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THE MEDICAL TREATMENT OF PATIENTS WITH HOME CARE BY DISTRICT NURSES FROM THE FAMILY PHYSICIAN'S PERSPECTIVE

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ABSTRACT

Background and aim: The aim of this thesis has been to shed light on home care patients, their problems and comprehensive care, and the family physicians' experiences of providing medical treatment for home care patients.

Material and methods: One quantitative study (resulting in two articles) from a suburban city area in 1996 concerning one third of the patients receiving home care by district nurses (DNs) (n=116). Information on the patients, their problems and comprehensive care was collected from several sources. One qualitative study used grounded theory methodology (GTM) (resulting in two articles). Data were collected through semi-structured interviews with 13 Swedish FPs concerning one of their patients with home care by a DN, and the treatment of this patient.

Results: A typical patient with home care by DNs was an older single woman with multiple diseases and functional problems. Many care providers were involved in her comprehensive care including both home help staff and hospitals. Several different physicians were often involved. The patients usually visited the FP at the health centre (HC) on average twice a year, but not all patients visited their FP in a year. Many FPs' measures were undertaken without a visit. The patients' problems influenced the FP's ability to remain in charge of the medical treatment. Patients with reduced functional ability and patients who wanted to manage on their own did not provide information and many could not handle their own treatment. FPs had to rely on the DNs, who saw the patients on average once a week or every other week, for information and help with home care medical treatment. When patients had complex conditions or did not comply with recommendations it was hard to make adequate decisions on the goal of the medical treatment. FPs had to rely on close observation and follow-up by the DNs for information as a basis for constant evaluation of the goal. The DNs' working conditions, attitudes and the type of disease the patient had determined whether or not the grounds for relying on the DNs were adequate. The FPs took either the role of a *medical conductor*, retaining the initiative in the medical treatment, or the role of a *medical consultant*, leaving the initiative to the DNs. One FP could take different roles in different situations. Which role the FP chose or was forced to take depended on their working conditions, attitude and the type of disease. Conditions for providing home care medical treatment are good enough when there are adequate grounds for relying on the DNs and problematic when there aren't, regardless of the role taken by the FP.

Conclusion: Due to the problems of home care patients, FPs' consultations with the patient cannot provide the usual foundation for medical decisions. They have to be able to rely on information and collaboration with the DNs in home care medical treatment, much like the collaboration in a hospital ward. As conductors, FPs detect when conditions are problematic and when no adequate grounds for relying on the DN exist. As consultants, however, they will not detect inadequate grounds as they will receive little or no information from the DNs. In order to stay in charge of the medical treatment as consultants, the FPs' working conditions must allow them to know if adequate grounds for relying on the DNs exist. The FPs' working conditions must also allow them to be conductors when necessary. The comprehensive care of home care patients includes many different care providers, just like a hospital ward, but without its geographical, organisational and temporal unity. Time and routines to support collaboration is needed and all care providers need to know when they are responsible.

Key words: Primary health care, home care, general practitioner, family physician, district nurse, specialised medical care, reduced functional capacity, collaboration

The essential element in civilisation is the ethical perfecting of the individual as well as society. At the same time, every spiritual and every material step forward has significance for civilisation. The will to civilisation is, then, the universal will to progress that is conscious of the ethical as the highest value. In spite of the great importance we attach to the achievements of science and human prowess, it is obvious that only a humanity that is striving for ethical ends can benefit in full measure from material progress and can overcome the dangers that accompany it.....' Albert Schweitzer (Out of my life and thought: an autobiography p 148)

LIST OF PUBLICATIONS

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LIST OF ABBREVIATIONS AND DEFINITIONS

ABBREVIATIONS

ADL	Activities of Daily Living
DN	District nurse
GP	General practitioner used in paper I, II
FP	Family physician used in paper III, IV and this thesis
PHC	Primary health care
HC	Health centre in primary health care, used in paper IV and this thesis
GTM	Grounded theory methodology

DEFINITIONS USED

District nurses: District nurses, nurses without specialised training as DNs and assistant nurses under the supervision of the district nurses in Swedish primary care home nursing/home care by DNs. DNs are referred to as *nurses in primary health care (PHC)* in paper I and II and as *district nurses (DNs)* in paper III, IV and this thesis.

Family physician: Family physicians (FPs) in Swedish primary care are specialists in family medicine and responsible for the medical treatment of patients with home care who are registered with them. They are referred to as *general practitioners (GPs)* in paper I and II and as *family physicians (FPs)* in paper III, IV and this thesis.

Home care by district nurses: Home care performed on a regular basis by DNs in primary care is a well-known form of home care in Sweden. It is referred to as *primary care home nursing* in paper I and II and as *home care by DNs* in paper III, IV and in this thesis.

Home care patients: Patients receiving home care by DNs

Home help services: In Sweden, the municipalities are responsible for providing home help and support with ADL for those who need it. *Home-help organisation:* The organisation that delivers home help services. Home help organisers organise and provide home help services. *Home help* and *home help staff:* The people who deliver care at home. These are people who do not necessarily have medical training or any special training. They are sometimes called home help providers. *Needs assessment officers:* A social worker that assesses the need for and the amount of subsidised home help and other forms of subsidised support a person with decreased functional capacity can get from the municipalities.

Hospital-at home: *Hospital at home* is medical care in the home performed by a multi-professional team with a physician in charge. Patients with this care were not included, but some patients in paper I and II had had this form of care during the study year.

Specialised medical care: Specialised medical care is medical care outside of primary health care, often performed at hospitals or in outpatient clinics.

1 INTRODUCTION

1.1 DEFINITION OF HOME CARE PROVIDED BY DISTRICT NURSES

It was difficult finding a definition of home care provided on a regular basis by DNs in primary care. Though this form of care is well known in Sweden it had no Swedish standardised definition (or an internationally accepted definition) at the end of the twentieth and the first years of the twenty-first century when these studies were carried out.

According to the Swedish National Board of Health and Welfare, home health care in Sweden today is defined as:

‘Health care when it is provided in the patient’s residence or the equivalent and where the responsibilities for the medical procedures are continuous over time. Home health care shall have been preceded by care planning’ [1]. However, home health care, including home care by DNs, is defined differently in different parts of Sweden. There are no national statistics on home care by DNs and the county councils and the municipalities register care in different ways, making it even more difficult to compile national statistics. Thus, there is no way to know how many patients in Sweden are registered as home care patients, what problems they have or what care and treatment they receive. A recent study of home care estimated that 250,000 people received home health care in 2007 [2]. As described above, the problems in home care not only depend on the patients’ needs but also on how society organises health and social care [3].

In 2003 three researchers from Lund, Sweden [4] stated that ‘In spite of the fact that home care has grown considerably during the last few years, and will continue to grow even more in the future, home care as a phenomenon and a concept is not clearly defined.’ (p. 860 [4]). By reviewing empirical literature on home care they were able to find a description of home care as a phenomenon.

‘Home care as a phenomenon was the care provided by professionals to people in their own homes with the ultimate goal of not only contributing to their life quality and functional health status, but also to replace hospital care with care in the home for societal reasons; home care covered a wide range of activities, from preventive visits to end-of-life care’ (p. 861 [4]).

This definition, when delimited to home care provided by DNs, is what best describes the form of care of the patients included in this study.

1.2 THE PATIENTS IN HOME CARE

The majority of patients in home care are elderly and can be described as people with multiple diseases and functional problems [5-10]. Approximately 12 per cent of all elderly people living at home required some type of home health care [8]. Palliative care can also be part of home care by DNs [11]. The description of the patients in home care reveals that they should be highly prioritised according to priority commission (1993) that stated that the highest priority should be given to:

- A. ‘Care and treatment of diseases that are life threatening. Care and treatment of diseases that, if untreated, lead to permanent disabling conditions or premature death.’

- B. 'Care and treatment of severe chronic diseases. Palliative care at the end of life. Care and treatment of people with reduced autonomy.' (p. 30 [12])

The growing number of elderly patients [13] with multiple diseases and reduced functional capacity [14] increases the need to study and develop processes that can handle their complex care needs and medical treatment in an effective and safe way [15]. Also the changes in the health and social care system to meet increasing demands without increasing financial means has led to a transfer of more responsibilities to patient, family and friends and often moved the place of care out of the hospital, increasing the need for home care and for more advanced home care [2, 16-18]. Thus there is a need to study the processes in home care in order to provide a basis for development of the conditions for providing medical treatment for home care patients.

1.3 DEVELOPMENT INFLUENCING HOME CARE BY DNs

1.3.1 Early development

Traditionally, in Sweden as elsewhere, the elderly and disabled were cared for by their families. 'The poorhouse' was the alternative for those who were too poor or disabled to support themselves and who had no family to look after them. In Catholic countries the convents and monasteries played an important role in the care of sick people. The women in the family were generally responsible for medical care. In earlier periods, lay midwives and women with nursing experience and knowledge of medically effective herbs played an important role [19].

Physicians were few and worked mainly in the cities. By as early as the beginning of the eighteenth century the Swedish government had instituted a system of public health care physicians but for a long time this was a very limited resource. At the beginning of the twentieth century there were still only 400 physicians in the whole country who worked in the area of public health care outside of hospitals, corresponding to fewer than one physician per 10,000 inhabitants [19, 20].

Opportunities for elderly people to receive good care at home differed according to socio-economic status. A study of living conditions conducted in 1930 showed that 25 to 60 per cent of elderly people living in the Swedish countryside lived with their children. Approximately 43 per cent of middle-class elderly people in the city of Lund in southern Sweden lived with their children, 35 per cent with a servant, and 18 per cent lived alone. Among labourers, approximately 40 per cent lived with their children, two per cent with a servant, and 32 per cent lived alone [21].

1.3.2 Development after the war

Expansion of acute-care hospitals had already begun by the beginning of the twentieth century and increased after the Second World War. Since the 1940s social developments have resulted in society taking over responsibilities for people in need of help. Special housing and nursing homes for people needing general or medical care were built and subsidised home help service was developed. Hospitals and clinics for long-term medical care were established during the 1960s, 1970s and the beginning of

the 1980s [18, 21, 22]. This is also the period when more women began working outside the home, thereby changing one of the conditions for home-based care.

Since 1963 the county councils have been responsible for both hospital care and PHC, and the first period of PHC expansion coincided with hospital expansion in the 1970s. HCs were established with two or more FPs, often in the same building as units for long-term care. During the 1980s, PHC staff increased further and came to include not only FPs and DNs, but also assistant nurses, secretaries, physiotherapists and occupational therapists. The FP and the DN became jointly responsible for the patients in a district, and teamwork was developed to promote cooperation, especially in the home care of patients[21].

Nursing the sick in their homes had always been a part of the work of DNs [23], just as home visits had been included in the duties of FPs [20]. The establishment of HCs and the emphasis on cooperation among different health care professions and the social services seem to have been prerequisites for the development of home care as an alternative to institutional care, especially for the chronically ill.

1.3.3 Development during the last decades

The last decades of the twentieth century and forward saw a reduction in the number of hospital beds, a trend found in many Western countries [16, 24].

From 1993 to 2007 the number of hospital beds in Sweden decreased by 45 per cent and the number of days in hospital care for patients aged 65 or older decreased by 40-42 per cent (number of days in hospital/100,000 inhabitants) [24]. In 2005 Sweden was the country with the highest share of inhabitants aged 80 or older and the lowest share of hospital beds for the whole population (2.2 per 1,000 inhabitants) compared to other western countries [25]. This resulted in medical care and treatment previously provided in hospital now being provided as outpatient care or home care. Thus the number of people in need of home care medical treatment by DNs increased, as did the need for physician involvement. Simultaneously there was a shift in the way the municipalities granted social support in the form of institutional beds in special housing. Only people with significantly reduced functional ability were now granted a bed in special housing, which increased the number of very disabled elderly people living at home. This in combination with an ageing population with a greater need for medical care increased the demands for home care and for more advanced home care procedures [2, 16, 26-32]. The development has also increased the overall demands on FPs [3, 29, 33, 34].

As the demands on the FPs and DNs in PHC and home care increased, several other changes affected the conditions for providing PHC. The new law of 1992 (the Ädel reform) changed the conditions for home care. The responsibility for home care by DNs and rehabilitation in home care of these patients could be transferred from the county councils to the municipalities to facilitate collaboration with the home help staff. The idea was to strengthen support for social wellbeing and to put less emphasis on health care problems. However, even if the municipalities took over the responsibility for home care the FP responsible for the medical treatment of the patients in home care remained in the HC run by the county council. The result was that in areas where the

municipalities took over home care, FPs and DNs responsible for home care worked in separate organisations. Today, this is the case in more than half of Sweden and the number of municipalities taking over home care by DNs is increasing [26, 35]. In the city of Stockholm, where the first study was performed, DNs, assistant nurses and FPs still work in the same organisation.

A new law in 1994 (the Family Doctor reform) followed a general trend to increase individual choice in both health and social care [36]. FPs are no longer responsible for the medical treatment of the population in a district, just for a list of people who have chosen, or been allocated to them. The DNs, on the other hand, are often still responsible for home care in a geographical district. This means that a geographical district no longer functions as a natural basis for teamwork, making it more complicated to develop conditions that facilitate collaboration and teamwork in home care.

Health care has also been exposed to competition and budgetary incentives to enhance productivity, increasing the number of patients seen per day. The demand that patients should be able to see their FP without delay has led to a shift from 'planned' to 'on-demand' care in Swedish primary care. The result is that many FPs no longer initiate regular check-ups for patients with chronic diseases. Instead patients initiate check-ups when they want help [37-39].

Even after these changes PHC, in Sweden still had to handle a situation of growing demands and insufficient resources. A study of Swedish PHC in 1998 shows that the organisation of PHCs vary widely throughout the country and that there is a shortage of DNs and FPs in many areas [40]. A plan from the government to strengthen the development of PHCs and to increase the number of FPs in the country has not had the intended effect [29, 41]. A recent study of Swedish home care shows that more patients are receiving home care and more advanced tasks are being performed. This puts more strain on resources. At the same time there is a shortage of nurses and physicians available for this care, resulting in a gap between resources and demands that might jeopardise good quality care and home care patients' safety [2].

1.4 THE ROLE OF THE FP IN HOME CARE

Family medicine has been described as the first line of care, focusing more on the patient and the patient's total health care needs and situation than on the individual diseases, thus adopting a more holistic view [42, 43]. Continuity of FP care, i.e. the continuous contacts over a long period of time, makes it possible for the FP to obtain knowledge of the patients and their homes, families and situations. The FP should detect and treat new problems, treat chronic diseases, undertake preventive measures and help the patient function as well as possible by prescribing technical aids and home adaptations [44-52]. Working with other professionals in the primary care setting and making efficient use of health care resources through co-coordinating care are expectations that are especially relevant for home care medical treatment. Table 1 describes the characteristics of family medicine according to the European organisation of family physicians and general practitioners.

Table 1 - The European definition of characteristics of General Practice/Family Medicine (GP/FM) of Wonca Europe 2005. [43]

a)	GP/FM is normally the point of first medical contact within the health care system, providing open and unlimited access to its users, dealing with all health problems regardless of the age, sex, or any other characteristic of the person concerned.
b)	GP/FM makes efficient use of health care resources through co-coordinating care, working with other professionals in the primary care setting, and by managing the interface with other specialties taking an advocacy role for the patient when needed.
c)	GP/FM develops a person-centred approach, orientated to the individual, his/her family, and their community.
d)	GP/FM has a unique consultation process, which establishes a relationship over time, through effective communication between doctor and patient.
e)	GP/FM is responsible for the provision of longitudinal continuity of care as determined by the needs of the patient.
f)	GP/FM has a specific decision making process determined by the prevalence and incidence of illness in the community.
g)	GP/FM manages simultaneously both acute and chronic health problems of individual patients.
h)	GP/FM manages illness that presents in an undifferentiated way at an early stage in its development, which may require urgent intervention.
i)	GP/FM promotes health and well being both by appropriate and effective intervention.
j)	GP/FM has a specific responsibility for the health of the community.
k)	GP/FM deals with health problems in their physical, psychological, social, cultural and existential dimensions.

A study from the USA showed that PHC physicians usually assumed overall responsibility for medical care, at least for elderly patients, in contrast to most other specialists [53]. PHC physicians either performed the care or coordinated it in advance, e.g. through referrals [54]. Thus the physician assumes responsibility not only for different diseases and ailments, but also for the patient's entire medical care. Health care expenditures were lower for patients who had a personal primary care physician, and patients were hospitalised less often when they identified a physician outside the hospital as their primary source of care [55, 56].

In a British study, FPs were found to perceive the multiple pathology of older people as complex and sometimes threatening as their conditions could be difficult to diagnose, and some problems could not be explained by medical science. Because of a steadily increasing workload, the FPs were rarely able to care for the elderly in the manner they wished [57].

Even if FPs conduct home visits more often than other physicians, the number of home visits is low and infrequent [58-61]. The descriptions of FP treatment of home-bound patients often concern the treatment of certain problems like patients with Alzheimer's

disease, patients in need of palliative care, ethical conflicts and also the cooperation between FPs and those providing specialised care [62-65].

An important factor influencing the role of the FPs in Sweden is the partnership with the DNs. FPs in Swedish PHCs work in partnership with the DNs who take over some of the responsibilities typical of FPs in other countries, like doing follow-up checks for such chronic diseases as diabetes and prescribing technical aids.

There has been a general problem in offering continuity of FP care. When a sample of the Swedish population was questioned, only 57 per cent (35–73%) said that they have one permanent physician in PHC [66]. Continuity of FP care is required if some of the characteristics of family medicine are to be met as it takes a long time or many visits for the FP to acquire the in-depth knowledge about the patients on which part of family medicine rests [67]. One reason is that there are few FPs in Sweden [68]. Between 2001 and 2007 there was an increase of four per cent in sharp contrast to the national intention of an increase of around four per cent per year resulting in 6,000 PHC physicians by 2010 [24, 29]. There just are not enough FPs for everyone to have a personal FP. Yet other factors that influence the continuity of care include the FPs changing of positions over time and PHC organisations not always prioritising continuity of FP care, leading to discontinuity and inability to take the role described above.

Medical treatment has been transferred from inpatient hospital care to home care by DNs affecting the medical treatment that the FPs are responsible for, thus making the work load heavier [2].

1.5 THE ROLE OF THE DN

There is extensive literature concerning the general role of nurses. Henderson, a pioneer in nursing theory, identified two aspects; the unique role and the delegated role. She described the unique role as assisting ‘the individual, sick or well, in the performance of those activities contributing to health or recovery (or to a peaceful death) that he would do unaided if he had the necessary strength, will or knowledge, and to do this in such a way as to help him gain independence as rapidly as possible’ (p13 [69]). There is also the delegated role, often emanating from medicine and involving medical treatment, where the nurse helps the patient utilise the physician’s help [69]. There is also a third role, comprising clinical observation and assessment, where the nurse, who sees more of the patient than the physician, relates her observations to the physician when she suspects that something could be wrong. This may also include assessing the effects of medication [70].

Swedish DNs are licensed nurses specialised in primary care nursing with a comprehensive and psychosocial care perspective. They are responsible for coordinating and directing health services in a geographic district. Care should be based on thoughtfulness and respect for the autonomy and integrity of the patients and, as far as possible, be planned and performed in cooperation with the patient. The main responsibility of the DNs is to prevent illness in the population and to plan, give and evaluate the nursing care of children, adults and the elderly. The DNs also examine,

treat, inform and educate the patients, both independently and in cooperation with others on the health care team [23, 71, 72]. Historically DNs worked independently with home care. Later they were integrated into the multi-professional HCs that developed during the later part of the twentieth century [71, 73].

1.6 COLLABORATION AND TEAMWORK

The need for better cooperation between home help staff and the DNs providing home care has been emphasised and was one of the reasons behind some of the changes in the law in 1992 [35]. The need for better cooperation between primary and secondary care following inpatient care has also been pointed out, and the National Board of Health and Welfare has issued directives in this regard [40, 62, 74, 75].

As the need for more advanced medical care for patients with home care by DNs has increased [2], the need for FPs to play a more active role and to collaborate with the DNs in home care has also increased. The need for and the positive effect of collaboration between nurses and physicians in primary and palliative care, e.g. to enhance quality of care and the ability to adopt a holistic view, has been identified [42, 76-80]. Actively working to improve FPs' and DNs' collaboration, using guidelines or protocols and also providing support of others like social workers or geriatric support team, improved the quality of care and reduced acute care utilisation among high risk groups [7, 64, 65, 81, 82]. External factors like the remuneration system, the organisation of the health care and the increased work load for FPs can be obstacles to collaboration [83]. Some of the changes in the health care system during the last decades (described above) can actually make it more difficult to develop favourable conditions for collaboration and teamwork, for example FPs and DNs in home care now working in different organisations [26]. Another example is that a joint responsibility to provide home care and treatment for patients in a geographical district that previously was a ground for developing collaboration and teamwork, no longer exists [36]. Also, developing teamwork requires time and deliberate strategies, where the shortage of nurses and physicians in home care might be an obstacle [84, 85]. The fact that FPs and DNs sometimes have different views on how to handle matters and how to cooperate can also be an obstacle [86].

1.7 COMPARISONS TO OTHER COUNTRIES

International comparisons are difficult due in part to the lack of a uniform terminology and in part to different traditions and organisations, resulting in considerable variation in the conditions for home care by nurses.

In some European countries, including the UK and Italy, medical care at home is part of the work of FPs. In Israel, long-term home care is considered to be the province of the FP [87, 88].

The FPs' responsibilities regarding ambulatory care and home care for their patients are regulated in many countries. In the UK, FPs can prescribe other services such as social services, domiciliary or respite care and in-home medical care. A referral from the FP is needed for specialist care and FPs plan and coordinate therapies and assist community nurses. FPs must perform a minimum of one health review annually for all patients over the age of 75 [87, 89].

According to law, FPs in Germany should act as coordinators of care for the elderly, a task that can be problematic. In fact, FPs are often missing from the network that provides care for the elderly. In an interview study, FPs in Hamburg described the care organisation they were supposed to coordinate as an impenetrable jungle. They also stated that both economic and organisational factors, as well as the lack of nursing staff, prevented cooperation [90].

In the USA and Canada, PHC physicians are not considered the main providers of home care, usually called home health care. Home health care is delivered by teams provided by special agencies. Home health care teams may be multidisciplinary or consist entirely of nurses and volunteers, as health insurance does not always cover physicians' work outside hospitals or outpatient clinics. In these countries there are also rules and regulations regarding the responsibilities of the different care providers [87, 91].

In the USA, the nurses in home health care coordinate most of the services of other home health care providers and cooperate with the physician. Physicians can refer patients to home health care agencies. Medicare stipulates that there should be a written plan that is periodically reviewed by a physician. Drugs and treatments are administered by agency staff only as ordered by the physician. Primary care physicians are the physicians that are most likely to do home visits [8, 60, 87, 92, 93].

In Canada, the extent of home health care services varies with the service descriptions and eligibility criteria established provincially. Many housebound elderly do not have access to primary medical care, as nearly half of the physicians either cannot or will not make house calls [7, 94].

1.8 A PERSONAL COMMENT

I started my studies of patients with home nursing in the late 1980s. I had experienced the problems associated with the care of these patients both as an FP and as head of the local PHC. I wanted to understand the problems connected with their care and discover the reasons behind the heavy burden of care that many experienced, and I wondered why I seldom saw these patients once home care by DNs had started. In addition, I also wanted to show that PHC could care for these patients, something that had been questioned, and to demonstrate that some of the reforms that were supposed to improve home care (the Ädel reform) and strengthen the right of patients to choose their FP (the Family Doctor reform) had had negative effects on the care of patients with home care by DNs.

Thus I began this work with a strong personal agenda and no scientific experience. I collected material over a period of several years that proved in the end to be almost impossible to use in any scientific way. It took me many years to progress from a personal, political agenda to a more scientific view of how to investigate the care of vulnerable patients with home care by DNs.

My first study left me with a feeling that contact with and medical treatment of these patients differs from contact with and the medical treatment of the patients that we see

during repeated consultations over time. The consultation did not seem to have the same key role as it had for many other patients. I asked myself what was important in FP contacts concerning home care patients. I also asked myself questions concerning the quality of the medical treatment when so many decisions were made without direct contact with the patient. It has been a privilege to listen to and ask the interviewed FPs about their efforts to stay in charge of the medical treatment, an experience much like the privilege of listening to and asking the patients about their struggles with health-related problems. For many years I have been buried in stories of the interviews and struggled to understand what they reveal about what is specific and important in FP contacts/consultations concerning home care patients and what is important for quality in home care medical treatment. I hope the result will help develop the medical treatment of the vulnerable patients in home care and also help FPs who struggle to provide high-quality home care medical treatment.

2 AIMS

The overall aim of this thesis was to shed light on the home care patients, their problems and comprehensive care and the family physicians experience of providing medical treatment for home care patients.

2.1 SPECIFIC AIMS

To identify/survey and enhance the knowledge concerning

1. Home care patients' comprehensive care picture
2. Home care patients and their problems
3. Factors in the home care patients' situations that influence their health care
4. FPs' medical treatment of home care patients
5. Collaboration between FPs and DNs concerning home care patients.

3 MATERIALS AND METHODS

The thesis is built on two studies. A quantitative study (study I), the foundation for articles I and II, and a qualitative study (study II), the foundation for articles III and IV.

3.1 STUDY I

3.1.1 Setting

The study was carried out in 1996 in a suburban area of Stockholm with 40,000 inhabitants, 18 per cent of whom were aged 70 or older. The care of patients living in ordinary houses or flats, who were registered for home care by DNs, was studied. Registered for home care were those patients who received regular home care from DNs for a period of more than two weeks.

There were three HC centres with a total of 21 FPs, 20 DNs and 10 assistant nurses in the area. The HCs were run by the Stockholm County Council. Care and treatment of home care patients constituted only part of the duties of the FPs and DNs. On average one FP was responsible for 23 and one DN for 24 home care patients. FPs, DNs and assistant nurses in the study area worked in the same organisation, run by the county council, while the home help service was run by the municipalities. FPs had a list of patients who were registered with them, DNs and the home helpers were responsible for the home care of patients in a geographical district. A local district of the municipality of Stockholm was responsible for the home help service.

In Stockholm, patients can choose to go to any of the hospitals or outpatient departments in the city. At the time of the study there were 11 emergency hospitals and several smaller geriatric hospitals and a rich supply of specialised outpatient care facilities located at the hospitals or in separate locations. Two emergency hospitals, two geriatric hospitals and two wards for psychiatric inpatient care were located in or close to the study area. Compared to other parts of Sweden there was a very rich supply of different hospitals and outpatient care centres.

3.1.2 Patients

During the registration week (21 to 27 October 1996), 486 patients in the study area, living in ordinary houses or flats, were registered for home care by DNs. Each DN sent a list of home care patients registered with them. Using a random table a sample of a third of the patients from each list were selected for the study ($n=158$) [5]. However, only 116 patients (73%) were included as some patients did not want to participate, had died or were hospitalised or some were not included due to problems in obtaining the necessary data.

3.1.3 Data collection

The study was designed as a retrospective study of the comprehensive care of patients with home care by DNs, including care at home as well as care provided in other places. It was also designed to study whether non-medical factors influenced the care. Data were obtained from questionnaires, the medical and nursing records in the PHC and from the official statistics. Table 2 and the text below describe the data and how they were obtained.

Table 2 - Data in study 1

Official statistics

Swedish County Councils'

Retrospective data for one year¹

- Inpatient care
 - Outpatient visits
 - In specialised medical care
 - To physiotherapists and occupational therapists
 - Home visits by and practice visits to DNs
-

Information from DNs

Nursing records from 20 DNs responsible for the patients' PHC

Retrospective data for one year¹

- Nursing procedures⁴

Questionnaires to the DNs responsible for the patients' PHC

Data concerning the registration week²

- Patient's personal, social factors (age, sex and if the patient lived alone)
- Patient's ADL capacity⁴
- Patient's ADL capacity concerning mobility⁴
- Patient's cognitive capacity⁴
- Patient's symptoms⁴
- DN's contacts with other care providers
- Whether relatives assumed responsibility for a substantial amount of the care

Data concerning the last four weeks³

- DN's contacts with other care providers

Retrospective data

- When the patient was registered as a home care patient
 - If the patient had contact with a physician in private specialised medical care
-

Information from FPs

Medical records of 21 FPs responsible for the patients' PHC

Retrospective data for one year¹

- FP care
 - number of notes
 - type of contact
 - reason for contact
 - who had been in contact
 - measures undertaken
 - The diagnoses of the patients
Diagnoses were grouped mainly in accordance with the chapters in ICD-9P[95]. Patients with several diagnoses were included in all relevant groups
-

Information from home help organisers

Questionnaires to responsible home help organiser

Data concerning the registration week²

- If the patient had subsidised home help
-

¹ October 28/1995 – October 27/1996

² October 21-27/1996

³ September 30 – October 27/1998

⁴ Protocols were used to obtain some types of data. The protocols are described in the text.

Visits to medical specialists and physiotherapists in private practice are not included in the official statistics. The only information concerning this came from the questionnaires to the DNs.

The protocol for extraction of information about nursing procedures from the nursing records was comprised of 18 questions with fixed-alternative answers and was designed for the study in cooperation with a group of DNs.

The questionnaire was distributed the week following registration week. The questions were chosen so that the DN responsible for the care could answer them without additional assessments of the patients, either because the information would be well known to them since they were responsible for the nursing care or because the answers were based on assessment tools used in regular care.

The Katz index was used to evaluate ADL capacity [96, 97] and the patients were grouped according to the degree of ADL dependency. Patients in Group 1 were either without functional deficiencies or dependent only regarding cleaning, shopping and/or transport. Patients in Group 2 were also dependent with respect to cooking, bathing and/or dressing, but not eating, and patients in Group 3 were also dependent concerning eating. Mobility was excluded from these ADL groups as this was assessed separately. Toileting and continence were excluded, as the answers were not consistent when compared with answers to questions concerning the same functions in other parts of the questionnaire.

Questions regarding the patient's ADL capacity concerning mobility included whether the patient was able/unable to move a) in the immediate surroundings, b) in the house, c) between rooms, d) between chairs and bed or e) move in bed; patient's cognitive capacity concerned whether the patient could or had problems a) knowing the day of the week, b) finding the way home and/or c) recognising relatives/caregivers. To evaluate the patient's symptoms questions were taken from different questionnaires used in previous nursing homes studies. The questions were modified to make them fit the home care situation. This was done by the Stockholm Gerontology Research Centre in cooperation with a group of district nurses[5]. The result was a 23 item protocol with different symptoms.

Older patients (> 80 years of age) in one of the practices were used as a control group. All FP notes made during 1996 concerning the control group were compared with the notes made for the study patients from the same practice.

3.1.4 Statistics

As the number of visits, care periods and other types of contacts did not have a normal distribution median, interquartile range (IQR) and minimum–maximum were used as descriptive measures. As non-parametric statistical methods the Mann-Whitney test and cross tabulation with χ^2 (with low count, Fisher's exact test) were used to compare differences between groups. Conditional logistic regression was used to study whether personal, social or functional factors influenced the chance (expressed as Odds ratio) that study patients would have made visits to or had had inpatient specialised medical

care during the study year. The different factors were first tested by univariate logistic regression. The factors that showed significant influences were included in a multiple, logistic regression model. One of these factors (home help) showed no significant influence when included in the multivariate model and was therefore excluded from the main effect model [98]. We also tested to include the factors without significant influence in the univariate model, in the multivariate model, but no significant influence was found. The SPSS data analysing system was used for the analyses.

3.2 STUDY II

Medical treatment of patients with home care provided by DNs and the collaboration between FPs and DNs is an important but largely unknown process. Grounded Theory Methodology (GTM) was chosen because it is a method for studying social processes in areas where little is known [99-102]. The medical treatment and the collaboration were explored from the FPs' points of view using interviews with FPs.

There is an ongoing debate concerning GTM and what methods to use in the various repetitive steps of sampling, gaining data, analysing and coding data on the way to identifying a theoretical model grounded in data. Glaser, Corbin and Strauss and Charmaz are researchers advocating various methods in the GTM process. Also, reading the work of the same researchers over time reveals there eventually is a change concerning how the analysing is described [103, 104]. In the debate some researchers advocate integrating various steps from the different procedures in GTM described by the researchers above [105], others describe the difficulties of integrating them as the different approaches reflect different basic philosophical paradigms [106]. The GTM model used in this study is built on an analytic process that integrates the steps from the different researchers above [101, 105, 107]

The researcher SM, who conducted the theoretical sampling and the interviews, has done previous research and worked with home care in various capacities and thus has a preconception that could have influenced sampling, interview guides and interviews and could have influenced the analyses. Therefore, during the analyses SM has been careful to stay close to the data in order to remain open to what is actually happening and not force any preconception on the emerging concepts.

3.2.1 Participants and settings

The setting was primary care in Sweden. The FPs were asked to talk about a patient listed with them who had home care provided by DNs.

Table 3 - Number of patients receiving home care by district nurses, registered with the interviewed family physicians

Label following quotes	Number of interviewed family physicians	Number of registered patients with home care	Special home care family physician
A	2	50-60	Yes
B	5	20-35	No
C	4	< 10	No
D	2	Did not know	No
	Σ 13		

Thirteen FPs working in a city centre and in suburban, but not rural, areas were interviewed; seven men and six women, ranging in age from 36 to 58. They had worked between one and 20 years as specialised FPs, and between six months and 13 years at their present HC. Both private HCs and HCs run by a county council were included. All but three FPs worked in the same organisation as the DNs. The number of FP positions at the HCs varied (4-15), as did the proportion of FP positions filled by FPs (from one third to all). The number of DN positions also varied (2-8 per HC), as did the proportion of positions filled (from one third to all). The number of home care patients per FP also varied (Table 3). In two HCs some of the FPs were responsible for all home care patients. Work with home care patients thus made up a substantial part of these physicians' day to day work.

3.2.2 Theoretical sampling

The sampling was conducted as theoretical sampling in accordance with GTM [99, 101, 107], i.e. data were collected continuously and in interaction with data analyses. For a first sample, three HCs were invited and one FP from each HC agreed to participate. FPs were asked to talk about the last home care patient, age 65 or older, living in ordinary housing, in whose medical treatment they had been involved. However, as FPs did not always know which of their patients had home care they chose a patient that they thought was the last one. Therefore, in interviews 4-12, the request was changed to a memorable home care patient, aged 65 or older, in whose care they had been involved. The FPs were much more involved and updated concerning the medical care of these patients. Age was omitted as a selection criterion in interviews 6-13 as the analyses showed that age did not seem to be of importance. For the second sample 24 FPs in one city were invited by letter, and eight agreed to participate. In the first two samples all but one FP worked in the same organisation as the DN. Thus, for the third sample two FPs from a city where the FPs and the DNs typically work in different organisations were selected, both of whom agreed to participate. Thirteen interviews were conducted. To obtain variation, the FP in interview 13 was again asked to talk about the last home care patient in whose medical treatment he had been involved. After 13 interviews saturation was judged to be reached and no more essential information was discovered. Typically, in GTM this is a judgement with a certain amount of subjectivity.

3.2.3 Data collection

Before each interview the project was presented by a letter. Face-to-face semi-structured interviews lasting 45-90 minutes were performed in the FP's office at the HC by the first author who issued the invitations. Informed consent was secured. FPs were asked to give a description of the last time they were involved in the care of the selected patient, what problems the patient had and how they were handled, what the patient could manage on his/her own, who else participated in the care and what they handled. The interview guide was changed according to the analyses of prior interviews. New questions were added to explore factors that had emerged during previous interviews and analyses, gradually adding more and more questions to the questionnaire. During the interview, many FPs consulted the patient's medical and nursing records. Two FPs chose to talk about two patients to exemplify conditions they found problematic. Thus 15 patients were included. The sample of patients in the study as described by the interviewed FP is presented in table 4.

Memos were written directly after each interview and during the analyses. The interviews were audio-taped and transcribed verbatim. The transcripts were analysed

before the next interview to identify important issues, questions and ideas about links between emerging codes. The memos were used to modify the interview guide and were a basis for the analysis.

Table 4 - The sample of patients in this study described by the interviewed family physicians

	Age	Sex	Medical, functional and other problems encountered
1	-	Female	Depression, Pain, Overuse of painkillers
2	61	Male	Alcohol abuse, Epilepsy, Dementia
3	> 75	Female	Dementia, Pain, Epilepsy
4	78	Female	Depression, Dementia and Aphasia after stroke, Incontinence
5	82	Male	Impaired peripheral circulation, Ulcers, Pain
6	85	Female	Asthma, Diabetes, Dementia, Infections
7	86	Male	Prostate hypertrophy, Uraemia
8	87	Female	Dementia, Heart failure, Incontinence, Diabetes
9	87	Male	Diabetes, Obesity, Neuropathy, Both legs amputated, Ulcers, Infections, Pain
10	87	Male	Metastasised kidney cancer, End of life care
11	89	Female	Glaucoma, Bad eyesight, Aortic stenosis, Dizziness and falls, Fractures
12	89	Female	Severe anaemia, Leg ulcers
13	90	Male	Diabetes, Osteoarthritis, Heart failure, Spanish speaking
14	95	Female	Aged, Deteriorating health, Pneumonia, End of life care
15	Old	Male	Aged, Heart failure, Angina, Prostate hypertrophy, Dizziness and falls

3.2.4 Data analyses

Based on the GTM method, open, axial and selective coding were performed to enable the emerging theoretical model to be grounded in data. In the coding process the transcribed interviews were read and coded line by line to identify the different factors regarding how they had acted, seen and experienced the process that was described by the FPs. Codes were generated to define different factors in the process, formulated in words used by the FPs. Through constant comparison, similar codes were detected and labelled. Data were read repeatedly to find variations and to ensure that the codes were grounded in data. The central role of the patient and the DNs in the different narratives could be detected at an early stage, ‘internal’ factors arising from the patients’ problems and more ‘external’ factors like working conditions of the DNs affected the FPs ability to provide medical treatment.

Codes with the same meaning were grouped in descriptive categories and the theoretical properties of the categories were generated through comparison. The categories were sorted into higher-order categories and subcategories that were subsequently compared with one another to form concepts such as the concept of *patients with reduced functional ability* and the *medical conductor* or *medical consultant*. Constant comparisons were carried out until saturation was judged to be attained.

During axial coding the concepts were related to each other and patterns were analysed. It became obvious that the emerging pattern was so complex that it was impossible to

describe it in a single model in an understandable way. Therefore the coding process was divided. One process concerned the FP's description of the patient and the patient's problems and how they affected the FP's ability to provide medical treatment. The other process concerned the FP's description of collaboration with the DN. Two core concepts emerged: *to stay in charge of the medical treatment* and *to rely on the DN in home care medical treatment*. The two processes were separated and were described in articles III and IV.

All the authors participated in the analysis. The team comprised people with different backgrounds (two FPs, a DN, a psychologist, a researcher specialising in GTM) to bring a variety of knowledge and preconceptions to the process. Open coding was mainly done by the first author (SM), who is an FP. The team members followed the progress and expressed their views. The other researchers actively participated in the axial and selective coding process. The computer program NVivo was used. Quotes are used to illustrate the findings. The number at the end of each quote is related to factors about the patients, presented in table 4, and the letter is related to factors about the FPs presented in table 3. The resulting model in article III was discussed in a focus group with seven new FPs to validate the fit, relevance and work.

3.3 ETHICAL ISSUES

The projects were approved by the Research Ethics Committee South, Karolinska Institute, Stockholm. This approval included the design of the study as well as the way informed consent was obtained from the individual patients in study I and the interviewed FPs in study II. In study I all patients gave their written permission for the information to be obtained and used. For patients with cognitive impairment, the next of kin was asked for permission. As only groups of patients were investigated, it was not possible to identify any individual patient or caregiver. In study II the FPs who gave their permission were interviewed; in this study it was not possible to identify the individual patient.

4 RESULTS

4.1 THE COMPREHENSIVE CARE PICTURE

The comprehensive care picture corresponds to aim 1, articles I and II

4.1.1 Home help or help from family members

All patients with home care by DNs either had help from family members or home help (table 5). Patients who lived alone were more likely to have assistance from home help staff and less likely to have assistance from family members. Patients who got help from family members were less likely to have help from home help staff [108].

4.1.2 Help from DNs

The fact that all patients had home help from DNs is the result of the definition used in this study as only patients with regular home care provided by DNs were included.

Table 5 - The comprehensive care of 116 patients with home care by DNs

Help from	Patients, %
Home help	65%
Family member	35%
DN visits	100%
FP notes in record	97%
FP visits	72%
FP home visits	24%
Visit to physician in specialised care	70%
Visits to more than one type of speciality apart from FP	32%
Treatment by physiotherapist or occupational therapist	33%
Inpatient care	56%

4.1.3 Help from FPs

The FPs were involved in the care of almost all patients, as could be seen from the notes in the FP records. However, they had only met around three quarters of the patients and made home visits to one quarter of the patients during one year (table 5). Most common was to see the patient twice in a year.

When comparing FPs' care of study patients from one HC to that of a control group of patients of a similar age from the same HC we found that the home care patients saw their FP less often than other patients of similar age, but there were more notes without a visit. Much of the FP care of home care patients was handled without direct contact with the patient. Sixty-seven per cent of the notes were made without direct contact with the patient. Those notes concerned, e.g. telephone calls, prescriptions and contact with other care providers about the patient [109].

4.1.4 Paramedical care

One third of the patients had visited either a physiotherapist or occupational therapist (table 5). Half of those visits took place in the PHC, the rest at a hospital. Physiotherapists in private practice were not included [108].

4.1.5 Inpatient care

More than half of the study patients had been admitted to the hospital during the study year and often more than once, many times spending more than three weeks in hospital. Fifteen specialties were represented. Care by specialists at various emergency hospitals represented more than half of the care periods, while geriatric care was the cause of more than half of the days of inpatient care. Almost all care periods were spent at the two emergency hospitals, the two geriatric hospitals and the two local psychiatric wards located in or close to the study area. Six other emergency hospitals and one other geriatric hospital also provided care for these patients [108].

4.1.6 Many different physicians were involved

During the study year the majority of the home care patients also made outpatient visits to physicians in specialised care (table 5). More than half made three visits or more. Approximately one third of the patients saw physicians from two or more different specialties excluding family medicine. This meant that for one third of the patients three or more different types of physicians were involved in the medical treatment during the study year.

Twenty-two different specialties were represented. Visits to departments of general internal medicine were most common followed by visits to departments of surgery, orthopaedics and ophthalmology. Most of the visits took place in the hospitals and departments located in or close by the study area. Thirteen different locations were visited [108].

4.1.7 Referrals

Referrals (including discharge notes) are well-established forms of co-operation between PHC and specialised care, and for transferring information and responsibility. In 15 per cent of the FP notes some form of communication with specialised care was mentioned, in eight per cent of the notes as a referral (or discharge note) from specialised care, and in six per cent of the notes as a referral to specialised care (for 30 per cent and 27 per cent of the patients, respectively). Only one per cent of the notes concerned a direct consultation with a specialist [110].

4.1.8 The comprehensive care situation – one example

Figure 1 illustrates the comprehensive care situation with all the care providers engaged in one patient's care (Study II). For example, responsibility for medication was divided up among many hands – prescribed by the FP, the neurologist and the geriatrician. Who was responsible for discontinuing one type of medicine became unclear. The FP was responsible for providing the DN with a list of medicine for dispensing tablets to be given to the patient by the home help, but the FP did not feel quite comfortable about continuing some of the medicines prescribed by the other physicians.

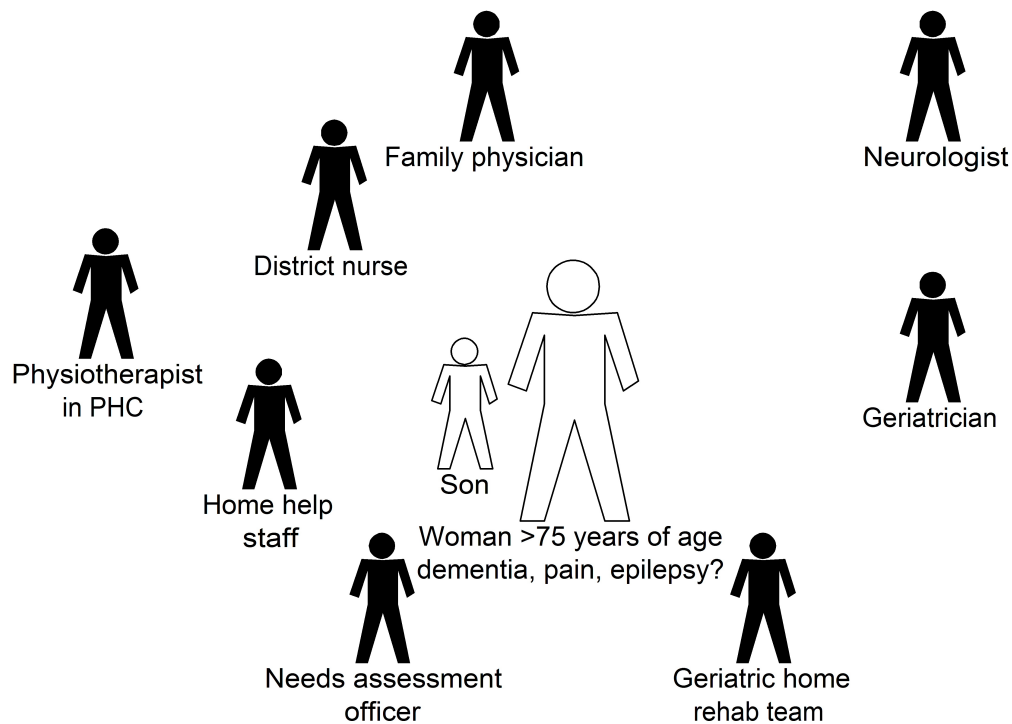


Figure 1 - The comprehensive care situation from an individual perspective
Care providers involved in the care of one patient living alone (patient 3, table 4)

4.2 THE HOME CARE PATIENTS

The home care patients correspond to aim 2, articles I, II and III.

4.2.1 General description of the patients and their problems

The patients with home care by DNs were elderly. The majority were women living alone. Most of the patients had several functional problems, several symptoms and several diagnoses (table 6) [109].

Table 6 - Characteristics of the 116 home care patients. The most common forms of reduced functional ability, types of diagnoses and symptoms

Age	83 (median)
Women	74%
Living alone	70%
Reduced functional ability	
Mobility	50%
Vision	46%
Cognitive ability	33%
Type of FP diagnoses	
Cardiovascular disorders	42%
Psychiatric disorders including dementia	27%
Disorders of the musculoskeletal system	21%
Symptoms	
Musculoskeletal pain	53%
Fatigue	46%
Anxiety	44%

4.2.2 Problems staying in charge of medical treatment

There were three types of patients where the FP had problems staying in charge of the medical treatment. They were *patients with reduced functional ability*, *patients who were fixed in their ways* and *patients with complex conditions*.

Patients with reduced functional ability

This included patients who were weak and had reduced initiative because of their medical condition, old age or reduced cognitive ability. It also included patients with specific communication problems due to aphasia, language problems or dementia. A third group was patients with impaired vision and physical weakness. This resulted in poor ability to communicate, inability to contact healthcare professionals when their health deteriorated, and inability to relate what had happened or how they felt. This could also result in diminished ability to manage their treatment, i.e. handle their medicine and evaluate their condition and the effect of the treatment [111].

Patients who were fixed in their ways

These were patients who wanted to manage on their own, even when they needed medical attention according to others (FP, DN, home help staff, family or friends). These patients did not contact healthcare professionals, did not mention when they had problems, or did not comply with recommendations. Staying in charge of the treatment became a problem when the patients had a medical condition and refused, for instance, to comply with recommendations about medical treatment. Examples of this behaviour included overusing or discontinuing prescribed medicine, not wanting to adapt their home environment to home care, and refusing care outside the home [111].

Patients with complex conditions

These were patients in home care with complex medical conditions or a combination of medical conditions and other types of problems. Complex conditions resulted in medical treatment difficulties such as inability to conduct investigations, receiving no answers, or receiving information that was ambiguous or hard to interpret. There were difficulties treating complex conditions and the FP had problems getting medical advice. Patients in this category included those who abused alcohol or overused painkillers, those with side effects from the appropriate treatment, or those approaching the end of life [111].

4.3 FACTORS INFLUENCING HEALTH CARE

Factors influencing health care correspond to aim 3, articles I, II and III.

4.3.1 Non medical factors influencing health care

Patients with cognitive problems had more psychiatric symptoms, but did not otherwise differ from other patients with home care by DNs. Nevertheless, compared to the other home care patients they seldom met their FP and the FPs made fewer notes in their records. The notes often concerned medicine and then usually repeat prescriptions while notes about new symptoms occurred less often [109].

The influence of personal, social and functional factors on the chance of receiving specialised medical care was tested. Patients with a high degree of ADL dependence (needing help to eat) were less likely to make outpatient visits, in contrast to patients who had help from family members, who were more likely to make outpatient visits for specialised medical care [108].

4.3.2 Problems influencing FPs' ability to stay in charge

It was difficult for the FPs to stay in charge of the medical treatment because of the patients and their problems. The FPs had *problems gaining sufficient insight, making adequate decisions and maintaining appropriate medical treatment*.

Problems gaining sufficient insight

Patients with reduced ability to communicate could not call for help or relate what was happening. Patients who were fixed in their ways did not want to call for help. For these patients FPs had problems gaining sufficient insight, e.g. when a patient needed medical attention, because of a new disorder or deteriorating medical condition[111].

Regarding a patient with dementia: *The interviewer: 'Does she contact you if she gets sick?' '...she used to do that herself but now she relies on her friends, they check on her'...6 B*

Regarding patients fixed in their ways: *'I wanted that ...that they (the district nurses) would check on him...but he didn't want that, he wanted to manage on his own... he's very stubborn...'15 B*

Problems making adequate decisions

When patients were fixed in their ways, making adequate decisions was challenging, e.g. providing medical treatment and care when the patient refused changes in the home that were considered necessary in order to provide home care, or refused to use their medicine in the prescribed way. When attempts to influence the patient failed, the FP was sometimes uncertain what to do.

When the patients had complex conditions, making adequate decisions was difficult. When an investigation was difficult or gave no answers, the basis for making decisions was uncertain. When patients were getting older, approaching the end of life, decisions about adequate treatment could also be problematic.

'How closely should you follow up on an 80-year-old diabetic patient? ...You have to learn this on your own, I suppose...It's much easier to see long-term factors when you have a young patient in front of you...'5 A.

Decisions concerning the medical treatment of patients who abused alcohol were also complicated. Home care was described as the last resort when all other forms of care had been tried. The home care situation could be complicated as well as decisions about the medical treatment of a person who was regularly intoxicated.

'At one time they didn't want to go there...sometimes he had friends there who abused alcohol, and once there were a lot of weapons on the table, which they found a bit scary...'2 C.

'...during one period he was fast asleep when they were supposed to give him his medicine so they couldn't give it to him...' The interviewer: 'Because he

was drunk, or...?’ ‘Yes, we’ve decided that we can’t give him any medicine then, it’s not possible’ 2 C. (ref)

Problems maintaining appropriate medical treatment.

Maintaining appropriate treatment of patients with reduced functional ability who could not handle their own treatment was a problem. For instance, when patients with reduced cognitive ability also had other conditions like infections, asthma or diabetes, or needed complex treatment, or when patients with reduced functional ability and impaired vision could not manage their medication [111].

‘An 85-year-old woman with asthma, diabetes ...developing dementia...she’s getting worse and worse...and even though the district nurse makes home visits every day, we’re not sure that she’s taking all her medicines as she should or that she uses her inhalers the way she should...’6 B.

4.4 FPS MEDICAL TREATMENT

FPS medical treatment corresponds to aim 4, articles I and III.

4.4.1 What the FPs did

The most common reasons for FPs’ involvement in the care were new or changed symptoms (35 per cent of all FP contacts) or medicine-related problems (30 per cent). As mentioned above, 67 per cent of the notes concerned measures undertaken without a consultation where the FP could see, talk to and examine the patient.

Medication dominated the measures that were undertaken and concerned repeat prescriptions in 34 per cent of the notes and changed or new medicine in 26 per cent of the notes. Medicine-related measures were usually handled without a visit.

Investigations were the second most common measures. There were referrals for tests in 19 per cent of the notes and referrals to other clinical specialists in six per cent of the notes. Referrals for physiotherapy or occupational therapy were the third most common measure and appeared in two per cent of the notes [109].

4.4.2 Strategies used in order to stay in charge

In their effort to stay in charge of the medical treatment of patients with home care by DNs, FPs used four different strategies to overcome the problems they experienced. The FP relied on information from the DN and the other care providers participating in home care to gain good enough insight. The FP supported close observation and follow-up by the DN and others participating in home care to be able to make adequate decisions and was also always ready to change the goal of the treatment based on this information. The FP relied on treatment provided by the DN and others participating in home care to maintain appropriate treatment [111].

Relying on information from the DN and others

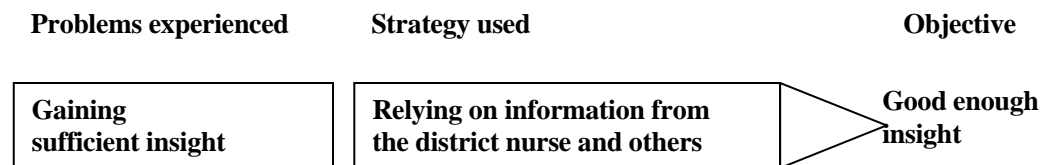


Figure 2 - Relying on information from others as a strategy for gaining good enough insight.

When the FPs had problems in gaining sufficient insight, they relied on the DN and the other home care providers to alert them when necessary and to give them information. (Figure 1)

The interviewer: 'Who contacts you if she feels worse?'... 'The district nurse, or her children, or home help staff. Usually the home help staff actually' 3 B.

They particularly relied on information from the DN who visited the patient regularly, could do tests, and also was in contact with other care providers. Some FPs expressed frustration. They missed the direct contact with the patient and found it difficult to stay in charge when they had to rely on information from others. Since the patients did not contact the FP themselves, information about the patient's own wishes and reactions was mediated through the DN and was consequently second or third-hand information. Although this was the strategy that was used, some of the FPs felt uneasy about it as they did not always get the information they considered important [111].

The interviewer: 'How do you feel looking after her works out?' 'It's a bit uncertain, no grip on it. It's not like with people you have contact with yourself. It's like this with many patients with home care by district nurses, when it goes through another person, the district nurse and home help. You're not updated on how things are going, you have to trust your district nurse and hope they alert you at the right time...' 4 B

Supporting close observation and follow-up by DNs

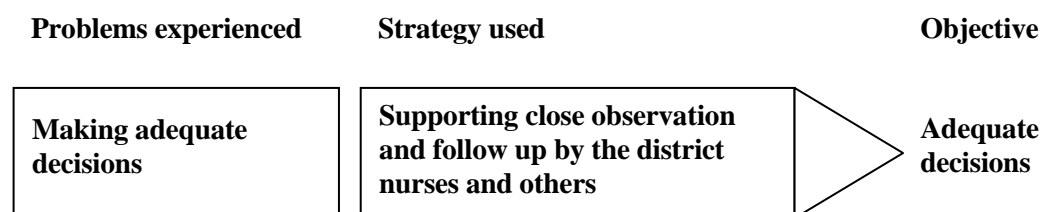


Figure 3 - - Supporting close observation as a strategy for making adequate decisions

In complex conditions and difficult care situations where the FPs had problems making adequate decisions, they had to support home care providers. In situations where the basis for decisions was uncertain or decisions concerning adequate treatment were problematic, they supported follow-up and close observation by others. Thus their own role was changed. The DN followed the patient's condition closely and assessed the risks. Support of and follow-up by the family and the home help staff was also essential (Figure 2).

‘...We still feel that he needs nursing home care...we can’t do anything as long as he doesn’t want it...We try to support his wife...as soon as there’s a problem I talk to the wife...I must say that we’ve given up a bit. It sounds terrible to say that, but that’s how it is. We can’t do more for him at the moment but it’s important to support his wife, and then we’ll see’’ 9 D (ref art III).

Being constantly ready to change the goal of the treatment

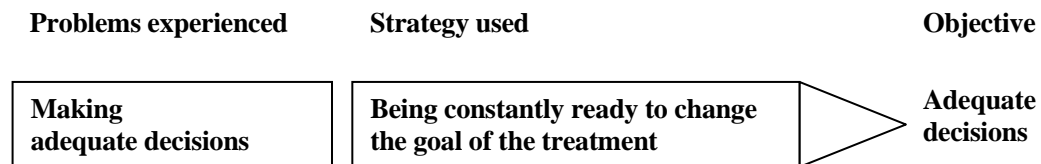


Figure 4 - Being constantly ready to change the goal of treatment as a strategy for making adequate decisions

When the basis for decisions concerning the goal of the interventions was uncertain, FPs had to base decisions on the information that was possible to obtain. FPs then had to be ready to change and adjust the goal when there was new information, relying on getting information from the follow-ups by the DNs (Figure 3).

The FP had to evaluate the situation and be ready to adapt the goal to what was acceptable to the patient, possible to carry out, and medically appropriate when it was difficult to make decisions about adequate treatment. How that treatment should be maintained was problematic. Information from the DN and other home care providers was essential to evaluate whether the plan was correct or had to be changed. The goal could be to maintain the best possible state of well-being for the patient and to avoid risks.

‘Her blood count is sometimes as low as 80; despite extensive testing we don’t understand why/.../we monitor her blood count regularly/.../ our goal is for her to feel as good as she does and to maintain that’ 12 C.

When the patient was treated in home care by DNs at the end of life, the FP was the only physician available to make decisions concerning palliative care. Changing the goal of the treatment towards palliative care could sometimes seem natural to the FP and sometimes be difficult.

‘She was tired of life, she was ready and wanted to die at home...it was hard to argue’ 14 D.

‘In the end you have to assume greater responsibility (stop the tests and start more palliative care)/.../which I find relatively difficult’ 10 A.

In difficult situations, like treating patients with alcohol abuse, the FP sometimes did not know what to do. The FP and the DN had to evaluate the situation and the treatment and change the goal of the treatment in order to maintain the best possible state of well-being for the patient and avoid risks for both the patient and the care providers [111].

Relying on the DN and others to provide treatment

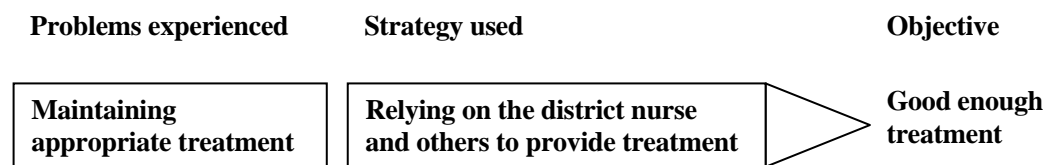


Figure 5 - Relying on others for treatment as a strategy for maintaining appropriate treatment

When the patients had problems maintaining appropriate medical treatment the FPs had to rely on the DN. Family members and home help staff also assisted the patient with medicines. (Figure 4)

So, for FPs to stay in charge of the medical treatment of patients with home care by DNs, they had to make difficult decisions on uncertain bases and it was essential to be able to rely on and collaborate with the DNs[111].

4.5 FP – DN COLLABORATION

FP – DN Collaboration corresponds to aim 5, articles I and IV.

4.5.1 What the DNs did

The DNs usually met the patients once every week or every second week and then usually at home. Approximately one third of the patients had started home nursing during the study year, and about half had had home nursing for more than two years.

The most common nursing procedures were assessment of the patients' conditions or dealing with problems related to the patients' medicine. The nurses assessed the patients' conditions during the visits or by means of various tests. Dispensing tablets was the most common medicine-related procedure, followed by injections, infusions and inhalations. The district nurses also helped some of the patients to take their medicine.

The DNs had an extensive circle of contacts. According to the questionnaires, during the registration week the DNs had been in contact with FPs, assistant nurses, physiotherapists, occupational therapists, needs assessment officers, home help organisers, home help staff, staff at the social day care centre in the municipality, emergency departments, psychiatric outpatient departments and the medical aid centre. The most frequent contacts were with assistant nurses and the FPs [109].

4.5.2 The FPs' reliance on collaboration with the DNs

In their efforts to stay in charge the FPs had to rely on and collaborate with the DNs concerning the home care medical treatment and most of them were very satisfied with this collaboration. It was 'fundamental' to be able to rely on the DNs in this and all expressed a need for frequent DN contacts and easy access through regular meetings, on-demand meetings or telephone calls.

'I know that they are very competent...So I can rely on them' 8 B – 'The district nurse and the doctor have to be a team/...that's a fundamental condition in order to call it home nursing.' 3 B – 'Without the nurse I would have had problems managing this, I think she's invaluable' 13C.

Good home care was seen as a basis for providing medical treatment. The FPs expected the DNs to assess the need for and provide necessary home care, handle contacts and meeting with family and neighbours, home help staff and hospitals and coordinate care and treatment. *'I really feel that the district nurse that should be the spider in the web'* 5A

Relying on *the DN for medical treatment in home care* meant that the FP had to trust the DN to carry out investigations and treatment initiated by the FP, to keep the FP informed and mediate contact with patients when asked. However, 'rely on' also meant that the FPs trusted the DNs to mediate contact between them and the patient on their own initiative, and to alert them when unexpected problems appeared, e.g. if a patient's health deteriorated or if a patient did not take their medicine. *'Well, the district nurse is there every day, she gives insulin every day - (if something happens) she calls, yes, I get alerted directly'* 9D. Rely on also meant that FPs trusted DNs to take the initiative in the medical treatment, e.g. to send a patient to hospital in the event of accidents or other emergency situations [112].

4.5.3 Medical conductor or medical consultant

How much of the initiative the FP retained or left to the DN differed among the different FPs and in different situations. Consequently, 'rely on' was described differently depending on situation. Two different roles were identified; the *medical conductors who retain the initiative* and the *medical consultants who leave the initiative to the DNs* (here called conductor and consultant). The individual FPs could adopt the role of conductor regarding one disease and consultant regarding another and could also adopt only some of the features of the two roles [112].

Factors that influence the role of the FPs

Sometimes FPs left the initiative to the DNs because they found it satisfactory, sometimes working conditions forced them to leave more of the initiative to the DNs than they found satisfactory. Three different factors influenced whether FPs adopted the role of conductor or consultant; working conditions, attitude and disease. (Table 7)

The FP's *working conditions* could influence the FP's role. The FPs mentioned insufficient time, insufficient routines at the health care centre and organisational boundaries.

Insufficient time for medical treatment in home care could be due to heavy work load due to too many patients, shortness of staff among FPs (vacancies or too few positions) and demands for many visits per day. The result could be that the meetings with the DNs were too few and too short, that matters had to be handled during breaks or between visits, that home visits were considered to be too time consuming and had to be done by the DNs and also that there was only time for urgent medical problems and matters and no time to familiarise themselves with the whole picture of the patients' problems, and no time to discuss and plan future care and treatment.

'You have insufficient time to familiarise yourself with a case, you just have to handle the problem of the day and try to get sufficient information to know that

you do the right thing at the moment. Yes, there can be things that are done twice, and yes you can lose things too' 12C.

Table 7 - Factors that influence whether family physicians take the role of conductor or consultant

Conductor (retains initiative for medical treatment)	Consultant (leaves initiative for medical treatment to the DN)
<ul style="list-style-type: none"> • Working conditions: FPs' working conditions are good enough • Attitude: FPs have a positive attitude towards being a conductor • Disease: The type of disease in need of FP initiative 	<p><i>FPs feel forced to take a role as consultant:</i></p> <ul style="list-style-type: none"> • Working conditions: FPs' working conditions are problematic • Attitude: FPs have a positive attitude towards being a conductor instead of a consultant <p><i>FPs choose to take a role as consultant</i></p> <ul style="list-style-type: none"> • Attitude: FPs have a positive attitude towards being a consultant • Disease: The type of disease not in need of FP initiative

Insufficient routines at the HC could be lack of information and lack of routines for home visits and meetings with the DNs. The result could be that the FP did not know which patients had home care, that home visits were more time consuming and were hard to manage in an emergency situation, and that the FPs only had on-demand contact with the DNs.

Organisational boundaries when FPs and DNs worked in different organisations could mean insufficient transfer of information and changes in responsibilities in connection with frequent reorganisation. The FP lacked information about who had home care from the home care organisation and had no access to the nursing records. Also, after reorganisations it was difficult for the FP to know what DN to contact as well as to know when the FP or the physician in the home care organisation was responsible for the medical treatment of a patient. This caused problems especially when the FPs referred patients to the hospital and they were referred back to the home care organisation, leaving the patient without proper medical support [112]. *'As physicians we still stand as responsible even though we really don't know' 7D.*

The *attitude* of the individual FP also played a role. Some FPs found it important to keep close contact with the patients, retained the initiative and planned future visits for chronic diseases. Others adopted on-demand care and expected patients to initiate all FP visits, even follow-up visits for chronic diseases. Then it was natural for FPs to rely on the initiative of the DNs if these patients could not manage to do this [112].

'When they cannot look after themselves they become home care patients. Up till then they look after themselves; we do not send appointment notifications' 15B.

The type and stage of *the disease* was also influential. The individual FP could retain the initiative, plan future visits, investigations and treatment of one type of disease such as recurring anaemia, and leave the initiative to the DNs for the treatment of another type of disease such as leg ulcers that the FPs felt that she could handle independently [112].

Medical conductor or medical consultant

Medical conductors retain the initiative. They plan medical treatment and future visits for patients with chronic diseases. They feel that they have an extra responsibility for home care patients and that it is important to know who these patients are. Conductors get more involved when patients have home care by DNs as compared to other patients, see these patients as often as other patients and also have frequent inter-professional consultations with the DNs where they ask for information, discuss problems and make joint decisions. They regard home visits as a special opportunity to gain information and contact and do not always rely on the DNs to coordinate. They can also introduce new routines when old ones are insufficient [112].

'I try, if it is a chronic patient where I know that I will treat the patient, I usually initiate a care planning. If you can call it care planning, at least a dialogue with those who are involved/.../I find that very important. Like doing a preliminary examination of the patient' 10A.

Medical consultants leave the initiative to the DNs. They rely on the DNs to arrange future FP visits for chronic diseases at agreed frequencies and arrange visits in between if the DNs find it necessary because of a change or if something new comes up. They also rely on the DNs to handle some diseases independently, contacting the FPs when necessary. They do not experience any special responsibility for home care patients and do not feel a need to know who they are. If anything, they feel that they can see patients who have help from the DNs less often than other patients. They do not express a need for home visits but do home visits at the request of the DNs. They expect the DNs to contact them when they have new information, need medical advice or support or think an inter-professional discussion is necessary [112].

4.5.4 Adequate grounds for relying on DNs

Even if most FPs felt that there were adequate grounds for relying on the DNs there were exceptions. The attitude and the working conditions of the DNs as well as the disease influenced the grounds for relying on the DNs. (Table 8)

The DNs' working conditions could influence whether there were adequate grounds to rely on the DNs. The FPs mentioned insufficient time and short-time substitutes as negative factors.

Insufficient time was due to shortages of DNs to fill the posts or too few posts. The result could be that the DNs did not have time to acquire sufficient information, to provide the FP with information or to participate in inter-professional discussions. Information in connection with requests for prescriptions was mentioned. One FP wanted to know how a patient took a medicine and if it helped but the DNs did not know. *'The DNs are so stressed that they forget their profession. They just take orders'* 5A. Another result of insufficient time could be mistakes and errors.

Table 8 - Factors that influence the grounds for FPs to rely on DNs

Factor	Adequate grounds for relying on DN	Inadequate grounds for relying on DN
• Working conditions	• DNs' working conditions are good enough	• DNs' working conditions are problematic
• Attitude	• DNs have a positive attitude to collaborating with FP	• DNs do not have a positive attitude to collaborating
• Disease	• Type of disease that DNs can handle	• Type of disease that DNs have problems handling

Short-term substitutes meant that the DNs did not have the formal training, had less information to provide as they did not know the patients and their problems, and that the information could be incorrect. Short-term substitutes could also have a short-term attitude concerning how to handle problems [112].

'...has a different approach than someone who knows that she will stay longer, so there can be poor – what can I say – poor empathy with the patient's problems, so to speak. It's more about solving the problems of that day' 5A.

DNs' attitudes towards collaboration influenced whether there were adequate grounds to rely on the DNs. The FPs relied and depended on the DNs to provide information and involve the FPs when necessary. However, they did not always agree on when the FP should be involved or how a problem should be solved. This could mean that the FP did not get information, did not get involved and did not agree with the solutions of the DNs. In particular, problems with getting sufficient information when the DNs wanted new prescriptions were mentioned [112]. 'I sort of sat here with a lot of notes and prescribed a lot of medicines but I was not sure if they were my patients or not. It was sort of just a job that had to be done because the DNs had to fill the dose dispensers' 1B.

The type and stage of a *disease* influenced what FPs felt were adequate grounds for relying on the DNs for independent medical treatment. Nutritional problems, leg ulcers, incontinence and follow up of diabetes between yearly FP visits were examples that were mentioned[112].

4.5.5 Conditions for providing home care medical treatment

If we combine '*the role the FP chooses or is forced into*' and '*whether adequate grounds for the FP to rely on the DN exists or not*' we create different conditions for providing home care medical treatment. (Table 9)

Conditions for providing medical treatment in home care can be described as good enough when there are adequate grounds for relying on the DN and as problematic when there are inadequate grounds for relying on the DNs regardless of the role of the FPs.

However, when conditions are problematic FP conductors use various strategies to overcome the inadequacies of not being able to rely on the DNs. They mentioned that

they demanded information, initiated regular meetings and demanded more time for the meetings.

FPs who want to be conductors but are forced by their working conditions to be consultants use strategies to transform their role from consultant to conductor when they experience problems. They mentioned that they used lunch breaks and unexpected free time to be able to make home visits and to familiarise themselves with the patients' problems. They also established their own priorities, their own routines and bent the rules to be conductors when they felt it necessary.

FPs who chose to take the role of consultants, however, are not aware of problematic conditions for medical treatment as they do not get information and are not alerted to problems when there are no adequate grounds for relying on the DNs. This leaves the home care patients without sufficient support for medical treatment [112].

Table 9 - Good-enough or problematic conditions for medical treatment

	Adequate grounds for relying on DNs	Inadequate grounds for relying on DNs
FPs take the role of conductor	a. Good enough conditions for medical treatment	c. Problematic conditions for medical treatment The FPs use strategies to overcome the inadequacies
FPs take the role of consultant	b.	d.
1. FPs feel forced to take the role of consultant	b.1. Good enough conditions for medical treatment	d.1. Problematic conditions for medical treatment FPs use strategies to transform their role from consultant to conductor
2. FPs choose to take the role of consultant	b.2. Good enough conditions for medical treatment	d.2. Problematic conditions for medical treatment FPs not aware of problems

5 DISCUSSION

5.1 MAIN FINDINGS

The typical home care patient was an elderly woman living alone who had multiple functional problems, symptoms and diseases, often including reduced cognitive ability. A variety of care providers were involved in the care and treatment, including family members and home help staff, DNs, FPs, physiotherapists and occupational therapists. Many also had inpatient and outpatient hospital care. Family members or home help staff and the DNs provided home care. In spite of their reduced functional ability, home care patients usually met the physicians at the HCs or at the hospital. Many had treatment from several different physicians. FPs played an active role and made notes in the record due to contact with or information from the patient, the DNs or the specialised care staff on average once every other month. However, they typically met with the home care patient twice a year. In summary, we have a picture of frail patients with multiple problems and very complex care and treatment, where many different organisations and care providers are involved in parallel [108, 109].

The FPs' experiences providing medical treatment for home care patients were dominated by how the home care patients and their problems influenced the FPs' abilities to stay in charge of the medical treatment. This in turn resulted in the FPs relying on collaboration with the DNs. Consultation with the patient could not provide the usual foundation for decisions concerning medical treatment. For patients with reduced functional ability and patients that didn't accept FP help, the FPs had to rely on the DNs for information and help with the medical treatment. FPs also relied on the DNs for information and discussions concerning the patients that the DNs met regularly and for information and coordination of the care provided by other care providers. Due to complex conditions when it was hard to make adequate decisions on medical care, and patients fixed in their ways did not comply with recommendations, the FPs had to rely on the close observation and follow-up of the DNs to get information on developments. This information was absolutely crucial as it was the basis for constant re-evaluation of the treatment goal. Thus adequate grounds for FPs to rely on the DNs for medical treatment are needed in home care medical treatment. Working conditions, the attitude of the DNs and the type of disease influenced whether the grounds for relying on the DN were adequate [111, 112].

In home care medical treatment FPs can take the role of medical conductors or medical consultants, retaining or leaving the initiative of the medical treatment to the DN. One FP can take on different roles in different situations. The role the FP chooses or is forced to take is influenced by the working conditions and the attitude of the FP and the type of disease. Regardless of the role of the FP, conditions for medical treatment can be seen as 'good enough' when there are adequate grounds for relying on the DN and problematic when there are inadequate grounds. However, if the grounds for relying on the DNs are inadequate, only FPs who are or want to be conductors are aware of this and use different strategies to overcome the inadequacies or to change their role. FPs who chose to be consultants, however, will not be aware of problematic conditions for providing medical treatment as they will not get information and will not get involved by the DNs [112].

5.2 METHODOLOGICAL CONSIDERATIONS

5.2.1 Definitions and organisations

The fact that there is no uniform way of describing home care by DNs was a problem throughout the study. It has been a challenge finding relevant literature and describing the results in an understandable way, and in a way that makes it possible to use the findings in future studies.

As conditions regarding the care of patients with home care by DNs differ, the results from studies in one area are not necessarily valid in other areas. On the other hand, studies that cover several areas run the risk of missing problems that may only exist under certain conditions. Study I was conducted in an area with relatively well-defined conditions, and could serve as a starting point for further studies. Study II covered different, but not rural conditions and can also serve as a starting point for further studies.

5.2.2 The number of FP visits in Study I

Information from official statistics is commonly used to describe medical care. In this study, the official statistics agreed with the information retrieved from the nursing records. But when official statistics were compared with the computerised FP records there was a pronounced discrepancy. In the official statistics, 466 FP visits, including home visits, were recorded for the study period, whereas the FP records only showed 221 visits. This could partly be due to the fact that some notes had been made that were not part of the computerised record, but instead were part of special documents that were still in use for some types of measures. The main reason, however, appeared to be that patients paid the same fee for FP visits as for tests that were prescribed and assessed by the FPs but performed by the nurses during home visits. The official statistics thus showed the number of financial transactions, not the number of actual FP visits. This raises questions concerning the validity of the official statistics, at least in this respect.

5.2.3 Data in study I

A randomised third of the population of patients receiving home care by DNs is thought to provide a sufficient basis for conclusions about all the patients, and a participation rate of 73 per cent is acceptable. The patients who were excluded were of the same age as the participants but might have had more severe conditions as patients who had died or who were admitted to hospital during the registration week were excluded. These patients probably did not receive less medical care than those who were included.

Data about the functional and medical problems of the patients are based on the professional judgment of the FPs and DNs using standard clinical methods, and should provide an adequate picture. Data in the records represent what the caregivers considered important to record, which is influenced by many factors. This might explain why matters concerning medicines and investigations were predominant.

5.2.4 To interview one's peers

The fact that the interviewer (SM) in Study II was an FP who interviewed her own peers with whom she had had previous contact, is both a methodological weakness and a strength. If the interviewer is seen as a peer and confidant, this may facilitate access and result in richer and more personal accounts of attitudes and behaviour, but it can also influence the researcher's ability to obtain data because of a shared understanding that is not explored [113, 114]. On the other hand the research team participating in the data analyses consisted of researchers with different backgrounds that may have compensated for this.

5.2.5 The theoretical sampling in study II

A theoretical sampling was done, letting the analyses from the previous interviews guide the choice of FPs to invite, the type of patients they were asked to talk about and the follow-up questions that were asked. The sampling procedure contributed to the provision of rich data but also to the lack of data concerning patients with whom the FPs as consultants were less actively involved. Interviews with FPs about *any* patient in home care would have given more information about consultants not knowing about problematic conditions. However, interviewing FPs about situations that are problematic because they are not informed about them is, in itself, problematic. Thus more mixed research methods would be required to explore this potentially difficult type of situation.

5.2.6 Using GTM

Most agree that GTM is a method that is well suited for studying social processes like the one we have explored. There is an ongoing discussion about GTM analyses as different researchers describe and advocate different ways of doing the analyses [99-101, 103-106, 115]. As mentioned in the methods and material chapter, the analytical model used here integrates the steps from different researchers. It has been important to stay close to the data, constantly checking new ideas about the data FPs discuss in the interviews. We also let preconceptions contribute to ideas about what questions to put to the data, but made sure that only answers that were grounded in data remained. In that way my preconception has been an advantage. It has been a long and difficult but also satisfactory process to identify two processes of importance for home care medical treatment. Having a supervisor familiar with the process of analysis in GTM was essential to achieve this result and to learn the power of using GTM.

5.2.7 The relevance and fit of the result in study II

In this study we were able to distinguish specific processes: 'the effort to stay in charge of the medical treatment' and 'to rely on the DNs in home care medical treatment', describing the collaboration between the FPs and the DNs from the perspective of the FPs. We created models depicting factors that influence these processes and the effect of these factors on the ability to stay in charge and the conditions for providing home care medical treatment. As is always the case with GTM, further research is needed to try the relevance in other collaborative situations between FPs and DNs. However, a focus group with participants who had not been part of the study recognised both the

problems involved in staying in charge of the medical treatment and the strategies used by the FPs in their efforts to do so. Most important was that they experienced that now this was put into words for the first time! [111]. Even if the model of relying on the DNs presented in article IV was not elaborated at the time of the focus group, the necessity of relying on the DN in the effort to stay in charge of the medical treatment was discussed and recognised in the focus group. To our knowledge these two partly intertwined processes have not been described before.

5.3 DISCUSSION OF THE RESULTS

5.3.1 Patients with complex problems and complex care

In study I the study patients were elderly and had the same types of problems as described in other studies of patients receiving home care by DNs [5-7, 109, 116]. The home care procedures performed by DNs resemble those described in studies of home care by nurses and in classifications of home care activities by nurses [109, 116-121]. Other studies also confirm that FPs make few home visits, and that physicians with many home care patients spend considerable time with telephone calls and paperwork [58, 92].

Due to the problems of acquiring statistics about these patients, there were few studies about the FPs' involvement in their care and their use of specialised care. When the result from study I was published, this was partly new knowledge. Since then the Swedish government has initiated a longitudinal study (SNAC) in four different regions regarding the problems and the care of patients receiving home help and/or home care by DNs. The population in the SNAC studies includes all patients with home care by home help staff and hence is only in part the same as in our studies. SNAC studies from Stockholm also identified that many individuals with home care have inpatient care and, for example, that reduced functional ability negatively influences the chance of receiving both inpatient and outpatient care [108, 122].

Our study gives the picture that the medical treatment of frail home care patients with multiple and complex problems, often in combination with reduced cognitive ability, is divided among many hands. The FPs had to rely on the DNs and the other care providers to gain sufficient insight, giving rise to questions about how the physicians in specialised care who see the patient at hospital a few times can gain sufficient insight to make adequate medical decisions. To verify this picture and study the consequences for the quality of the medical treatment of home care patients requires more studies. This study took place in a city area with easy access to specialised care and limited PHC resources, which might have increased the use of specialised care [108, 111].

5.3.2 Implications for definition of home health care

The definitions of home care used in this thesis and the current Swedish definition of home health care are restricted to what is performed in the patient's home [4, 123]. Almost all home care patients also saw the FP at the HC and physicians in specialised care at the hospital and many measures concerning patients with home care were carried out between visits outside of the home. Since home care medical treatment

involving DNs depends on decisions made elsewhere and includes more than what is performed in the patients' homes, we need a definition that allows a more integrated view of the care and treatment of these patients [108, 109, 111, 112].

5.3.3 Family medicine in home care medical treatment

Physician-patient consultation is not enough

Personal contact with the patient in the physician-patient consultation is usually one of the cornerstones of family medicine. During a number of consultations over time the contact between the patient and the FP as well as the FP's understanding of the patient and of the patient's situation is supposed to develop. Research is being conducted into various important aspects of the consultative process to develop this [42, 67].

We have identified two types of patients for whom using consultations as a cornerstone in the contact and treatment of home care patients is a problem. Patients with reduced functional ability and patients fixed in their ways cannot or will not contact and tell the FP about their problems. In order to stay in charge of the medical treatment it is not enough to meet the patient, the FPs have to rely on information from and collaboration with the DNs. We find that it is equally important to support further research in order to develop this collaboration and the criteria for family medicine in home care medical treatment [111].

Relying on and collaborating with the DN

Not only did the FPs have problems getting good enough insight through the consultations with the patients, the patients could not handle the treatment and had complex problems where both investigation and treatment and compliance were problematic, making it hard to make adequate decisions. Therefore it was essential to be able to rely on and collaborate with the DNs [111].

The FPs had to rely on the DNs for information and to be alerted when there was a problem. They also had to rely on assessments and close observation in combination with follow-up of the patient's condition and treatment, and finally they had to rely on the DNs for help with the treatment. These tasks are described in the delegated role of the nurse to 'help the patient utilise the physician's help', and in descriptions of the work of the DNs, which include clinical observations and assessments and working both independently and in cooperation with the others in the health care team [69, 70, 72, 111].

However, the FPs' expectations when relying on the DNs goes beyond this and might be a result of how the FP and DN roles regarding home care patients have developed over time. The change in health care in the past few decades has resulted in more advanced medical treatment in home care with less time for health promotion. Before these changes, home care was largely handled independently by the DNs. This may have influenced both FPs and DNs to expect DNs to handle many aspects related to home care today as well [2, 71].

In the FPs' descriptions of collaboration with the DNs we find that FPs also relied on the DNs to keep in contact with the other care providers, coordinating the care and

mediating information between the FP, the patient and the other care providers. Judging by the number of contacts with other caregivers that the DNs had during one week, coordination of care and contact with other care providers must be seen as another main task of the DNs. In comparison to home care in other countries, the roles of the FPs and DNs seem to resemble those in Canada or the USA more than those in the UK, i.e. with a relatively large amount of responsibility placed on DNs to coordinate much of this complex care [87, 110, 112].

National studies have shown that DNs were increasingly less satisfied with their collaboration with FPs regarding home care patients, while they consider other forms of collaboration with FPs to be good and unchanged [121]. Many of the changes in the Swedish health care system, mentioned in the background, may have contributed to this as other studies have found that FPs handle this increased workload by shifting tasks to the nurses [3]. However, it could also be because the increased work load results in lack of time for collaboration and home visits, as we found [112]. The dissatisfaction of the DNs is in contrast to the experience expressed by the FPs in these studies. They expressed that the ability to rely on collaboration was essential in home care medical treatment and most of them were satisfied with this collaboration.

5.3.4 Medical conductor or medical consultant

Conditions for taking the role as medical conductor

To stay in charge of home care medical treatment, the FPs need working conditions that allow them to take the role of medical conductors when necessary. They have to be able to allocate time for being updated about the patient's complex condition in order to plan future medical treatment instead of just handling the problem of the day and the most urgent matters. However, the increasing workload means that FPs are rarely able to practice medical care of the elderly as they wish [57, 112].

Having time and routines for home visits as well as for meetings or other forms of contact for discussions and care planning with the DNs was also important. First, there must be routines allowing the FPs to know who the home care patients are, for whom the FPs have to rely on collaboration with the DNs. Second, there is a need for routines to secure the transfer of information and knowledge about who is responsible when there are organisational boundaries and reorganisation. Third, new routines have to be instigated as there is a change towards more advanced treatments in home care resulting in a greater need for FP participation in the medical treatment. Finally, new routines to secure the conditions for collaboration with the DNs are necessary due to the transfer of home care by DNs to the municipalities. The abovementioned organisational changes in the healthcare system, in addition to changes transferring care from the hospitals to the PHC in a situation when there is a shortage of FPs, have increased the FPs' workload and can explain why the routines are sometimes still insufficient [2, 3, 29, 35-41, 111, 112].

The attitude towards being a conductor or a consultant differed, not only with the type of disease, but also with the interviewed FPs' attitudes towards retaining or leaving the initiative to the DNs. The WONCA description of family medicine describes a conductor rather than a consultant (table 1). However, the shift from 'planned' to 'on-

demand' care in PHC may have paved the way for FPs as consultants. When home care patients can no longer manage to contact their FPs the initiative is transferred to the DNs. Being a consultant in the situation when there were adequate grounds for relying on the DNs could be one way of making efficient use of health care resources [38, 39, 43, 111].

The medical consultant an effective use of resources

The FPs saw home care patients who have complex problems on average only twice a year and less often than other patient of comparable age. This can be one way of making efficient use of healthcare resources in a situation with a shortage of FPs, if they can rely on information and collaboration with the DNs who visit the patients regularly and assess their conditions. The FPs can stay in charge of the medical treatment, make efficient use of healthcare resources and secure good enough conditions for providing medical treatment as a medical consultant. But only in a) situations when the FPs feel that it is adequate to leave the initiative to the DNs and b) if they know that it is adequate to rely on the DNs. In order to know that, they have to know that the working conditions of the DNs are such that there are adequate grounds for relying on them including when FPs and DNs work in different organisations which is common today [2, 26, 29].

The FPs in this study usually said that they could rely on collaboration with the DNs if the DNs had the right working conditions. This is in contrast to studies of the DNs' experience of collaboration in the multi-professional PHC of today reporting that DNs feel that their work is dominated by the physicians' medical agendas when working together. This might have negatively influenced their attitude towards collaboration [71, 124]. Thus FPs have to be aware of the DNs' attitudes towards collaboration and if FPs' and DNs' views on medical treatment agree. A lack of inter-professional knowledge concerning other care providers' strategies can negatively influence collaboration and the FPs' abilities to know if there are adequate grounds for relying on the DNs. Many of the FPs had collaborated with the DNs for a long time, which should facilitate that type of awareness. However, others worked with new DNs, with DNs in a separate home care organisation or with short-term substitutes without formal training, which would make it more difficult. Interdisciplinary team-building exercises, meetings and regular face-to-face contacts have been found to be essential for integrating physicians into home care services. But many FPs in our study stated that it was not possible to take time to plan future treatment together; only the most urgent matters could be handled. This meant that an essential factor for getting to know each others' expectations and strategies was missing [76, 78, 84, 86, 112].

Interactions and expectations in collaboration with DNs

The home care situation resembles that in a hospital ward with many different care providers participating in the care of a single patient making collaboration necessary. However, conditions for collaboration are very different in these settings. With treatment taking place in the home of the patient, the care providers' workplaces located in different places and organisations, lack of common meeting places and responsibility for prescribing medical treatment divided among many hands, collaboration in home care is much more difficult than in a hospital ward. Evaluation of a shared-care concept for FPs and DNs with guidelines, clarifying of roles and

accountabilities, showed a positive effect for the patients and on acute service costs [79]. Active collaboration between FPs, nurses and social workers for home care patients reduced FP visits, hospital care and maintained health status of the patients [80]. Thus active measures to develop the conditions for collaboration are important for the care and treatment of home care patients.

The many care providers participating in the care of a single patient makes collaboration necessary, much in same way as it is necessary in a hospital ward. Therefore, it is tempting to look to collaboration in the hospital ward for ideas on how to develop collaboration in home care. We find that FPs rely on getting information about follow-up and assessments of the DNs, of discussions and sometimes joint decisions concerning problems in home care medical treatment and also of being able to leave the initiative to the DNs when there were adequate grounds for this [111, 112]. In sharp contrast to this, according to the literature, nurses in hospital wards stated that it was hard to get time to present their knowledge of the patients when decisions concerning further treatment were made during ward rounds. [125, 126]. Differences in how the roles and expectations are seen by physicians and nurses in the collaboration in a hospital ward also causes problems and other studies advocated mutual discussions to change this situation [127-129]. Therefore, ideas about collaboration from the hospital wards have to be used with care and with awareness, when transferring them to PHC. Studies of how the DNs in the PHC feel show a different picture than at the hospital ward, but the DNs still feel dominated by the FPs' medical agendas when they collaborate [71, 124]. This thesis presents the FPs' points of view showing that FPs expect a very independent role of the DNs in their collaboration but also that there is no time for discussions that would clarify for DNs and FPs how they see each other's roles. This is necessary if DNs and FPs are to know each other's expectations in the collaboration [111, 112].

Making adequate decisions about complex conditions

The home care patients had complex medical conditions or a combination of medical and other types of problems, making adequate decisions about investigation and treatment difficult. These decisions include treatment when there were side effects of the medicine, how aggressively to investigate and treat when patients were approaching end of life, when to change the direction to palliative care, medical treatment of patients with both medical problems and alcohol abuse or reduced cognitive ability [111]. This is in agreement with FPs finding the multiple pathology of older people complex and threatening, and their symptoms not always being explainable by medical science [57]. Inter-professional consultations with the DNs were used both to get information and to discuss how to handle difficult situations [112]. No FP mentioned discussing this with fellow FPs at the HC, which is a method advocated by the FP organisations for collegial support in understanding and learning from difficult situations [130]. Only one per cent of the FP notes in study I referred to direct consultations with a physician in specialised care [110]. In the literature examples we found how the implementation of protocols and guidelines for difficult situations can facilitate and enhance the quality of the medical treatment, how support teams or the possibility for inter-professional telephone consultations could have the same effect, e.g. when there were ethical problems, patients with Alzheimer's disease, or a need for palliative care. These studies show different ways to meet the problems encountered by the FPs in our study [7, 64,

65, 76, 81]. Maybe such methods of meeting the problems could also replace some of the many visits made to physicians in specialised care at the hospital [108].

6 CONCLUSIONS

Due to the complex problems of home care patients, the FP's consultation with the patient cannot provide the usual foundation for decisions. They have to be able to rely on information and collaboration with the DNs in home care medical treatment, much like the physician and nurse collaboration in a hospital ward. FPs rely on DNs assessing, closely observing and following up condition and treatment, providing treatment, coordinating care and supplying information from other care providers. The complex conditions of the patients makes it difficult for the FP to make adequate decisions about the goal of the medical treatment. Therefore, information from the follow up of the DNs is crucial as the goal has to be constantly evaluated based on this information. The working conditions and attitudes of the DNs and the disease influence whether there are adequate grounds for the FP to rely on the DN.

FPs can take the role of medical conductors who retain or medical consultants who leave the initiative in the home care medical treatment to the DN. What role FPs take is influenced by their working conditions and attitudes and the disease. One FP can take different roles concerning different diseases. Conditions for providing home care medical treatment can be seen as good enough if there are adequate grounds for relying on the DN and as problematic if they are inadequate regardless of the role of the FP. To stay in charge of the medical treatment FPs must have working conditions that allow them a) to take the role of conductor when adequate grounds for relying on the initiative of the DNs do not exist and b) as consultants to be able to know if adequate grounds for relying on the DNs exist. Today's working conditions often make it difficult to take the role of conductor or to plan future care and treatment so as to get to know if there are adequate grounds to rely on the DNs.

Home care medical treatment takes place at home but is shaped by decisions made by FPs at the HC and the physicians at the hospitals. Many DNs' and FPs' measures take place between visits and not in the patient's home. The situation resembles that of a hospital ward, where many different care providers and many different professions are involved in the care of the same patient. However, home care does not have the ward's geographical, organisational and temporal unity. FPs having to rely on information from the DNs to gain sufficient insight for medical decisions gives rise to questions concerning how the physicians in specialised care can gain sufficient insight during isolated outpatient visits. The situation ought to influence how home care medical treatment is defined and organised and requires routines to support it, time for collaboration and for all care providers to know when they are responsible.

7 FUTURE RESEARCH

To confirm the results reported here, new studies must be made in other areas with different conditions, such as in rural areas. Further research is needed to test the relevance in other situations affecting the FPs' abilities to stay in charge of home care medical treatment and collaboration between FPs and DNs. More studies are needed in different contexts to explore how common the factors are that we have identified as influencing collaboration. Also, more studies are needed to better understand the characteristics of the role of the FP in home care medical treatment.

It is urgent to study the situation with problematic conditions for providing medical treatment due to inadequate grounds for relying on the DNs, especially when FPs as consultants are not aware of that situation. A more multifaceted study design is needed for this. It would also be of interest to explore home care medical treatment and the collaboration from the perspective of the patients and the DNs, and simultaneously from the three different perspectives.

There are studies concerning care at home. It would be of interest to study the experience of patients, FPs and DNs and the effect of home care medical treatment when the comprehensive care of home care patients, the support of collaboration among the care providers and the support for difficult and complex conditions are arranged in different ways.

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9 SUMMARY IN SWEDISH

SAMMANFATTNING PÅ SVENSKA

9.1 BAKGRUND

På grund av minskade vårdplatser på sjukhus och allt fler äldre, med ökade sjukvårdsbehov, i befolkningen har kravet på basal hemsjukvård ökat. En nationell studie av hemsjukvård som Socialstyrelsen nyligen genomförde visade att allt fler patienter får hemsjukvård och det har också skett en utveckling mot allt mer avancerade hälso- och sjukvårdsinsatser. De framgick också att tillgången till läkare och sjuksköterskor i hemsjukvården i många fall inte är tillräcklig i förhållande till de krav som utvecklingen i hemsjukvården ställer. Samtidigt har olika reformer lett till ändrade och mer komplicerade förutsättningarna för samverkan mellan DSK och DL när det gäller just patienter med basal hemsjukvård. När studierna i den här avhandlingen startade saknades kunskap om dessa patienters samlade vård. Tidigare studier av hemsjukvård var begränsades till den vård som ägde rum i patientens hem. En försvårande omständighet för studierna i den här avhandlingen var att det saknas en enhetlig definition av basal hemsjukvård. I studierna har 'home care by district nurses' dvs. vård i hemmet av distriktssköterskor använts angående basal hemsjukvård och detta är också kriteriet för urval av patienter till studierna. Tidigare studier har funnit att patienter med vård i hemmet samtidigt ofta har flera olika sjukdomar och funktionsproblem. Historiskt har DSK arbetat mer självständigt men arbetar sedan flera decennier mer integrerat i den multiprofessionella primärvård som nu finns. Det har bland annat inneburit ökad samverkan med DL bland annat rörande hemsjukvårdspatienter. Samtidigt har ökningen av hemsjukvård lett till ökade krav på samverkan med kommunal hemtjänst. Kunskapen om DL's behandling av dessa patienter är emellertid bristfällig. Studier har visat att DL gör få hembesök, DL kan uppleva äldre patienters multipla patologi som komplex och ibland skrämmande samtidigt som en ökande arbetsbelastning inneburit att de sällan haft möjlighet att sköta deras vård som de skulle vilja. Sverige har brist på DL i primärvården samtidigt som utflyttningen av vård från sjukhusen lägger ökat ansvar på DL, inte minst för patienter i basal hemsjukvård.

9.2 MÅLSÄTTNING

Den övergripande målsättningen med denna avhandling var att skapa ökad klarhet angående patienter med basal hemsjukvård, deras problem och samlade vård, samt DL's erfarenhet av att ge medicinsk behandling till patienter med basal hemsjukvård.

9.3 MATERIAL OCH METODER

Avhandlingen innehåller en kvantitativ och en kvalitativ studie. Den kvantitativa studien omfattar en tredjedel (116) av alla patienter med basal hemsjukvård i en Stockholmsförort, 1996. Information om patienterna, deras problem och deras samlade vård samlades in från olika källor. I den kvalitativa studien har grundad teori använts och data insamlats med semistrukturerade intervjuer med 13 DL angående en patient som hade basal hemsjukvård, samt dennes behandling.

9.4 RESULTAT

En typisk patient med basal hemsjukvård var en äldre ensamboende kvinna som hade flera olika sjukdomar i kombination med nedsatt funktionsförmåga. Många olika vårdgivare var inblandade i patienternas samlade vård, som inkluderade både anhöriga, hemtjänst, primärvård och sjukhus. Flera olika läkare var ofta inblandade. Patienterna besökte oftast DL på vårdcentralen, i medeltal två gånger per år, men alla patienter träffade inte sin DL under ett år. Många DL åtgärder, som förskrivningar och remisser för undersökningen, vidtog utan att DL träffade patienten. Patienternas problem påverkade DL's förmåga att bibehålla kontrollen över den medicinska behandlingen. Patienter med nedsatt funktionsförmåga kunde inte och patienter som ville försöka klara sig utan hjälp ville inte ge DL tillräcklig information och många kunde inte sköta sin egen behandling. DL var tvungen att förlita sig på att DSK, som träffade patienterna varje till varannan vecka, försåg dem med information och hjälpte patienten med medicinsk hemsjukvårdsbehandling. När patienterna hade komplexa tillstånd eller vägrade följa de rekommendationer de fick var det svårt att fatta beslut om målet för den medicinska behandlingen. DL var tvungen att förlita sig på noggrann uppföljning och bedömning av DSK för att få information som kunde utgöra underlag för konstant omvärdering av målsättningen. DSK's arbetsförhållanden och attityd samt sjukdomen påverkade om det var adekvat att förlita sig på DSK eller ej. DL kunde ta rollen som medicinsk ledare och behålla initiativet, eller rollen som medicinsk konsult och överlämna initiativet i den medicinska behandlingen till DSK. Samma DL kunde inta olika roll i olika situationer. Vilken roll DL valde eller tvingades anta var beroende av deras arbetsförhållande och attityd samt sjukdomens art. Oavsett vilken roll DL valde så var förutsättningarna för att ge medicinsk hemsjukvårdsbehandling tillräckligt bra om det var adekvat att förlita sig på DSK och problematiska om det inte var adekvat.

9.5 SLUTSATSER

På grund av hemsjukvårdspatienternas problem kan patientens konsultation inte, som den brukar, utgöra tillräckligt underlag för DL's beslut om behandling. De är tvungna att kunna förlita sig på information och samarbete med DSK i den medicinska hemsjukvårdsbehandlingen. Som medicinska ledare, upptäcker DL när förutsättningarna för medicinsk hemsjukvårdsbehandling är problematiska på grund av att det inte är adekvat att förlita sig på DSK. Som medicinska konsulter kan de inte upptäcka det eftersom de inte får information av DSK. För att bibehålla kontrollen över den medicinska hemsjukvårdsbehandlingen som konsulter, måste deras arbetsförutsättningar vara sådana att de vet om det är adekvat att förlita sig på DSK eller ej. Arbetsförutsättningarna måste också vara sådana att de tillåter dem att ta rollen som medicinsk ledare när detta krävs. Den samlade vården påminner om den på en vårdavdelning med många olika vårdgivare som deltar i de enskilda patienternas vård. Det kräver samverkan men den basala hemsjukvården saknar vårdavdelningens geografiska, organisatoriska och tidsmässiga sammanhållande faktorer. Problem uppstår när arbetsförutsättningarna är sådana att det saknas tid och rutiner för att DL ska kunna ta ansvaret och för tydlig ansvarsfördelning och samverkan i medicinsk hemsjukvårdsbehandling.

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