoorden van vragen naar de effecten van transmurale zorg in de dagelijkse praktijk. Op basis van de gevonden resultaten is de algemene conclusie dat transmurale zorg inderdaad een effect kan hebben op de gezondheidstoestand van patiënten, op de mening van patiënten over deze zorg en op de doelmatigheid van zorg. Deze effecten zijn echter bescheiden en bovendien niet eenduidig. Wij concluderen dan ook dat de algemeen heersende opvatting omtrent de positieve effecten van transmurale zorg niet terecht is. Een algemeen geldende uitspraak over de effecten van transmurale zorg kan niet worden gedaan, het is veeleer het specifieke ontwerp per project dat de uitkomsten ervan in de praktijk bepaalt.
Op basis van deze resultaten kan men zich afvragen of transmurale zorg verder moet worden gestimuleerd, of juist worden afgebouwd. In dit laatste hoofdstuk wordt beargumenteerd dat dit laatste niet verstandig zou zijn om diverse redenen. Ten eerste is aangetoond dat transmurale zorg in bepaalde gevallen positieve effecten teweeg kan brengen, en dit zou patiënten (en de samenleving) niet moeten worden onthouden. In de tweede plaats hebben wij transmurale zorg geëvalueerd aan de hand van drie uitkomstparameters. Het is niet uitgesloten dat andere indicatoren, zoals bijvoorbeeld de tevredenheid van zorgaanbieders, hierbij ook van groot belang zijn. In de derde plaats kan worden beargumenteerd dat transmurale zorg een eerste, voorzichtige stap is naar een meer omvattende benadering zoals 'disease management' of 'integrated care'. Keuze voor een dergelijke aanpak zou in vergelijking met transmurale zorg mogelijk ook tot grotere verschillen in uitkomst kunnen leiden.

Maar wat ook de uitkomst zal zijn van die discussie, het belang van adequate monitoring van (neven-)effecten kan niet genoeg worden benadrukt. Op basis van de resultaten van dit onderzoek bevelen wij sterk aan om a) nieuwe (en bestaande) transmurale projecten te monitoren en evalueren, en b) deze kennis ter beschikking te stellen aan iedereen die hierbij is gediend. Het bijeenbrengen van de reeds opgedane kennis en expertise in de vorm van een kenniscentrum, of panel van deskundigen, is te overwegen. Initiatiefnemers

zouden hier hun transmurale voornemens kunnen voorleggen alvorens daadwerkelijk van start te gaan. Op deze wijze wordt optimaal gebruik gemaakt van bestaande kennis over succes- en faalfactoren van transmurale projecten.

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- Jandirk. Ruim 20 jaar ver weg en toch altijd dichtbij. Nauwelijks een halfjaar geleden keek je me aan en vroeg of je de afronding van dit proefschrift nog zou halen. We dachten allebei van wel. Het mocht niet zo zijn. Ik mis je. Je brede grijns zie ik nog iedere dag voor me. En die zal nooit meer verdwijnen.
- Vera, het laatste woord is voor jou. Wat had je graag de afronding van dit proefschrift meegemaakt. En wat vind ik het erg dat het niet zo mocht zijn. Ons leven is sinds 17 februari 2002 voorgoed veranderd. Ik draag dit proefschrift graag aan jou op, en wil je danken voor alles wat je ons hebt gegeven. Het verdriet zal nooit verdwijnen, maar de vreugde om wie je was ook niet.

CURRICULUM VITAE

Henk Rosendal was born on June 11, 1961 in Ede, The Netherlands. After graduating secondary school at the Streeklyceum in Ede, he started his training as a nurse at the regional hospital in Bennekom. After graduating in 1983, he started his training as psychiatric nurse in Wolfheze. Subsequently, he worked between 1986 and 1988 as a team manager at the Lucas Hospital in Amsterdam. In 1988 he started his study Health Sciences (Health Policy and Health Management) at the Maastricht University, and passed the final examination in 1992.

In the period 1992-1995 he worked as a policymaker at the Dutch Ministry of Health until he was asked to join TNO, The Netherlands Organisation for Applied Scientific Research. He worked at TNO Prevention and Health for over 6 years, and started the studies as described in this thesis in that period. Besides these studies on transmural care, he was the projectmanager of various health policy assessments, for example on the waiting times in ambulatory mental healthcare[1,2], on the law concerning exceptional medical procedures[3,4] and on the law on organdonation[5,6]. In 2000 he became manager of the sector Health Technology Assesment at TNO. He left TNO in 2002 and started to work at the Dutch Society for Home Care, as a sector manager.

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GLOSSARY

AIDS	Acquired Immune Deficiency Syndrome
CABG	Coronary Artery Bypass Graft
CI	Confidence Interval
DM	Diabetes Mellitus
DHP	Diabetes Health Profile
DTSQ	Diabetes Treatment Satisfaction Questionnaire
COPD	Chronic Obstructive Pulmonary Disease
HbA1c	Glycated Haemoglobin
HRQ	Hip Rating Questionnaire
LOS	Length Of Stay
OCS	Observational Cohort Study
PTCA	Percutanous Transluminal Coronary Angioplasty
RA	Rheumatoid Arthritis
RCT	Randomised Controlled Trial
SIP	Sickness Impact Profile
THR	Total Hip Replacement
TIA	Transient Ischemic Attack
TNO	Netherlands Organization for Applied Scientific Research

Transmural care refers to care given 'through the (virtual) walls' of the existing healthcare system, and is most often directed towards bridging the gap between different levels of healthcare providers. In spite of its widespread application, little is known about the effects of transmural care in daily practice.

In order to increase knowledge about the effects of transmural care in structurally embedded practice, we carried out three different observational, comparative cohortstudies. In all three studies, transmural care is compared with usual care. The first model concerned patients with diabetes mellitus, the second concerned patients undergoing total hip replacement and the third model concerned patients with a stroke. These studies are described in this thesis.

Based on the results we conclude that there is no clear justification for the general belief in the positive effects of transmural care.

Recommendations are given for clinicians, healthcare managers as well as for policymakers.