# SUMMARY

The End Stage Renal Disease Program (ESRD-program) in the Netherlands as well as in other countries is an expensive health program. Benefits of the program are gains in the quantity and the quality of life, but those benefits can only be realized if relatively large amount of health care funds, both per patient and in total, are allocated. Therefore a cost-effectiveness analysis of the ESRD-program has been carried out to determine the costs and effects of different options for the ESRD-program in the future. Although it will not be possible within the framework of this study to compare the cost-effectiveness of the ESRD-program with that of other health care programs in the Netherlands, the results of this study could be used in comparisons with cost-effectiveness studies using the same concepts for costs and effectiveness. The focus of this study is restricted to the comparisons of scenario's of the ESRD-program itself. So the results of this study do not enable to decide upon the desirability of the ESRD-program as such, but once it is decided to allocate health care means to the ESRD-program, decisions about the direction in which the ESRD-program should develop from the point of view of cost-effectiveness could be made with the results of this study in mind.

Chapter 1 is the introduction to the subject of the study.

Chapter 2 provides backgrounds about the policy concerning the ESRD-program of the government and the health care financing institutions. The government in the Netherlands has been entitled to limit the capacity of the dialysis program, or of parts of that program, such as the dialysis program of centres in hospitals. It is described that the government has been using this power in a gentle way. In fact, the limits which were set on the ESRD-program have been adapted to the needs formulated by a number of advisory committees within the framework of the Health Council. In the period 1980 - 1985 the limits, set on the dialysis program, have not been adapted again, and the number of dialysis patients increased to levels above those indicated in the regulations of the government. In practice the physicians, responsible for the patients, and civil servants, responsible for the implementation of the planning regulations, found more or less formal ways to legitimize the number of patients treated. Advisory committees in the Netherlands have been stressing the importance of increases in the number of transplantations. The target of 400 transplantations a year (about 30 per million of inhabitants), set in 1972, has however not been implemented in the seventies. A secondary recommendation concerned an increase of the share of both home and limited care centre haemodialysis. Those recommendations were the subjects of continuous debate between policy makers and physicians, but until now little progress has been made.

In chapter 3 some medical backgrounds are described. In very general terms End Stage Renal Disease is characterized and the different forms of treatments are circumscribed and defined. Numbers of patients, treated with different treatment forms are tabulated.

Chapter 4 provides a scope for the analytical parts of the study. Definitions of cost-effectiveness and financial analysis are set out. A survey of existing literature concerning the planning of the ESRD-program in the US and UK is given. Markov-chain modelling has been used in the past in the UK but this tradition of research has always been directed to the calculation of optimal combinations of dialysis and transplant capacities of ESRD-centres, given transition-probabilities between treatment groups. The use of Markov-chain models to forecast the ESRD program on a national level has advantages above multi-cohort analysis, which is applied often in the US. The Markov-chain model, to be used to forecast numbers of patients, costs and effects of the ESRD-program for non-diabetic patients in the Netherlands, is specified.

The incidence of ESRD in the Netherlands is the subject of chapter 5. Definitions are formulated of constructs such as absolute and relative theoretical incidence and absolute and relative program incidence. The possibilities to forecast the incidence of ESRD in the Netherlands are discussed, but no other possibility than a linear extrapolation of the relative program incidence remains, because of the absence of data. It is forecasted that the number of new non-diabetic ESRD patients per million of the population will increase to nearly 60 per million in 1990. The corresponding age specific relative program incidences for age groups from 0 to 44, from 45 to 64 and above 65 years of age, are estimated at 30, 125 and 100 per million of inhabitants in that age group.

To determine transition probabilities, to be used in the Markov-chain forecast, an actuarial analysis has been made of datafiles of patient records, supplied by the European Dialysis and Transplant Association and EUROTRANSPLANT, covering the period 1972-1983. This is described in chapter 6. The interval division of these life tables is chosen in accordance with the interval division of a main states of the markov model. A terminal event of a life table is defined as a transition to another main state. Thus the hazard rates of the life tables can be used directly in the matrix of transition probabilities in the Markov-chain.

Patient histories of Dutch ESRD patients are registered by the European Dialysis and Transplantation Association (EDTA). Every transplantation in the Netherlands is being followed up by Eurotransplant. Conditional probabilities of death and transplantation of dialysis patients on haemodialysis are calculated using EDTA-data, that were also used to derive probabilities of transitions between the haemodialysis main states. Conditional haemodialysis main states are calculated on EDTA-data. Conditional probabilities of death of transplanted patients and graft rejection were calculated on Eurotransplant data. For death and treatment change probabilities of CAPD patients, data of the Amsterdam Medical Hospital (AMC) were used.

Different transition probabilities were used for the same main states in different age groups, and for the same main states before and after transplantation, if the Lee-Desu statistic indicated a difference in the relevant life tables at the 95 percent level of significance. A difference was identified with respect to different age groups for transplantation probabilities, death

probabilities after transplantation, death probabilities in dialysis main states, but not for graft rejection probabilities. Death probabilities of patients with a functioning first and a functioning second graft differed, as did death probabilities of patients on dialysis before and after first transplantation. No difference has been encountered between death probabilities of patients on dialysis after a first and a second transplantation. Graft rejection probabilities of patients after a second transplantation were higher than those of patients after a first transplantation.

A significant improvement in survival was determined for patients, who were transplanted after 1977, compared to survival of patients transplanted between 1972 and 1976. In this case the more recent hazard rates were used. as far as those were available. This phenomenon could only be established for patient survival after a first transplantation in the age group between zero and 44 years. The same kind of difference was also encountered for transplantation probabilities in this age group. Patient survival in the various modes of haemodialysis was assumed to be identical, because individual prognoses do not depend on the level of participation of the patient in his own treatment. Transplantation in the age group older than 65 years was neglected.

Cost estimates are presented in chapter 7. Cost estimates of ESRD treatments have been made according to the principles of cost-effectiveness analyses. This means that costs to society are estimated without regard to who or which institution pays and following as much as possible the principles of opportunity costing. Besides the actual costs the financial costs of ESRD treatments were estimated. Financial costs are the costs that the funding institutions of health care will have to pay to health care providers according to the agreements that exist between the financing institutions and health care producers. Financial costs of all ESRD treatments, except home haemodialysis and treatment of transplanted patients for two or more years after transplantation, proved to be higher than costs according to the principles of cost-effectiveness analysis accounting.

In chapter 8 differences in the quality of life of patients in different treatment groups are explored. The construct 'Quality of Life' as it is used in cost-effectiveness or cost-utility analysis is explored and a number of theoretical problems and assumptions are indicated. Although it was not possible, within the framework of this research project, to determine empirically Quality of Life measures, the literature surveyed, justifies the use of different quality of life measures for dialysis and transplanted patients.

For (juvenile onset) diabetic ESRD patients a separate forecast has been made, which is presented in chapter 9. A Markov-chain model has been used for the calculations of the ESRD diabetic program, which provides for a supplementary number of patients, costs, lifeyears gained and quality adjusted life years gained. Data about diabetic ESRD patients were lacking and a number of assumptions had to be made to develop an estimate of the diabetic ESRD program. Assumptions, model and results are described in this chapter. Of the ESRD-program for diabetic patients only one scenario is forecasted.

The figures resulting from the scenario for diabetic patients, are added to the outcomes of each of the scenario's for non-diabetic patients.

Chapter 10 provides the results of model forecasts of the ESRD program in the Netherlands. Different scenario's of this program have been forecasted to explore policy options and uncertainties. Foremost under the policy options is an increase in the number of transplantations per year to a level, which permits 95 % of the patients in the age group from 0 to 44 years, and 75 % of the patients in the age group from 45 to 64 years to be transplanted. Additional policy measures concern the share of active dialysis treatments in the flow of patients entering the ESRD program. Uncertainties are investigated with respect to death probabilities and the incidence both of non-diabetic and diabetic patients. The time horizon of ESRD scenario's is varied (1990, 2000, 2100). Program costs are calculated according to costs to society and costs to health care financing institutions.

An increase in the number of transplantations proves to be the most important way to save costs and to increase the number of quality adjusted life years resulting from the program. Cost savings resulting from the increase in transplantation activity amount to about 5 % of a five year program and increase relatively in the course of time. Promotion of active dialysis seems to offer relatively modest cost saving possibilities, unless extreme policy options are implemented and the potential for cost savings by increasing the share of several active dialysis treatments in the inflow of patients does not differ very much. Financial costs of scenario's are generally higher than costs to society, indicating that income transfers to institutions involved in the ESRD program occur. Cost saving resulting from measures to influence the patient mix are modest in comparison with measures to eliminate the difference between financial and societal costs. Because the ratio between societal and financial costs of different treatments differs, the currents set of financial prices provides adverse incentives for the development of the ESRD program.

In chapter 11 a number of recommendations are formulated. To increase the number of transplantations it is recommended to introduce a Required Request system that obligates hospitals to identify donors and to ask permission of the next of kin for donation. It is recommended to stimulate active dialysis as far as possible. Passive haemodialysis should only be a possible treatment in cases where a clear medical necessity exists. In view of the uncertainty about the differences in costs of active dialysis a policy of equal shares of CAPD, home haemodialysis and limited care centre haemodialysis is recommended. To control the costs of the ESRD program a policy of functional budgeting is advised. In the end the author states that according to his subjective opinion the ESRD program in the Netherlands should be financed, provided the program is implemented in an efficient way. Costs per life year in that case would amount to about 50.000 dutch guilders.