Intensified Primary Health Care for Cancer Patients

Utilisation of Medical Services

BY

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ABSTRACT


The aim of the present thesis is to evaluate the effects of an Intensified Primary Health Care (IPHC) intervention on GPs’ and home care nurses’ possibilities to monitor and support cancer patients, and on cancer patients utilisation of medical services. A further aim is to identify determinants of cancer patients’ utilisation of such services. A total of 485 patients newly diagnosed with breast, colorectal, gastric or prostate cancer were randomised to the intervention or to a control group. The follow-up period was 24 months for all patients.

Patients randomised to the IPHC were referred to the home care nurse. The home care nurse and the GP received copies of the medical record each time the patient was discharged from hospital after a period of in-patient care, or had visited a specialist out-patient clinic. In addition to this, recurrent education and supervision in cancer care were arranged.

The IPHC resulted in a marked increase of home care nurse follow-up contacts. The majority of control patients (74%) reported no such contacts, while 89% of IPHC patients reported this. High age (≥80 yr) was the strongest predictor within the IPHC group for reporting a continuing home care nurse contact. Furthermore, the IPHC increased GPs’ knowledge about patients’ disease and treatments, and appeared to facilitate their possibilities to support the patients. The IPHC reduced the utilisation of specialist care among elderly cancer patients. The number of days of hospitalisation for older patients (≥70 yr) randomised to the IPHC were 393 less than for older control patients during the 3 first months after inclusion. Regression analyses defined diagnosis, extensive treatment, comorbidity, low functional status, pain and socio-economic factors as predictors of a high utilisation of medical services.

Key word: Cancer, home care services, general practitioner, utilisation of medical services, prediction.

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“This is not the end. It is not even the beginning of the end. But it is, perhaps, the end of the beginning.”

Winston Churchill
This doctoral theses consists of the present summary and the following papers, which are referred to by their Roman numerals.


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INTRODUCTION

Trends in the Swedish Health Care Organisation

A strong ambition of Swedish health care authorities during the last decades has been to increase patient utilisation of primary health care and reduce the utilisation of specialist care (1). According to the Swedish Health and Medical services Act (SFS 1982:763, 5 §), responsibilities of the primary health care are defined as follows:

“Primary care as a part of out-patient care shall, with no restriction as to illness, age or patient categories, cater to the need of the population for such basic medical treatment, nursing, preventive work and rehabilitation as do not require the medical and technical resources of hospitals or other special competence.

The county council shall organise primary care in such a way that everybody living within the county council area will have access to and be able to choose a permanent medical contact. Such a physician shall have specialist competence in family medicine. (SFS 1995:835)”

Increased investments in the primary health care sector and implementation of several important reforms during the nineties, such as the Ädel Reform and the Family Doctor Act, have been the means to achieve this.

The Ädel Reform

The Ädel Reform, implemented in 1992, aimed to facilitate the possibilities to co-ordinate and improve the care of the elderly and disabled, thereby reducing the utilisation of specialist inpatient care (2). The reform stated that the municipalities should have the statutory responsibility for all types of institutional housing, nursing homes and care facilities for the elderly. The municipalities were also made responsible for the health care for the elderly within these institutions. Furthermore, the municipalities were offered the possibility to take over the home care services, and about half of them did so. The reform stated that the municipalities are financially responsible for long-term institutional care, including patients regarded as “bed blockers” in acute somatic hospital care and geriatric clinics. In an evaluation performed 1996 it was revealed that the problem of “bed-
blockers” had diminished and that the number of special housing alternatives for the elderly had increased (2).

*The Family Doctor Act*

The investments in the primary health care sector have also resulted in an increasing number of GPs within this sector (3). During the period from 1986 to 1996, the number of inhabitants per GP decreased from 3 109 to 2 370. Correspondingly, the proportion of outpatient visits to GPs increased from 39 to 42 per cent from 1991 to 1996. Nevertheless, in 1995 Sweden was still the country in Europe with the smallest proportion of GPs per specialist (0.25 GP per specialist). The Family Doctor Act was implemented in January 1994. The aim was to improve the continuity and accessibility of care and thereby reduce the need for other specialist care. The act states that all Swedish residents should have the possibility to choose a personal GP (1). Before the reform, GPs were responsible for a specific county district, and not for specific patients. In September 1994, about 81% of the population had chosen a family doctor. The reform was abolished already by mid-1995 by a new government, partly due to problems in establishing co-operation with other caregivers in the community, such as nursing homes for the elderly. However, for those who prefer such an arrangement, it is still possible to choose a personal GP, and a substantial part of the population in Uppsala county are still registered within this system.

Examples of other strategies to increase utilisation of primary health care services are to engage GPs’ as consultants at specialist clinics, and to facilitate the transfer of patient care from such clinics to the primary care sector (3). Another example is that specialists from the Department of Oncology at the Uppsala University Hospital are engaged as consultants at several primary health care centres in the county (4).

Despite these efforts to facilitate an increase of the utilisation of primary health care services, several evaluations performed during the nineties have identified problems with regard to the co-operation between the home care sector, GPs and specialist clinics (1-3, 5). A main problem is that the routines for exchanging information between the organisations are deficient. There is also a need for improved co-operation between caregivers in cases where the responsibility for the care of the patient is transferred between the sectors. Furthermore, increased involvement of physicians in
home care activities is warranted, and improvement and development of staff training programs, especially for home care staff is needed. Thus, there is still a need to improve the possibilities for the primary health care sector to take a greater responsibility for medical services in Sweden.

Similar conclusions have been drawn in a recent international review of 20 (quasi-) experimental studies (published between 1982 and 1998) evaluating innovations in the nursing care of chronically ill patients (6). According to a categorisation based on the availability of primary care and the supply of specialist secondary services, Sweden was defined as a country oriented towards secondary health care together with Canada and the USA. Comparisons were made with the Netherlands (with a supply of both primary and secondary health care at an average level), and the UK and Ireland (focusing more on primary health care). The authors concluded that there is an ongoing process of integration between generalist and specialist services in all the countries. Three kinds of innovations were identified, “advanced nursing practice”, “hospital-at-home innovations” and innovations in an “integrated care setting”. Only one Swedish study (7) (described below) was identified, included in the “integrated care setting” group.

Literature review

The purpose of the literature review is to provide a background to the Intensified Primary Health Care intervention, evaluated in this thesis. Thus, it serves to illuminate patient needs and desires for a co-ordinated care (including home health care), obstructive and facilitative factors related to such care, and to illuminate the effects of co-ordinated care. The selection of studies included in the review is based on methodological considerations such as random selection of the study population in descriptive studies, and/or a reasonable high response rate, and a clearly presented study design. The review of studies evaluating the effects of interventions to increase the involvement of the primary health care sector in medical services is restricted to controlled, prospective studies. A further aim is to present studies from various countries to provide an international perspective.

*Feasibility of and needs for improved co-operation between health care sectors, and post hospitalisation home health care*

A national survey of British hospital patients’ (n=5 150) experiences of care provided data suggesting a need for improved discharge planning (8). Patients were interviewed 2-4 weeks after
discharge with detailed questions regarding what happened during their stay in hospital, covering subjects from pre-admission to discharge planning. A majority of the patients reported a lack of information about appropriate foods (73%), appropriate activities (60-62%) and of information about warning signs to look for (70%). These results indicate a need for follow-up after hospital discharge, provided by hospital staff or by primary health care personnel.

A study from the USA estimated the effect of post hospitalisation home health care on patients (n=2 127) functional status (activities of daily living and instrumental activities of daily living) (9), as compared to their status before hospitalisation. Use of home health care was defined as the total Medicare payment for such services for each patient, six months after hospital discharge. As expected, home health care users were older and had a poorer baseline function compared to non-users. However, the results also suggest that home health care users experienced greater improvements in functional status compared to non-users. The authors concluded that limitations of the access to home health care may result in a poorer health outcome for subgroups of patients.

Continuity of care is one important argument for the increased investments in the Swedish primary health care sector (1). Gill and Mainous (10) examined the association between continuity of ambulatory care and future hospitalisation in a Medicaid population (n=13 495) during a two-year period. Continuity of ambulatory care was assessed for each patient during the first year and hospitalisations were studied the second year. Ambulatory care visits were defined as face-to-face encounters with physicians, nurse practitioners or physician assistance. Provider continuity was measured by a continuity index ranging from 0 (each visit to a different provider) to 1 (all visits to the same provider). Hospitalisation was defined as a dichotomous variable reflecting whether or not each patient had an acute inpatient hospital admission. The results indicated that higher continuity of ambulatory care during the first year was associated with a lower likelihood of hospitalisation. This was true also after controlling for other predictors of hospitalisation such as age, disability and number of ambulatory visits.

Addington-Hall and McCarthy (11) conducted an interview survey in England of significant others (n=2 074 of 2 915) to a random sample of people who had died from cancer. The interview schedule covered the last year of life and included questions about symptoms and symptom control, sources of informal and formal care, the deceased’s use of and the respondent’s satisfaction with
several sources of care including community nursing, and GP services and information from and communication with health professionals. Fifty-five per cent of the deceased spent less than one month in hospital during the last year and only 10% spent more than three months. Sixty per cent had received care from a district nurse, but 31% were reported to have needed more help with activities of daily life than they received. Eighty-seven per cent rated the help and care given by district nurses as excellent or good. Eighty-one per cent of the deceased saw their GP within one month of death and 28% of respondents thought it would have been helpful if the GP had visited more often at home. Overall, 72% of the respondents rated the care received by GPs as excellent or good. Thus, the study suggests that the utilisation of inpatient care was low, and that a majority of the cancer patients did receive care from district nurses as well as from GPs, and that these services were regarded as proficient. Nevertheless, according to a substantial proportion of the respondents the need for home care was not satisfied.

Terminally ill cancer patients’ preferences for the place of final care were assessed by Townsend et al. (12). Patients who were expected to die within a year were interviewed monthly or at two-week intervals if expected to live less than 2 months. Their main carer was interviewed 3 months after the patient’s death. Eighty-four of 98 randomly selected patients agreed to be interviewed, and a structured questionnaire was used. Patients’ view of her/his illness was sought, and they were also asked about the availability and use of a variety of health and social services, medication and activities of daily life. In addition, quality of life, level of pain and other symptoms were assessed. Furthermore, they were asked about their plans and requests for future care, and if they were content with their present place of care. If the initial questions did not elicit information about the preferred place of death, further questions were posed such as “And if your illness gets worse, were would you like to be?” Only answers with an unambiguous response were included in the analysis. Fifty-nine (84%) of the 70 patients who died during the study expressed their preference for place of death, given the existing circumstances. Thirty-four (58%) preferred to die at home, 12 (20%) in hospital, and one elsewhere. The corresponding figures given more ideal circumstances were 41 (67%) at home, 10 (16%) in hospital and 9 (15%) in hospice. Seventeen (94%) of 18 who died at home also preferred this place of death, whereas 22 (69%) of those who died in hospital had stated a preference to die elsewhere, of whom 11 would have preferred to die at home. Also, of 18 relatives to patients dying in hospital, who stated an opinion on where the patient had died, 5 would have
preferred to care for the patient at home. The conclusion was that 50% more cancer patients could be supported to die at home with increased resources in community care.

These results are confirmed in an evaluation of the Hospital Based Home Care (HBHC) of Motala, the first palliative home care programme in Sweden (13). The aim of the programme was to provide an alternative to hospital care for those patients who preferred to be cared for in their own home. To achieve this, the patients were provided with all resources of the hospital (“a hospital bed in the patient’s own home”), and access to a 24-hour professional home care service (nurses and a physician). Patients were guaranteed help within 30 min. from a telephone call. In a 10-year evaluation of the programme, data were collected from the medical records of all patients (n=179, mean age=70 yr, range 2-91 yr) admitted to the HBHC during the period 1977-1986. Analysis revealed that a majority of the patients were admitted from acute clinics (70%), and that the main reason for admission was a wish to live at home until death (81%). Also, 89% of those patients who wished to live at home until death actually did so.

Slevin et al. (14) investigated British cancer patients’ attitudes to different sources of emotional support. The aim was to find out what kind of support patients would choose if all sources were freely available, and to rate patient satisfaction with support systems already used. Patients (n=431 of 575) were asked to determine how likely it was that they would use different sources of information ranging from media, support groups (self-help groups, groups led by health care professionals, weekend seminars) and individuals (health care professionals and non-medical people such as family, friends, other patients). They were also asked if they had used these sources. Satisfaction with a source was rated by analysing data from those patients who had used a source and whether they indicated that they would definitely use that. The patients’ family (73%) and cancer specialists (63-73%) were rated to be the most important sources of emotional support. The satisfaction with such support was also high (around 80% ). Also, GPs were regarded as an important source of emotional support. Overall, 43% of the patients would definitely use GPs. The corresponding proportion of those who already had used such support was 63%. The proportion of patients who would definitely use community nurses (overall about 25%) was only marginally larger than the proportion of those who would use sources such as psychiatrists, psychologists, chaplains/priests and social workers (overall 15-20%). The corresponding number for those who had already used such support was about 60% for community nurses and 30-50% for remaining
sources. Doctor-led and nurse-led groups were perceived to be the most important sources of group support. The patients were also asked to make a single choice as the most important source of emotional support from a list were all sources were divided into five categories: doctors, nurses, support group, information and family/friends. Doctors were rated as the most important source, family/friends as the second, and nurses as the third. In conclusion, doctors and nurses (including GPs and community nurses) are suggested as more suitable sources of emotional support than other professional sources. Furthermore, support from family/friends was perceived as highly important, which indicates the significance of patients’ possibilities to reside in their own home.

A Dutch study aimed to evaluate the usefulness of continuity visits of community nurses after hospital discharge, and to describe the kind of care needs reported by cancer patients (15). One hundred and twelve (33%) of 337 patients received a first, 50 a second and 24 a third visit. Patients diagnosed within the last 6 months, older patients and those lacking social support more often agreed to receive a continuity visit. Ninety-three per cent of those who received a first visit mentioned one or more physical, psychological or social problems. Most physical problems were found in the “activity-exercise” area, including fatigue and impaired physical mobility. Nutrition problems such as lack of appetite, nausea and weight loss were reported by almost 30%. A major part (70%) also mentioned a need for information. Fifty-three per cent wanted to know more about their illness and the treatment, 21% were interested in the possibilities of home care, and were concerned about how to manage their household activities. Both patients and nurses evaluated the first visit positively. The conclusion was that an offer of continuity visits to cancer patients can be useful.

Mor and colleagues (16) investigated determinants of need and unmet need for assistance with activities of daily living (personal care, household activities and transportation) among US patients with advanced cancer (n=629 of 1 004), who were initiating a course of chemo- and/or radiation therapy. More than half of the patients reported need for assistance with household activities (51%) and transportation (58%), and 14% for help with personal care. Factors associated with need for assistance were stage of disease, functional status, old age (>65 yr) and low income. Thirty-three per cent of patients reporting need for help with household activities reported insufficient help. The corresponding proportion for those needing help with transportation was 16 per cent. Factors associated with unmet needs were morbidity (restriction of daily activity), low income, no children
living nearby, and low confidence in the ability of social networks to provide care. The findings highlight the importance of appropriate assessment of patient symptoms and impairments, and of informal care resources, in order to achieve reliable decisions about who should be referred for home care services.

Oberst and James (17) studied post-discharge crisis following cancer surgery in the USA. Patients and their spouses (n=40 pairs) were interviewed repeatedly with regard to health concerns, self-appraisal, work, finances, etc. Data collection took place 1-2 days before discharge and at 10, 30 and 60 days post discharge. The results revealed that 33-40% of the patients had difficulties carrying out self-care tasks within two months from discharge. Furthermore, almost all patients (95%) reported symptom distress 10 days after discharge and this was also true for 75% at 60 days. Patients as well as spouses were affected by symptom distress. Their incidence of illness and somatic complaints started to escalate between 30 and 60 days after the patients’ hospital discharge. The conclusions were that there is a need for improved discharge preparation and for active follow-up care for both patients and their significant others.

A review of the literature between 1980 and 1991 concerning strategies for improvement of continuity of care for cancer patients (18) yielded the conclusion that the need for care remains at a high level for several cancer patients also after hospital discharge, but that the care given or arranged is limited. The authors concluded that standard care routines for discharge planning are insufficient. Also, there is a need for increased outpatient follow-up including referrals to home care agencies to secure the continuity of care for cancer patients. Thus, routines in standard care were identified as factors obstructing collaboration between health care sectors, thereby limiting continuity of care for cancer patients.

**Collaboration between different health care sectors: Obstructive and facilitative factors**

Grunfeld and colleagues (19) investigated 252 British cancer specialists’ (postal questionnaire) and 180 GPs’ (standardised interview) views of follow-up of patients with breast cancer in remission. Both groups indicated that routine follow-up by themselves was the most preferred system (70% and 69%, respectively). Sixty-nine per cent of the GPs considered that they had the necessary skills to do the follow-up, whereas only 25% of the specialists did so. However, a majority of GPs (58%)
also agreed that GPs required further training in order to perform routine follow-up of their breast cancer patients. A larger proportion of GPs (82%) than specialists (25%) thought that GPs have a better position for providing psychosocial support to their patients, compared to hospital breast clinics. On the other hand, a majority of the specialists (79%) agreed that hospital follow-up is important because it provides psychosocial support to the patient, whereas only 18% of the GPs did so. Thus, the study identified disagreements between specialists and GPs concerning the feasibility of routine follow-up in general practice compared to routine hospital follow-up.

Wood and colleagues (20, 21) conducted qualitative studies with Canadian family physicians (n=26, focus group interviews) and oncologists (n=10, in-depth interviews). The aim was to explore the process of cancer patient follow-up and to elicit family physicians’ perception of their role in the remission stage of cancer. Both studies identified barriers to communication and collaboration between oncologists and family physicians. Family physicians were dissatisfied with the specialists’ failure to assign them a specific role in follow-up care (20). Furthermore, the identification of which oncologist to talk to regarding a specified patient was recognised as a problem. Moreover, lack of information about discharge and follow-up plans, and inability to access information about guidelines for follow-up were identified as additional barriers. Poor communication was identified as a key issue in the collaboration between specialists and family physicians. The oncologists viewed family physicians as variable and unpredictable in their interest and commitment to cancer care, and noted the difficulty to become acquainted with the large number of family physicians within their catchment area (21). Furthermore, the oncologists complained about a lack of information from family physicians about what happened to the patient between the visits to the cancer centre. The oncologist also expressed a feeling that family physicians may convey a negative attitude to patients regarding cancer treatment.

In a Danish study, oncologists and GPs were interviewed together in focus groups (2 groups with 2 oncologists and 4 GPs/group) regarding the care of cancer patients (22). Both obstructive and facilitative factors for collaboration were identified. Facilitating factors were a shared view of the problem and its solution among GPs and specialists, a willingness to co-operate and a willingness to dialogue and to exchange of information. Obstructive factors were the GPs’ limited knowledge about cancer treatment and prognosis, the oncologists’ lack of confidence regarding the GPs
competence to care for cancer patients, and a lack of knowledge within both groups regarding the other group’s tasks and abilities.

The attitudes towards GPs and primary care among British senior house officers (SHOs) in accident and emergency departments were investigated by Dale and colleagues (23). Questionnaires were sent to all newly appointed SHOs in 27 departments in the South Thames region at the end of the first and 6th month of their attachment. They were asked to respond to statements (100 mm visual analogue scale) about the quality of GP services in their area, and their attitudes toward treating primary care patients in the accident and emergency department. One-hundred-and-four (61%) of 170 SHOs responded to both questionnaires. The results revealed that negative attitudes toward GP services and treatment of patients with primary care needs were established early among the SHOs. Furthermore, the overall trend was that attitudes became more negative during the SHOs tenure at the department. Statements scored most negatively were those concerning GP accessibility, perception of patient satisfaction with GP services, GP education of patients about use of services, and the frustrations in and lack of reward for treating primary care patients. The authors concluded that the SHOs’ negative attitudes toward GP services may result in care that is more hospital focused, and that these issues need to be addressed to improve the quality of the interface between primary care and accident emergency departments.

An Australian study (24) explored referring physicians preferences regarding the content of letters from the consultant physician after a new patient consultation. Ninety-five (88%) of 108 referring physicians (including 49 GPs) completed a questionnaire concerning the preferred contents of such letters. Furthermore, the content of actual letters (n=94) from medical oncologists to the patients’ GPs were analysed, together with the contents of letters to the patients from the same oncologists. The results suggest that the letters sent by the consulting oncologist were not well tailored with regard to the information preferred by the referring physicians. However, the content of the patient letters seemed to be more in agreement with these preferences.

A Swedish study examined how GPs (n=204 of 295) and cancer specialists (n=48 of 66) assessed the importance of 17 aspects of information about cancer management (25). They were asked to estimate how important they deemed the 17 information aspects to be in a discharge letter from the specialist clinic to the GP. They were also asked to assess how important these items were
perceived to be by their counterparts in the other health care sector (primary health care vs. specialist hospital care). The results revealed that overall, the GPs (especially females) rated the items higher than the specialists. The differences were most pronounced regarding caring and psychosocial dimensions. Further, GPs deemed specialists to be more interested in technical items and less in psychosocial items compared to themselves, whereas specialists deemed GPs to have a view similar to their own. The conclusion was that the differences between GPs and specialists may reflect different professional strategies in cancer management and thereby constitute an obstacle for collaboration in cancer care.

Specialists have also been shown to play an important role in the dissemination of information to family physicians. Cullen (26) conducted structured interviews with GPs (n=34) concerning their use of various sources of information. The three main sources were identified to be textbooks, colleagues (in their own practice), and specialists in private practice or based at hospital. Thirty-three of the family physicians turned to specialists for information at least once a week, and the specialists was also the source of information with which the family physicians were most satisfied.

*Interventions to increase the involvement of the primary health care sector in medical services.*

The Southampton Integrated Care Project (SHIP) (27) evaluated the effectiveness of a programme for co-ordination and support of follow-up care of myocardial infarction and angina in general practice. The intervention aimed to co-ordinate secondary preventive care through improved communication between hospital and general practice, and by encouragement of general practice nurses to provide structured follow-up. Sixty-seven practices were randomised to the intervention or to a control group. The intervention was led by three specialist cardiac liaison nurses, who were responsible for the transfer of responsibility of patient care between hospital and general practice, and for the support of practice nurses. This support comprised telephone contacts and visits to each practice every 3-6 months. Furthermore, practice nurses were encouraged to participate in initial training on behavioural changes, and an ongoing support group with the aim to tackle their information needs. Five-hundred-and-ninety-seven (87%) of 686 patients admitted to hospitals due to a myocardial infarction, or seen in a chest pain clinic due to angina of recent onset, agreed to participate in the trial. Patients were followed at 1 and 4 months and 1 year after recruitment. The one-year assessment included questions about life style factors, medication, attendance at
rehabilitation courses, use of health services, current symptoms, psychological state and quality of life. Furthermore, patients were assessed clinically including a walking test, measurement of blood cotinine and repeated measurements of baseline variables (Body Mass Index, blood pressure, serum total cholesterol). The intervention resulted in an increased proportion of patients attending a rehabilitation session, and in an increase of the number of consultations with the general practice nurse. However, there were no statistically significant differences between the intervention group and the control group with regard to the outcome measures. The conclusion was that simply co-ordinating and supporting existing health care services is insufficient to improve health outcomes in this diagnostic group.

The Grampian Asthma Study of Integrated Care (GRASSIC) (28) aimed to evaluate integrated care of asthma in clinical, social and economic terms. In 1989, an integrated care scheme was implemented for patients with asthma regularly attending outpatient chest clinics in the North East of Scotland. Chest physicians reviewed patients in this scheme annually, using a computer-based patient record system and interim reviews took place in general practice. Patients were sent computer generated questionnaires from the chest outpatient clinic at the time of the review, inviting them to make an appointment with their GP, and asking for information about symptoms, use of oral steroids, utilisation of GPs, and hospital admissions. They were asked to give the completed questionnaire to their GP at the consultation. Simultaneously, the patient’s GP was sent a computer-generated questionnaire about the patients pulmonary function, medication and utilisation of medical services. The GP returned both documents to the consultant and the information is added to the computerised patient record. Copies of the updated record were sent to the GP together with eventual suggestions for management changes. Patients receiving conventional care were seen at their regular outpatient clinic and during the study period, and this group of patients was sent a questionnaire before each visit, to be returned to the specialist. Seven-hundred-and-twelve patients were eligible for randomisation, 363 were assigned to integrated care and 349 to conventional care. The evaluation at 1 year did not suggest that type of care was associated with any of the clinical or psychosocial outcomes. Patients who had experienced integrated care saved about forty pound a year compared to those in conventional care. This was explained by the fact that patients in the latter group utilised GPs services to the same extent as the former, but in addition visited the chest outpatient clinic. Patients assigned to integrated care were also more likely to select such care as their preferred course of future management, compared those assigned to conventional care.
Stewart and colleagues (29) examined the effect of a home-based intervention for patients with chronic congestive heart failure in Australia. The primary endpoint was frequency of unplanned events plus out-of-hospital death within six months. In addition to standard care, patients assigned to the intervention received a structured home visit by a cardiac nurse 7-14 days after hospital discharge. During this visit, the nurse assessed the patient with regard to her/his clinical status (symptoms, physical function etc.), compliance with the treatment regime, use of available community-based resources, extent of psychosocial support, and understanding of disease process. Further interventions were decided on after this initial assessment. If required, patients could also be referred to the primary care physician for medical treatment. In all cases, the patients’ primary care physician and the cardiologist were provided with a detailed report of the home visit. If necessary, the nurse could initiate changes within the treatment regime after consultations with the physicians. Additional home visits were made only in cases were the patient had two or more unplanned admissions within six months. However, the nurse contacted all patients by telephone at 3 and 6 months. Two-hundred (70%) of 285 clinically eligible patients were randomly assigned to the intervention (n=100) or to a control group (n=100). The 6 month follow-up revealed that patients in the intervention group remained event-free to a larger extent than control patients. Overall, there were fewer unplanned readmissions and associated days of hospitalisation among intervention compared to control patients. This reduced utilisation of hospital resources also resulted in a reduction of hospital costs (490 300 Australian $ compared to 922 600 A$).

Furthermore, at 3 months the intervention group had significantly improved quality of life scores compared with standard care patients. However, at 6 months, quality of life scores were the same for the surviving patients in both groups.

The aim of an Italian study was to evaluate the effect of an integrated social and medical care programme among frail elderly people living in the community (30). Main outcomes were admission to an institution, use and related costs of health services, and physical and cognitive function. All people ≥65 year, living in the town of Rovereto in 1995, who were recipients of home health services or home assistance were identified. Two-hundred (89%) of 224 agreed to participate and were randomly assigned to an intervention or a control group. The control group received primary and community care within the conventional organisation of such services. The intervention group received case management and care planning by a community geriatric
evaluation unit (including a geriatrician, a social worker, and several nurses) in co-operation with 21 of 24 GPs, who had agreed to participate in the trial. All intervention patients were assessed by a case manager soon after randomisation and every 2 months thereafter. The case managers were constantly available to deal with problems, to monitor the provision of services, and to guarantee extra help as requested. Patients were evaluated with regard to symptoms of depression, cognitive function, and personal and instrumental activities of daily living. The assessment also included a complete list of diagnoses, drug treatments and the number of home visits provided by GPs. The evaluation at 1 year revealed that the proportion of patients who were admitted to hospital, nursing home or emergency room was smaller in the intervention group than in the control group. Furthermore, the intervention group had improved physical function and a reduced decline of cognitive status compared to the control group. The estimated financial savings in the intervention group were in the order of 1 800 US $ per year.

The effects of follow-up of breast cancer patients in general practice compared to hospital follow-up was evaluated by Grunfeld et al. (31). Main outcome measures were time from first presentation of symptoms to the confirmed diagnosis of recurrence, quality of life and anxiety and depression. Two-hundred-and-ninety-six (66.5%) of 445 eligible patients agreed to participate and were randomised between continued routine follow-up in outpatient clinics (hospital group) and routine follow-up by their own GP (general practice group). A total of 115 GPs had at least one patient allocated to the intervention. The GP received a discharge letter from the hospital consultant outlining the patient’s breast cancer history and describing the recommended follow-up routines. The GP was also assured that rapid referral was possible if any problem developed and an educational handbook on breast cancer follow-up accompanied the letter. Clinical data were collected prospectively by the doctors for all patients at all breast cancer related consultations. Health-related quality of life was assessed at baseline, mid-trial (6-12 months) and at the end of the trial (18 months). During the study period, 26 women presented with a recurrence of breast cancer. In most cases (n=18), the woman herself identified an abnormality and presented it between routine visits. The results showed no differences in time from symptoms to confirmed recurrences of breast cancer between the hospital group and the general practice group. Neither were there any differences between groups in quality of life, or in levels of anxiety and depression.
The effects of co-ordinating services available for terminally ill cancer patients and their families within the British National Health Services (NHS), local authorities and the voluntary sector were investigated by Addington-Hall and colleagues (32). All patients received routinely available services. In addition, the co-ordination group received assistance by two nurse co-ordinators, whose role was to ensure that the patients received a well co-ordinated services, tailored to their individual needs. To prevent diffusion of the intervention between groups, general practices in the trial district were randomly allocated to the co-ordination or the control group. Cancer patients expected to live for less than a year who were residents within the trial area were allocated to co-ordinated care or standard care depending on the general practice with which they were registered. Independent interviewers, who were not informed about which group the patient were in, interviewed patients at baseline at home, and at different intervals (follow-up) until death or the end of the trial. The interview interval depended on the severity of the disease as assessed by the Spitzer Quality of Life index. Also, carers were interviewed at follow-up and eight weeks after bereavement. A total of 554 patients entered the trial, of whom 281 (51%) received a baseline interview, of whom 203 (72%), 104 in the co-ordination group and 99 in control group, had at least one follow-up interview. A total of 118 carers (58%) were interviewed at least once and 94 were interviewed after the bereavement. There were only small differences between the groups with regard to patient quality of life and satisfaction with care. Co-ordination group patients were less likely to report itchy skin symptoms and to suffer from vomiting. They were also more likely to report effective treatment of the latter problem. Their carers were less likely to rate patients’ swallowing difficulties to be severe or to report effective treatment of anxiety. They were also more likely to contact a specialist nurse in a night time emergency, and less likely to feel angry about the patient’s death.

Subsequent analysis compared the cost-effectiveness of the intervention with standard services (33). Data regarding inpatient care (hospital and hospice), outpatient attendance, specialists referrals and home care visits were collected from patient records. Data on contacts with GPs were collected through the patient interviews. Complete service use and outcome data were received for 86 (83%) of the 104 in the co-ordination group and for 81 (82%) of the 99 control group patients, included in the of quality of life and care satisfaction analysis. The co-ordination group used significantly fewer inpatient days and nurse home visits. Also, the mean cost per co-ordination group patient was almost half of that of control group patients. These differences persisted even if comparisons were made only for deceased patients, in order to control for putative differences in disease severity.
between the groups. The conclusion was that co-ordinated care was more cost effective than standard care, since the same outcomes were achieved at a lower use of services.

An intervention programme, “transmural care”, was implemented in the Netherlands (34), offering terminally ill cancer patients specially tailored care, provided by caregivers from primary care and hospital teams. It was hypothesised that the improved communication, co-ordination and continuity of care achieved through this intervention would reduce re-hospitalisation. The design of the study was quasi-experimental, i.e. patients living in Eindhoven were allocated to the intervention group whereas patients living in the surrounding areas constituted the control group. The intervention consisted of four main components. 1) A specialist nurse co-ordinator who prepares the necessary patient discharge arrangements (co-ordination of professional services) on request from the treating specialist. 2) A 24-hour telephone service, manned by nurses from an oncology ward, which can be reached by a direct line should problems arise at home. If medical questions arise, a specialist consultant can be contacted using this service. A copy of the patient’s home care dossier containing all medical and nursing details is at hand. 3) If nursing problems can not be solved by the primary care team, support can be provided by trained nurses from a hospital-based home care team. 4) A home care dossier is used, including an informed consent form, a list of all caregivers involved in the care, discharge reports for those involved in the care of the patient (GP, community nurse and others), a medication list, a dietician’s report, and a multidiciplinary report were caregivers report main findings and changes in treatment/care plans. Main outcome measures were days of hospitalisation until death and quality of life. A total of 79 patients were included in the intervention group and 37 in the control group. The results revealed that the intervention lead to a statistically significant reduction of days of hospitalisation for the intervention group compared to the control group. The quality of life assessment suffered from an extensive drop-out and only a minor portion of the patients (n=45, 39%) could be evaluated in this respect. The results suggest that the intervention contributed positively to patients' “physical” quality of life at 1 month after hospital discharge. A subsequent report (35) investigated the costs of the home care intervention and compared them to those of the control group. Data were collected on costs covered by health care insurance companies (physicians’ aid, physical therapy, hospital admission, hospital day treatment, transportation and medical aid supplies), costs for community nursing (intensive community nursing, community nursing, home help) and costs for the intervention programme. Complete sets of data could be retrieved for 57 of 79 intervention patients and for 29 of 37 control patients. There
were no significant differences in total health care costs. However, pharmaceutical and re-
hospitalisation costs were significantly lower for the intervention group whereas costs for community nursing and home help services were higher than in the control group.

The literature search has identified only one controlled, prospective Swedish study, evaluating an intervention to increase the involvement of home care nurses and GPs in the care of cancer patients. Häggmark and Nilsson (7) conducted a quasi-experimental study in which 52 of 71 invited patients treated due to an advanced cancer disease were assigned to either an improved discharge planning group (n=28) or to a control group (n=24). The intervention meant that district nurses and GPs were informed about a patient in connection to the patients’ second treatment. They also received a copy of the patient’s medical record. Furthermore, both district nurses and GPs were invited to a discharge planning meeting at the hospital. At this meeting, they received additional information regarding the patient’s disease and treatment, and about the hospital-based oncology consulting team, to which they could turn for support in the care of the patient. Also, the patient was informed about available services provided by the GPs and the district nurses. Outcome measures included frequency of re-admissions to hospital, of problems causing re-admissions and of treatments prescribed for such problems. The analysis did not reveal any differences between the groups.

Summary of the literature review

There is substantial documentation of the needs for improved discharge planning routines, improved follow-up after hospital discharge and for increased home care facilities (8, 11, 13, 15-17). This is true not only for cancer patients, but for a variety of diagnostic groups. The results of several studies also suggest that high continuity of ambulatory care, and increased involvement of the primary health care sector, e. g. GPs and home care nurses, aiming for improvement of such services is feasible and well tailored to patient preferences. This is so, particularly for those who prefer to reside at home during the course of their illness (9-13, 15). Evaluations of controlled interventions aiming to improve collaboration between health care sectors and/or to increase GPs’ and home care nurses’ involvement in medical services have been found to reduce the need for inpatient care and the costs for health care services (28-30, 32-35). However, no study has been identified in which newly diagnosed cancer patients in all stages were randomly assigned to an
intervention aiming to improve home care nurses’ and GPs’ possibilities for patient monitoring and support, and for taking a greater responsibility in the care of such patients.

Some studies also suggest that such interventions may result in an increased patient quality of life (29, 30, 34), while others suggest no differences between the comparison groups in this respect (7, 27, 28, 31, 32). One explanation for this lack of differences in longitudinal studies based on patient self-reports, is the well-recognised problem of a substantial drop-out, due to patient death or severe stages of illness (32, 34). The result is an insufficient power and thereby reduced possibilities to identify differences. It should be noted that there are no indications that interventions aiming to increase involvement of the primary health care sector in medical services result in a deterioration of medical outcomes or patient quality of life.

Despite the well-documented opinion that improved co-operation between health care sectors may improve quality of care and decrease health care costs, several barriers to achieve this have been identified. The lack of routines for exchanging of information and for dialogue between health care providers is a key component in this matter (20, 21, 24, 25). There is also a lack of knowledge regarding assignments and abilities of counterparts in the different health care sectors (22, 23, 31). It is possible that an increased dialogue and exchange of information between the sectors may be a solution to this problem. Furthermore, GPs express a need for further education in cancer care (22, 31). This need can be met partly by increased collaboration, since specialist physicians have been identified as an important information source for GPs (26). Some studies also identify specific factors that may facilitate collaboration, such as a willingness to co-operate and to participate in dialogue and exchange of information (22).

The literature review revealed that a number of different terms are used to describe similar interventions: “integrated care” (30), “transmural care” (34), “multidisciplinary, home based intervention” (29) and “co-ordinated care” (32), all aiming to improve health care services by a co-ordination between health care sectors. This fact has made it difficult to identify studies appropriate for inclusion in the review. Thus, it is possible that the presented review lacks important studies due to a lack of agreement about the terminology. “Co-ordinated” care is the term chosen for in the present thesis.
The health care sector in Uppsala county includes specialist clinics at the Uppsala University Hospital and at the Enköping Hospital, and, during the project period (presented below), at the Samariterhemmet Hospital in Uppsala. The Ädel reform meant that, starting in 1992, the six municipalities within Uppsala county took on responsibility for the institutional housing, the nursing homes, the basic home care services, and in Uppsala municipality, also for the advanced home care services. These responsibilities also include the employment of nurses, assistant nurses and occupational therapists within such health care activities. However, the Ädel reform does not comprise health care provided by GPs. Thus, general practices and care centres including GPs, district nurses, physiotherapists and the child welfare centres remained as a responsibility for the county council (2).

An illustration of a co-ordinated health care system in Uppsala county is presented below (Figure 1). The illustration is based on the conclusions from the presented evaluations of the Swedish medical services and on the literature review. The focus of the illustration is the patient and her need/desires for a co-ordinated care. The arrows indicate routines for exchange of information and dialogue, components identified as facilitators of a co-ordinated health care system. The definitions of dialogue and information are adopted from The Concise Oxford dictionary (36). Dialogue is defined as: “discussion directed towards exploration of a subject or resolution of a problem” (p. 395). Information is defined as: “facts or knowledge provided or learned as a result of research or study” (p. 727). The need for routines for exchange of information between the different parts of the health care sector have been identified as essential for a co-ordinated care. Also, a continuing dialogue have been identified as a prerequisite for achieving knowledge regarding information needs, assignments and abilities of counterparts in the different sectors. Thus, sufficient routines for information exchange and dialogue between health care sectors facilitate the transfer of responsibility for patient care between them. Such an improvement facilitates the dialogue between patients and health care staff as well as staff possibilities to meet patient need for information. Consequently, the possibilities increase to fulfil patient needs for care, at home as well as in the specialist clinic. The illustration will be used as the basis for a critical examination of the Intensified Primary Health Care intervention, evaluated in this thesis.
Figure 1. An illustration of a co-ordinated health care system in Uppsala county. D = dialogue, I = information exchange.
The Support – Care - Rehabilitation project

The “Support - Care - Rehabilitation”- project was conducted in Uppsala county between October 1993 and December 1997, and the present thesis is based on parts of data from that project. The aim of the project was to investigate the effects of two types of interventions for cancer patients. The interventions were designed to detect, prevent and attend to psychosocial problems and nutritional difficulties. Furthermore, the aim was to develop a co-ordinated model of cancer care, characterised by increased continuity of care based on improved possibilities for home care nurses and GPs to monitor and support cancer patients. Patients were randomised between four groups. 1) Individual support (IS), starting at diagnosis. 2) Group rehabilitation (GR), starting approximately 4 months after diagnosis. 3) A combination of IS and GR. 4) Standard Care (SC). Patients included were newly diagnosed with prostate cancer, colorectal cancer, gastric cancer or breast cancer, or under examination for a suspected breast cancer. The follow-up period was 24 months for all patients.

Individual Support (IS)

The IS included three types of support:

(1) **Intensified Primary Health Care** (described in detail below).

(2) **Individual Psychological Support (IPS)** meant that all patients were contacted by a project psychologist. Current problems as defined jointly by the patient and the psychologist were the focus of the intervention. Techniques used were derived from cognitive behaviour therapy, including relaxation, identification and challenging of negative automatic thoughts, activity scheduling and daily planning (37). If no problems were identified, the contact was terminated, but the patient could call the psychologist, should problems arise. The IPS has been described in detail elsewhere (38).

(2) Patients with colorectal or gastric cancer also received **Nutritional Support (NS)**. A dietician made a dietary assessment (24-h recall) as soon as possible after diagnosis. After the interview, the dietician gave nutritional advice both immediately and after calculation of dietary intake. When needed, patients received prescriptions for supplements and nutritional enrichment. All patients were followed regularly during a period of two years. The NS is described in detail by Persson et al. (submitted).
Group rehabilitation (GR)

All patients randomised to this intervention were invited to participate in a group rehabilitation, led by an oncology nurse, a psychologist and a physiotherapist. The GR started approximately four months after diagnosis. It comprised 8 weekly sessions and one booster session after 2 months. Each session included two parts, one consisting of light physical training and relaxation, and one focusing on information (by physician or dietician), or training in techniques for handling anxiety, problem solving, distraction etc., based on the principles of cognitive behavioural therapy. The GR has been described in detail elsewhere (39).

Diagnoses

Breast cancer

Breast cancer is the most common cancer among Swedish women (40). About 5 800 women are diagnosed yearly with a malignant tumour in the breast. The corresponding figure for Uppsala county is about 160 cases a year. Breast cancer is rare before the age of 40 but about 50% of the women are diagnosed before the age of 65. Early detection of the tumour is essential for good prognosis, and the five-year relative survival among patients with a stage-I breast cancer is 90-100% (41). The most important prognostic factors are the number of positive axillary lymph nodes and the size of the tumour. In Sweden, virtually all women are treated surgically and many of them undergo breast-conserving surgery. A major goal of this technique is a cosmetically more acceptable result. The surgery is commonly combined with adjuvant radiotherapy to assure local tumour control. In addition to surgery and radiotherapy, women with a more advanced disease (stages II and III) are recommended adjuvant drug (systemic) therapy. This may include chemotherapy, antiestrogen or a combination of those. The duration and combination of systemic drugs depend on the stage of the disease. Preoperative therapy is generally given in locally advanced disease, often considered inoperable. In metastatic disease, both chemotherapy and hormone therapy may provide palliation.

Prostate cancer

Prostate cancer is the most common cancer disease among Swedish men (40). Almost 6 000 men are diagnosed yearly with a malignant tumour in the prostate and the corresponding figure for Uppsala county is about 200 cases a year. Prostate cancer is rare before the age of 55 and about 50% of the cases are diagnosed before the age of 70. The prognosis of clinically localised prostate
cancer is generally good, with a five-year survival ranging from about 65% to over 90% regardless of treatment (radical prostatectomy vs. surveillance) (41). There is still no consensus regarding the “treatment of choice” for patients with small localised tumours (<T3). An alternative curative treatment option for localised tumours is a combination of internal and external radiotherapy. Metastatic spread to lymph nodes is associated with a poorer prognosis and the chance for cure is limited. However, the time to progression varies and for patients with minimal metastases, it may be extended to several years. Hormonal therapy is the choice of treatment for advanced prostate cancer. This can be done either chemically or by surgical removal of the testes. When the tumour has become refractory to hormones, the tumour is generally unresponsive to most therapies.

Colorectal cancer

Colorectal cancer is the most common gastrointestinal cancer in Sweden (40). About 5 000 persons are diagnosed yearly with a malignant tumour in the colon or rectum, and the corresponding figure for Uppsala county is about 130 cases a year. Colorectal cancer is rare before the age of 55 and only about 35% of the cases are diagnosed before the age of 70. The prognosis at the earliest stage is good with a five-year survival exceeding 90% (41). Also, patients with regional lymph metastases may be cured, and overall relative 5-year survival is about 50%. However, to-day there is no cure for patients with distant metastases and the expected time of survival is less than 6 months. The only curative treatment for colorectal cancer is surgery. Some patients with colon cancer receive adjuvant postoperative chemotherapy, and rectal cancer patients often get preoperative radiotherapy to decrease the risk of recurrence.

Gastric cancer

The incidence of gastric cancer in Sweden is decreasing (40). About 1 200 persons are diagnosed yearly with a malignant tumour in the stomach and the corresponding figure for Uppsala county is about 30 cases a year. Gastric cancer is most common among the elderly and 65% of the patients are >70 years at diagnosis. The only curative treatment option is surgery and the five-year survival rate is high (70-95%) for small localised tumours (T1) (41). However, only 30-50% of surgically treated patients have a potentially curative resection. Thus, a large proportion of gastric cancer cases are diagnosed in an advanced stage of the disease and the possibilities for cure are limited. The prognosis for patients with distant metastases is poor and most die within six months.
AIMS

The overall aim is to evaluate the effects of the Intensified Primary Health Care intervention (IPHC) on GPs’ and home care nurses possibilities’ to monitor and support cancer patients, and on cancer patients’ utilisation of medical services. Comparisons are made between patients randomised to the IPHC (IS or ISGR) and patients randomised to standard primary health care follow-up (GR or SC). A further aim is to identify determinants of cancer patients’ utilisation of medical care services.

Research questions were:

− Does an IPHC intervention improve home care nurses’ possibilities to monitor and support cancer patients?
− To what extent does an IPHC intervention affect cancer patients’ utilisation of home care services 6 months after diagnosis, compared to patients with standard home care follow-up?
− Which factors affect cancer patients’ utilisation of home care services 6 months after diagnosis?
− How do cancer patients evaluate the home care nurses’ follow-up contacts?
− Does an IPHC intervention improve GPs’ possibilities to monitor and support cancer patients compared to GPs in standard care?
− To what extent does an IPHC intervention affect cancer patients’ utilisation of GP services 6 months after diagnosis, compared to patients with standard GP follow-up?
− To what extent does an IPHC intervention affect cancer patients’ utilisation of specialist care within 2 years from diagnosis, compared to patients with standard home care nurse follow-up?
− Which factors at diagnosis predict cancer patients utilisation of specialist inpatient care 2 years after diagnosis, and to what extent does information about survival affect the predictive power of such factors?
− Which cancer patients should be identified at diagnosis as having a potentially increased need of medical services, and thereby be recognised as candidates for referral to home care services?
METHODS

Patients
A series of consecutive patients was approached. They were newly diagnosed with prostate cancer (n=242), colorectal cancer (n=169), gastric cancer (n=54), or breast cancer, or under examination for a suspected breast cancer (n=337). Exclusion criteria were a need for constant hospital care (Karnofsky performance status, KPS <40), an earlier cancer diagnosis, inability to communicate in Swedish, and for patients with localised prostate cancer (T1-2, N0, M0), participation in an ongoing randomised trial. Patients who were found to have a benign breast tumour after inclusion (n=42) were excluded from all analyses in the present thesis (not eligible). Patients meeting inclusion criteria were approached by a research nurse as soon as possible after they had been informed of their diagnosis. Inclusion took place at all the three hospitals within Uppsala county with surgical and/or oncological wards. Of eligible patients (n=760), 224 (76%) with breast cancer, 105 (62%) with colorectal cancer, 37 (68%) with gastric cancer, and 119 patients (49%) with prostate cancer were included. Thus, totally 485 eligible patients agreed to participate, using a procedure approved by the local Research Ethics Committee. Seventy-three (n=73, 10%) of the eligible patients were not approached due to uncertainty about the correct diagnosis or administrative failure. A total of 202 patients (26%) rejected participation and the most common reasons for this was “no interest in participation” (n=80) and “too far to travel to participate” (n=51).

Randomisation
Patients were randomised by an independent oncological statistics centre (computer generated allocation schedule) to one of four alternatives: 1) Individual Support (IS), starting at diagnosis; 2) Group Rehabilitation (GR), starting 4 months after diagnosis; 3) a combination of Individual Support and Group Rehabilitation (ISGR), and 4) Standard care (SC). An exception was made for those colorectal and gastric cancer patients who were judged to suffer from a non-curable disease at inclusion (expected survival <6 months). Those patients were randomised only between IS and SC (no rehabilitation condition). Randomisation was stratified for diagnosis and stage of disease. Background data were collected from the medical records for all patients included in the analysis (Table 1).
### Table 1. Baseline demographic and medical characteristics of the study sample, n=481*.

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<td>6 (21)</td>
<td>8 (26)</td>
<td>7 (23)</td>
</tr>
<tr>
<td>N-stage&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N0</td>
<td>4 (0)</td>
<td>3 (21)</td>
<td>1 (33)</td>
<td>2 (13)</td>
</tr>
<tr>
<td>N1</td>
<td>1 (0)</td>
<td>11 (79)</td>
<td>1 (33)</td>
<td>10 (67)</td>
</tr>
<tr>
<td><strong>Curative surgically resection</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4 (100)</td>
<td>3 (21)</td>
<td>2 (67)</td>
<td>5 (33)</td>
</tr>
<tr>
<td>No</td>
<td>1 (0)</td>
<td>1 (79)</td>
<td>1 (33)</td>
<td>10 (67)</td>
</tr>
<tr>
<td>Not surgically treated&lt;sup&gt;c&lt;/sup&gt;</td>
<td>0 (0)</td>
<td>2 (14)</td>
<td>0 (0)</td>
<td>3 (20)</td>
</tr>
<tr>
<td><strong>Recurrence or new cancer within 24 month</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>6 (27)</td>
<td>8 (28)</td>
<td>10 (45)</td>
<td>7 (23)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>6 (27)</td>
<td>10 (34)</td>
<td>10 (45)</td>
<td>9 (29)</td>
</tr>
<tr>
<td><strong>Treatment in addition to surgery</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>15 (13)</td>
<td>25 (19)</td>
<td>10 (10)</td>
<td>27 (21)</td>
</tr>
</tbody>
</table>

<sup>a</sup> of 485 included patients were excluded from all studies. <sup>b</sup>No breast cancer patients with clinically distant metastases at inclusion <sup>c</sup>T-stage undefined for 5 breast cancer patients, 21 gastric cancer patients and 5 prostate cancer patients <sup>d</sup>Including cancer in situ, n=17, <sup>e</sup>N-stage undefined for 24 breast cancer patients, 20 gastric cancer patients and 77 prostate cancer patients<sup>f</sup>Patients with distant metastases.
The Intensified Primary Health Care (IPHC) intervention

The IPHC was implemented as one part of the IS intervention, evaluated in the “Support-Care-Rehabilitation”-project. The aim was to develop a co-ordinated cancer care model, characterised by increased continuity of care, through improved possibilities for home care nurses and GPs to monitor and support cancer patients. Several new routines were implemented to increase information exchange and to facilitate the dialogue between patients and health care staff, but also between the involved health care sectors.

Referral to the home care nurse

All patients randomised to the IPHC were asked to give their permission to be referred to the ordinary home care nurse, responsible for the district where the patient lived. Patients with colorectal and gastric cancer who were judged to suffer from a non-curable disease, and who lived in Uppsala municipality were referred to the advanced home care services. All home care nurses were contacted by telephone and informed about the patient’s diagnosis, treatments, and GP, and that the patient had agreed to home care nurse follow-up contacts. The nurses were provided with a home care dossier including a care planning document, a home care report and a symptom check list, developed in co-operation with oncologists responsible for the included diagnostic groups. For hospitalised patients, the home care nurse was contacted at discharge by the nurse responsible for the patient during the hospital stay. A total of 222 newly diagnosed cancer patients were referred to 90 different home care nurses (range of patients per nurse =1-7) during the period from October 1993 to December 1995. The frequency, timing, duration and contents of the follow-up contacts were decided jointly by the home care nurse and the patient. Two years after diagnosis, the project group collected a copy of the home care dossier for all patients. After the implementation of the Family Doctor Act (Sep. 1994), the patient’s personal GP was informed about the cancer diagnosis, treatments and the referral to the home care nurse. However, the IPHC intervention did not initiate GP follow-up contacts, why any initiatives to this had to be taken by either the GP or the patient. A total of 83 GPs were informed about the cancer diagnosis and the home care nurse referral regarding 134 patients (range of patients per GP =1-6).
The extended information routine

An Extended Information Routine (EIR) was implemented in the sense that GPs and home care nurses received copies of the medical record each time the patient was discharged from the specialist clinic after a period of inpatient care, or had visited the specialist outpatient clinic. Written permission for this procedure was obtained from the patient, who agreed to have such copies sent to the GP and home care nurse. This routine was sustained for each patient during a period of two years. In practice, these arrangements were organised as a co-operation between the project group and the medical secretaries. The secretaries took copies of those medical records that were marked with a particular logotype and the project group administered the copies to the patient’s GP and home care nurse.

Education in cancer care

Education in cancer care was arranged during the course of the trial. GPs and home care nurses were invited to initial seminars before patient inclusion (April to October 1993). At these seminars, the project was presented and nurses and GPs were educated in diagnostics and treatments of the cancer diagnoses, as well as in medical aids, pain, nausea and diet management, psycho-social support and care in the final stage of life. In addition, a booklet called “Oncology care”, including chapters on these subjects was developed and distributed to all attendees. After the initial seminars, home care nurses, GPs and 2 nurses from each specialist ward were invited to seminars on education in cancer care at least twice a year. Lecturers were mainly specialists (oncologists, surgeons, anaesthesiologist, specialist nurses, hospital priest and occupational therapist) from the Uppsala University Hospital and from the project group (specialist nurses, dietician, psychologists and physiotherapist). Group discussions were arranged on these occasions to encourage dialogue between personnel from the specialist clinics and the primary health care sector. A further aim of the group discussions was to elicit staff suggestions for further education seminars and their opinions about the project activities. A total of 12 different seminars were arranged on 27 occasions during a period of three years (Table 2). Also, 10 study visits to the radiotherapy department were arranged during this period.
Table 2. Education in cancer care

<table>
<thead>
<tr>
<th>Month and year</th>
<th>Seminar (Nr. of occasions)</th>
<th>Number of attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>GPs</td>
</tr>
<tr>
<td>April-June 1993</td>
<td>Initial seminar series for GPs (1)</td>
<td>31</td>
</tr>
<tr>
<td>August-September 1993</td>
<td>Joint 1/2-day initial seminar (3)</td>
<td>40</td>
</tr>
<tr>
<td>September-October 1993</td>
<td>Initial 2-day seminar for nurses (5)</td>
<td>130</td>
</tr>
<tr>
<td>November 1993</td>
<td>Joint 1-day seminar (2)</td>
<td>11</td>
</tr>
<tr>
<td>April 1994</td>
<td>Joint 1-day seminar (2)</td>
<td>7</td>
</tr>
<tr>
<td>October 1994</td>
<td>Evening seminar for GPs (3)</td>
<td>19</td>
</tr>
<tr>
<td>November-December 1994</td>
<td>Joint 1-day seminar (2)</td>
<td>5</td>
</tr>
<tr>
<td>1994-1995</td>
<td>Study visits to the radiotherapy department for nurses (10)</td>
<td>41</td>
</tr>
<tr>
<td>April-May 1995</td>
<td>Joint 1-day seminar (2)</td>
<td>2</td>
</tr>
<tr>
<td>April-May 1995</td>
<td>Evening seminars for GPs (1)</td>
<td>13</td>
</tr>
<tr>
<td>May-June 1995</td>
<td>Evenings seminar for nurses (2)</td>
<td>44</td>
</tr>
<tr>
<td>October-November 1995</td>
<td>Joint 1-day seminar (2)</td>
<td>5</td>
</tr>
<tr>
<td>March-April 1996</td>
<td>Joint 1-day seminar (2)</td>
<td>7</td>
</tr>
</tbody>
</table>

Supervision in cancer care

All home care nurses with patients randomised to the intervention were offered continuous supervision from an oncology team (the project group). The supervision was problem focused and aimed to support the nurse in dealing with the patient’s problems. A further aim was to secure that the nurse was informed about the patient’s diagnosis, treatments, impairments etc. The nurses were invited to participate in open supervision groups regularly. An oncology nurse (the author) lead the groups and was assisted by members of the oncology team i.e. dietician, psychologist, physiotherapist, urotherapist or a specialist nurse. A total of 55 supervision meetings were arranged at different places in Uppsala county during the project period. Nurses who did not participate in the supervision meetings were contacted by telephone regularly. All nurses had the possibility to
contact the oncology team, day time Monday to Friday every week during the project period. A nurse was contacted whenever a patient in her district was randomised to the intervention and a few weeks later for a first check-up. The extent of further supervision depended on the number of patients who were referred to a specific nurse and on the type of problems she had to deal with. The range of contacts between nurses and the oncology team was 4-26. Also, GPs were welcome to the supervision groups and to contact the project group when needed. However, the GPs initiated only occasional telephone contacts.

An illustration of the Intensified Primary Health Care Intervention

Figure 2 summarises information and dialogue routines implemented or facilitated through the IPHC intervention. The information routine from the specialist clinics to the GPs and home care nurses was implemented by the Extended Information Routine (I1 in Figure 2). The dialogue (D1) between these parties was facilitated through the increased contacts between specialists and GPs and home care nurses at several seminars arranged by the project group. The dialogue between home care nurses and patients (D2) was implemented by the follow-up contacts initiated through the referral to the home care nurse. This and the possibilities to provide patients with information (I2) was also facilitated by the home care nurses receiving increased information about the patients’ disease and treatments via the Extended Information Routine, education and supervision. The dialogue (D3) between GPs and patients, and the GPs possibilities to provide the patient with information (I3) was facilitated by the Extended Information Routine and cancer education, and by the patients’ knowledge that the GPs were informed. The dialogue (D4) between home care nurses and GPs was facilitated by their sharing information about the patients and by the joint education seminars. Furthermore, the GPs’ knowledge about the referral to the home care nurse constituted a facilitator here. Finally, the IPHC meant that a dialogue and information exchange routine were implemented (D5 and I5), mainly between home care nurses and the project group and to a lesser extent between the GPs and the latter.
Figure 2. An illustration of information and dialogue routines implemented or facilitated through the IPHC intervention.
Procedures

Collection of patient baseline data, Studies I, III and IV

Baseline data regarding quality of life, anxiety and depression, social characteristics and comorbidity were collected at inclusion before randomisation, for all patients. The patients were asked to respond to standardised questionnaires at home (>70%) or at the hospital, and in some cases in the project facilities. A large majority (>90%) of the patients completed the questionnaires on their own, but for patients who found this difficult due to a visual defect or for other reasons, there was always a possibility to be interviewed. Data on diagnoses, stages, treatments, age and living area were collected from the medical records.

Study I

All patients were surveyed with regard to their contacts with the home care nurse using a postal home care nurse questionnaire (HCN), 6 months after diagnosis. Comparisons were made between patients randomised to IPHC (ISGR+IS) and those randomised to Control (GR+SC).

Study II

A total of 20 GPs were selected for a semi-structured interview with open-ended questions about one specific patient per GP about 1 to 2 years after patient inclusion (mean=19.5 months, range 13-26). Ten of the GPs did receive extended information about this patient, and 10 did not experience this for any patient. All GPs agreed to participate, and the interviews were performed by telephone and audiotaped with one exception, which took place in the GP’s office and notes were taken. Content analysis was used to analyse the interviews. The audiotaped interviews were transcribed verbatim and carefully read through several times to determine variables, relevant to the aim of the study. The variables were constituted as nominal or ordinal scales, which could take on 2-5 values. Two independent raters categorised each interview into one category per variable and noted this on a separate rating sheet for each interview.
Studies III and IV

Data on patient utilisation of inpatient specialist care were obtained from the Uppsala County Council Patient Administration System. This register includes data from the three county hospitals where the study patients were diagnosed and/or treated. In Study III, analyses were made of visits to outpatient clinics and admissions for all reasons, from the day of inclusion in the project and the following three months. The length of stay was calculated for each admission as follows: The days of admission and discharge were counted as one day in all, but no days were counted if admission and discharge took place on the same day. The length of stay of each admission was summed to obtain days of hospitalisation per patient. Comparisons were made between patients randomised to IPHC (ISGR+IS) and those randomised to Control (GR+SC). In Study IV, analyses were made of admissions for all reasons, from the day of inclusion in the project and the following two years. The length of stay of each admission was calculated using the same procedure as in Study III.

Questionnaires

The Home Care Nurse questionnaire (HCN)

All patients were asked to complete the study-specific HCN questionnaire 6 months after diagnosis. This 18-item questionnaire was developed in co-operation with the home care nurses for the assessment of patients' contacts with the home care nurses and perceived benefits of these contacts. All patients reported the frequency of follow-up contacts with the home care nurse on a 6-grade scale (0 = no contact, 1 = one contact, 2 = occasional contacts, 3 = 1-2 times a month, 4 = once a week, and 5 = more than once a week). They were also asked if they still had contact with the nurse at the point of assessment (Yes or No). Patients randomised to the intervention were asked to rate on a category scale how they liked to be contacted (It was good that the nurse....., I didn’t mind being contacted..... felt unnecessary, I had preferred to take the contact myself) and to grade the appropriateness of the timing of the contact (too early, the right time, too late, I didn’t needed to be contacted). They were also asked to estimate to what extent the nurse gave them expected support (to a very large extent, to a large extent, in part, slightly, not at all), and to asses the perceived benefit of the contact.
with regard to nine different care aspects (medical services, medical services at home, medical aids, information and advice, disease-related dialogue, personal support, safety of care, provider continuity, in-hospital contacts) rated on a 4 grade scale (0=No benefit at all, 1=Some, 2=Much and 3=Very much). The possibility to judge an aspect as “Not appropriate” was also given. Finally, they were asked if they would recommend a contact with the home care nurse to a friend in the same situation (yes, perhaps, probably not, absolutely not). After the Family Doctor Act was implemented, a question about GP contacts was added for patients randomised between IPHC and standard care follow-up (No contact, Only during the period of diagnosis, Only during the period of treatment and follow-up, All the time since the first symptoms appeared).

The Hospital Anxiety and Depression Scale (HADS)

Anxiety and depression at inclusion were assessed by the HADS (42, 43). This is a fourteen-item self-assessment instrument consisting of two subscales, measuring anxiety (7 items) and depression (7 items). The patient is asked to rate the presence of problems during the last week on a four-grade scale from 0 to 3. The total score varies from 0 to 21 for both subscales. Two cut-off scores have been suggested, >7 to indicate patients with a potential need for further psychiatric investigation, and >10 for patients with a clinical level of anxiety/depression. The HADS has been used widely in research (42).

The Inclusion Questionnaire

An Inclusion Questionnaire was developed for the “Support-Care-Rehabilitation”-project. This was completed at project inclusion and included questions about comorbidity, normal and actual weight, marital status, highest level of education completed (elementary school-university), and yearly family income before taxes (an ordinal scale ranging from <70 000 SeK to >280 000 SeK). Furthermore, an earlier developed social interaction scale (44, 45) was included, as well as “The Göteborg Quality of Life Instrument” (46) including a symptom check list.
The EORTC QLQ-C30

All patients also completed the EORTC-QLQ C30 (version 1.0) (37) at inclusion. This is a widely used quality of life questionnaire, developed for cancer patients. Five functional scales are used to assess physical (5 items), emotional (4 items), cognitive (2 items) and social functioning (2 items). Three symptom scales assess fatigue (3 items), pain (2 items) and nausea/vomiting (2 items). An additional six symptoms (dyspnoea, insomnia, appetite loss, constipation, diarrhoea and financial difficulties) are assessed by single items. Also, a global health status scale is included (2 items). Responses are linearly transformed before analysis to a 0 to 100 range. A high score reflects a high functional status or a high level of symptoms.

Table 3. Patients included and withdrawn in Studies I, III and IV

<table>
<thead>
<tr>
<th>Study</th>
<th>n</th>
<th>ISGR</th>
<th>IS</th>
<th>GR</th>
<th>SC</th>
<th>Excluded after project inclusion</th>
<th>Dead/ Reject participation</th>
<th>Failed to complete measures</th>
<th>Sum</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>381</td>
<td>1</td>
<td>3</td>
<td>11</td>
<td>23</td>
<td>14</td>
<td>26</td>
<td>9</td>
<td>5</td>
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<tr>
<td>III</td>
<td>416</td>
<td>2</td>
<td>3</td>
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<td>6</td>
<td>6</td>
<td>8</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>IV</td>
<td>393</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>6</td>
<td>6</td>
<td>8</td>
<td>16</td>
</tr>
</tbody>
</table>

*a= Comparisons were made between patients randomised to IPHC (ISGR+IS) and those randomised to Control (GR+SC) in Studies I and III.

Table 4. Overview of questionnaires used in the different studies

<table>
<thead>
<tr>
<th>Questionnaires</th>
<th>Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I</td>
</tr>
<tr>
<td>HCN questionnaire</td>
<td>X</td>
</tr>
<tr>
<td>HADS</td>
<td>X</td>
</tr>
<tr>
<td>EORTC QLQ-C30</td>
<td></td>
</tr>
<tr>
<td>Inclusion questionnaire</td>
<td>X</td>
</tr>
</tbody>
</table>
Statistical analysis

Mann-Whitney U-tests were used to test differences between patients randomised to the IPHC and Controls regarding the frequency of contacts with the home care nurses. Chi-square tests were employed to analyse contact/no contact 6 months after diagnosis and to study IPHC patients’ satisfaction with the home care nurse contacts. Logistic regression models using the maximum likelihood function were used to analyse the association between different variables at diagnosis and having a home care nurse contact after 6 months.

The inter-rater reliability of the content analyses in Study II was determined by Kappa or percent agreement. When appropriate, Fisher’s exact probability test and the Mann-Whitney U-test were used to compare GPs who had experienced the extended information routine with those who had not. The Chi-square test was used to investigate if IPHC was related to patients’ GP contacts 6 months after diagnosis.

ANCOVA was used to analyse the effects of randomisation (IS/Control) and age (<70/≥70 yr.) on number of admissions, days of hospitalisation and number of visits to outpatient clinics 3 months after diagnosis. Adjustments were made for weight loss (Yes/No) and anxiety/depression (total HADS score) at inclusion, and for number of days between project inclusion and completed primary surgery (breast, colorectal, and gastric cancer) or diagnosis (prostate cancer). Tukey’s HSD test was used for comparisons among means in case of significant interactions. T-tests were used for comparisons of days of hospitalisation at 1-24 months after project inclusion between patients randomised to IPHC and Control. Chi-square analyses were used in the comparisons of proportion of patients utilising acute specialist care.

Hierarchical regression analyses were performed on data from the two-year period to determine if addition of information regarding age (<70 yr./≥70 yr.), comorbidity (no, 1, or >1 comorbid conditions), functional status (physical and emotional), symptoms (pain, fatigue, and weight loss), and socio-economic variables (married/cohabitant, university education, social interaction, family income, and living outside Uppsala) improved prediction of utilisation of specialist inpatient care beyond that afforded by cancer diagnoses, stage of disease (not advanced/advanced) and cancer treatment (not extensive/extensive). All models were adjusted for randomisation.
RESULTS

Summaries of Studies I-IV

Study I
The aim of this study was to evaluate the effects of IPHC on the frequency of contacts with the home care nurse, and the proportion of patients with a continuing contact 6 months after diagnosis. Further aims were to determine the possibility to predict patients’ home care nurse contacts at 6 months, and to evaluate patients' satisfaction with the home care nurse follow-up contacts.

The IPHC intervention resulted in a marked increase of follow-up contacts. The majority of control patients (n= 131, 74%) had no follow-up contacts with the home care nurse during the first 6 months after diagnosis, while 178 (89%) of IPHC patients reported this, of whom 67 (38 %) reported at least 1 contact per month. Control patients with advanced disease constituted the subgroup with the largest portion of control patients reporting follow-up contacts (10 of 28, 36%). The corresponding proportion of IPHC patients with advanced disease was 37 of 41 (90%). Six of 22 (27%) of the oldest control patients (≥80 yr.) and 24 of 26 (92%) of the oldest IPHC patients reported follow-up contacts. None of the 6 control patients with gastric cancer reported follow-up contacts, while all gastric cancer patients (n=10) in the IPHC group did so.

Logistic regression analysis identified the IPHC as the strongest predictor for reporting a continuing contact 6 months after diagnosis. IPHC patients were 14 times more likely (Odds ratio, OR=14.2, 95% Confidence Interval, CI=6.8-29.7) than controls to report a such contact. Within the IPHC group, the oldest patients (≥80 yr.) were 5 times more likely (OR=5.2, 95%, CI=1.4-20.0) to report a continuing contact 6 months after diagnosis compared to the youngest (<50 yr.) Also, IPHC patients with advanced disease were more likely than patients with non-advanced disease to report a continuing contact (OR=2.6, 95% CI=1.2-5.4), and living outside Uppsala municipality was positively associated with reporting a contact (OR=2.1, 95% CI=1.1-4.0).
IPHC patients evaluated the home care nurse contacts positively. One-hundred-and-forty-one (77%) stated that “it was good that the home care nurse contacted me”, 27 (15%) did not mind being contacted, but felt that the contact was unnecessary, and 12 (6%) would have preferred to take the contact themselves. A majority (n=129, 70%) assessed the time for the first contact as the “right time”, and 124 (67%) stated that the nurse gave expected support to a very large or large extent. Comparisons between IPHC patients with and without a continuing contact 6 months after diagnosis revealed that patients with a continuing contact were the most satisfied concerning these variables.

Figure 3 presents IPHC patients’ perceived benefit of the home care nurse contacts. The “Sum of benefit” for each aspect is the sum of all patients’ estimates of the perceived benefit of this aspect (range=0-3). “Nr. of pat. reporting benefit” is the number of patients who reported at least “Some” benefit of the specified aspect, and “Nr. of pat. deeming the aspect as not appropriate” is the number of patients who had deemed the aspect as not appropriate. The highest sum score was noted for the “provider continuity” aspect (sum score=300) followed by “safety of care” (sum score =263) and “disease-related dialogue” (sum score =241). This result corresponds with those for the number of patients reporting perceived benefit, reflecting the proportion of patients who chose the “provider continuity” aspect (n=117 of 170), followed by “disease related dialogue” (n=109 of 170) and “safety in care” (n=108 of 171).

In conclusion, the IPHC resulted in a marked increase of follow-up contacts with newly diagnosed cancer patients by home care nurses, and most patients where satisfied with the implemented routines. The results suggest that routines like those implemented through the IPHC strongly improved accessibility and continuity of care, by providing home care nurses with increased possibilities to monitor and support patients. Patients who were old, who had advanced disease and lived outside Uppsala municipality were most likely to report continuing contact six months after diagnosis.
Figure 3. Perceived benefit of home care nurse contacts within IPHC patients
Study II

The aim of this study was to evaluate the effects of the Extended Information Routine (EIR) on the GPs’ contacts with one specified patient, knowledge about that patient’s disease and treatments, and what information the GP wanted vs. received from the specialist clinic. Comparisons were made with control GPs who did not experience the EIR.

The results revealed that all EIR GPs received information from the specialist clinic whereas only 6 control GPs experienced this (F ex pr. p<0.05). Two control GPs had no knowledge about the patient’s cancer diagnosis, and 2 did refer the patient to the specialist clinic due to a suspected cancer, but had received no further information. All EIR GPs were informed about the diagnosis as well as the treatments. The results also revealed differences between the comparison groups with regard to their satisfaction with the information from the specialist clinics. Only 2 control GPs were satisfied with the received information compared to all EIR GPs. Yet, 4 of them missed information about other patient problems such as psycho-social status and about the GP’s role in the care of the patient.

The results also suggest that the EIR increased the GPs’ possibilities to determine patients’ needs of support compared to GPs in the control group. Four control GPs did not receive any information about their patient’s disease and treatments, and only three deemed their possibilities to follow the patient through the course of the disease as satisfying compared to all GPs in the EIR group (F ex pr. p<0.01). However, 4 GPs in the EIR group expressed the opinion that the patient did not need his/her support.

Thirteen of the 20 GPs were involved in the diagnostics of the cancer, and 13 had a contact with the patient during the treatment and follow-up periods. There was no evidence of differences between the comparison groups with regard to GP contacts with the patients. These results are confirmed by data from the HCN-questionnaire 6 months after diagnosis. A total of 305 patients were included in the project after the implementation of the Family Doctor Act, which meant that the IPHC patients’ personal GP was informed about the cancer.
diagnosis, treatments and the referral to the home care nurse, and subsequently received copies of the specialist clinic records. About 79% (n=241) of these patients completed the HCN questionnaire and the question about GP contacts. Chi-square analysis did not reveal any differences between IPHC patients and controls. Seventy (63%) of 111 control patients reported “no contacts” with the GP, 18 (16%) reported contacts “only during the period of diagnosis”, 12 (11%) reported contacts “only during the period of treatment and follow up” and 11 (10%) reported contacts “all the time since the first symptoms appeared”. The corresponding figures for IPHC patients were 71 (55%) of 130, 32 (25%), 11 (8%) and 16 (12%).

In conclusion, the information from the specialist clinic to the GP is insufficient in standard care. The EIR intervention increased the GPs’ knowledge about the disease and the treatments and appeared to facilitate their possibilities to determine the patients’ need for support. However, the intervention did not seem to affect GP contacts with the patients, a result confirmed by patient reports.

Study III

The aim of Study III was to evaluate the effect of the IPHC on newly diagnosed cancer patients’ utilisation of specialist care within 3 months from project inclusion, in comparison to control patients. A further aim was to investigate if such an effect is modified by patient age after adjustment for weight loss and level of psychological distress.

The analysis revealed that the IPHC resulted in a lower utilisation of inpatient care, but only for older patients (≥70 yr.). The mean Number of Admissions (NoA) for older IPHC patients (n=82) was 0.4 compared to 0.9 for older control patients (n=79). Also, mean Days of Hospitalisation (DoH) was lower for older IPHC patients (mean=3.8) compared to older control patients (mean=8.9). Thus, the number of DoH for older patients randomised to the intervention were 393 less than that for older control patients. These differences were statistically significant also after adjustment for weight loss and psychological distress. The higher means for older control patients compared to older IPHC patients were reflected also in
the data for the different diagnostic groups. Thus, the mean DoH (3.8) for older IPHC breast cancer patients was lower than the corresponding mean (5.5) for older control breast cancer patients, mean DoH (5.5) for older IPHC GI (colorectal + gastric) cancer patients was lower than the corresponding mean (14.4) for controls, and mean DoH (2.0) for older IPHC prostate cancer patients was lower than the corresponding mean (3.4) for older control prostate cancer patients. Also, the proportion of older patients who utilised acute specialist care was smaller compared to older control patients. Four (5%) older IPHC patients experienced an acute admission during the study period compared to 12 (15%) older control patients (p<0.05). Furthermore, the proportion of older intervention patients who paid an acute visit to the specialist outpatient clinic was smaller (12%, n=10) compared to the proportion of older control patients (28%, n=22) experiencing this (p<0.05). However, there were no differences between comparison groups regarding planned visits to specialist outpatient clinics.

Additional DoH data for the sample included in the Study III analyses (n=416) during 1 to 24 months after project inclusion are presented in Figures 4-6. Multiple t-tests showed statistically significant differences between older IPHC and control patients at 2, 3 and 4 months after inclusion (t=1.99-2.32, df=159, p<0.05), and no differences between younger patients. Figure 4 suggests that the identified differences for older patients at 2-4 months after diagnosis diminish at 5 months, disappear at 10 months and changes for the opposite at 19 months. However, t-tests did not reveal any statistically significant differences from 19 to 24 months. An analysis of DoH at 24 months, identical to that performed on data at 3 months failed to show significant differences between patients randomised to IPHC and Control. Since the medical background data (Table 1) suggest that IPHC breast cancer patients tended to have a more serious disease compared to controls (despite randomisation and stratification), a separate exploration of DoH from 1 to 24 months was conducted for this diagnostic group. The results presented in Figure 5 reveal that older IPHC breast cancer patients (n=19) presents a more rapid increase in DoH from about 6 months after project inclusion compared to older Controls (n=18). T-tests revealed statistically significant differences between the groups during the period from 20 to 24 months (t=2.19 - 2.27, df=35,
A further exploration of medical background data of “high-consumers” reveals that 4 (21%) of the 19 older IPHC breast cancer patients experienced a breast cancer recurrence or were diagnosed with a new cancer within 24 months compared to only 1 (6%) of the 18 control patients. However, the 3 older IPHC breast cancer patients with the highest DoH at 24 months (147, 131 and 98 days) were found to suffer from comorbid conditions such as a benign brain tumour, extensive back problems resulting in a stabilisation surgery, and vascular disease resulting in slow-healing wounds and a need for surgical interventions during the study period. Thus, an obvious explanation of the rapid increase of older IPHC breast cancer patients’ DoH is that this subgroup was more seriously disabled compared to older controls. Figure 6 presents DoH data for the remaining diagnostic groups during the period from 1 to 24 months after inclusion. These data suggest that the identified differences for older patients at 3 months tend to remain throughout the period. Older controls presents an increased utilisation of inpatient care compared to older IPHC patients and the groups of younger patients. However, there were no statistically significant differences (t-tests) in Figure 6 between older IPHC patients and older controls from 5 to 24 months.

In conclusion, utilisation of specialist care 3 months after diagnosis was reduced among older patients randomised to IPHC compared to older control patients. This was true after adjustment for weight loss and level of psychological distress, which were main targets for the Nutritional and Individual Psychological support that accompanied the IPHC intervention. Additional analyses revealed a trend indicating a lower utilisation for older IPHC patients compared to older controls throughout the study period, except for the subgroup of older breast cancer patients. Thus, a reasonable assumption is that improved possibilities for home care nurses and GPs to care for patients provided a cornerstone for decreasing the utilisation of specialist care among elderly cancer patients, especially during the period of diagnosis and primary treatment.
**Figure 4.** Cumulative frequencies of Days of hospitalisation 1-24 months after inclusion. All patients included in Study III analyses, n=416.

*= Statistically significant unpaired t-tests (t=2.0-2.3, df=159, p<0.05) in comparisons between older (≥70 yr) IPHC and Control patients.
**Figure 5.** Cumulative frequencies of Days of hospitalisation 1-24 months after inclusion. Breast cancer patients included in the Study III analyses.

*= Statistically significant unpaired t-tests (t=2.2-2.3, df=35, p<0.05) in comparisons between older (≥70 yr) IPHC and Control breast cancer patients.
**Figure 6.** Cumulative frequencies of Days of hospitalisation 1-24 months after inclusion. Colorectal, gastric and prostate cancer patients included in the Study III analyses.

*= Statistically significant unpaired t-tests (t=2.1, df=122, p<0.05) in comparisons between older (≥70 yr) IPHC and Control Colorectal, gastric and prostate cancer patients.
Study IV

The aim of Study IV was to gain knowledge that can be used to facilitate early identification of cancer patients with an increased need for medical services, who can be assumed to benefit from follow-up contacts by home care services. This was done through determination of factors at diagnosis that are related to utilisation of specialist inpatient care two years after diagnosis, after adjustment for randomisation. Furthermore, we wanted to explore to what extent the predictive power of identified factors was affected by information on days of survival.

The first step in the regression analysis included information about cancer diagnosis, stage of disease and treatment ($R^2=0.1$, $p<0.001$). The result revealed that prostate cancer was associated with a higher DoH compared to both breast and GI cancer. Furthermore, patients with a more advanced disease had a higher DoH compared to those with a more limited disease, whereas extensive treatment was not identified to be associated with the dependent variable.

Information about age (step 2) added significantly to the model ($R^2$ change=0.03, $p<0.001$) and revealed that high age was associated with a higher DoH. The adjustment for age also meant that information about treatment turned out to be significantly associated with the dependent variable, suggesting a higher DoH for patients experiencing a more extensive treatment compared to those who did not.

Inclusion of information about comorbidity, functional status and symptoms (step 3) explained another 6% ($p<0.001$) of the variance. The presence of comorbid conditions was found to be related to a higher DoH, as was a high level of pain. Also, physical function was related to DoH, suggesting a higher DoH for patients with a lower level of function. Furthermore, the effect of advanced disease on DoH was reduced due to inclusion of information about comorbidity, functional status and symptoms. Thus, information about stage of disease did not remain significantly related to DoH after adjustment for the information included in step 3.

Inclusion of information about socio-economic factors (step 4, final model) added significantly to the model ($R^2$ change=0.04, $p<0.05$). High income was associated with a lower DoH, and living outside Uppsala municipality was associated with a higher DoH. The inclusion of information about socio-economic factors also reduced the effect of age on DoH, which did not reliably improve $R^2$ after adjustment for such information.
Information about days of survival was included in the final model, revealing that an extended time of survival was associated with a lower DoH (R²-change = 0.9%, F = 4.4, df=369, p<0.05). However, all the statistically significant determinants in the final model (step 4) remained so with the exception of Family income for which Beta decreased from -0.15 (p=0.05) to -0.14, resulting in only a marginally significant effect (p=0.06). Thus, information about days of survival affects utilisation of inpatient care, but does not appear to seriously confound the identified determinants of utilisation of such services.

In conclusion, the results suggest that the identification of candidates for referral to home care services warrants thorough assessment. Factors such as diagnosis, advanced disease and high age should be considered. However, data on treatments, comorbidity, functional status, troublesome symptoms such as pain, and socio-economic factors must also be assessed in the efforts to offer cancer patients care, specially tailored to their individual needs.

GENERAL DISCUSSION

Home care nurses’ and GPs’ possibilities to monitor and support cancer patients and patient utilisation of such services

The results presented in Studies I and II indicate that home care nurses’ and GPs’ possibilities to monitor and support newly diagnosed cancer patients are limited in standard care. Only a minority of patients (26%) in standard care reported home care nurse follow-up contacts. This was true also for patient-reported follow-up contacts with GPs. About 20% of the patients in standard care reported this. Four of ten control GPs in Study II were not informed about the patients’ cancer diagnoses, even though two of them referred their patient to the specialist clinic due to a suspected cancer. Furthermore, only three GPs judged their possibilities to follow the patient through the course of disease as satisfying.

The IPHC strongly improved home care nurses' possibilities to monitor and support cancer patients, since a basic prerequisite for doing this is to stay in contacts with them. The findings suggest that the IPHC not only lead to increased follow-up contacts in general, but that available resources were allocated differently to patients with more or less needs for such services. Predictors of a continuing
contact among IPHC patients were high age, advanced disease and living outside Uppsala municipality. All of these variables were also identified as determinants of a high utilisation of inpatient care in Study IV. It is notable that this marked increase of contacts did not require a higher number of nurses, but was brought about within the limits of available resources. Thus, it is likely that home care nurses judged the follow-up contacts as an important part of home care services, worthy of stretching an already strained schedule. This opinion is supported by the large number of home care nurses attending the seminars in cancer care throughout the course of the trial.

Furthermore, the continuous dialogue during several years with nurses caring for IPHC patients supports the notion that the possibility to get to know cancer patients in an early phase of their disease furthers the effectiveness of home care services. This is true especially for patients who have an increasing need for home care services, due to the cancer or to other disabilities.

The IPHC patients were satisfied with the home care nurses’ follow-up contacts and patients with a continuing contact six months after diagnosis where found to be the most satisfied. These results are supported by earlier studies, documenting cancer patients’ need for home care services as well as their satisfaction with such services (11, 15, 16). The assessment of the perceived benefit of different care aspects demonstrated “provider continuity”, “disease related dialogue” and “safety of care” as those aspects that the largest proportions of patients judged that they had benefited from. Thus, the IPHC appears to have resulted in an increased continuity of care as well as facilitation of the dialogue between patients and nurses. Perceived benefit of medical services was divided into three aspects, i.e. “medical services”, “medical services at home”, and “medical aids”. This is a poor classification due to the overlap among the three aspects. Thus, it is difficult to draw any conclusions regarding patients’ perceived benefit of medical services. However, it can be concluded that home care nurse follow up-contacts may serve more purposes than strictly medical ones. In conclusion, the high patient satisfaction and the increased frequency of follow-up contacts suggest that the aim to improve the possibilities for home care nurses to monitor and support cancer patients can be judged to have been achieved to a large extent.

The IPHC also improved GPs’ possibilities to monitor and support cancer patients. However, the EIR did not fully meet the GPs’ needs for information. Four GPs reported a lack of information about their role in the care of the patient and about patient problems besides the cancer. Thus, the EIR lead to an improvement compared to standard care but it did not result in an optimal information routine to satisfy all GPs’ needs of information. These results and results from earlier studies, suggesting that the content of consulting oncologist letters are not well tailored to referring
The IPHC did not affect the extent of GP contacts with the patients. This result was evident both from the GP interviews and from patient reports. This may be an effect of the reorganisation of the GPs’ work due to the implementation and rapid abolition of the Family Doctor Act during the study period. It is reasonable to assume that this may have meant that the GPs’ possibilities for extra contacts were limited. Another explanation is that GPs who received extended information were aware of the fact that the specific patient was randomised to Individual Support and thereby assumed that the patient was well cared for. The present finding that four GPs experiencing the EIR expressed the opinion that the patient did not need his/her support, endorses such an explanation. Thus, the combination of a strained work situation, lack of information about their role in the care of the patient, and the presumption that the patient was well cared for is a probable explanation of the lack of effects of IPHC on patients’ GP contacts. The results of Study II suggest that the aim to develop a cancer care model, characterised by improved possibilities for GPs to monitor and support cancer patients was only partly fulfilled.

**Utilisation of specialist care**

The results of Study I revealed a marked increase in home care nurse follow-up contacts. This finding gave rise to the question whether or not this had affected the utilisation of specialist care. Since high age was the strongest predictor of a continuing contact 6 months after diagnosis, it became of interest to explore if an effect of the IPHC on utilisation of specialist care was modified by patients’ age. It was therefore decided to analyse data from the first 3 months to explore the effect of the IPHC during the period of diagnostic work-up and primary treatment including hospital discharge. Several studies have concluded that there is a need for follow-up contacts during this period (8, 15, 17, 18). The results of Study III revealed that the IPHC reduced the utilisation of specialist care, but only for older patients (≥70 yr.). Both Number of Admissions and Days of Hospitalisation (DoH) were significantly lower among older IPHC patients, compared to older control patients. In total, the DoH for older IPHC patients was 393 fewer than for older control patients. Also, the number of acute admissions and acute visits to the outpatient clinics was reduced. Thus, the results suggest significant savings with regard to both costs and workload for the specialist clinics. Furthermore, the reduced need for hospitalisation and acute specialist care must be considered as an improvement for the patients. The reduced utilisation of inpatient care is...
supported by similar results from several earlier studies evaluating the effects of co-ordinated care 
(30, 33, 34). It has also been shown that continuity in ambulatory care is associated with a lower 
likelihood of hospitalisation (10). Thus, it can be concluded that the improved continuity of care 
due to the home care nurses improved possibilities to monitor and support patients, must be 
considered as the probable explanation of the association between the IPHC and reduced utilisation 
of inpatient care.

The analysis of data from the entire two-year period reveals that the effects of the IPHC on 
utilisation of specialist care do not remain. The t-tests suggest a difference between older IPHC and 
control patients also at 4 months, but no differences could be identified for the remaining study 
period. However, the results also suggest that the older IPHC breast cancer patients constituted a 
severely diseased subgroup. Medical background data indicate that this group had a more advanced 
cancer and suffered from severe comorbid conditions, resulting in a high utilisation of inpatient 
specialist care. Such differences between groups are supposedly handled by an experimental design 
with a sufficient number of patients. However, the older breast cancer patients in the present study 
probably constituted too small a subgroup for an equal distribution of confounding variables. It is 
difficult to predict the effects the of the IPHC on utilisation of specialist inpatient care if equivalent 
subgroups of older breast cancer patients had been available. However, it is reasonable to believe 
that such conditions may have strengthened the trend in Figure 6, suggesting an association between 
the IPHC and older cancer patients’ utilisation of specialist care throughout the study period.

Another possible explanation is that implemented routines (referral to home care nurses, and 
extended information to nurses and GPs) did not involve all kinds of specialist clinics, and thereby 
limited the effect of the IPHC on utilisation of specialist inpatient care. Furthermore, the IPHC was 
limited also in time, due to the withdrawal of the implemented routines at project termination. Thus, 
the IPHC did not constitute an optimal co-ordinated health care system.

An important question is to what extent patient quality of life was affected by the increased home 
care nurse follow-up contacts and reduced utilisation of specialist care. Data on quality of life were 
collected by the EORTC-QLQ C30 (37) (version 1) at inclusion and at 3, 6 and 12 months after 
diagnosis. These data have recently been analysed (Hellbom et. al., submitted), revealing similar 
improvements between inclusion and 12 months in role, emotional and social functioning and for 
global quality of life, nausea/vomiting, pain, appetite and diarrhoea in IPHC and Control patients.
Thus, there is no indication that the reduced utilisation of inpatient specialist care has affected quality of life in the IPHC group negatively.

Factors associated with an increased use of medical services

Study I identified high age, advanced disease and living outside Uppsala municipality as determinants of a continuing home care nurse contact 6 months after diagnosis. This result corresponds with those in Study IV which demonstrated that these variables were associated with a higher utilisation of inpatient care 24 months after diagnosis. Thus, it seems possible to identify patients with a strong need for specialist medical services at diagnosis. Also, these patients can be expected to benefit from being identified as candidates for referral to home care services.

Study IV revealed that the effect of advanced disease and high age on utilisation of specialist inpatient care was reduced given additional information about disabilities and socio-economic factors. Comorbidity, a lower physical function, and pain were identified as determinants of a higher number of DoH. The exploration of the subgroup of older IPHC breast cancer patients, revealing the highest DoH for patients with comorbid conditions, supports this result. It is reasonable to believe that improved home care follow up services within a co-ordinated health care system may lead to interventions decreasing the need for hospital readmissions for patients experiencing such difficulties.

Living outside Uppsala municipality was related to a higher DoH. This was true also after adjustment for all other variables included in the regression analysis. The most obvious explanation of this result is the limited possibilities to receive advanced home care services outside the city. It is well known that such services are crucial for advanced cancer patients’ possibilities to reside at home (13). Also, Study I identified this variable as a predictor of a continuing home care nurse contact. These findings indicate that patients living far from the hospital would benefit from a referral to home care services in a co-ordinated health care system. Increased co-operation between specialist clinics and home care services could strongly improve patients’ possibilities to reside at home, since their possibilities to consult with and to receive care from an initiated home care nurse may prevent some visits to the hospital.

Also a low family income was associated with an increased utilisation of specialist inpatient care. This result is supported by previous research suggesting that low income among cancer patients is a
determinant of need for assistance with activities of daily life, as well as with unmet needs for this (16). This was true also after adjustment for health status. There is no obvious explanation of why low income is associated with a higher need/utilisation of health care services. However, it can be concluded that patients’ socio-economic status should be considered in the determination of cancer patients’ needs for health care services.

To sum up, it is possible to identify patients with an increased need for medical services, and it is reasonable to assume that such patients would benefit from improved home care services. However, such an identification warrants thorough assessment. Factors such as advanced disease and high age should be considered. Data on treatments, comorbidity, functional status, troublesome symptoms such as pain, and socio-economic factors must also be assessed in the efforts to offer cancer patients care, specially tailored to their individual needs.

**Limitations**

One of the aims of the “Support-Care-Rehabilitation” project was to develop a co-ordinated cancer care model, characterised by increased continuity of care, by improving the possibilities for home care nurses and GPs to monitor and support cancer patients. This was done by the implementation of routines stimulating an increased co-ordination between specialist care, GPs and home care services. The referral to the home care nurses, the extended information from the specialist clinics to GPs and nurses, the cancer care education and the supervision of home care nurses, were routines developed and maintained by the project group, and not by the regular health care services. This arrangement meant that the extended information and referral routines could only be maintained if the patients visited the specialist clinics engaged in the research project. Hence, for patient admissions and visits to specialist clinics not involved in the project, these routines could not be implemented.

A further limitation is that the extended information routine implemented in the IPHC was not bilateral. A co-ordinated health care system implies that GPs and home nurses receive information from the specialist clinic, but also that the specialist clinics receive information from the GP and the home care services. Finally, the implemented routines were withdrawn at project termination. Thus, the IPHC has several limitations compared to what could be achieved in an optimal co-ordination between available health care sectors in Uppsala county. The differences between an optimally co-
ordinated health care system and the IPHC intervention can be seen in a comparison of the earlier presented Figure 1 (p. 26) and Figure 2 (p. 37).

IPHC patients were referred to 90 nurses in Uppsala county. This fact implies differences in follow-up contacts with regard to contact intensity and contents due to nurses’ various workloads, skills, knowledge and interest in cancer care. These circumstances complicate the evaluation, since there is no guarantee that the patients randomised to the IPHC were subjected to identical interventions. On the other hand, the fact that the IPHC was carried out by the regular nurses increases the possibilities that the present thesis provides a realistic idea about the effects of an increased co-ordination between available home care and specialist care services.

The fact that the Family Doctor Act was implemented 1994 meant that the work situation for the GPs was characterised by considerable uncertainty. This motivated the decision that the IPHC would not involve an initiation of GP follow-up contacts. Furthermore, the act was abolished already in 1995. Thus, the results of the evaluation regarding the effects of the IPHC on GP involvement in patient care, must be interpreted with these exceptional working conditions in mind.

**Methodological considerations**

The design of the “Support - Care - Rehabilitation”- project implies several threats to internal validity, since the aim of the present thesis is to evaluate the effects of the IPHC. Patients were randomised between four groups: 1) Individual support (IS), 2) Group rehabilitation (GR), 3) A combination of IS and GR (ISGR), and 4) Standard Care (SC). Two of the groups included IS, consisting of IPHC combined with Individual Psychological Support for all patients, and with Nutritional Support for patients with colorectal and gastric cancer. This problem is particularly evident in Studies I and III.

Study I evaluated the effect of the IPHC on utilisation of home care nurse services 6 months after diagnosis. Comparisons were made between patients randomised to IS or ISGR and those randomised to GR or SC. On the one hand, the effect of the GR could be considered to be a minor problem, since half of the patients in both comparison group were randomised to this condition. On the other hand, an interaction of treatments cannot be ruled out. Thus, a comparison between IPHC and Control, including patients subjected to the GR, may reveal a different result than a comparison been groups where patients have not been subjected to this. The GR was implemented 4 months
after diagnosis and comprised 8 weekly sessions, and a booster session after 2 months. Hence, a substantial part of the patients participated in the GR at the assessment 6 months after diagnosis. However, it not obvious how participation in the GR could have affected patients’ home care nurse contacts, or their evaluation of such services. Nevertheless, a possible interaction of treatment effects should be considered in the interpretation of the results of Study I. The multiple logistic regression analysis in Study I provided adjustment for the effects of the Individual Psychological Support and the Nutritional Support. The analysis revealed no association between the extent of psychologist contact and a continuing contact with the home care nurse 6 months after diagnosis. Neither was there any association between diagnosis and home care nurse contacts at 6 months. Thus, it is reasonable to assume that the IPHC is the main determinant of home care nurse contacts.

Study III evaluated the effects of the IPHC on utilisation of specialist care 3 months after diagnosis, before the GR was implemented. Also, adjustments were made for weight loss and psychological distress, considered as main targets for the Nutritional Support and the Individual Psychological Support, respectively. The information about psychological distress at inclusion did not provide a statistically significant adjustment either of Number of Admissions or of Days of Hospitalisation. Weight loss was associated with the dependent variables, but the results revealed that patients with no weight loss had a higher use of specialist care compared to those with weight loss. This was interpreted as an effect of younger breast cancer patients’ high utilisation of specialist care, due to extensive primary treatments. In view of these considerations, it reasonable to assume that the IPHC is associated with a lower utilisation of specialist care among older cancer patients.

In conclusion, various measures have been taken to overcome threats to internal validity. Thus, it reasonable to assume that the presented results provide a realistic idea about the effects of a more co-ordinated cancer care in Uppsala county. However, there is a need for further research, in additional populations of cancer patients, and preferably, with less complicated experimental designs, to gain additional knowledge of the effects of a co-ordinated care model on cancer patients.
Conclusions

- GP and home care nurse follow-up of newly diagnosed cancer patients is rare in standard care. A lack of a co-ordinated health care system, including sufficient routines for information exchange and dialogue between different health care sectors has been identified as main problems.
- The IPHC strongly improved home care nurses possibilities to monitor and support cancer patients. A majority of the patients (89%) randomised to the IPHC reported home care nurse contacts, compared to only 26% of Control patients.
- Predictors of a continuing home care nurse contact among IPHC patients were high age, advanced disease and living outside Uppsala municipality. Thus, the IPHC did not only lead to increased follow-up contacts in general, but available resources were allocated differently to patients with more or less needs for such services.
- The patients were satisfied with the home care nurse follow-up contacts. A majority (77%) stated that “it was good that the home care nurse contacted me”, 70% assessed the time for the first contact as the “right time”, and 67% stated that the nurse gave expected support to a very large or large extent.
- The IPHC increased GPs knowledge about patients’ disease and treatments, and appeared to facilitate their possibilities to support the patients. However, there is no evidence that GP follow-up contacts with the patients were affected by the IPHC.
- The IPHC reduced the utilisation of specialist care among elderly cancer patients, especially during the period of diagnosis and primary treatment. The number of Days of Hospitalisation for older IPHC patients were 393 less than that for older Control patients 3 months after inclusion.
- It is possible to identify patients with a strong need for medical services at diagnosis, without knowledge about the duration of their time of survival. Furthermore, these patients can be expected to benefit from a referral to home care services.
- Old patients and patients with an advanced disease should be considered for a referral to home care services. Also, patients with extensive treatments, comorbid conditions, low functional status and/or troublesome symptoms should be considered as candidates for referral to such services.
- Socio-economic factors such as living outside Uppsala municipality, and low income should be assessed in the determination of cancer patients’ need for health care services.
IMPLICATIONS FOR CANCER CARE

The findings in the present thesis suggest that routines such as those implemented by the IPHC resulted in a more co-ordinated care and thereby in improved possibilities for home care nurses to monitor and support cancer patients. Such an improvement meant that the utilisation of specialist care was reduced among older cancer patients, especially during the period of diagnosis and primary treatment. Thus, the results indicate savings with regard to both costs and workload for the specialist clinics. Furthermore, a reduced need for hospitalisation and acute specialist care must be considered as an improvement for the patients. However, the IPHC has several limitations compared to what could be achieved in an optimal co-ordination between available health care sectors in Uppsala county. Hence, routines like those implemented by the IPHC could preferably be developed and maintained by regular health care personnel.

_The development and implementation of the following routines are suggested:_

− Improved routines for exchange of information between different health care sectors.

− Yearly joint seminars in cancer care for staff from specialist clinics, GP practices, and home care services.

− Improved consultation possibilities in all parts of the health care system

− Improved methods for identification of patients who would benefit from home care services.

− Increased referral to home care services for old patients, patients with advanced disease, extensive treatments, comorbid conditions, low functional status and/or troublesome symptoms.

− Establishment of co-ordinators with the responsibility for a continuous evaluation and development of the suggested routines.
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