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# Health economic studies on advanced home care

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## ABSTRACT

The aim of this thesis was to examine the cost-effectiveness of specific advanced home care and home rehabilitation interventions and to improve economic evaluation methods when applied to advanced home care. This included a comparison of two alternative ways of administering oxygen at home to patients with chronic hypoxaemia, as well as a review of scientific evidence on costs and effects of home rehabilitation after stroke. Also included were studies on prominent methodological issues in advanced home care - the redistribution of care efforts among caregivers and costing of informal care efforts.

For patients with chronic hypoxaemia, a randomised, controlled trial showed that mobile liquid oxygen was considerably more costly compared to concentrator treatment. However, the treatment effects showed that liquid oxygen had a better impact on patient quality of life. The literature review revealed that the outcomes and costs of home rehabilitation after stroke are equal to those of alternative treatment strategies. Similar results were obtained in a study comparing hospital-based and home-based stroke rehabilitation, which also showed that there is a considerable redistribution of costs between health care providers and social welfare providers. Studies of patients in advanced home care in the county of Östergötland, Sweden, showed that the cost of informal care constitutes a considerable part of the care effort in all costing approaches used. Also, informal care costs were higher among patients who were men, who were younger, who had their own housing and had a cancer diagnosis.

This thesis reveals that advanced home care interventions can differ regarding costs as well as effects, and thus comparisons between alternative home care interventions must also be performed. Further, redistribution effects are important to consider in evaluations. The cost of informal care is substantial in advanced home care. These costs must be included in evaluations with a societal perspective or else the comparisons will be biased.

*Key words:* health economics, economic evaluation, advanced home care, redistribution, cost, informal care.



## LIST OF PAPERS

The thesis is based on the following original papers, which will be referred to by their Roman numerals:

- I. Andersson, A., Ström, K., Brodin, H., Alton, M., Boman, G., Jakobsson, P., Lindberg, A., Uddenfeldt, M., Walter, H. & L-Å. Levin, 'Domiciliary liquid oxygen versus concentrator treatment in chronic hypoxaemia: a cost-utility analysis', *European Respiratory Journal*, Vol. 12, no. 6, 1998, pp. 1284-1289.  
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- II. Britton, M., & A. Andersson, 'Home rehabilitation after stroke. Reviewing the scientific evidence on effects and costs', *International Journal of Technology Assessment in Health Care*, Vol. 16, no. 3, 2000, pp. 842-848.  
*Reprinted with the permission of Cambridge University Press.*
- III. Andersson, A., Levin, L-Å., Öberg, B., & L. Månsson, 'A comparison of home based and routine rehabilitation after stroke', (*Accepted for publication in Scandinavian Journal of Caring Sciences*).  
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- IV. Andersson, A., Levin, L-Å. & B. G. Emtinger, 'The economic burden of informal care', *International Journal of Technology Assessment in Health Care*, Vol. 18, no. 1, 2002, pp. 46-54.  
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- V. Andersson, A., Carstensen, J., Levin, L-Å. & B. G. Emtinger, 'Costs of informal care for patients in advanced home care – a population based study', (*Accepted for publication in International Journal of Technology Assessment in Health Care*).



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## INTRODUCTION

Institutional care has traditionally dominated the health care system in Sweden. Expansion of institutionalised care was substantial during the 1960s and 1970s, and this period is sometimes referred to as ‘the hospital building era’. However, due to financial difficulties in the 1990s, most Western European countries and OECD<sup>1</sup>-countries have tried to cut or restrain health care expenditures<sup>2</sup>. Reasons for the rise in health care expenditures are similar in most Western European countries and other high-income countries<sup>3</sup>. One of the contributing factors is the changing age structure and the subsequent increase in the need for care.

In recent years new forms of home care have emerged in Sweden as well as in other countries such as Canada and the United States<sup>4</sup>. However, the concept of health care at home, such as that provided by midwives and visiting nurses, is not a new idea, as 40 deaconesses were providing organised home care for people living in Constantinople as early as 400 AD<sup>5</sup>. In Sweden, the care given by district nurses in rural parts of the country assumed a more definitive shape during the 1920s<sup>6</sup>. More organised home care in Sweden began in the late 1940s<sup>7</sup>. It was intended to be a temporary solution for solving the problems associated with insufficient hospital accommodations for long-term patients. It initially involved financial support that was given to patients to compensate for the additional costs of being cared for at home. In the United States, home care was traditionally a nursing service, appearing for the first time in organised form during the period 1885-1889<sup>8</sup>. The role of the physician developed later, as home care expanded and

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<sup>1</sup> Organisation for economic cooperation and development.

<sup>2</sup> WHO, 1997, *Health Sector Reform in Europe – Analysis of Current Strategies*, (WHO Regional Publications, European Series No. 72), Copenhagen.

<sup>3</sup> The National Board of Health and Welfare (1998), *Sjukvården i Sverige 1998*, [Health Care in Sweden 1998], Stockholm.

<sup>4</sup> For example, funding for home care in Saskatchewan, Canada, had increased 90% over 1991 levels by 1995-96, and during the same time period the acute care budget was reduced by more than five percent and the long-term care budget increased by less than five percent (Health Services Utilization and Research Commission (HSURC), 1996, *The Cost-Effectiveness of Home Care. A rigorous review of the literature*, (Background paper), Saskatoon. In the mid 1990s home care in the United States was the fastest growing area in the health care sector (Wickström, E., Carlsson, M. & M. Strinnö, ‘Hemsvård ett växande område’, *Svensk Farmaceutisk Tidskrift*, Vol. 99, no. 11, 1995, p. 42).

<sup>5</sup> Saltzman, B. N., ‘Is home health care cost effective?’, *The Journal of the Arkansas Medical Society*, Vol. 81, no. 8, 1985, pp. 429-431.

<sup>6</sup> Emanuelsson, A., Wendt, R. *I folkhälsans tjänst. Sju decennier med den svenska distriktssköterskan*. (FoU-rapport /Vårdförbundet SHSTF; 43). Stockholm, 1994.

<sup>7</sup> SOU (Statens Offentliga Utredningar) 1983:64, *Ledighet för anhörigvård*, (Betänkande av Anhörigvårdscommitén), Socialdepartementet, [Department of Social Affairs], Stockholm, 1983.

<sup>8</sup> Buhler-Wilkerson, K. ‘Home care the American way. An historical analysis’, *Home Health Care Services Quarterly*, Vol. 12, no. 3, 1991, pp. 5-18.

home care technologies became more advanced or more medically complex<sup>9</sup>, allowing for patients with more serious conditions to be cared for at home.

## Terminology related to home care

Different definitions and descriptions of home care<sup>10</sup> have arisen over the years in Sweden, as well as in other countries, as this form of care has evolved. The diverse definitions and differences in organisational structures of home care sometimes make comparisons over time and between countries, as well as statistical data, difficult to interpret. A wide variety of concepts like *advanced home care*, *specialised home care*, *medically extensive*<sup>11</sup> *home care*, *advanced primary home care*, *basic home care*, *general home care*<sup>12</sup>, *home health care*, *home medical care*, *home care*, *hospital at home*, *hospital based home care*, *primary home care*, *home rehabilitation*, etc. are being used in the literature and in current debate. Sometimes different concepts are synonymous and sometimes they represent different types of home care and/or organisational structures.

In Sweden, all medical services that do not involve a stay in hospital are defined as non-institutional care<sup>13</sup>. Thus, home care is categorised as non-institutional care<sup>14</sup> but can organisationally belong to primary health care as well as to hospital care. Home care can be provided to patients living in their own housing as well as to people living in housing provided by the municipalities. What is included in home care service and how it is organised depends on the responsible authority.

There is no official definition of home care in Sweden. The Swedish Federation of County Councils has suggested the following definition: “non-institutional care, undertaken and provided by formal caregiver, and given to the patient in his or her residence or principal place of residence”<sup>15</sup> (own translation). It is also stipulated that the care should be provided for a minimum of two weeks. In reality, however, shorter care episodes do occur.

In addition, there are no official terms for the two major forms of home care. It has, however, been suggested by the Public Health and Medical Services Committee that home care in Sweden should be categorised as *basic home care* and *specialised home care*<sup>16</sup>. *Basic*

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<sup>9</sup> Kavesh, W. M., ‘Home care: Process, Outcome, Cost’, *Annual Review of Gerontology and Geriatrics*, Vol. 6, 1986, pp. 135-195.

<sup>10</sup> Home care services is not to be confused with home help services. In Sweden, home help service mainly involves domestic help, usually provided by the municipalities.

<sup>11</sup> My translation of the Swedish term *medicinskt omfattande*.

<sup>12</sup> My translation of the Swedish term *allmän hemsjukvård*.

<sup>13</sup> The National Board of Health and Welfare (1998).

<sup>14</sup> The National Swedish Board of Health and Welfare (1976/1977). National, The Swedish Board of Health and Welfare, *The Swedish Health Services in the 1980's, HS80*. Legally responsible editor: Sven-Olof Hedengren, Stockholm, 1975-1976.

<sup>15</sup> The Swedish Federation of County Councils. *Hemsjukvårdens roll inom sjukvården*, (Rapport nr 1/00), Stockholm, 2000.

<sup>16</sup> Public Health and Medical Services Committée. [Hälso- och sjukvårdsnämnden]. Stockholms läns landsting. *Borta bra men hemma bäst. Hemsjukvården i Stockholms län*. Preliminary report, version 13 januari 2002. (Unpublished).

*home care* can be viewed as a complement to hospital care; it deals with conditions that normally do not require hospitalisation. However, the boundaries are not clear, and basic home care is moving in the direction of taking care of a wider variety of patients. Basic home care is still primarily elementary in nature and is given mainly by a district nurse or assistant nurse. A physician and/or support from an evening and night patrol can occasionally be involved, but as a rule care is given during planned visits during the daytime. A hospital bed can only be provided on referral. Basic home care is given to patients in a restricted catchment area<sup>17</sup> and the care is rarely terminal. Basic home care is provided by the county councils and is given to patients living in their own housing. Basic home care delivered by the municipalities is given to patients in housing provided by the municipality. However, these boundaries may become more flexible in the future, and specialised home care (advanced home care) may provide care for patients in municipal housing.

The term *specialised home care* is synonymous with *advanced home care*, which is the term that is used more frequently internationally (in Sweden the Public Health and Medical Services Committee has suggested the term specialised home care as the official term). Hereafter I will nevertheless use the term *advanced home care*. Advanced home care often has an organisation that is separate from other hospital departments and is managed by a team of medical professionals (multiprofessional team). The team can consist of a medical doctor, registered nurse, assistant nurse, physical therapist and so on, depending on patient needs. The care is to be available 24 hours a day. One purpose of advanced home care is to constitute an alternative to in-hospital care, i.e. otherwise the patient would have to be hospitalised. However, the boundaries are not clear here either. Another purpose is to shorten or avoid in-hospital care, and also to meet a patient need or wish. This standpoint has been taken by Beck-Friis<sup>18</sup>. Other features are that the care is medically extensive or complex, and most of the patients are seriously ill (palliative care<sup>19</sup>). Further, the catchment area is large<sup>20</sup>. Advanced home care can be managed by either a hospital or a primary care unit.

Home rehabilitation is often (but not always) categorised as advanced home care, as it is team-based and a medical doctor usually directs it in co-operation with a physical therapist and an occupational therapist, for example. While it is appropriate to schedule training and rehabilitation activities during the daytime, the team should be available as backup 24 hours a day, and a hospital bed should also be available if needed.

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<sup>17</sup> A limited geographical area that usually corresponds to the catchment area of a care centre.

<sup>18</sup> Beck-Friis, B., *Hospital-Based Home Care of Terminally Ill Cancer Patients; The Motala Model*. (Comprehensive summaries of Uppsala dissertations from the Faculty of Medicine: 393), Uppsala, 1993.

<sup>19</sup> The WHO definition of palliative care (1990) reads as follows: "Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families".

<sup>20</sup> A large geographical area that usually corresponds to the catchment area of one of the health care districts within a county council.

## Advanced home care in Sweden

The first hospital-based home care programme in Sweden was started in Linköping, Östergötland, in 1962 in order to meet the needs of people with life-threatening diseases such as cancer. However, this programme was only available during the daytime. Initiative for the first programme of advanced home care known as the Motala Model<sup>21</sup>, was taken in 1976 and the programme got underway in 1977. The original aim was to offer severely ill and dying patients, or patients with an extensive need for care, an alternative to hospitalisation. The concept characterising the Motala Model was availability around the clock, seven days a week. In addition, the same doctors provided care on a continuous basis so that hospital based home care constituted an alternative to hospital care. These features differentiated the programme from the hospice movement in England and Ireland (which was well underway at the time), where coverage was not as extensive. In 1977 the Motala unit produced 10 000 care-days and had expanded to 33 000 care-days by 1994<sup>22</sup>. Advanced home care programmes in Sweden are still dominated by palliative care (44% in 1998) and chronic diseases (34% in 1998)<sup>23</sup>. Home care has thus been a part of Swedish health care for several decades.

Calculations made by the Swedish Council on Technology Assessment in Health Care show that advanced home care in Sweden produced five percent of all care days in 1996-1997<sup>24</sup>. These figures are based on an inventory by the Swedish Institute for Health Services Development. Estimations of proportions of advanced home care show that about 50 units provided advanced home care and cared for about 10 000 – 12 000 patients during 1998<sup>25</sup>. However, basic home care provides care for more patients than advanced home care. The difference is tenfold<sup>26</sup>. The number of posts in advanced home care is estimated to be between 19-24 per 100 000 inhabitants and in more expansive areas up to 60 posts per 100 000 inhabitants<sup>27</sup>.

The inventory by the Swedish Institute for Health Services Development also shows that the average cost per care day in 1997 in advanced home care (based on costs for 30 advanced care units) was 717 SEK<sup>28</sup> (range 151-1 700) not including social insurance costs (sociala avgifter)<sup>29</sup>. The total cost for 49 advanced home care units was estimated at

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<sup>21</sup> Beck-Friis (1993).

<sup>22</sup> County, The Council of Östergötland (Emtinger, B. G.), *Vårda och vårdas hemma. Kartläggning av LAH- den Lasarettanslutna Hemsjukvården i Östergötland*, Landstinget i Östergötland, [The County Council of Östergötland], Linköping, 1996.

<sup>23</sup> Swedish, The, Council on Technology Assessment in Health Care [Statens beredning för medicinsk utvärdering, SBU]. *Avancerad hemsjukvård och hemrehabilitering. Effekter och kostnader*. [Advanced home health care and home rehabilitation – reviewing the scientific evidence on costs and effects], (SBU-rapport 1999:146), (In Swedish), SBU, Stockholm, 1999.

<sup>24</sup> The Swedish Council on Technology Assessment in Health Care (1999).

<sup>25</sup> Högberg, M. & J. Gertz, *Avancerad sjukvård i hemmet: redovisning av enkät till enheter som bedriver avancerad sjukvård i hemmet*, del A, Stockholm, 1998, The Swedish Council on Technology Assessment in Health Care (1999).

<sup>26</sup> The Swedish Federation of County Councils (2000).

<sup>27</sup> The Swedish Council on Technology Assessment in Health Care (1999).

<sup>28</sup> Swedish Crowns.

<sup>29</sup> Högberg & Gertz (1998).

about 445 million SEK<sup>30</sup>. Including social insurance costs the total cost was about 580 million SEK per year<sup>31</sup>. The total cost incurred by the county councils for producing health care was 128 000 million SEK in 1996.

### **Increased interest in advanced home care – why?**

A factor behind the ‘new’ interest in home care, primarily advanced home care, is that it is now possible to carry out a number of medical treatments in the patients’ home environment. This is due to new or modified technology or improved drugs and also to better living standards (i.e a larger living area, improved accessibility, improved technical standard). Other contributing factors are changes in the health care organisation in the direction of a more decentralised organisation, a notion that advanced home care could be a cost containment option due to a shortened length of stay in hospital, and also the wishes of patients and their next of kin. The National Board of Health and Welfare in Sweden stated in 1988 that advanced home care was the fastest growing part of the health care sector<sup>32</sup>. However, in a preliminary report by the Public Health and Medical Services Committee in Stockholm it was concluded that the expansion of advanced home care units in the Stockholm county council reached its peak during the 1980s, and that the increase was poor during the early 1990s and that it stagnated during the latter half of the decade<sup>33</sup>. One cause that is mentioned in the report is that advanced home care as an alternative to other forms of care is not as well known in Stockholm as in Motala, for example. Another aspect that may hamper the provision of appropriate care to the elderly in need of advanced home care is the effects of the Care of the Elderly reform (the so-called Ädel-reform) where responsibility for the elderly was transferred from the County Councils to the Municipalities. The boundaries remain unclear, for example, regarding who is responsible for care for elderly patients with severe chronic illness.

One major reason behind the search for cost containing care alternatives involves the demographic development in the country. Demographic trends in Sweden indicate that the population of Sweden is not going to undergo a substantial increase; on the contrary, population growth is slowly declining. However, the proportion of the very old, i.e. over 80 years of age, will increase in future years<sup>34</sup> and thus also the need for care. Similar trends have been revealed throughout the Western World. In Sweden in 2000, the average life expectancy at birth was 77 years for men and 82 years for women, which can be compared to 75 years for men and 80 years for women in 1990<sup>35</sup>. In 1980 a little more than three percent of the population was over 80 years of age, compared to almost five

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<sup>30</sup> The Swedish Council on Technology Assessment in Health Care (1999).

<sup>31</sup> The Swedish Council on Technology Assessment in Health Care (1999).

<sup>32</sup> The National Board of Health and Welfare (1998).

<sup>33</sup> The Public Health and Medical Committee (2002).

<sup>34</sup> National, The Board of Health and Welfare. *Folkhälsorapport 2001*, [Socialstyrelsen], Stockholm, 2001.

<sup>35</sup> Statistics Sweden [Statistiska Centralbyrån] (2001a). (www.scb.se) Befolkningsstatistik. Befolkning och välfärd – *Livslängdstabell för åren 1751-2000*.

percent in 1998<sup>36</sup>. Thus, years of life increases over time, but the number of years with full health has not increased at all between 1975-1999<sup>37</sup>. Johansson<sup>38</sup> discusses several consequences of the changing age and demographic structure in Sweden with respect to care of the elderly. For one, there will be more single households in the future, which is also a contributing factor to an increased need for care. This is supported by statistics showing an increase of 48% between 1960 and 1990 in the number of single households, while the increase in the total population was 15%<sup>39</sup>. This trend is still ongoing according to more recent data<sup>40</sup>. The number of households with at least one person over 65 years of age has increased by 35% since 1970, and the number of households with solely persons over 65 years of age increased by 72% between 1970 and 1990<sup>41</sup>. In addition, the fact that future generations are likely to have fewer children, i.e. potential informal caregivers, will contribute to the increased need for care and services. However, Andersson<sup>42</sup> points out that even if fewer children are born in the future, there will not be fewer children who survive to adulthood since mortality was considerably higher in the past.

### Economic consequences of advanced home care

Home care in general has several interesting aspects from a health economic point of view. One is whether or not home care can contribute to containing health care expenditures. In 1985 Hermesse<sup>43</sup> made some interesting remarks:

“The primary cost reduction of implementing health technology at home comes from reducing the use of professional attendants. Therefore, managing the illness with nonprofessionals such as family, neighbors, and friends should be possible. This help will positively influence the outcome of the CEA. Without it, the use of advanced health technology at home is not economical.”<sup>44</sup>

*Hermesse (1985).*

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<sup>36</sup> Statistics Sweden [Statistiska Centralbyrån, SCB]. Population 2001 (2001b). *Programmet för befolkningsstatistik* [Population], Tablell 1.2 Folkmängd efter kön och ålder 1750-1998 [Population by sex and age 1750-1998].

<sup>37</sup> The National Board of Health and Welfare (2001).

<sup>38</sup> Johansson, L., *Caring for the Next of Kin. On Informal Care of the Elderly in Sweden*. (Thesis no. 330), (Socialmedicinska institutionen), Uppsala, 1991.

<sup>39</sup> Statistics Sweden [Statistiska Centralbyrån]. *Folk- och bostadsräkningen 1990* (FoB 90) [Population and housing census 1990]. Sveriges officiella statistik, Stockholm, 1992.

<sup>40</sup> Statistics Sweden (2000 b).

<sup>41</sup> Statistics Sweden, FoB 90.

<sup>42</sup> Andersson, L., ‘The service system at the crossroad of demography and policy making – Implications for the elderly’, *Social Science and Medicine*, Vol. 32, no. 4, 1991, pp. 491-497.

<sup>43</sup> Hermesse, J., ‘Cost-effective health technology at home is an avenue for reducing national health expenditures. A view from Government’, *International Journal of Technology Assessment in Health Care*, Vol. 1, No. 2, 1985, pp. 289-300.

<sup>44</sup> CEA, cost-effectiveness analysis.

Hermesse's remarks may implicitly suggest that the value of care efforts provided by non-professionals, such as informal caregivers, should be excluded from the cost analysis or possibly be set to zero. From a socio-economic point of view this is incorrect. In a socio-economic analysis it is important to study the consequences for all the involved parties in society, including the redistribution of resource use and the societal consequences of introducing home care. A societal perspective in cost effectiveness analyses is the most useful perspective for resource allocation and it is recommended by leading health economists<sup>45</sup>.

If patients are cared for in their own homes rather than in hospital, it may be natural to draw the conclusion that fewer hospital beds will be needed. Studies have also reported shortened lengths of stay in hospital for some patient groups such as those receiving home rehabilitation<sup>46</sup>. However, a general decrease in hospital stay has been reported, which makes this effect of home rehabilitation difficult to interpret<sup>47</sup>. It is also difficult to determine whether this potential over-capacity will actually result in financial savings, or if it will be used for taking care of other patients who may be in a waiting line for care<sup>48</sup>. Regarding home care in Sweden, hospitals also have a responsibility to keep a bed available at all times for advanced home care patients in case this is needed, and beds should be available on referral for patients in basic home care.

Another possible consequence is that home care could increase the need for non-institutional care, such as home help service, home equipment and the need for nursing homes, and thus increase these costs. This could mean a redistribution of resource use from the county councils/health care providers (responsible for hospital care) to the municipalities/social welfare providers (responsible for non-institutional care and housing for the elderly). The National Board of Health and Welfare in Sweden has discussed the redistribution between formal caregivers and informal caregivers<sup>49</sup> as a consequence of a decreased number of hospital beds. Similar statements can be found in the literature<sup>50</sup>. Among countries other than Sweden, a small amount of studies discuss substitution effects between institutional and informal caregivers<sup>51</sup>. However, few studies and the diverse settings makes comparisons difficult among caregivers and across countries.

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<sup>45</sup> Torrance, G. W., Siegel, J. E. & B. R. Luce, 'Framing and designing the cost-effectiveness analysis', In: *Cost-Effectiveness in Health and Medicine*, (eds.) M. R. Gold, J. E. Siegel, L. B. Russel, & M. C. Weinstein, Oxford, 1996.

<sup>46</sup> Rudd, A. G., Wolfe, C. D. A., Tilling, K. & R. Beech, 'Randomised controlled trial to evaluate early discharge scheme for patients with stroke', *British Medical Journal*, Vol. 315, no. 7115, 1997, pp. 1039-1044., Widén Holmqvist, L., von Koch, L., Kostulas, V., Holm, M., Widsell, G., Tegler, H., Johansson, K., Almazan, J. & J. de Pedro-Cuesta, 'A randomised controlled trial of rehabilitation at home after stroke in Southwest Stockholm', *Stroke*, Vol. 29, no. 3, 1998, pp. 591-597., Rodgers, H., Soutter, J. Kaiser, W., Pearson, P., Dobson, R., Skilbeck, C. & J. Bond, 'Early supported hospital discharge following acute stroke: pilot study results', *Clinical Rehabilitation*, Vol. 11, no. 4, 1997, pp. 280-287.

<sup>47</sup> The Swedish Council on Technology Assessment in Health Care (1999).

<sup>48</sup> The Swedish Federation of County Councils (2000).

<sup>49</sup> The National Board of Health and Welfare (1998).

<sup>50</sup> Landstingsförbundet (2000), The Swedish Council on Technology Assessment in Health Care (1999).

<sup>51</sup> Nyman, J. A. 'Assisted living: will it reduce long-term costs?' *Aging and Social Policy*, Vol. 6, no. 4, 1994, pp. 33-51. Ereth, J., Chapko, M., Hedricks, S. C. & J. E. Savarino, 'Cost of a VA adult day health care programs and their effect on utilization and cost of care', *Medical Care*, Vol. 31, no. 9, 1993, pp. SS50-61.

In order to decide if home care will be efficient from a societal point of view, the costs for the health care service must also be compared with the effects gained. For example, these effects can be decreased mortality, morbidity or effects on the quality of life of the patient as well as the informal caregivers.

### **Methodological issues in economic evaluations of advanced home care**

In most studies of different types of home care the relatively 'new' home care alternative is compared to traditional or conventional hospital care or hospital rehabilitation<sup>52</sup>. However, in advanced home care and home rehabilitation it might not always be a new technology that is being used. Instead, the intervention consists of using an established (sometimes modified or improved) technology in a different environment and perhaps also as part of a new organisation. Thus, the comparison between traditional alternatives and home care alternatives is sometimes also a comparison of two different organisations rather than two different interventions. Studies that compare the cost-effectiveness of two home care interventions are not as frequent, but they are also important.

The redistribution of resource use is an important issue in home care. Redistributions of money from one part of society to another, so-called income transfers, are not costs to society (i.e. no resources are necessarily consumed) and should thus be excluded from cost effectiveness analyses. These redistributions do not affect the total costs to society or the value of the available amount of resources. Taxes are one example that involves a transfer of purchasing power from one group in society to another but that does not increase costs. Transfers of this sort should thus be excluded, but the redistributive effects of interventions are still of importance. The redistribution of resource use from one health care provider to another that is discussed in this thesis may not involve additional health care costs to society (there might be friction costs here, but that issue lies outside the demarcations of this thesis). However, the redistribution of resource use between formal health care providers or from formal health care providers to informal caregivers is certainly an issue here if this aspect is consciously excluded from cost calculations in evaluations of home care programmes. The fact that a redistribution occurs might create incentives for the involved parties to act accordingly. Also, if a shift of resource use and/or of responsible authority occurs, sub-optimal decisions affecting society can be made, as the whole cost scenario is not accounted for.

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<sup>52</sup> See for example Hughes, S., Cummings, & F. Weaver, 'A randomised trial of cost effectiveness of VA hospital based home care for the terminally ill', *Health Services Research*, Vol. 26, no. 26, 1992, pp. 801-817., Jessop, D. J. I. & R. E. Stein, 'Who benefits from a pediatric home care program?', *Pediatrics*, Vol. 88, no. 3, 1991, pp. 497-505., Dougherty, G., Soderstrom, L. & A. Schifftrn, 'An economic evaluation of home care for children with newly diagnosed diabetes: result from a randomized controlled trial', *Medical Care*, Vol. 36, no. 4, 1998, pp. 586-598., Beech, R., Rudd, A. G., Tilling, K. & C. D. A. Wolfe, 'Economic consequences of early inpatient discharge to community-based rehabilitation for stroke in an inner-London teaching hospital', *Stroke*, Vol. 30, no. 4, 1999, pp. 729-735.

## The informal caregiver

Informal care is defined in this thesis as the care provided by family and significant others (non-professionals). During the 1990s the effects of the Care of the Elderly reform (the so-called Ädel-reform) resulted in a redistribution of care efforts from the county councils to the municipalities as well as to the patients' families<sup>53</sup>. Informal care is of great importance in advanced home care. In this context the role of the informal caregiver is often changed from being a visitor at the hospital to being an active participant in the care process. A recent Swedish study states that "...family caregivers describe themselves as primarily bearing responsibility and providing care for their dying relatives"<sup>54</sup>. The importance of the informal caregiver role is also acknowledged, and supportive systems are encouraged (for example, psychological help and financial support)<sup>55</sup>. However, in economic evaluations of home care interventions the efforts of informal caregivers are rarely included. One reason for this is that in conventional hospital care, informal care represents only a fraction of the efforts and can thus often be disregarded as insignificant. However, it has been shown that informal care constitutes a substantial part of the total care effort needed in advanced home care<sup>56</sup> and in the care of the elderly<sup>57</sup>. This may also be one reason why home care has been marketed as a cost-effective alternative, i.e. that professional care can be reduced in favour for unpaid care performed by non-professionals.

Informal care is not only given to patients treated at home. A study by Muurinen<sup>58</sup> showed that family members of patients in palliative care spent at least five hours per day with the patient when he/she was hospitalised. In home care these efforts increased to at least ten hours per day. Annerstedt et al<sup>59</sup> reported from a study in Malmö, that the median amount of 'own caring time' given by spouses of patients with dementia was 168 hours per week. The burden on caregivers, such as stress and effects on emotional well being, has been documented in for example dementia and Alzheimer's disease. An older study reported that informal care represented two thirds of the care given by professional caregivers to elderly patients in their own homes in Sweden<sup>60</sup>.

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<sup>53</sup> The National Board of Health and Welfare (1998).

<sup>54</sup> Wennman-Larsen, A. & C. Tishelman, 'Advanced home care for cancer patients at the end of life: a qualitative study of hopes and expectations of family caregivers', *Scandinavian Journal of Caring Sciences*, Vol. 16, no. 3, 2002, pp. 240-247.

<sup>55</sup> The Public Health and Medical Services Committee (2002).

<sup>56</sup> See for example Beck-Friis (1993), Muurinen, J. M., 'The economics of informal care. Labour market effects in the National Hospice study', *Medical Care*, Vol. 24, no. 11, 1986, pp. 1007-1017., Andersson, A., Levin, L-Å. & B. G. Emtinger, 'The economic burden of informal care', *International Journal of Technology Assessment in Health Care*, Vol. 18, no. 1, 2002, pp. 46-54., The Public Health and Medical Services Committee (2002).

<sup>57</sup> Johansson (1991).

<sup>58</sup> Muurinen (1986).

<sup>59</sup> Annerstedt, L, Elmståhl, S, Ingvad, B. & S. M. Samuelsson, 'Family caregiving in dementia. An analysis of the caregiver's burden and the "breaking-point" when home care becomes inadequate', *Scandinavian Journal of Public Health*, Vol. 28, no. 1, 2000, pp. 23-31.

<sup>60</sup> Johansson (1991).

In Sweden, one can be reimbursed by health insurance (law SFS<sup>61</sup> no. 1988:1465<sup>62</sup> Reimbursement when taking a leave of absence to care for a next of kin<sup>63</sup>) when refraining from paid work in order to care for a close relative or friend with a severe disease or illness<sup>64</sup>. The number of people receiving health insurance reimbursement for care of a close relative may indicate that the number of informal caregivers is increasing. Between 1990 and 2001 the number of people receiving reimbursement for caring for a close family member increased from 2 574 to 8 827. In 2001, 70.7% of the people receiving reimbursement were women.

In this work (IV, V) the role of the informal caregiver will be acknowledged as a part of the care effort and costed in monetary terms based on care time.

### Economic evaluation – a brief description

In the past, medical decision-making and health policy decisions were mainly based on clinical safety and efficacy<sup>65</sup>. However, financial strain in the health care sector resulted in demands to include other variables such as costs in the decision-making process. In order to prioritise between different alternatives and for the purpose of decision-making, instruments for socio-economic evaluations were developed.

The most commonly used methods are cost-effectiveness analyses (CEA) and cost-utility analysis (CUA). In CEAs and in CUAs, outcomes are measured in quantitative terms, but in CUAs the patient's own valuation of the effect is taken into consideration. In CEAs the results are expressed as the average cost per unit of effectiveness. Examples of desirable effects are gained life years and number of saved lives. In CUAs outcomes are instead measured in terms of utility or quality of life. The results of such an analysis are expressed as a ratio, the numerator expressing the costs and the denominator expressing the effects (or health effects). The results of, or the outcome of, a health care intervention represent the change in health or utility experienced by a population from the start-off point of an intervention until the end of the chosen observation period (or death). The most uncomplicated evaluation method is the cost-minimisation study. This method is used when the treatments have identical effects. The method is used to identify the least costly treatment option.

The evaluation process is usually divided into three phases, the 'identification phase', the 'quantification phase', and the 'valuation phase'. The remainder of this chapter focuses on *informal care* using these three phases as a point of departure.

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<sup>61</sup> The Swedish Code of Statutes.

<sup>62</sup> SFS (Svensk författningssamling) 1988:1465. Lagen om ersättning och ledighet för vård av närstående. [The Swedish Code of Statutes 1988:1465].

<sup>63</sup> In Swedish: Lagen (1988:1465) om ersättning och ledighet för närstående.

<sup>64</sup> Also, the patient is sometimes entitled to financial support from the County Council as a compensation for increased expenditures when being cared for at home.

<sup>65</sup> Luce & Elixhauser (1990).

## The identification phase

The first phase of a study or an evaluation is the identification of relevant costs and effects of the intervention at hand, the golden standard being that *all* relevant costs as well as effects should be considered. Traditionally, costs have been labelled ‘direct costs’<sup>66</sup> and ‘indirect costs’<sup>67</sup>. Direct costs are costs that can be attributed to the changes in resource use due to the health care intervention. Indirect costs are negative changes such as in the productivity of an individual due to disease or illness or due to the results of an intervention, such as the time the patient spends waiting for care or the time the patient’s next of kin spend helping the patient.

There is still no consensus regarding how and whether to include so-called indirect costs in evaluations of health care programmes<sup>68</sup>. Gold et al<sup>69</sup> have chosen to avoid the term ‘indirect’, as it has become a concept with diverse interpretations. Instead, they recommend the use of the term ‘productivity cost’ to represent costs associated with morbidity and mortality.

The time an informal caregiver spends on caring for a next of kin in advanced home care can be viewed as an indirect cost as well as a direct cost. From a strict provider perspective, i.e. that of the county councils, it may be logical to label the cost of informal care as an indirect cost, as informal care is a resource outside the county council. However, from a societal, opportunity cost perspective it is more logical to include the cost of informal care as a direct cost, as it is a resource used within a care process. Had the care service been purchased and performed by a nurse, for example, it would obviously be perceived as a direct care cost. In this study an opportunity cost approach is used, and from this point of view it is also logical to label the cost of informal care as a direct cost. Gold et al suggest that ‘the time family members or volunteers spend to provide home care... may also be considered a direct non-health care cost’<sup>70</sup>. This approach seems appropriate in the present study, and the monetary value, or cost, of informal care should thus be placed in the numerator of the cost-effectiveness ratio. In order to value the time a family member spends, the opportunity cost must be estimated, which is often the same as loss of productivity. In advanced home care the costs of informal care are substantial. If the cost of informal care were to be excluded in

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<sup>66</sup> In Luce & Elixhauser (1990), direct costs are described as ‘Changes in resource use attributable to the intervention being studied; includes both medical and nonmedical resources’ (quoted from the glossary).

<sup>67</sup> In Luce & Elixhauser (1990), indirect costs are described as ‘Monetary value of the negative changes in the productivity of a patient that result from the intervention’ (quoted from the glossary).

<sup>68</sup> Commonwealth of Australia, *Guidelines for the Pharmaceutical Industry on Preparation of Submissions to the Pharmaceutical Benefits Advisory Committee: Including Economic Analyses*, Department of Health and Community Services, Canberra, 1995., Canadian Coordinating Office for Health Technology Assessment, *Guidelines for Economic Evaluation of Pharmaceuticals*, (Canadian Coordinating Office for Health Technology Assessment (CCOHTA), (2<sup>nd</sup> ed.), Ottawa, 1997.

<sup>69</sup> Gold, M. R., Siegel, J. E., Russel, L. B. & M. C. Weinstein, (eds.), *Cost-Effectiveness in Health and Medicine*, Oxford University Press, Oxford, 1996.

<sup>70</sup> Gold (1996) p. 179.

evaluations of advanced home care, the results would be biased. If a societal perspective is used in the evaluation, all costs should be included – regardless of which label is used.

### **The quantification phase**

The quantification phase deals with a number of practical measuring issues. The level of precision in an analysis depends in large part on the prospect and means for collecting relevant data. As for informal care, quantification of the effort can be done in terms of time and content. One issue is how to extract the time the informal caregiver actually spends caring. Many normal household chores can be performed at the same time or during caring, i.e. joint production exists. Some informal caregivers state that they give care ‘around the clock’. However, this may include lighter chores or surveillance and may be an expression of the feeling of being tied down rather than reflecting actual care time. McDaid<sup>71</sup> has raised several important issues regarding difficulties in defining and measuring informal care. For example, attention should focus on the fact that the time spent caring could be combined with ordinary household chores or normal family socialising. The use of diaries or detailed interviews, or perhaps a combination of both, may help to collect truthful data.

### **The valuation phase**

The third phase in the evaluation process is the methods by which cost components are to be valued and measured. A central problem of economic evaluations in health care is that there is no agreed upon method to determine the monetary value of informal care. It would be theoretically correct to estimate the value of leisure time by the individual’s willingness to pay (WTP). However, this method has some practical limitations (it is for example very expensive) and an estimate of the individual’s marginal wage net of taxes is often used instead. In *the willingness to pay* or *contingent valuation method* the informal caregivers (in this case) would be asked how much they would be willing to pay for being relieved of their informal care task (or how much they would be willing to accept in order to continue to perform the care task). However, this method would be time consuming and difficult to conduct with large materials. Instead calculation of the *opportunity cost* of informal care is the approach recommended in textbooks<sup>72</sup>. This approach suggests that the cost of informal care should be set equal to its best alternative use. Assuming a general approach, the best alternative use would be the informal caregiver’s normal activities prior to the informal care situation. In this approach, normal activities are given a value for the time working that is forgone. The gross salary or wage rate is often used as

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<sup>71</sup> McDaid, D., ‘Estimating the costs of informal care for people with Alzheimer’s disease: Methodological and practical challenges’, *International Journal of Geriatric Psychiatry*, Vol. 16, 2001, pp. 400-405.

<sup>72</sup> Gold (1996).

an estimate. Lost leisure time or other unpaid activities are often excluded or priced at a lower rate. Also, any utilities attached to work or leisure are often excluded.

Other suggested methods are *the market price method* or *replacement method*, in which the informal caregiver's time that is spent giving care is priced at its market value, or rather the cost of care had it been purchased on the market (the price of hiring a professional caregiver). However, this method may not reflect the cost of the informal care in a satisfactory way, as it does not take into account the sacrifices made by the informal caregiver, i.e. the loss of his/her normal activities<sup>73</sup> or utility in providing help for a loved one.

*The human capital approach*<sup>74</sup> and *the friction cost method*<sup>75</sup> are both methods that value time absent from work (as a loss to society) by its opportunity cost. Both models focus on the reduced paid production due to mortality and morbidity. The human capital approach<sup>76</sup> estimates the value of lost production due to disease up to the age of retirement. In a wider interpretation of the human capital approach<sup>77</sup> the costs are defined as the lost gross value during time absent from usual activities. The more recent friction cost model defines costs of disease as "the value of production lost to society due to illness, with respect to paid labor as well as unpaid labor"<sup>78</sup>. In the friction cost model the indirect costs for long-term absence mainly occur during the time it takes to replace a worker (the search for and training of a new employee) - the friction period. The theory is based on the assumption that persons who are unemployed constitute a labor reserve within companies that can replace a worker. For instance, non-urgent work can be put off into the future or put off altogether, companies can reallocate resources in order to compensate for a sick employee, and so on. These assumptions will result in a lower cost compared to the human capital approach. The friction cost model has been discussed and criticised on several points<sup>79</sup>.

Liljas argues that we should separate paid and unpaid production. Absence from paid work due to disease, or in this case a close relative or friend's disease, should be costed as lost gross income, while lost unpaid production, i.e. leisure time, should be costed according to the individual's own valuation of leisure time. The concept of separating paid and unpaid production is applied in *Papers IV and V*.

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<sup>73</sup> Brouwer, W. B. F., Van Exel, N. J. A., Koopmanschap, M. A. & F. F. H. Rutten, 'The valuation of informal care in economic appraisal. A consideration of individual choice and societal costs of time', *International Journal of Technology Assessment in Health Care*, Vol. 15, no. 1, 1999, pp. 147-160.

<sup>74</sup> Weisbrod, B. A., 'The valuation of human capital', *Journal of Political Economy*, Vol. 69, 1961, pp. 425-436.

<sup>75</sup> Koopmanschap, M. A. & B. M. van Ineveld, 'Towards a new approach for estimating indirect costs of disease', *Social Science and Medicine*, Vol. 34, no. 9, 1992, pp. 1005-1010.

<sup>76</sup> Weisbrod (1961).

<sup>77</sup> Liljas, B., 'How to calculate indirect costs in economic evaluations', (Pt 1), *Pharmacoeconomics*, Vol. 13, no. 1, 1998, pp. 1-7.

<sup>78</sup> Koopmanschap & van Ineveld (1992).

<sup>79</sup> See for example Liljas (1998) and a discussion between Johannesson, M. & G. Karlsson, 'The friction cost method: A comment', *Journal of Health Economics*, Vol. 16, no. 2, 1997a, pp. 249-255. and Koopmanschap, M. A., Rutten, F. F. H., van Ineveld, B. M. & L. van Roijen, 'Reply to Johannesson's and Karlsson's comment', *Journal of Health Economics*, Vol. 16, 1997, pp. 257-259.

Neither the U.S. Panel on cost effectiveness nor Drummond et al offers a practical method for how to cost informal care. The U.S. Panel recommends the approach “to value the time at its market or reservation price, similar to the methods suggested for valuing the time of housewives or househusbands”<sup>80</sup>. For the value of time for a person who “is of working age but does not work for pay (e.g., housewives or househusbands), one option for valuing time is to use the hourly wage of individuals with similar characteristics... who do work for pay”<sup>81</sup>. Brouwer et al<sup>82</sup> discuss methods for the costing of informal care in economic evaluations in general and suggest that a method like the friction cost method could be used when the caregiver gives up paid labour time in order to become an informal caregiver. Unpaid work and leisure time, on the other hand, include aspects of quality of life and should therefore, according to Brouwer et al, be captured in the measurement of quality of life. This approach is also suggested by Johannesson, who says “it seems reasonable to assume that individuals take into account the change in leisure in assessments of quality weights”<sup>83</sup>. However, it should be noted that it is not likely that a value or cost of informal care time will be incorporated in patient quality of life. That is possible only if the quality of life of the informal caregiver is measured.

Informal caregivers who give up time, paid work time, unpaid work time or leisure time in order to care for a close relative or friend experience a change in utility. It seems that there are good arguments for that lost paid work time should be valued as a production loss and lost unpaid work time and lost leisure time should be incorporated in quality weights. However, in home care or home rehabilitation the lost unpaid work time or lost leisure time is replaced by a caring activity that should be given a monetary value in cost effectiveness analyses, i.e. the informal caregiver performs a task that, for example, a nurse would otherwise have done. Thus it seems reasonable to include the cost of informal care as a direct non-medical cost.

## Summary and study questions

In this introductory chapter several questions have been raised regarding advanced home care and health economic evaluation. A wide variety of diseases can be treated or followed up in advanced home care. This is due in part to refined methods of care, refined drugs and adapted technologies, and also to improved home standards. There has also been an increased demand for expanded advanced home care from the patients themselves, as well as from home care advocates. Another factor contributing to the increased demand for advanced home care is the increasing number of elderly in the

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<sup>80</sup> Gold (1996) p. 203.

<sup>81</sup> Gold (1996) p. 202.

<sup>82</sup> Brouwer (1999).

<sup>83</sup> Johannesson, M., ‘Avoiding double-counting in pharmacoeconomic studies’, *Pharmacoeconomics*, Vol. 11, no. 5, 1997b, pp. 385-388.

population, which in turn leads to an increased demand for care. Advanced home care has also been marketed as a possible way to reduce health care expenditures at a point where the need to cut costs is urgent. However, the scientific evidence as to whether advanced home care is more cost effective than in-hospital care is inconsistent. Sometimes home care also causes a redistribution of care efforts from one formal caregiver to another (from the County Councils to the municipalities) and from formal caregivers to informal caregivers. These effects have not been fully explored. In health economic evaluations the role of the informal caregiver has been overlooked. Since informal care constitutes a minor part of the care effort in in-hospital care, these costs have often been excluded. In home care the role of the informal caregiver is significant and should constitute a direct non-medical cost in health economic evaluations.

This dissertation deals with a few of the aspects described above. Two evaluations were performed, one comparing a home care technology (concentrator treatment vs mobile liquid oxygen treatment for patients with chronic hypoxaemia) with another technology (*I*), and one comparing the effects of reallocation between home rehabilitation and in-hospital rehabilitation after stroke (*III*). In addition, a literature review was performed exploring the scientific evidence regarding whether home rehabilitation is more cost effective compared to other treatment alternatives (*II*). *Papers IV and V* concern methods for estimating costs of informal care in economic evaluations. *Paper V* also involves some factors that have an influence on informal care costs.



## AIMS

The aim of this thesis was to examine the cost-effectiveness of specific advanced home care and home rehabilitation interventions and to improve economic evaluation methods when applied to advanced home care.

This included a comparison of two alternatives for administering oxygen at home to patients with chronic hypoxaemia as well as a review of scientific evidence on costs and effects of home rehabilitation after stroke. Also included were studies on prominent methodological issues in advanced home care - the redistribution of care efforts among caregivers and costing of informal care efforts. The specific aims of the five studies on which this thesis is based are listed below.

The aim of *Paper I* was to compare two main regimens for oxygen administration in the long-term oxygen treatment at home of patients with chronic obstructive pulmonary disease in terms of costs and patient utility.

*Paper II* is a literature review analysing whether rehabilitation in the home is more efficient or less expensive than conventional treatment strategies, i.e. rehabilitation in hospital.

The aim of *Paper III* was to analyse the redistribution of costs between health care providers and social welfare providers in home rehabilitation and routine rehabilitation after stroke.

*Paper IV* addresses the question of how to estimate the cost of informal care in advanced home care and also analyses the outcome of using different models with empirical data.

*Paper V* had three aims. The first was to estimate the time cost of informal care of patients treated in advanced home care. Two opportunity cost models were used for estimating the cost of informal care, one including leisure time and the other excluding leisure time. The second aim was to study which factors have an influence on costs associated with informal care in advanced home care. The third aim was to compare different diagnosis groups regarding costs of informal care.



## QUESTIONS AND METHODS

### Study overview

The studies (*I-V*) in this thesis all concern advanced home care or home rehabilitation. The health economic issues discussed, such as the redistribution of resource use between caregivers, are features that occur in advanced home care where the alternatives hospital care vs home care are obvious.

The empirical studies underlying this thesis cover several aspects of advanced home care, and different study designs have been used. The patient material covers specific diagnosis groups such as chronic hypoxaemia (*I*) and stroke (*II, III*) but also cross-sectional based material including mixed diagnosis groups (*IV, V*). An overview of the studies is presented in *table 1* below.

Table 1: Study overview.

Paper	Type of study	Data collection years	Diagnosis	Number of patients	Geographical setting	Main outcome measurements
I	Comparative, randomised, longitudinal	1993-1994	Chronic hypoxaemia	51	Uppsala, Gävle, Linköping, Boden, Örebro, Stockholm	Caregiver costs, quality of life
II	Literature review	1966-1998	Stroke	-	Worldwide	Study quality, rehabilitation outcome, costs
III	Comparative, non-randomised, longitudinal	1996-1998	Stroke	121	Linköping, Eksjö, Nässjö	Formal caregiver costs
IV	Descriptive, cross-sectional	1999	Mixed	59	Linköping municipality	Informal care costs
V	Descriptive, cross-sectional	1995	Mixed	451	County of Östergötland	Informal care costs

The first study is a comparative, experimental study (randomised controlled trial, RCT) where two alternative treatments are assessed regarding caregiver costs as well as quality of life (I). The second is a literature review that was performed in order to try to establish whether home care is better and/or less costly than conventional alternatives (II). Main outcome measurements in *Paper II* were study quality, rehabilitation outcomes and costs. The third study is a comparative, non-randomised study in which two alternative rehabilitation strategies are mapped out in order to analyse formal caregiver costs and whether or not the resource distribution between caregivers differs in the two alternatives (III). Papers IV and V are descriptive, cross-sectional studies in which mixed patient groups are described. In the fourth and fifth studies, models for the costing of informal care are discussed and tested.

## Paper I

### Study background

Chronic obstructive pulmonary disease (COPD) is the most frequent diagnosis among lung diseases within in-hospital care<sup>82</sup>. The prevalence of COPD increases with increasing age, and reaches a maximum at 70 years of age. In Sweden the prevalence is about three to five percent. Approximately 15-20% of all smokers develop COPD. In Sweden, the number of reported patients who were discharged before 1994 with long-term oxygen treatment was 3 345<sup>83</sup>. During 1994, 701 patients were discharged with long-term oxygen treatment. And during 1994 1 972 patients received long-term oxygen treatment in their home<sup>84</sup>.

There are three different ways to administer oxygen for treatment at home. Concentrator treatment is the standard treatment. Mobile liquid oxygen was introduced later and is four times as concentrated as gas contained in a high-pressure cylinder, making it possible to use smaller containers and thus allowing the patient to be more mobile. Oxygen can also be administered in bottles with compressed gas. The bottles are relatively heavy and must generally be pulled on a small cart. The patients in the study used bottles as a complement, mainly to concentrator treatment. In Sweden only two percent of the patients receiving home oxygen treatment use mobile liquid oxygen<sup>85</sup>.

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<sup>82</sup> The County Council of Östergötland, *Medicinskt program för andningsorganens sjukdomar*, (Medicinskt program i Östergötland), Linköping, 1999.

<sup>83</sup> The counting started in 1987 when the Oxygen Register was started at the initiative of Svensk Lungmedicinsk förening. The Oxygen Register registers all patients who receive long-term treatment at home for chronic respiratory insufficiency.

<sup>84</sup> The Swedish Society of Respiratory Medicine. [Svensk Lungmedicinsk Förening]. *Årsrapport för 1994. Oxygen-Studien*. Svensk Lungmedicinsk Förening, 1994.

<sup>85</sup> Swedish, The, Council on Technology Assessment in Health Care. [Statens beredning för medicinsk utvärdering, SBU]. *Behandling av astma och KOL. En systematisk kunskapsammanställning*. (SBU-rapport 2000:151), (In Swedish), SBU, Stockholm, 2000.

In this study we sought to test the hypothesis that long-term oxygen treatment with mobile liquid oxygen improves patients' health-related quality of life, but at a higher cost compared to concentrator treatment.

## Method

This study was designed as a prospective, randomised multicentre trial comparing oxygen concentrator treatment with mobile liquid oxygen treatment. The economic evaluation method used was a cost-utility analysis with a societal perspective. Patient outcome was measured as changes in quality of life in terms of EuroQol and the Sickness Impact Profile (SIP).

All patients meeting study criteria (n=51) from six different departments of pulmonary medicine in Sweden were randomised to the two alternative treatments. One patient withdrew from the study for personal reasons and two patients died during the study period. The study period was six months. Inclusion criteria were chronic hypoxaemia caused by pulmonary disease (the cutoff point for hypoxaemia was 7.0-7.5 kPa or, in the presence of signs of cor pulmonale or a hematocrit above 50%, around 7.5 kPa)<sup>86</sup>, eligibility for treatment with mobile liquid oxygen, the ability to use mobile equipment. Exclusion criteria were patients who were confined to their homes or not able to handle mobile equipment.

The patients were asked to keep a 'diary' in which they registered their contacts (visits or telephone consultations) with physicians, nurses, physical therapists, almoners, medical technicians, as well as their use of transportation services. The diary notes regarding the patients' visits and/or telephone contacts with medical professionals, and their use of transportation services, were used to estimate costs during the trial. The data concerning consumption of mobile liquid oxygen and, for a few patients, small amounts of gas oxygen, were collected from invoices sent by a gas company to the local pharmacies.

Estimation of the cost of the use of resources registered in the patient diaries was made retrospectively, using information collected from each department involved in the study. A median cost was calculated for each category. All costs are expressed in 1996 prices. Value added tax was not included. One SEK equals US\$<sup>87</sup> 0.13.

The concentrators underwent maintenance service by a medical technician twice a year on an average, or after about 3 000 hours. One service was estimated to cost between US\$ 234-260 (SEK 1 800 – 2 000). The average cost of a concentrator was calculated at

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<sup>86</sup> Chronic hypoxia means deteriorated absorption of oxygen that has lasted for more than six months. Cor pulmonale means that the right side of the heart has to work harder in order to compensate for a disease of the lungs that makes it more difficult for the blood to pass through the pulmonary system. This condition often causes hypoxia since the blood is also poorly saturated with oxygen in the lung. The hematocrit is obtained by a blood test that determines the ratio of red blood cell volume to blood volume. Normally this is 45%, but persons with lung disease have a higher percentage of red blood cells in order to compensate for their deteriorated oxygen saturation. The oxygen level in the lung is expressed in kilo Pascal (kPa). A normal pressure is about 13 kPa.

<sup>87</sup> United States dollars.

US\$ 3 510 (SEK 27 000). This entails a depreciation cost of US\$ 351 (SEK 2 700) for the six-month period using the traditional method of historic cost depreciation<sup>88</sup>. The depreciation cost of the portable container was US\$ 130 (SEK 1 000) for the six-month period. The same cost was used for both visits and telephone consultations. The transportation service cost was estimated using information from the responsible local taxi company<sup>89</sup>.

The quality of life analysis was based on 47 patients (n=27 for the group with mobile liquid oxygen and n=20 for the group with concentrator treatment) for whom satisfactory data were collected. The SIP<sup>90</sup> and the EuroQol<sup>91</sup> instruments were used at the start of the trial and after six months in order to measure patient outcome. The SIP is a generic instrument, containing several dimensions of importance to health-related quality of life that can be weighted together into one single score. The higher the score the worse the quality of life.

The EuroQol is also a generic instrument developed for measuring health related quality of life. The instrument consists of one part with questions regarding six dimensions<sup>92</sup> and a second part in which the respondent is asked to grade his/her general health status on a scale. The categories/dimensions of mobility, self-care, usual activity, pain, discomfort, anxiety/depression and better/worse are graded on three levels. The three levels reflect increasing degrees of difficulty (level 1=no problem, level 2=some or moderate problems, level 3=unable or extreme problems). The scores for the six categories/dimensions should therefore be interpreted as the lower the score the better the quality of life. The score for the scale should be interpreted as the higher the score the better the quality of life.

## Data analysis

In this study t-tests were used. A one-sided p-value of <0.05 was considered significant due to the hypothesis that long term oxygen treatment with mobile liquid oxygen had a better impact on patients' quality of life, but that it is also more expensive compared to long-term oxygen treatment with concentrator treatment. The t-test was used for the

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<sup>88</sup> Sugden, R. & A. Williams, *The Principles of Practical Cost-Benefit Analysis*, Oxford, 1978.

<sup>89</sup> The calculation of the total cost can be summarised by the following expression:

Total cost = (number of O<sub>2</sub> tanks x cost) + (number of freights x cost) + (number of days with rent for the stationary container, L x cost) + (number of services x cost) + depreciation portable unit/depreciation concentrator + cost estimated by the diary + ((medical technician time + travel time) x cost). In this equation medical technician time occurs twice. This is due to the fact that different hospitals use different organisations regarding medical technician service. The total cost of one patient will thus only have one kind of cost for medical technician service, never both, which would result in double counting.

<sup>90</sup> Bergner, M., Bobbitt, R. A., Carter, W. B. & B. S. Gilson, 'The Sickness Impact Profile: Development and final revision of a health status measure', *Medical Care*, Vol. 19, no. 8, 1981, pp. 787-805.

<sup>91</sup> EuroQol Group, 'EuroQol – a new facility for the measurement of health-related quality of life', *Health Policy*, Vol. 16, no. 3, 1990, pp. 199-208.

<sup>92</sup> The instrument was later reduced to five dimensions, the EQ-5D instrument.

analyses presented in the results section. For analysis of the demographic and clinical data (I, table 1), a two-tailed independent samples t-test was used.

## Paper II

### Study background

Home rehabilitation differs from other home care in that it is not a straightforward alternative or substitute for hospitalisation as may otherwise be the case. Home rehabilitation only substitutes for hospitalisation to a certain degree; it continues after the time when the hospitalisation period would normally have ended. Thus, home rehabilitation is an alternative for hospitalisation and for day care or polyclinic care. Patients recovering from hip surgery and stroke are the dominating patient groups. Studies have shown that the length of stay in hospital can be reduced when home rehabilitation teams are used<sup>93</sup>. Appelros<sup>94</sup> survey of home rehabilitation units in Sweden during 1997 concluded that 44 units carried out home rehabilitation (of 94 replies from 101 hospitals). The results of a survey by Högberg and Gertz<sup>95</sup> were published in 1998 showed that the number of home rehabilitation units was 21.

The question addressed in this review is whether home rehabilitation after stroke is more effective and/or costs less than conventional alternatives. This study was designed as part of an extensive review of the scientific evidence regarding advanced home care and home rehabilitation<sup>96</sup>. We defined home rehabilitation generally as a part of advanced home care and specifically as a specific training strategy, usually managed by a team of professionals, to rehabilitate stroke patients in their own homes directly following the acute hospital stay.

### Method

In this study the scientific literature on home rehabilitation after stroke was systematically searched for controlled studies comparing outcomes and costs. The databases Medline, Cochrane Library, Cinahl, Econlit, ArbSpriline, ABI Inform, and Sociological Abstracts from 1966 to December 1999 were used to extract possible studies of interest. The keywords used were stroke, rehabilitation, home care services, domiciliary services,

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<sup>93</sup> Rodgers (1997), Rudd (1997), Widén Holmqvist (1998), Koch, L. von, *Early Supported Hospital Discharge and Continued Rehabilitation at Home After Stroke*. (Unit of neuroepidemiology and health services research, division of neurology, Department of clinical neuroscience, occupational therapy and elderly care research, Huddinge University Hospital and the Department of physical therapy), Stockholm, 2000.

<sup>94</sup> Appelros, P., 'Allt fler, allt sjukare patienter rehabiliteras i hemmet', *Läkartidningen*, Vol. 95, no. 17, 1998, pp. 1939-1942.

<sup>95</sup> Högberg & Gertz (1998).

<sup>96</sup> The Swedish Council on Technology Assessment in Health Care (1999).

economics, randomised and controlled studies. Controlled, randomised and quasi-experimental studies were included. Excluded were studies where patients represented mixed disease groups and studies in which the experimental group as well as the control groups received conventional rehabilitation and only extra contacts with nurses or social workers at home were tested.

In this study a formal meta analysis was not possible since the outcome measures varied. In order to capture outcomes striving in the same direction, non-significant tendencies were analysed. These tendencies were denoted by 'NS<sup>97</sup> positive' for a positive tendency, suggesting benefits from home rehabilitation, and 'NS negative' suggesting a negative tendency.

The search for literature yielded 204 studies that were reviewed by two individuals independently of one another. After a first screening of the material 89 studies remained and were reviewed in greater detail. Some additional studies were also reviewed. A total of seven studies addressing the effects of home rehabilitation were identified and found to be of acceptable quality<sup>98</sup>. The selected studies were thoroughly analysed and discussed in a larger group (nine persons, medical professionals as well as health economists). When in doubt about the interpretation of the methods or results, the respective authors were contacted for clarifications.

The quality of the economic estimates was evaluated using a three-grade scale: high, moderate and low. These criteria were based on Drummond and Jefferson<sup>99</sup>. In order to have high quality, there had to be a randomised controlled study design. In addition to the RCT criteria, the study also needed to be based on a relatively large patient material and also to maintain acceptable standards regarding the criteria presented by Drummond et al<sup>100</sup>. The need for a comparison including two or more alternative care strategies is important regarding costs, amongst other things. This indicates that cost-effectiveness studies and cost-utility studies (and in some cases cost-benefit studies) are considered to have higher quality as compared to cost analyses without a control group or cost-minimisation studies. Studies with a before-after design have been regarded as higher in quality if the same population has been followed rather than if different patients have been studied before and after an intervention. Studies with a societal perspective have been regarded as higher in quality compared to those with a narrower perspective. Studies

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<sup>97</sup> NS, non-significant.

<sup>98</sup> Wade, D. T., Langton-Hewer, R., Skilbeck, C. E., Bainton, D. & C. Burns-Cox, 'Controlled trial of a home-care service for acute stroke patients', *Lancet*, Vol. 1, no. 8424, 1985, pp. 323-326., Young, J. B. & A. Forster, 'The Bradford community stroke trial: Results at six months', *British Medical Journal*, Vol. 304, no. 6834, 1992, pp. 1085-1089., Gladman, J., Lincoln, N. B. & D. H. Barer, 'A randomised controlled trial of domiciliary and hospital-based rehabilitation for stroke patients after discharge from hospital', *Journal of Neurology, Neurosurgery & Psychiatry*, Vol. 56, no. 9, 1993, pp. 960-966., Gladman, J., Forster, A. & J. Young, 'Hospital- and home-based rehabilitation after discharge from hospital for stroke patients: Analysis of two trials', *Age and Ageing*, Vol. 24, no. 1, 1995, pp. 49-53., Rudd (1997), Rodgers (1997), Widén Homqvist (1998), Baskett, J. J., Broad, J. B., Reekie, G., Hocking, C. & G. Green, 'Shared responsibility for ongoing rehabilitation: A new approach to home-based therapy after stroke', *Clinical Rehabilitation*, Vol. 13, no. 1, 1999, pp. 23-33.

<sup>99</sup> Drummond, M. F. & T. O. Jefferson, 'Guidelines for authors and peer reviewers of economic submissions to the BMJ', *British Medical Journal*, Vol. 313, no. 7052, 1996, pp. 275-283.

<sup>100</sup> Drummond & Jefferson(1996).

that include direct costs as well as indirect costs have been given a higher score compared to studies that include direct costs only. A high quality study also needed to include all cost components associated with the intervention at hand, and shortcuts as average costs and charges should, if possible, be avoided. Due to the small number of available studies high tolerance has been used in the present study regarding this last aspect. Discounting and sensitivity analyses in relevant cases increase the quality. A systematic rating of other quality aspects was also performed and has been reported elsewhere<sup>101</sup>.

## Paper III

### Study background

The incidence of stroke is strongly age-related, with a threefold increase for every 10 years of life. In Sweden about 30 000 people are afflicted by stroke each year, and for about 20 000 of them this is a first time stroke. Cerebrovascular disorders are the third most common cause of death in Sweden, representing approximately 10-12% of all deaths<sup>102</sup>. In *Paper II* the overall conclusion was that costs (and outcomes) of home rehabilitation after stroke seem to be comparable to the costs of alternative treatment strategies. A study by von Koch et al<sup>103</sup> showed similar results, i.e. that early supported discharge with continued rehabilitation at home, as compared to hospital-based rehabilitation, proved neither less beneficial nor more expensive (similar costs and effects). Anderson et al<sup>104</sup> found that early discharge and home-based rehabilitation after stroke was less costly compared to conventional hospital care, although the cost saving was not statistically significant.

Some of the studies comparing home rehabilitation with conventional alternatives exclude severely ill patients<sup>105</sup>. The suitability of severely ill patients for home or outpatient rehabilitation has been discussed<sup>106</sup> and it has been proposed that home

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<sup>101</sup> The Swedish Council on Technology Assessment in Health Care (1999).

<sup>102</sup> Wester, P. O., Asplund, K., Eriksson, S., Holm, J., Marké, L. Å., Norlund, A., Norrving, B., Normell, L. & S. Rehncrona, *Slaganfall. Stroke*. (In Swedish), (The Swedish Council on Technology Assessment in Health Care (SBU), No. 116), Stockholm, 1992.

<sup>103</sup> Koch, L. von, Widén Holmqvist, L., De Pedro-Cuesta, J., Kostulas, V. & J. Almazán, 'Randomized controlled trial of rehabilitation at home after stroke: One-year follow-up of patient outcome, resource use and cost', *Cerebrovascular Diseases*, Vol. 12, no. 2, 2001, pp. 131-138.

<sup>104</sup> Anderson, C., Ni Mhurchu, C., Rubenach, S., Clark, M., Spencer, C. & A. Winsor, 'Home or hospital for stroke rehabilitation? Results of a randomized controlled trial. II: Cost minimization analysis at 6 months', *Stroke*, Vol. 31, 2000, pp. 1032-1037.

<sup>105</sup> Beech (1999), von Koch (2001), Anderson (2000).

<sup>106</sup> Smith, D. S., Goldenberg, E., Ashburn, A., Kinsella, G., Sheikh, K., Brennan, P. J., Meade, T. W., Zutshi, D. W., Perry, J. D. & J. S. Reedback, 'Remedial therapy after stroke: a randomised controlled trial', *British Medical Journal*, Vol. 282, no. 6263, 1981, pp. 517-20., Hermans, E., Diederiks, J. P. & H. Philipsen, 'Home care – a realistic alternative for bed-blocking stroke victims in acute hospital wards? The conceptions in six disciplines concerned', *Scandinavian Journal of Caring Sciences*, Vol. 10, no. 2, 1996, pp. 81-87.

rehabilitation should be directed to moderately disabled patients<sup>107</sup>. In the studies presented by Young and Forster<sup>108</sup> and Gladman et al<sup>109</sup>, the initial acute care ward period was excluded. Due to housing difficulties that may occur when the patient is to be transferred from the acute care ward to home, i.e. when new housing is needed due to the stroke, the acute care ward cost may have an important impact on the total cost. Further, there may be an extended need for home help service in the home care alternative, and these requirements must be met before the patient can return home. An extended acute care ward stay could also indicate that home rehabilitation might not be suitable for all stroke patients. To my knowledge, no study has reported a possible reallocation of costs from health care providers to social welfare providers, nor has home rehabilitation been evaluated for a stroke patient group with as wide-ranging a degree of impairment as in this study.

*Paper III* aimed to analyse the redistribution of costs between health care providers and social welfare providers in a comparison of home-based rehabilitation and hospital-based rehabilitation after stroke.

## Method

This study analyses home-based and in-patient rehabilitation (hospital-based rehabilitation) in a prospective cohort study in two Swedish cities during the period 1996 to 1998. The involved hospitals were the University Hospital in Linköping and Eksjö County Hospital and its associated rehabilitation clinic in Nässjö. The primary catchment areas for the University Hospital in Linköping and Eksjö County Hospital comprise 150 000 and 115 000 inhabitants, respectively. The home-based rehabilitation option was within the scope of ordinary home rehabilitation. The home rehabilitation group spent their initial acute period in a stroke unit and continued the rehabilitation process at home. The first evaluation was made upon admission to the acute care ward and then this was subsequently followed up at discharge from the acute care ward. The patients were thereafter followed up on admission and discharge from the rehabilitation programme and also at six and twelve months post stroke. Standardised forms were used for all data collection.

There were a total of 124 patients, 56 in the home-based group and 68 in the hospital-based group. Three patients had to be disregarded due to a misunderstanding in the data collection process, thus leaving 53 patients in the home-based group. All patients had a diagnosis of stroke and needed continuous rehabilitation after discharge from the acute

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<sup>107</sup> Holmqvist, L. W., von Koch & L., & J. de Pedro-Cuesta, 'Use of health care, impact on family caregivers and patient satisfaction of rehabilitation at home after stroke in southwest Stockholm', *Scandinavian Journal of Rehabilitation Medicine*, Vol. 32, no. 4, 2000, pp. 173-179.

<sup>108</sup> Young, J. & A. Forster, 'Day hospital and home physiotherapy for stroke patients: A comparative cost-effectiveness study', *Journal of the Royal College of Physicians of London*, Vol. 27, no. 3, 1993, pp. 252-258.

<sup>109</sup> Gladman, J., Whynes, D. & N. Lincoln, 'Cost comparison of domiciliary and hospital-based stroke rehabilitation. DOMINO Study Group', *Age and Ageing* Vol. 23, no. 3, 1994, pp. 241-245.

care ward. Two patients in the hospital-based group moved during the study period, and four declined further participation. In addition, at the time of the 12-month follow-up 14 patients had died in the hospital-based group. In the home-based group one patient declined further participation and at the time of the 12-month follow-up eight patients had died. At the 12-month follow-up 44 patients remained in the home-based rehabilitation group and 48 patients in the in-patient rehabilitation group. With respect to data collection from files on home-help service kept by the municipalities, five patients in the hospital-based group and two in the home-based group declined to participate.

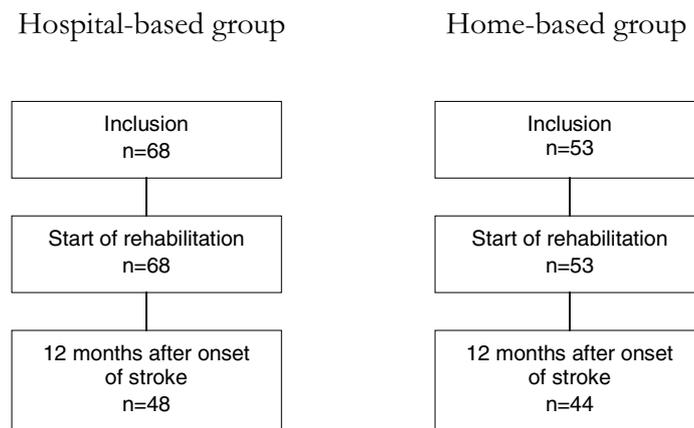


Figure 1: Number of patients at different points in time.

The average age at onset was 76 (SD<sup>110</sup>=6) for the home-based group and 79 (SD=9) for the hospital-based group. The baseline variables showed no significant differences regarding age, sex, housing, first stroke, diabetes, atrial fibrillation, angina pectoris, acetylsalicylic acid (ASA)<sup>111</sup> use or warfarin<sup>112</sup> use. However, there were significantly (p=0.012) more patients with hypertension in the hospital-based group. The clinical diagnosis at onset was cerebral infarction for 81% of the patients in the hospital-based group and for 87% of those in the home-based group. The Katz ADL<sup>113</sup>-index was used to measure level of dependency in activities of daily living. The instrument has a seven-grade scale, A-G, where A is independent and B-G represent gradually increasing dependence. Patients in the home-based group were significantly worse with respect to functions measured by the Katz ADL-index (p=0.034) at onset of stroke.

Data on resource use were collected prospectively and divided into two parts, cost attributed to the health care provider (acute care ward cost and rehabilitation cost) and cost attributed to the social welfare provider (home-help service, nursing home). Information regarding prices for the acute care and the rehabilitation periods was

<sup>110</sup> SD, standard deviation.

<sup>111</sup> ASA, acetylsalicylic acid, a drug used to prevent ischaemic stroke.

<sup>112</sup> Warfarin, a drug used to prevent ischaemic stroke.

<sup>113</sup> ADL, activities of daily living.

retrieved from internal cost estimates at Centre for Neuroscience (Neurocentrum), University Hospital in Linköping. The prices include overhead cost and some additional non-specific cost (for example journal keeping). Costs were calculated for 53 patients in the home-based group and 68 patients in the hospital-based group. Costs for the acute care ward episode had to be retrospectively reconstructed for three patients in the home-based group, and for the rehabilitation episode they were reconstructed for five patients due to insufficient data in the original data collection. The average cost was used as an estimate for the reconstruction. Corresponding reconstructions were made for four patients and seven patients, respectively, in the hospital-based group, also due to insufficient data.

### Data analysis

The Mann-Whitney U test was used to assess the statistical differences between the hospital-based group and the home-based group with respect to the Katz ADL-index at baseline. For the other baseline characteristics, the chi-square was used. For the analysis regarding costs, a two-tailed independent samples t-test was used. In all analyses a two-sided p-value ( $<0.05$ ) was considered significant. A linear multiple regression analysis was used to assess the significance of different baseline factors with respect to costs. Variables included as potential predictors were age, sex, housing, first ever stroke, history of diabetes, history of atrial fibrillation, history of angina pectoris, history of hypertension, ASA use, warfarin use, and the Katz ADL-index at onset of stroke.

## Paper IV

### Study background

In this study, models that are traditionally used for calculating indirect costs have been used to estimate costs of informal care. In *Paper IV* the term indirect cost is also used to label these costs. In *Paper IV* (and *V*) an opportunity cost approach is used to estimate the cost of informal care. This line of argument is based on the hypothesis that cost of informal care in advanced home care and home rehabilitation includes lost unpaid work time or lost leisure time but is replaced by a caring activity that should be given a monetary value in cost effectiveness analyses, i.e. the informal caregiver performs a task that, for example, a nurse would otherwise have done. Further, if the quality of life of the informal caregiver is changed the cost must also be considered in economic evaluations. These two arguments, the opportunity approach and the importance of measuring the effects of informal caregiving leads to the conclusion that the cost of informal care can be considered a direct non-medical cost.

This study focused on costing of the care provided by the informal caregiver in home care in health economic evaluations. The study also addressed the question of how to estimate the cost of informal care in advanced home care. The outcome of using different approaches (the friction cost model and the human capital approach) for estimating the cost of informal care in advanced home care was analysed using empirical data. We have not considered costs attributed to health care providers or social welfare providers.

## Method

The empirical data were obtained from the County Council of Östergötland, Sweden. The data represent all patients registered in hospital-based home care at the University Hospital in Linköping, Sweden, during a one-week period in November 1999. Data on 59 patients were collected using a standardised form. The data include background variables, length of the care episode, information regarding types of visits, visit frequencies, diagnosis, control of symptoms, procedures, questions regarding informal care (primarily amount of time the informal caregiver provided care).

The patients were enrolled in home care for less than one week, 1-2 weeks, 2-4 weeks, 1-2 months, 2-6 months or more than 6 months. The informal caregiver 'worked' 24 hours per day, either during the daytime or at night 7 days/week, at least one day/night per week, or several times a month during the enrolment period.

The background data (*Table 2 below*) show that there was an equal distribution of men and women and the average age of the patients as well as the informal caregivers was 70 years, i.e. old people are obviously taking care of old people. A majority of the patients lived in ordinary housing (block of flats or single-family house) with a spouse. Most of the patients in this study were cared for in palliative home care.

Further, 40% were in need of continuous home care and 44% had professional home care at least one day per week. Only 17% needed home help service. Sixty-six percent of the patients had an informal caregiver. Sixty-six percent of the informal caregivers stated that they were needed for care service 'around the clock'.

Table 2: Background data, n=59.

	Frequency	Percent
<i>Age</i>		
Mean age of caretakers (range)	70.2 (range 28-94)	
Mean age of caregivers (range)	70.3 (range 30-84)	
<i>Sex</i>		
Male	31	52.5
Female	28	47.5
<i>Type of home</i>		
Ordinary housing	56	94.9
Municipal housing	3	5.1
<i>Family relations</i>		
Living alone	17	28.8
Living with husband/wife	37	62.7
Living with others	5	8.5
<i>Type of home care</i>		
Palliative home care	45	76.3
Acute home care	14	23.7
<i>Advanced home care visits</i>		
Continuous	24	40.7
At least one day per week	26	44.1
Less than one day per week	9	15.3
<i>Home help service</i>		
Yes	10	16.9
Three times per day or more	7	70.0
1-2 times per day	2	20.0
Less than once per day	1	10.0
<i>Informal care</i>		
Yes	39	66.1
Around the clock	26	66.7
Daytime 7 days/week	3	7.8
Nights 7 days/week	2	5.1
At least one day or night per week	4	10.2
A few times per month	4	10.2

## Data input and demarcations

### *Data input in the models based on the friction cost model*

The data used in the friction cost model<sup>114</sup> are described below, although some simplifications will be made. The cost of informal care was calculated for one average care episode of home care for this patient group. Individual data on length of absence from usual activities and number of hours worked was used. Loss of production was estimated to equal the average monthly labour costs for a full-time Swedish employee in 1999

<sup>114</sup> Koopmanschap, M. A. & F. F. H. Rutten, 'A practical guide for calculating indirect costs of disease', *Pharmacoeconomics*, Vol. 10, no. 5, 1996, pp. 460-466.

including payroll taxes<sup>115</sup> (the average monthly labour cost is set at SEK 19 400 per month).

Three time episodes were used in this model, very short-term absence, short-term absence and long-term absence. Very short-term absence was defined as less than two weeks, short-term absence as less than three months, and long-term absence as more than three months. Very short-term absence is not assumed to cause indirect costs in the friction cost model. The elasticity of annual working time versus productivity was assumed to be 0.8 based on Dutch estimates<sup>116</sup>. A 40-hour working week was used, 160 hours per month, which resulted in an hourly salary of SEK 121.25. The data did not allow adjustment of the model for sex, disability, mortality, education level or profession. The training cost for a new employee was estimated as one double monthly salary and the training period was set at one month. An assumption was made that there is unemployment and thus no extra cost for recruiting labour. This demarcation was made since this cost is assumed to vary considerably from one case to another and must therefore be considered on a case to case basis. It is also important to note that these costs were not calculated as due directly to disease but rather due indirectly to disease, since the informal caregiver is not the one who is ill.

### ***Data input in the models based on the human capital approach***

In the human capital approach the same data on absence and wages were used, with the only difference being the friction period. The calculations were based on the broader interpretation of the human capital approach as suggested by Liljas<sup>117</sup> and included the gross value of time absent from usual activities. The model can thus be extended and can include all informal caregivers regardless of age.

Data on informal care were used as the base for calculating the *informal care cost* (IC). Six models were used; models 1-3 were based on the friction cost model and models 4-6 were based on the human capital approach.

### ***Models based on the friction cost model***

Model 1.  $IC=0$

Model 2:  $IC=((\text{lost gross income} * \text{reduced productivity}) * 8 \text{ hours}) * \text{number of days absent from work}$

Model 3:  $IC = \text{cost of the friction period (FP), where,}$

$FP = ((\text{lost gross income} * \text{reduced productivity}) * 8 \text{ hours}) * \text{days before replacement} + \text{training cost for new worker}$

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<sup>115</sup> Statistics Sweden [Statistiska Centralbyrån]. *Statistical Yearbook of Sweden 2000*. Stockholm (2000a).

<sup>116</sup> Koopmanschap & Rutten (1996).

<sup>117</sup> Liljas (1998).

### ***Models based on the human capital approach***

Model 4:  $IC = ((\text{hourly gross wages} * 8 \text{ hours}) * 5 \text{ days}) + ((\text{marginal wage net of taxes} * 16 \text{ hours}) * 5 \text{ days}) + ((\text{marginal wage net of taxes} * 24 \text{ hours}) * 2 \text{ weekend-days})$

Model 5:  $IC = ((\text{hourly gross wages} * 8 \text{ hours}) * 5 \text{ days}) + ((\text{marginal wage net of taxes} * 8 \text{ hours}) * 5 \text{ days}) + ((\text{marginal wage net of taxes} * 16 \text{ hours}) * 2 \text{ weekend days})$

Model 6:  $IC = ((\text{hourly gross wages} * 8 \text{ hours}) * 5 \text{ days})$

The first alternative (1) using the friction cost model illustrates very short-term absence, i.e. less than two weeks, and model (2) illustrates short-term absence and model (3) long-term absence. In the first alternative (4) in the human capital approach we show the most extreme case in which the cost is for one week. The cost is calculated for time absent from usual activities and all time over and above working time is regarded as leisure time. This assumption was made in order to differentiate between different time episodes during a day. Model (5) also calculates the cost for one week and assumes a normal working day of eight hours, five days a week, and that the informal caregiver gets paid to be “on call” 24 hours/day, allowing for no personal time. However, leisure time is assigned a lower cost (marginal wage net of taxes, i.e. gross wages reduced by payroll taxes, 30%) compared to working time in order to distinguish between paid and unpaid time. This model is unrealistic, but it represents the most extreme case. For example the value of production may be less when working at home caring for a relative than when working in the labour market. This is also dependent on the caregiver’s level of education and occupation. Some of the time working at home may also be used to carry out normal household chores. Leisure time should also be less than 16 hours per working day and less than 24 hours per weekend day, since some of the time is spent on activities such as sleeping and is not to be referred to as leisure time. A more realistic model (5) excludes time for sleep (8 hours/day). And in the last model (6) no leisure time is included at all.

## **Paper V**

### **Study background**

In 1995 the total population of the county of Östergötland, Sweden, was 415 000. The county comprised 13 municipalities, two of which were among Sweden’s ten largest. The age structure in Östergötland corresponds to that reflected in national data. The cost for advanced home care was calculated to be SEK 66 million, which constituted 2.5% of the total cost for hospital care. In 1995 there were 2 100 hospital beds in Östergötland and there were 6 500 accommodations in nursing homes and similar facilities run by the municipality. In the same year, 1 600 patients were treated in advanced home care and home rehabilitation, an average of 410 patients per day. This represented 30 percent of all

patients treated within advanced home care in Sweden<sup>118</sup>. Östergötland is a forerunner in advanced home care in the country, and this type of home care has been a part of the health care structure since 1976. Advanced home care is mainly palliative. The original aim of advanced home care was to offer gravely ill and dying patients, or patients with extensive care needs, an alternative to hospital care. This group of patients is still the dominant group in advanced home care<sup>119</sup>.

The aims of this study were to estimate the time cost of informal care among patients treated in advanced home care and also to study which factors have an influence on costs associated with informal care. A third aim was to compare different diagnosis groups regarding costs of informal care.

## Method

In this population-based study data collected for the purpose of mapping out the proportions of advanced home care and home rehabilitation were used. Data on 451 patients were collected during one week in October 1995, and included all patients who were registered in advanced home care (92%) or home rehabilitation (8%) within the county council of Östergötland. A standardised form was used containing 23 questions regarding background data, diagnosis, time spent giving care by home care providers, home help service and informal care. The amount of informal care was estimated on a five grade scale with the alternatives “around the clock”, “daytime seven days per week”, “night-time seven days per week”, “at least one day/night per week” and “a few times per month”. The patients were also categorised into four patient disease groups based on primary diagnosis<sup>120</sup>.

The patients in the study were divided into four major disease categories: cancer (41%), diseases of the circulatory system (23%), diseases of the respiratory system (16%) and other diseases/injuries (20%) such as, for example, fractures, poisoning, psychological disorders and diseases of the musculoskeletal system. Most of the patients lived in their own housing and most of them did not have home-help service. The mean age of the patients was 72 years and 47% were men. Almost 65 percent of the patients had an informal caregiver, either a close relative or significant other, and 69% of those had informal care around the clock. Ten percent of the patients with an informal caregiver had care during the daytime seven days per week. Fifteen percent had informal care at least one day or night per week, and five percent once or twice per week. None of the included patients had informal care seven days per week during the nights only. Regarding formal care, the patients had an average of 5 visits per week and each visit lasted for almost half an hour. Thirty percent of the patients had scheduled daily contact with the advanced home care team and 52 percent had at least one scheduled contact per week.

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<sup>118</sup> County, The Council of Östergötland (Emtinger, B. G.), (1996).

<sup>119</sup> County, The Council of Östergötland (Emtinger, B. G.), (1996).

<sup>120</sup> *International Classification of Diseases and Related Health Problems*, 9<sup>th</sup> revision, ICD9. Geneva, 1980.

Sixty-one percent of the visits took place during the daytime, 21% during the evening and 18% during the night. Seventy-four percent of the visits were made by a single caregiver. A physician was present during 9% of the visits.

Table 3: Background data, n=451.

	Frequency	Percent
<i>Age</i>		
Mean (range)	72.0 (0-105)	
<i>Sex</i>		
Male	211	46.8
Female	240	53.2
<i>Type of home</i>		
Ordinary housing	391	86.7
Municipal housing	59	13.1
Missing	1	0.2
<i>Advanced home care visits</i>		
Continuous	132	29.3
At least one day per week	84	18.6
Less than one day per week	231	51.2
Missing	4	0.9
<i>Home help service</i>		
Yes	181	40.1
Three times per day or more	81	44.8
1-2 times per day	97	53.6
Alarm and home help	3	1.6
<i>Informal care</i>		
Yes	291	64.5
Around the clock	201	69.1
Daytime 7 days/week	30	10.3
At least one day or night per week	43	14.8
A few times per month	13	4.5
Missing	4	1.3

Background data on the consecutive sample of 451 patients are shown in *table 3*. Compared to the smaller material in *Paper IV* it can be noted that the number of patients who have informal care is similar, 64.5 in the larger material (*Paper V*) and 66.1 in the smaller (*Paper IV*). Further, 40% of the patients in the larger material (*Paper V*) have home help service compared to 17% in the smaller (*Paper IV*).

## Costs

In this study the cost of informal care was determined through its opportunity cost estimated as lost gross value during time absent from usual activities<sup>121</sup>, as opposed to time absent from work. Thus, retired or unemployed persons who provide informal care are not excluded. It was assumed that usual activities consisted of three parts, main activity (8 hrs), and leisure time (8 hrs) and time for sleep (8 hrs). The value of time spent providing informal care was estimated by its market price as recommended by Luce et al<sup>122</sup>, i.e. the hourly gross salary. However, a targeted wage was not used since we did not have adequate data on the characteristics of the informal caregivers. The hourly gross salary is the employer's labour cost, i.e. the salary including payroll taxes (SEK 160 per hour) for an average full-time Swedish employee in 1999<sup>123</sup>. The cost of leisure time is estimated as the hourly net salary (after taxes), i.e. an estimated cost of the time spent by the informal caregiver (SEK 77 per hour) and thus an estimate of the informal caregiver's valuation of his/her leisure time.

Two models were designed in order to fit the patient data. Both models assumed a 40-hour working week. In the first model, which included leisure time, the cost of informal care for the "around the clock" alternative was estimated assuming eight hours of main activity, eight hours of leisure time and eight hours of non-care time each day. The alternatives 'one day' and 'one night' are assumed to be eight hours. In the second model, leisure time was excluded. The cost of informal care during one week was calculated using the following expressions:

Model 1: Informal care cost including leisure time = ((hourly gross salary \* 8 hours) \* 5 days) + ((hourly net salary \* 8 hours) \* 5 days) + ((hourly net salary \* 16 hours) \* 2 weekend-days)

Model 2: Informal care cost excluding leisure time = ((hourly gross salary \* 8 hours) \* 5 days)

## Data analysis

A linear multiple regression analysis was used to estimate the influence of different background factors on the costs for informal care. Background factors were age, sex, housing and diagnosis. In the regression analysis the diagnostic categories diseases of the circulatory system, diseases of the respiratory system and other diagnoses were merged

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<sup>121</sup> Liljas (1998).

<sup>122</sup> Luce, B. R., Manning, W. G., Siegel, J. E. & J. Lipscomb, 'Estimating costs in cost-effectiveness analysis', In: *Cost-Effectiveness in Health and Medicine*, (eds.) Gold, M. R., Siegel, J. E., Russel, L. B. & M. C. Weinstein, Oxford, 1996.

<sup>123</sup> Official Statistics of Sweden, *Statistical Reports No. AM 61*, 1999, Stockholm, 1999.

into one large group since there were no substantial differences in costs between these groups.

## RESULTS

### Paper I

The main results showed that mobile liquid oxygen treatment was more expensive than concentrator treatment, but had a better impact on quality of life measured by the Sickness Impact Profile (SIP).

The group with mobile liquid oxygen attained improvement in 13 out of 15 categories/dimensions. In the categories of eating and home management a slight deterioration could be noted. The group with concentrator treatment attained improvement in four categories/dimensions (work, sleep, home management and recreation). None of the changes described above were significant. Significant differences between the two groups were found in four categories/dimensions and in total SIP-scores. The group with mobile liquid oxygen showed an improvement in these categories/dimensions, while the group with concentrator treatment became worse.

A subanalysis regarding quality of life, measured by the SIP-instrument, of the COPD patients with a PaO<sub>2</sub> on air of below 7.4 kPa was performed (n=15 for the group with mobile liquid oxygen and n=10 for the group with concentrator treatment). A comparison of the changes (before - after) in health of the subgroups showed significant changes in five categories/dimensions (body care, ambulation, psychosocial function, sleep and total SIP-score) including total SIP-score. The group with mobile liquid oxygen showed an improvement in all but one of these categories/dimensions while the group with concentrator treatment became worse. In the category sleep, both groups became worse; the group with mobile liquid oxygen worsened more than the group with concentrator treatment.

The improvements observed in the SIP-score were not as obvious in the EuroQol. The group with mobile liquid oxygen showed some improvement in all categories/dimensions and the group with concentrator treatment showed improvement only in the categories/dimensions of usual activity and better/worse. However, when the changes (before - after) in health were compared for the two groups, no significant differences were found.

The cost calculations were based on 48 patients (n=27 in the group with mobile liquid oxygen and n=21 in the group with concentrator treatment). There were no significant differences between the two groups regarding the health care consumption profiles or the estimated costs. A slight difference in the consumption of medical technician services was revealed. Forty percent of the patients in the group with mobile liquid oxygen used medical technician services during the trial for an average of 190 minutes, and 91% of those in the group with concentrator treatment used medical technician services for an average of 202 minutes. However, the difference was not significant. The mean total cost per patient per six-month period in the group with mobile liquid oxygen was US\$ 4 950

(SEK 38 100) and the corresponding cost for the group with concentrator treatment was US\$ 1 310 (SEK 10 100) (1996 prices converted to US\$, exchange rate 7.7).

A formal cost-utility ratio was not presented as a final result since there were no differences in EuroQol.

## Paper II

The results of the literature search finally yielded seven studies that addressed the effects of home rehabilitation and that were of acceptable quality. One of the seven studies was Swedish<sup>125</sup>, and it was also one of the two most recent. Six of the studies were appropriately randomised, and the non-randomised study used concurrent control groups living in the same health-care district, but in a different area than the patient who received home rehabilitation<sup>126</sup>.

In the reviewed studies, only two statistically significant differences between home rehabilitation and conventional alternatives occurred. In the study by Young and Forster<sup>127</sup> ADL-functions and motor function were found to be significantly improved in the home rehabilitation group. However, when pooled with Gladmans et al<sup>128</sup>, yielding 451 patients, the differences between the groups disappeared.

The overall results are that there are no statistically significant differences between home rehabilitation and conventional care regarding ADL-functions, depression, quality of life, social activities in patients, nor regarding stress, social activities, satisfaction, depression and quality of life for family members. Three studies showed a shortening of the hospital stay by 6-14 days; this was achieved through the involvement of the study team for hospital discharge and planning. The four randomised studies that included an economic analysis had a provider perspective, and they all had the characteristics of cost-minimisation analyses. Two of the studies<sup>129 130</sup> included the initial inpatient period.

Indirect costs were calculated in one of the four studies. Young and Forster assessed the indirect cost as the emotional distress of the patient and main caregiver. Measurement of lost earnings was not considered relevant since the majority of the patients and main caregivers were retired.

It appears that home rehabilitation costs less than regular day care. In comparison with conventional care it appears that home rehabilitation is not less expensive, even though the average length of hospital stay could be reduced. Conventional care seems to be less costly when the patient's symptoms are mild and ambulatory care service is an alternative. Home rehabilitation can be more economically advantageous if it is combined with early discharge from hospital, but then only for patients with reduced mobility and more complex transportation needs.

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<sup>125</sup> Widén Holmqvist (1998).

<sup>126</sup> Wade (1985).

<sup>127</sup> Young & Forster (1992).

<sup>128</sup> Gladman (1993).

<sup>129</sup> McNamee, P., Christensen, J., Soutter, J., Rodgers, H., Craig, N., Pearson, P. & J. Bond, 'Cost analysis of early supported hospital discharge for stroke', *Age and Ageing*, Vol. 27, no. 3, 1998, pp. 345-351.

<sup>130</sup> Beech (1999).

Table 4: Costs of home rehabilitation compared with conventional rehabilitation (in hospital, by day care, outpatient visits, or combinations thereof as needed).

Author	Study design, no. of patients	Follow-up period	Relative costs of home care	Economic study quality rating
Young and Forster <sup>131</sup> (1993)	RCT 95	8 weeks	- 62%	High
Gladman et al. (1994)	RCT 327	6 months	+ 27%	Moderate
McNamee et al. (1998)	RCT 92	6 months	- 4%	Moderate
Beech et al. (1999)	RCT 331	12 months	- 8%	High

Abbreviations: RCT = randomised controlled trial.

### Paper III

The number of acute care ward days after a decision was made about rehabilitation was 3 in the hospital-based group (SD=3, median=7) and 9 in the home-based group (SD=8, median=7), and the difference was significant. There were no extreme outliers in the home-based group that could explain the difference. The hospital-based group thereafter had a mean duration of 28 in-hospital rehabilitation days (SD=17, median=24) and the home-based group had 36 days (SD=28, median=36) of home-rehabilitation. The number of hours with home-help service was significantly lower in the hospital-based group. However, there was no difference in days spent in a nursing home between the two groups. During the study period a total of 20 patients spent some time in a nursing home, eight in the home-based group and 12 in the hospital-based group.

The hospital-based group had significantly fewer hospitalisation days after a decision was made at the acute care ward about rehabilitation, and consequently the cost for the corresponding period was significantly lower ( $p < 0.001$ ). With respect to the rehabilitation period, the cost was significantly lower for the home-based group ( $p < 0.001$ ). When the costs attributed to the acute care ward after a decision was made about rehabilitation were combined with the cost for rehabilitation, i.e. the total cost for the health care provider, the home-based group had significantly lower costs ( $p < 0.001$ ). The mean total cost for the health care provider was SEK 126 100 (95% CI<sup>132</sup>=107 219-145 114) for the hospital-based group and SEK 54 500 (95% CI=43 471-65 531) for the home-based group. As expected, the costs for home-help service were significantly higher in the home rehabilitation group ( $p < 0.001$ ). The costs for nursing home care did not differ significantly between the groups. The total cost for the social welfare provider was thus also significantly higher in the home-based group ( $p = 0.007$ ). However, the total cost for

<sup>131</sup> In this study all conventional patients had regular day care only.

<sup>132</sup> CI, confidence interval.

the care episode was not significantly different between the two groups ( $p=0.88$ ). Obviously, costs were reallocated from the health care providers to the social welfare providers in the home-based group.

The results of a regression analysis showed that the total costs for the health care provider were higher in patients with angina ( $p=0.042$ ) and diabetes ( $p=0.014$ ). Age also had a positive correlation with social welfare costs ( $p=0.030$ ). As for total costs, the female gender ( $p=0.028$ ) and diabetes ( $p=0.033$ ) were positively correlated to high costs. The Katz ADL-index at onset initially increased costs, but did not affect social welfare costs or total costs.

### Paper IV

The inclusion of costs for informal care in the numerator in economic evaluations such as CEA will have implications for the cost-effectiveness of home care, since it may raise costs. How much depends on the model used for estimating these costs.

In this study 39 patients out of 59 (66%) had an informal caregiver. Depending on the model used for estimating a cost of informal care ranged between SEK 920 200 - 5 215 600. The friction cost model only amount to 18-44% compared to models based on the human capital approach. The model based on the human capital approach assuming a normal working day of 8 hours, 5 days a week, and that the informal caregiver is on call 24 hours per day, allowing for no personal time (model 4) renders the highest cost. The models based on the friction cost model (models 1-3) rendered the lower cost. The result indicate that, regardless of the method used to estimate indirect costs, the cost of informal care in evaluations of home care programs is often underestimated due to the exclusion of indirect costs.

### Paper V

The costs of informal care are shown in *table 5*. The mean cost of informal care including leisure time was SEK 5 880 per week per patient. When leisure time is excluded from the calculations, the mean cost of informal care was SEK 3 410 per week per patient. The annual health care costs for advanced home care, including home rehabilitation, were calculated to be SEK 66 million. The cost per week was thus calculated to be SEK 2 810 per patient. This would mean that the cost of informal care including leisure time was twice as high as formal caregiver costs (home help service not included). When leisure time was excluded, the cost of informal care was still 1.2 times higher. We also made a comparison of diagnosis groups regarding informal care costs. Patients with cancer had the highest informal care cost, while the differences between other groups were small.

Table 5: Mean (SEM) costs, SEK, of informal care during one week distributed according to diagnostic groups.

Diagnostic group	Informal care cost including cost for leisure time	Informal care cost excluding cost for leisure time
All, n=451	5 880 (267)	3 410 (146)
Cancer, n=185	7 440 (398)	4 330 (216)
Circulatory system, n=105	4 710 (554)	2 650 (298)
Respiratory system, n=70	4 810 (675)	2 750 (364)
Others, n=91	4 870 (580)	2 920 (328)
p*	0.000	0.000

\*) The p-value shows the results of a variance analysis and that the mean costs differ significantly among the diagnostic groups.

### Factors influencing informal care costs

The results of multiple regression analyses showed that age, sex, housing and diagnosis influenced informal care costs. For older patients and female patients informal care costs were lower, while patients with their own housing who had cancer had higher costs for informal care.

Table 6: Result of a regression analysis of factors associated with informal care costs, SEK, during one week.

Cost item	Factor	B <sup>133</sup>	SEM <sup>134</sup>	p
Informal care cost, including costs for leisure time	Age, per added year	-65	16	<0.001
	Sex, female vs. male	-2 620	491	<0.001
	Housing, own vs. other	2 960	751	<0.001
	Diagnosis, tumour vs. other groups	1 820	508	<0.001
Informal care cost, excluding costs for leisure time	Age, per added year	-36	9	<0.001
	Sex, female vs. male	-1 310	269	<0.001
	Housing, own vs. other	1 720	410	<0.001
	Diagnosis, tumour vs. other groups	1 090	278	<0.001

A subanalysis regarding differences between diagnosis groups was also performed. The represented diagnosis categories are shown in *table 7* in descending order. Patients with a tumour disease/cancer are the dominating group. All represented main diagnoses are shown as well as the four main groups (*in italics*).

<sup>133</sup> Regression coefficient.

<sup>134</sup> Standard error of the regression coefficient.

Table 7: Distribution of main diagnosis, n=451.

	Frequency	Percent
<i>Tumours</i>	185	41.0
<i>Diseases of the circulatory system</i>	105	23.3
Cardiac insufficiency	60	13.3
Cerebrovascular diseases	16	3.5
Diseases of the nervous system	14	3.1
Ischaemic heart disease	9	2.0
Other circulatory disorders	6	1.3
<i>Diseases of the respiratory system</i>	70	15.5
<i>Other disorders/ diseases</i>	91	20.2
Fractures	23	5.1
Diseases of the musculoskeletal system	11	2.4
Diseases of the skin	9	2.0
Infectious diseases	6	1.3
Endocrine disorders	5	1.1
Mental and behavioural disorders	5	1.1
Diseases of the digestive system	5	1.1
Diseases of the genitourinary system	5	1.1
Injuries and poisoning	5	1.1
Other causes of care	3	0.7
Diseases of the blood	2	0.4
Congenital malformations	2	0.4
Symptoms, signs, not elsewhere classified	2	0.4
Missing main diagnosis	8	1.8

The patients were categorised into four larger patient disease groups based on the ICD9<sup>135</sup>. The one-way Anova test was used to test the homogeneity of mean cost in diagnostic groups, and Scheffe's test was used for a multiple pairwise comparison. The subanalysis showed that patients with a tumour disease had significantly higher informal care costs compared to the other diagnosis groups. However, total formal caregiver costs are equal in the four diagnosis groups.

<sup>135</sup> The International Classification of Diseases and related health problems, 9<sup>th</sup> revision.

## DISCUSSION

In this thesis various aspects of economic evaluations of advanced home care and home rehabilitation have been illustrated and discussed. The work has included a comparison of two alternative medical interventions as well as a review of scientific evidence on costs and effects. It has also included studies on methodological issues prominent in advanced home care – the redistribution of care efforts among caregivers and costing of informal care efforts.

### Evaluation of oxygen therapy at home

A prospective, randomised multicentre trial that compared two different regimens for long-term oxygen treatment at home was performed (I). It has been shown previously that long-term use of oxygen (more than 15 hours per day) increases the survival rate for patients with chronic hypoxaemia. It has also been shown that compliance is a problem in this patient group, and that 30% of the patients for whom oxygen is prescribed for a minimum of 15 hours per day actually use it for shorter periods of time<sup>136</sup>, resulting in lower survival rates and unnecessary morbidity<sup>137</sup>. It has, however, been more difficult to prove that it also increases quality of life. In this study quality of life measured by the SIP was shown to be significantly better in the categories of physical function, body care, ambulation, social interaction and total SIP-score for the group receiving mobile liquid oxygen. In concordance with the hypothesis, treatment with mobile liquid oxygen was also more expensive compared to concentrator treatment, oxygen being the heavy expense for mobile liquid oxygen. To my knowledge, these results have not been confirmed nor has a similar study been performed.

The study design (randomised controlled trial) is in accord with established practice in medical trials and health economic assessment when two distinct treatment strategies (medical technologies) are to be compared. The length of the study period (six months) is similar to other studies of matched patient groups<sup>138</sup>. However, from an economic point

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<sup>136</sup> Ström, K. & J. Boe, 'Swedish Society of Chest Medicine. Quality assessment and predictors of survival in long-term domiciliary oxygen therapy', *European Respiratory Journal*, Vol. 4, no. 1, 1991, pp. 50-58.

<sup>137</sup> Nocturnal Oxygen Therapy. Trial Group, 'Continuous or nocturnal oxygen therapy in hypoxemic chronic obstructive lung disease', *Annals of Internal Medicine*, Vol. 93, no. 3, 1980, pp. 391-398., Pépin, J-L., Bariffoux, C. E., Deschaus, C. & C. Brambilla, 'Long-term oxygen therapy at home. Compliance with medical prescription and effective use of therapy', *Chest*, Vol. 109, no. 5, 1996, pp. 1144-1150.

<sup>138</sup> For example Okubadejo, A. A., Paul, E. A., Jones, P. W. & J. A. Wedzicha, 'Does long-term oxygen treatment affect quality of life in patients with chronic obstructive pulmonary disease and severe hypoxaemia?', *European Respiratory Journal*, Vol. 9, no. 11, 1996, pp. 2335-2339 and Pépin (1996).

of view it may have been somewhat short. As an example, the concentrators were as a rule serviced once every six months. By coincidence, a cost for service was not registered for one patient. However, this did not have any impact on the overall results. The study period was motivated by the fact that the effect of the two treatment strategies was rather immediate and did not have an obvious long-term effect. Also, several of the patients were severely ill and a longer study period would inevitably have resulted in dropouts. The cost analysis based on the diary might be slightly underestimated due to the fact that the calculations were based solely on the diary, and thus no time for maintaining journals or documentation was added. However, there were no significant differences between the two groups regarding average consumption of healthcare services i.e. visits or phone contacts during the six-month period. (A patient diary places high demands on patients and the reliability of the data can be questioned).

In the quality of life analysis the differences between the groups that were seen in SIP were not as obvious in EuroQol. The decision to use EuroQol and SIP in order to measure quality of life was based on the ambition to measure quality of life in terms of utility, for which the EuroQol was originally developed. SIP, an instrument originally developed in the United States<sup>139</sup> as a behaviourally based assessment of the impact of illness on everyday life, was considered relevant for this patient group since one major issue in their treatment is compliance. The instrument was also shown reliable and valid at the time<sup>140</sup>. Our choice of the EuroQol was also based on the fact that it was the most frequently used instrument in the field at the time. Some criticism has been raised regarding the EuroQol for being generally insensitive<sup>141</sup>. Nevertheless, no other instrument could match the universal applicability and use of the EuroQol at the time of the study. The finding that long-term oxygen treatment did not improve quality of life for this patient group is in accordance with results presented by Okubajedo et al<sup>142</sup>. In this study some of the patients occasionally received complementary treatment with compressed gas. An analysis in which these patients were excluded showed that this did not influence the results. If all patients included in the study had received mobile liquid oxygen, the cost would have increased almost four-fold. This study is important, as it reveals a neglected aspect, namely that home care technologies may differ regarding costs as well as effects and thus comparative evaluations of alternative home care interventions must also be performed.

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<sup>139</sup> Bergner, M., Bobbitt, R. A., Kressel A, Pollard S. W. E., Gilson, B. S. & J. R. Morris, 'The Sickness Impact Profile: conceptual foundation and methodology for the development of a health status measure', *International Journal of Health Services*, Vol. 6, no. 3, 1976, pp. 393-415.

<sup>140</sup> Sullivan, M., Ahlmén, M., Archenholtz, B. & G. Svensson, 'Measuring health in rheumatic disorders by means of a Swedish version of the Sickness Impact Profile', *Scandinavian Journal of Rheumatology*, Vol. 15, no. 2, 1986, pp. 193-200.

<sup>141</sup> Brooks, R., with the EuroQol Group, 'EuroQol: the current state of play', *Health Policy*, Vol. 37, no. 1, 1996, pp. 53-72.

<sup>142</sup> Okubajedo (1996).

## Literature review regarding home rehabilitation after stroke

Home care has been marketed as a cost-reducing alternative to hospital care. The fact is that we still do not know if this is true. The purpose of the literature review (*II*) was to investigate peer-reviewed studies on home rehabilitation after stroke and to determine if it is less costly and/or more efficient compared to more conventional alternatives. As it turned out, surprisingly, less than three percent of the initial 204 studies evaluated in this review were randomised. Less than two percent included cost assessments of the compared alternatives.

The overall results of this review showed that there were no significant differences, or tendencies toward differences, regarding the outcome of home rehabilitation versus hospital-based alternatives. These results may be disappointing for professionals within home rehabilitation, but the explanations are many. For one, routine rehabilitation may function well and have a high level of goal fulfilment. And regarding rehabilitation after stroke, there may be a spontaneous recovery that is fairly independent of rehabilitation efforts. It is also possible that the positive effects of rehabilitation are more obvious for some subgroups, regardless of where they are being rehabilitated. In addition, factors such as type of housing, the patient's financial situation, relationship to close relatives, the patient's will to live, depression, etc., are important regarding the patient's recovery. These are factors that are difficult to capture by the instruments that are often used in evaluations.

In the four randomised studies that included cost assessments, home rehabilitation was not found to be less expensive than conventional alternatives. However, home rehabilitation was found to be less expensive than regular day care. Caution is advised in the interpretation of these results, as they are based on studies performed in Great Britain. There is a need of more economic evaluations based on Swedish data.

## The redistribution of costs and care efforts in stroke rehabilitation

The main purpose of the investigation was to determine whether there was a redistribution of costs and resource use after stroke between formal caregivers in two alternative rehabilitation strategies (*III*). In this study it was not possible to randomise patients to the two different rehabilitation options. However, there is an ongoing discussion on non-randomised trials and their contribution to evaluations of health care<sup>143</sup>. In this study the patients differed in only one of the background variables (there were significantly more patients with hypertension in the hospital-based group).

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<sup>143</sup> Black, N., 'Why we need observational studies to evaluate the effectiveness of health care', *British Medical Journal*, Vol. 312, no. 7040, 1996, pp. 1215-1218., Black, N., 'What observational studies can offer decision makers', *Hormone Research*, Vol. 51, no. 1, 1999, pp. 44-49.

According to Black, one drawback of randomised trials is that the participating patients may be atypical due to the exclusion criteria being used.

Recent studies have shown that the total duration of the hospital stay can be significantly reduced with home rehabilitation after stroke<sup>144</sup>. In this study (*III*) the home-based group had a significantly longer stay in the acute care ward after a decision about rehabilitation was made. This was also true if the whole acute care ward episode was considered. One explanation could be that all patients with a further need for rehabilitation were included. Another explanation could involve problems encountered when a patient needed a new type of housing before the home rehabilitation could start. Professionals involved in the study also confirmed this interpretation. Shortcomings in the co-operation between hospitals, primary health care and municipalities have also been reported on a regional level regarding stroke care<sup>145</sup>.

The main finding in this study was that there seems to be a reallocation of costs and resource use between health care providers in home rehabilitation after stroke. This finding is important, and the consequence is that a societal perspective in evaluations of home care is to be preferred. It is well known that an increased burden is put upon informal caregivers in home care. However, the reallocation of resource use between health care providers has rarely been discussed. In Sweden this is an important aspect, as the care of the elderly is handled primarily by the municipalities and health care by the county councils. Thus, increased home care will most likely increase the demand for services provided by the municipality.

### The costing of informal care

The inclusion of the costs of informal care in health economic appraisals will have implications for the cost-effectiveness of home care, as it will most likely increase costs (*IV*). How much depends on the method used for estimating these costs. Since these costs are rarely or never included in health economic appraisals of home care, the costs of home care programmes are thus often underestimated.

Regarding this work (*IV*, *V*) it must be clarified that the costing of informal care is not an attempt to estimate a value of human life, as is sometimes done in cost-benefit analyses, nor is it an attempt to estimate a true value of the given care. The valuation of the time that informal caregivers spend on care is made in order to incorporate this factor as an opportunity cost in health economic evaluations where informal care constitutes a substantial part of the care efforts.

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<sup>144</sup> Anderson (2000).

<sup>145</sup> National, The Stroke Register in Sweden, *Analyserande rapport från Riks-Stroke. För belåret 1998 och halvåret 1999*. (In Swedish). [Analyses by the National Stroke Register. For all of 1998 and half of 1999], Västerbottens läns landsting, 2000.

Overall, the results of *Paper IV* support the results of *Paper V*. The latter study (*V*) was based on a larger empirical material, and once again it was concluded that informal care constitutes a considerable part of advanced home care. The results of *Paper V* have shown that the efforts of informal caregivers can differ between diagnosis groups. It seems that informal care costs are higher among younger men who have their own housing and who are diagnosed with cancer. Patients with cancer are also the largest patient group (based on main diagnosis) in advanced home care in Östergötland (*V*), as is the case in Sweden as a whole<sup>146</sup>.

An informal care cost should be included in the assessment of advanced home care based on the following:

- Informal care constitutes a substantial part of the care in advanced home care (*IV*, *V*).
- For some patient groups home care without the support of informal caregivers is not possible to organise.
- Had the informal caregivers not spent time providing care, it is reasonable to assume that they would have spent time on something else, i.e. they have an alternative use for their time. It is also reasonable to assume that the value of this alternative use of time exceeds zero (*V*).
- Society considers informal care to have a value exceeding zero, since there is a reimbursement system for informal care.

Placing a monetary value on informal care is somewhat controversial. The dilemma is that if a monetary value is placed upon informal care, the total costs of home care will most likely increase, thus making the home care alternative less attractive in the eyes of those responsible for the health care budget. However, many patients and informal caregivers as well as health care professionals are highly satisfied with home care and do not want to go back to hospital care. If, on the other hand, the efforts put in by informal caregivers are not costed, informal caregivers may become an ‘invisible’ group and their situation not adequately discussed.

There is an ongoing discussion<sup>147</sup> on how to cost informal care, and several attempts have been made regarding the costing of informal care involving patient groups such as those who are chronically ill and seriously disabled<sup>148</sup>, elderly<sup>149</sup>, or have Alzheimer’s

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<sup>146</sup> The Swedish Council on Technology Assessment in Health Care (1999).

<sup>147</sup> See for example McDaid (2001) and Smith & Wright (1994).

<sup>148</sup> Arno, P. S., Levine, C. & M. M. Memmott, ‘The economic value of informal caregiving’, *Health Affairs*, Vol. 18, no. 2, 1999, pp. 182-188.

<sup>149</sup> Tennstedt, S., Harrow, B. & S. Crawford, ‘Informal care vs. Formal services: changes in patterns over time’, *Journal of Aging & Social Policy*, Vol. 7, no. 3-4, 1996, pp. 71-91.

disease<sup>150</sup>, cancer<sup>151</sup> and dementia<sup>152</sup>. One method that is used is the replacement cost approach, with a wage rate for paid employees providing similar services, i.e. nurses or nurse's aides<sup>153</sup>.

In this study it is concluded that informal care is a relevant cost component in evaluations of advanced home care and should thus be included. However, the significance of this cost component may vary. The results of *Paper V* indicate that factors that influence informal care costs can be identified and thus determine the impact or size of informal care costs. It is also concluded that informal care costs are best labelled as 'direct non-health care costs' and placed in the numerator in the cost-effectiveness ratio.

How informal care time should be measured is a delicate issue. Informal caregiving is naturally combined with ordinary household chores and normal socialising with a close relative, husband/wife or friend. Further, during time when only 'surveillance' is required, the informal caregiver can also engage in leisure activities such as watching television or reading books, i.e. there is joint production. When a patient is hospitalised, close relatives and friends also spend time visiting (including travel time) which is, to my knowledge, rarely accounted for in health economic evaluations. Thus, it is important to find ways to measure actual informal care time on a typical day of caring. It may also be necessary to differentiate time into 'blocks' in order to bring costs closer to the opportunity cost. McDaid reports that there are a number of developed and validated instruments for measuring caregiving<sup>154</sup>. Unfortunately, further focus on this subject has not been possible in this work.

In this study we have chosen to use 'time absent from usual activities', using an approach by Liljas<sup>155</sup>, as a first step (as opposed to absent from work). Also, we have divided the day into three main parts, main activity, leisure time and sleep. Each time period consists of eight hours. This line of reasoning is based on the assumption that different units of time can have a different value to a person. The value of time may also change over time. As an example, in the first episode of a caring venture the value of the time spent caring may be high, and after several years it may have declined, i.e. the satisfaction of providing care may not be constant over time. The rule of diminishing marginal returns may be true here, although exceptions may be found.

The most feasible way to price informal care is to estimate it by its opportunity cost. The theoretically correct way to place a value on an individual's time would thus be by measuring their 'willingness to pay', since this method has the possibility to take into account lost wages as well as intangible effects (for example, pain and suffering). However, this method inevitably raises practical and methodological difficulties. One

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<sup>150</sup> McDaid (2001).

<sup>151</sup> Hjortsberg, C. & P. Svarvar, *Kostnadsjämförelse mellan sluten sjukbusvård och medicinskt omfattande bemsjukvård – cancer i livets slutskede*, (IHE Arbetsrapport, 1992:2), Lund, 1999.

<sup>152</sup> Stommel, M., Collins, C. E. & B. A. Given, 'The costs of family contributions to the care of persons with dementia', *The Gerontologist*, Vol. 34, no. 2, 1994, pp. 199-205.

<sup>153</sup> See, for example, Tennstedt (1996) and Koopmanschap & van Ineveld (1992).

<sup>154</sup> Clipp, E. C. & M. J. Moore, 'Caregiver time use: An outcome measure in clinical trial research on Alzheimer's disease', *Clinical Pharmacology and Therapeutics*, Vol. 58, no. 2, 1995, pp. 228-236.

<sup>155</sup> Liljas (1998).

practical drawback is that the method is very expensive. A methodological issue is that the estimates largely depend on the initial wealth of the individual, i.e. a wealthy person is likely to be willing to pay more simply because he/she is able to pay more. A relatively new technique for measuring willingness to pay is the contingent valuation method. This method uses a hypothetical market in order to extract individual marginal willingness to pay for such things as different treatments in health care<sup>156</sup>. The contingent valuation method is promising, but is still wrestling with some methodological difficulties.

A more practical method may thus be preferable. In the literature, two main methods seem to be used more frequently than others. One costs the time of informal care through the salary of medical professionals<sup>157</sup> (usually nurse's aids or similar health care workers), and some include payroll taxes some do not<sup>158</sup>. Another method suggests imputing a salary of the informal caregiver<sup>159</sup>. One option is to use an average wage rate (a targeted wage rate can also be used). This salary is supposedly a shadow price of the informal caregiver had he/she been working (according to the above-mentioned 'absence from usual activities', the time for main activity is given this 'price'). We have chosen to use the latter based on the decision that the method is closer to the theoretically more correct WTP value reflecting the individual opportunity cost.

Then there is the question of retirement. How do we price the efforts of retired persons when they become informal caregivers? Some would choose to price these efforts to zero since retired persons does not give up 'paid work time' in order to become informal caregivers. The Washington Panel<sup>160</sup> suggests that unpaid work should be valued to 'the hourly wage rate of individuals with similar characteristics... who do work for pay'. Brouwer<sup>161</sup> suggests using the pay for a professional housekeeper as a shadow price for home production. Still, these informal caregivers play an important role in the sense that had they not taken on the task of informal caregiving, the patient would have to be cared for in hospital. Also, the tasks performed are not restricted to ordinary household chores as is implied in home production. In Sweden it should be possible to use the retired informal caregiver's pension as a shadow price for time. It also seems possible to use an estimated value of leisure time for an average employee. I believe that that would render a value closer to the 'true' individual opportunity cost.

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<sup>156</sup> McDaid (2001).

<sup>157</sup> See, for example, Arno (1999), Tennstedt (1996), Koopmanschap & van Ineveld (1992).

<sup>158</sup> Arno (1999).

<sup>159</sup> See, for example, Stommel (1994).

<sup>160</sup> Gold (1996).

<sup>161</sup> Brouwer (1998).



## CONCLUSIONS

In the evaluation of oxygen therapy for patients with chronic hypoxaemia, the main results were that

- Mobile liquid oxygen treatment proved to be significantly more expensive compared to concentrator treatment.
- Patients receiving treatment with mobile liquid oxygen improved their quality of life measured by SIP while the quality of life deteriorated for patients with concentrator treatment. Significant changes were found in four categories/dimensions and in total SIP-scores. Measured by EuroQol, there were no significant differences in health between the two groups.
- A subanalysis for chronic lung disease (COPD) patients (with a  $P_{a,O_2}$  on air  $<7.4$  kPa) showed significant changes between the two groups in five categories/ dimensions. The group with mobile liquid oxygen showed an improvement in all but one category/dimension whereas the group with concentrator treatment became worse.

In the literature review concerning home versus hospital-based rehabilitation after stroke, the main results were that

- No significant differences, or tendencies towards differences, were revealed as regards the outcome of home rehabilitation versus hospital-based alternatives.
- The results of the three randomised studies comparing home rehabilitation with hospital (conventional) rehabilitation showed no differences in costs even though hospital stays were shortened.
- Home rehabilitation may be more economically advantageous if it is combined with early hospital discharge and offered only to patients when they are less functional and have more complex transportation needs.

In the comparison of two alternative strategies for stroke rehabilitation it was shown that

- The home rehabilitation group spent significantly more days in the acute care ward after a decision about rehabilitation had been made compared to the hospital-based group, and the cost was correspondingly higher.

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- The number of rehabilitation days did not differ significantly between the two groups.
- The number of home help hours was significantly lower in the hospital-based group.
- Total cost for the care episode did not differ between the two groups.
- In this study there was a redistribution of costs between health care providers and social welfare providers in the home-based group.

Regarding the studies on costing of informal care, the main results of *Paper IV* were that

- The results show that the cost of informal care for this group (n=39) for the time of enrolment and amount of informal care range between SEK 920 200 - 5 215 600. The friction cost model only amount 18% to 44% compared to models based on the human capital approach.

In the population-based study *Paper V* regarding costing of informal care, the following conclusions were reached

- The cost of informal care proved to be at least 1.2 times higher compared to an estimate of the cost of formal care.
- Patients with cancer had the highest informal care cost while the differences between other diagnosis groups were small.
- Several factors such as age, sex, housing and diagnosis increased informal care costs. For older patients and female patients informal care costs were lower, while patients with their own housing who had cancer had higher costs for informal care.

## Policy implications

There are few health economic studies on advanced home care and home rehabilitation. However, there is growing interest in health economic studies in this relatively new field of health care. Evaluations reported in this thesis show small differences between advanced home care and other types of care, but there are examples showing home rehabilitation may be more cost-effective than traditional care. This indicates a potential for improvements by introducing more home care services. As there is a risk of underestimation of costs for home care, i.e. informal care, further expansion should be done with caution and accompanied by thorough evaluations.

Continued work on documentation and follow-up systems of home care is also needed. It is not possible today to make accurate comparisons and estimates of the extent, benefit and costs of home care on a national level.

### **Implications for further research**

Advanced home care often depends on the patient's family. This aspect needs to be investigated further regarding costing in evaluations as well as the effects of reimbursement systems. Willingness-to pay studies can reveal important information regarding individual valuation of informal care. Also, there is need to develop methods for quantifying and estimating cost of informal care. There is extensive research regarding next of kin in the care of the elderly, with the main focus on stress, coping and similar factors. However, it is still difficult to measure and quantify the extent and cost of informal care.

Demographic trends in Sweden indicate that the population is becoming increasingly older, and that the number of single households is increasing as well. Home care is an important factor for solving the increasing need for care with which we are faced. However, the fact that home care sometimes depends on informal family caregivers may have to change. Home care needs to develop new techniques and consider care methods where care can be supervised by professionals and not rely only on informal caregivers.

More research is needed regarding health economic aspects, caregiver and patient roles, and psychosocial consequences of old persons and family caregivers. A cross-disciplinary research project including aspects of sociology, psychology, medicine and health economics is greatly needed.



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