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Home care with regard to definition, care recipients, content and outcome: systematic literature review

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Summary

- In spite of the fact that home care has grown considerably during the last few years and will continue to grow even more in the future, home care as a phenomenon and a concept is not clearly defined.
- The aim of this study was to review the empirical literature for the description of home care as a phenomenon and as a concept, especially with regard to who the care recipients are, what actions and assessments are performed and what effects are achieved for the care recipient in terms of functional health status and quality of life (QoL).
- Twenty-six relevant studies meeting the inclusion criteria and requirements for methodological quality were identified.
- The phenomenon of home care is described through content, outcome and objectives. The content of home care involved a range of activities from actions preventing decreased functional abilities in old people to palliative care in advanced diseases.
- The outcome had two different underlying foci: (1) for the benefit of the patient based on the assumption that being cared at home increases their QoL, (2) in the interests of the society, to minimize hospital care by moving activities to the home of the patient.
- The objectives were found to be aiming at improving the QoL and/or maintaining independence, by means of actions and assessments, based on the patient's needs, undertaken to preserve and increase functional ability and make it possible for the person to remain at home.

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

Keywords: actions and assessments, care recipients, concept, home-care, phenomenon, systematic review.

Introduction

Home care as a concept is not clear, which may lead to uncertainty in its application and in the training of those working in home care. It seems important to clarify the concept because the demands on it in the future will be even greater than today. To outline and develop home care, knowledge of its essence is required. One way of developing the concept of home care is to describe the phenomenon of home care, how it appears in practice, what the underlying goals are when it is applied, who its recipients are and what it consists of (Meleis, 1997). More knowledge of these aspects can be obtained by reviewing the empirical literature on home care.

In studies concerning home care, the concept is mostly loosely defined. The World Health Organization (Knight & Tjassing, 1994, p. 16) states: 'Home care can be defined as an array of health and social support services provided to clients in their own residence. Such co-ordinated services may prevent, delay or be a substitute for temporary or long-term institutional care'. The concept comprises a comprehensive field of actions and gives no clear understanding of the objectives of home care and who is the recipient, what is actually done and what effects would be desirable. A more specific clarification of the concept may be helpful in education and practice.

The target population seemingly differs substantially within home care. As population ageing will be a fundamental demographic change in the future, old people will probably be the greatest users of home care (SBU, 1999). With advancing age, many people develop functional impairments and need support to keep up with personal activities of daily living (PADL) and instrumental activities of daily living (IADL) to be able to remain in their own homes. Another target group is patients with incurable and advanced diseases. Studies from England and the USA indicate that most of the patients with incurable and advanced diseases would prefer to be cared for and remain at home until their death (Townsend *et al.*, 1990; Grande *et al.*, 1998; Karlsen & Addington-Hall, 1998).

Findings from meta-analyses (Hedrick *et al.*, 1989; Wiener *et al.*, 1990; Stuck *et al.*, 1993; Hughes *et al.*, 1997) showed the main outcome measures of the effects of home care to be mortality, impact on hospital days and admission to hospital or nursing home. These meta-analyses and a review (Jensen, 1997) confirmed an overall significant decrease in long-term mortality, impact on hospital days and admission to hospital or nursing home, as the effects of home care. However, no obvious explanations were given on an individual basis of the benefits for the care recipients.

During the last few decades home care has grown considerably in the USA in response to basic trends such as escalating costs of inpatient care, ageing of the population, increased technological capacity to provide sophisticated medical treatment in the home and the popularity among the consumers of remaining at home (Hughes *et al.*, 1997). In Sweden the trends are similar. The number of inpatient beds was reduced by about 70% from 1980 to 1999 (SBU, 1999). Although home care is common today, the trend is towards even more home care in the future as a way to provide care, above all to older people, and thus it is urgent to clarify its boundaries, meaning and content in order to make the concept clearer.

Concept development has been described as concept exploration (Meleis, 1997). Concept exploration is supposed to be appropriate for concepts that have been uncritically adopted in different disciplines without consideration for the values, assumptions and missions of a discipline. It is applicable when a concept is unknown or so familiar that it has been taken for granted, to the extent that the members of the discipline are not aware of its significance to the development of knowledge. Concept development of home care seems important because a more distinct understanding of it can guide planning and implementation in practice. Home care will be explored with regard to the content reflected in who the care recipients are, what care is provided and how the care affects the functional health status and quality of life

(QoL) of the care recipients – all with the aim of developing a firmer understanding of the concept.

Aim

The aim of this study was to review the empirical literature for the description of home care as a phenomenon and as a concept, especially with regard to who the care recipients are, what actions and assessments are performed and what effects are achieved for the care recipient in terms of functional health status and QoL.

Method

SEARCH STRATEGY

A literature search plan was developed and systematically applied. As Medline and CINAHL cover the majority of the medical and nursing literature, these two databases were consulted (Table 1). The inclusion criteria for the articles were being published in Scandinavian or English, empirical, prospective, preferably with a randomized controlled design when it came to outcome of home care and a high methodological quality, and including patients with medical diagnoses and/or functional disabilities that required home care, patients admitted to home care, different actions and assessments in the area of prevention or care carried out in the patient's home, and aspects of

functional health status and/or QoL. The following criteria were used for exclusion: economic aspects, intervention studies focusing only on a single specific aspect of home care, e.g. pain management, psychiatric illness or dementia, infants and children, caregivers and reviews.

The initial literature search resulted in 1096 articles (Table 1). Of those, 130 met the inclusion criteria concerning content and were sorted according to study design and evaluated regarding their methodological quality. A number of randomly selected articles were evaluated independently by the first two authors. The reviewers used a scoring list consisting of 12 methodological criteria (Appendix) based on Goodman (1996) and Polit & Hungler (1996). They referred to how the authors of the studies dealt with internal and external validity, reliability and critical discussion. After a decision concerning the strategy for evaluation, the first author evaluated all the studies. Difficulties in scoring were discussed with the co-authors. The most common shortcomings in methodological quality were indistinct description of subjects or intervention, using non-standardized instruments for assessment, studies made under local circumstances which could not be generalized, large attrition rate, deficiencies in the critical evaluation of the study in relation to other studies in the same area. The final sample was 26 articles meeting the inclusion criteria and requirements for methodological quality (Tables 2–4).

Table 1 Search strategy and outcome

Home care services in combination with	Search result	No. of papers identified
Medline 1985–1998		
Functional ability	113	15
Quality of life	74	28
Elderly	355	51
Health services needs and demand	102	0
Patient admission	13	8
Utilization	134	19
NOT child NOT infant NOT psychiatric NOT letters NOT editorials		
CINAHL 1985–1998		
Functional ability	2	2
Quality of life	17	2
Research	114	7
Diagnosis	31	2
Utilization	47	6
Elderly	79	10
Geriatrics	15	2
NOT child NOT infant NOT psychiatric NOT letters NOT editorials		

Findings

CARE RECIPIENTS

Most of the studies were of old people living at home, after discharge from hospital or utilizing home care. The definition of old people was lacking and they were treated as a homogeneous group. Some studies including old people were not related to any specific diagnosis group. Specific diagnoses were advanced cancer, acute surgical conditions, acute and chronic medical conditions and elderly medical patients. Most studies comprised more women than men.

DESCRIPTIONS OF HOME CARE AND HOME CARE AS A PHENOMENON

There was considerable variation in the descriptions and use of terms for home care. The terms used besides home care and home-care services were based on the content (in-home comprehensive assessment, in-home preventive assessment, palliative home care and home health care), the objectives (home-care rehabilitation, hospital at home

Table 2 Studies focusing home care related to individual needs

Authors	Design/care recipients	Objectives	Content	Outcomes
Axelsson & Sjöden (1998) (Sweden)	Prospective study over a period of 3 years, patients were asked to complete a QoL questionnaire at monthly intervals Incurable ill cancer patients $n = 37$ (median age 70; range 31–88; 14 women, 23 men)	To gather knowledge about the QoL both of terminally ill cancer patients receiving palliative home care and their spouses Improve QoL	Monthly assessment of QoL in palliative home care	Correlations to global QoL were: meaningfulness (0, 79), ability to do what one wants (0, 71), physical strength (0, 58), hours recumbent (0, 58) and ability to feel joy (0, 57) FHS not measured
Krach <i>et al.</i> (1996) (USA)	Cross-sectional, correlation design Old people aged 85 and over, cognitively intact and living in a home setting with various need for home care $n = 50$ (mean age 89; range 85–95; 67% women, 33% men)	To assess six components of adaptation; physical, mental, social, spiritual, economic and ADL factors Reach independence and maintain and/or improve QoL	Multidimensional assessment of components of adaptation and as predictors for use of services	Highest impairment in FHS was found in physical functioning (55%) and ADL (72%) Most of the subjects were satisfied with their life (98%)
Prescott <i>et al.</i> (1995) (USA)	Exploratory study using data collected from medical records, patient interviews and weekly visits and assessments by nursing students Patients ready for discharge from one urban university hospital age 18 and over $n = 145$ (mean age 53, SD 16; 51% women, 49% men)	To determine the degree to which patients with identifiable needs for services were referred to home health care and if selected clinical and functional measures were useful in distinguishing the need for service Reach independence	Identification of patients needs for care and professional judgement of indication for home health care	Patients in need of home-care services differed significantly ($P < 0.001$) in number of needs on dimensions in FHS as physical functioning and dependency at discharge, measured as physical and instrumental activities in daily living QoL not discussed
Bull (1994) (USA)	Prospective study Patients and caregivers were interviewed prior to and 2 weeks after discharge Patients aged 55 and over, hospitalized for an acute episode $n = 185$ caregiver/elders dyads (elders mean age 73, range 55–97; 52% women, 48% men)	To identify predischARGE predictors of resource use following hospitalization Reach independence	Assessments of need factors including physical health and ability to perform ADL	Dependency in ADL predischARGE and old age were statistically significant ($P < 0.001$) predictors of a greater number of home-care services postdischarge QoL not measured
Hinton (1994a) (UK)	Prospective study with semi-structured interviews weekly with patients and relatives for 8 weeks and then fortnightly for 6 months and then monthly Patients of all suitable adults with terminal cancer referred to St Christophers Home Care Service $n = 77$ (mean age 65, SD 10; 43 men, 34 women)	To assess whether patients with terminal cancer and their relatives found that competent home care sufficiently maintains comfort and helps adjustment Maintain QoL	Assessments of QoL reflecting activity, physical independence, well-being, support and mood	Patients QoL fell steadily during the final 8 weeks

Table 2 Continued

Authors	Design/care recipients	Objectives	Content	Outcomes
Hinton (1994b) (UK)	Prospective study with semi-structured interviews weekly with patients and relatives for 8 weeks and then fortnightly for 6 months and then monthly Patients of all suitable adults with terminal cancer referred to St Christophers Home Care Service $n = 77$ (mean age 65, SD 10; 43 men, 34 women)	To record the given reasons for admission and exploring a sequence of potential underlying factors Reach independence	Assessments of cancer-related problems as weakness, pain, depression, anxiety and fatigue	The reasons in FHS for admission were progress in symptoms and deterioration Attitudes of denial, conscious fighting of disease and optimism measured by scales during interview, were linked with increased late admission to hospice
McCorckle <i>et al.</i> (1994) (USA)	Non-randomized controlled trial Cancer patients with prognosis greater than 6 months $n = 49/11$ 25% age 50 and under, 25% aged 51–64, 50% aged 65+ (61% women and 39% men)	To evaluate the impact of home-care services on cancer patients following an acute care hospital stay Reach independence	Assessments of symptom distress, mental health, enforced social dependency and health perceptions	Patients receiving home care demonstrated significant improvement on mental health and social dependency
Solomon <i>et al.</i> (1993) (USA)	Prospective cohort study Elderly, aged 70 and over, medical and surgical patients discharged from acute care $n = 226$ (mean age 78.8, SD 5.7; 129 women, 97 men)	Studying the incidence and risk factors for home health care use in elderly medical and surgical patients discharged from acute care Reach independence	Assessments of ADL and/or IADL, cognitive impairment, support network and social support	One of four independent predictors for home care were impairment in FHS measured as ADL, IADL, cognitive impairment QoL not measured
Frederiks <i>et al.</i> (1992) (Netherlands)	Cross-sectional design A stratified sample of elderly people age 55 and over with comparable number of physical limitations with or without professional home care $n = 450$ (272 women, 178 men) (123 using and 327 not using professional care)	To investigate which characteristics among elderly people, besides physical limitation, that contribute to the utilization of home-care services Reach independence	Comparisons between people with physical limitations with and without home-care services	Elderly using home-care services were statistically significantly more impaired in ADL and IADL ($P < 0.01$) One dimension of QoL was measured as feeling of loneliness. This was statistically higher among elderly using home-care services ($P < 0.01$)
Mamon <i>et al.</i> (1992) (USA)	Prospective study Multicenter study Interviews with patients at discharge and a telephone interview 2-weeks postdischarge Random sample of patients at admission age 60 and over from five hospitals (Baltimore) $n = 919$	Evaluating two discharge planning strategies (usual or formal and interdisciplinary) in terms of the extent to which patient-reported home care needs are met and examine the extent to which improvements in hospital discharge planning might be expected to substantially reduce the occurrence of unmet needs Reach independence	Assessments of patients' needs and whether or not these needs were being met	The patients reported needs for care in 97% Formal discharge planning showed to be related to significant reduction of unmet needs QoL not discussed

<p>Mor <i>et al.</i> (1992) (USA)</p>	<p>Prospective study (This study presents the results of the baseline interview) Patients (age 21 and over) initiating a course of outpatient chemotherapy and/or radiation therapy <i>n</i> = 629 (54% women, 46% men)</p>	<p>To investigate the impact of physiological and social factors on cancer patients' need for assistance with daily activities and whether those needs were being met Reach independence</p>	<p>Identification and description of physiological and social determinants for needs and unmet needs in the area of personal care, instrumental tasks and transportation</p>	<p>Physiological and disease factors described as functional status and factors related to diagnosis were associated with need for assistance in areas of needs like personal care measured by ADL and IADL. Unmet needs were primarily associated with an insufficient social support system QoL not discussed</p>
<p>Branch <i>et al.</i> (1988) (USA)</p>	<p>Prospective cohort study over a 2-year interval All persons aged 65 and older in East Boston <i>n</i> = 3706</p>	<p>To examine the relationships between a number of baseline characteristics and subsequent entry into a comprehensive medical home-care programme Reach independence</p>	<p>Assessments of the impact of differences in demographic variables, FHS and mental status, on utilization of medical home care</p>	<p>Characteristics predicting utilization of medical home care were help needs in ADL, dependency in areas of functional health QoL not described</p>

and domiciliary rehabilitation) and sometimes on the form of service distribution (medical home care, home health visits and home nursing care services).

The definitions of home care, related to care recipients, content and outcomes, were implicit rather than explicit in the studies. It could be understood through the meaning of the phenomenon, i.e. the overall objectives, the content and outcomes, i.e. the effects on functional health status and QoL (Fig. 1). The broad objectives were to improve/maintain QoL, to optimize functional health status and achieve independence, with care based on recipients' individual needs, preventive actions and assessments, and actions and assessments after discharge (Tables 2–4).

THE OBJECTIVES OF HOME-CARE

The objectives focused partly on the benefits to the care recipients, partly on the interests of society and the health care system. The benefits to the care recipient, the overall objective of home care, were based on the implicit view that remaining at home is the best alternative for a person in order to attain independence and improve or maintain QoL. The objectives were in the area of optimizing QoL and well-being and attaining and maintaining the best possible functional health status. The benefits to society and the health care system were that home care was considered to be the most effective type of care compared with hospital care (Fig. 1). Remaining at home was taken to be a positive goal in itself. The objectives of home care for patients with advanced diseases were explicitly described, whilst for patients with terminal disease the objectives were to achieve physical and mental comfort to make the remaining life worthwhile, despite the effects of terminal cancer, and to make it possible to die at home. Another objective of home care was to help the patient to return to maximum independence.

CONTENT OF HOME CARE

The care recipient's individual needs

There was consensus in the studies that in home care the most common basis for planning and implementation should be focused on individual needs and their predictors. These comprised physical, psychosocial, social and cognitive dimensions. Thus, home care should be based on identification and professional judgement of the patient's levels of needs for services at discharge from hospital (Table 2).

Table 3 Studies focusing preventive actions and assessments in home care

Authors	Design/care recipients	Objectives	Content	Outcomes
Bernabei <i>et al.</i> (1998) (Italy)	Randomized controlled trial Older people (mean age 80/81) receiving conventional community care service $n = 99/100$ intervention group mean age 80.7, SD 7.1; 70 women and 29 men)	To evaluate the impact of a programme of integrated social and medical care among frail elderly people living in the community Reach independence	Care planning based on case management and comprehensive geriatric assessments	FHS improved as physical function in ADL ($P < 0.001$) and as reduced decline of cognitive status ($P < 0.05$) QoL not measured
Stuck <i>et al.</i> (1995) (USA)	Randomized controlled trial People in the community aged 75 years or older $n = 215/199$ mean age intervention group 81, SD 3.9; 149 women and 69 men)	To evaluate the effect of annual in-home comprehensive geriatric assessments and follow-up for people 75+ living in the community Reach independence	Annual comprehensive geriatric assessments on functional status and use of professional care	Significant reduction of requires in performing ADL QoL not measured
Fabacher <i>et al.</i> (1994) (USA)	Randomized controlled trial Community-living veterans! (male) 70 years and older $n = 131/123$ mean age intervention group 73.5 SD 4.3	To evaluate the effectiveness of in-home geriatric assessments as means of providing preventive health care and improving health and functional status of community-living veterans Reach independence	Assessments of medical, functional and psychosocial problems and follow-up with recommendations	Significant improvement in FHS as IADL ($P < 0.05$) QoL not measured
van Rossum <i>et al.</i> (1993) (Netherlands)	Randomized controlled trial People aged between 75 and 84 in a local area $n = 292/288$ intervention group: age group 75–79, $n = 210$, age group 80–84, $n = 82$ (170 women, 122 men)	To assess the effect of preventive home visits by public health nurses on the state of health of and use of services by elderly people living at home Reach independence and maintain QoL	Preventive home visits by a nurse	No significant differences in FHS and in QoL
Pathy <i>et al.</i> (1992) (UK)	Randomized controlled trial Patients aged 65 and over living in domestic accommodation registered with a general practice in Cardiff $n = 369/356$ Mean age intervention group 65–74 = 68.7, SD 2.8 75+ = 79.8, SD 4.1 (frequency women and men not discussed)	To describe the outcome of a 3-year randomized controlled study in an urban general practice of case-finding/surveillance programme based on self-reporting functional screening with follow-up by a health visitor Reach independence and maintain QoL	Visits with assessments, recommendations and follow-up by a health visitor	FHS measured as self-rated health status was superior in the intervention group ($P < 0.05$) No significant differences in QoL
Vetter <i>et al.</i> (1992) (UK)	Randomized controlled trial People aged 70 and over $n = 350/324$ proportion of men and women and age distribution were similar	To assess whether intervention by a health visitor could reduce the number of fractures over a 4-year period in those aged 70 and over Reach independence	Home visits including preventive assessments by a health visitor	No significant differences in FHS as physical functioning measured as falls and fractures incidence QoL not measured

Table 4 Studies focusing actions and assessments in home care after discharge from hospital

Authors	Design/care recipients	Objectives	Content	Outcome
Richards <i>et al.</i> (1998) (UK)	Randomized controlled trial Medically stable elderly who fulfilled the criteria for early discharge to 'hospital at home scheme' $n = 241/81$ intervention group mean age 79, range 72–84	To compare effectiveness and acceptability of early discharge to a 'hospital at home scheme' with that of routine discharge from acute hospital care Reach independence and maintain QoL	Hospital at home as a substitute for hospital care	No significant differences in FHS and QoL
Shepperd <i>et al.</i> (1998) (UK)	Randomized controlled trial Patients recovering from * hip replacement $n = 37/49$ (mean age 71, SD 7.7) * hysterectomy $n = 114/124$ (mean age 45, SD 9.4) * knee replacement $n = 47/39$ (mean age 68, SD 7.9) * elderly medical patients $n = 50/46$ (mean age 77, SD 11.6) * patients with COPD chronic obstructive airways disease $n = 15/17$ (mean age 71, SD 7.2)	To compare hospital at home care with inpatient hospital care in terms of patient outcomes Reach independence and maintain QoL	Hospital at home as a substitute for hospital care	No significant differences in FHS or QoL in any of the diagnose groups except in the hospital-at-home group for hip replacement, which reported a significant improvement in QoL Patients in all groups preferred hospital at home care except those with COPD
Forster & Young (1996) (UK)	Randomized controlled trial Patients with disability related to new stroke aged 60 and over $n = 120/120$ Intervention group median age 73, range 60–94 (54 women and 66 men)	To evaluate whether specialist nurse visits enhance the social integration and perceived health of patients with stroke or alleviate stress on caregivers in longer term stroke care Reach independence and maintain QoL	Visits by a specialist nurse providing information, advice and support	No significant differences in FHS except in a subgroup of mildly disabled, who had improved social outcomes ($P < 0.01$) No significant differences in QoL as perceived well-being
Strijbos <i>et al.</i> (1996) (Netherlands)	Randomized controlled trial COPD patients with moderate to severe airflow limitation $n = 17/15$ intervention group mean age 60, SD 7.8 (12 men and five women)	To assess the feasibility and application of a 12-week-home-care pulmonary rehabilitation programme Reach independence	Home-care rehabilitation programme carried out by different professionals with assessments, planning, implementation and follow-up	Significant improvement in FHS as physical functioning related to diagnosis QoL not measured
Gladman <i>et al.</i> (1993) (UK)	Randomized controlled trial Patients (mean age 70) discharged after acute stroke $n = 162/165$ intervention group mean age 70 (77 women and 85 men)	To compare the functional ability and perceived health status of stroke patients treated by a domiciliary rehabilitation team or by routine hospital-based services after discharge from hospital Reach independence and maintain QoL	Domiciliary rehabilitation service with assessments, planning and implementation provided by physiotherapists and occupational therapist	No significant differences in FHS as physical function and QoL

Table 4 Continued

Authors	Design/care recipients	Objectives	Content	Outcome
Melin & Bygren, 1992 (Sweden)	Randomized controlled trial Frail elderly (aged 80 and over) patients discharged after short-stay hospital treatment $n = 110/73$ intervention group mean age 80.5, SD 7.2 (78 women and 32 men)	To evaluate the impact of primary home-care intervention programme on patient outcomes after selected patients were discharged from short-stay hospital Reach independence To assess the effects of home nursing care for patients with progressive lung cancer Reach independence	Multidisciplinary primary home care providing assessments, individual treatment planning and home care on a 24 hours basis Three different home nursing conditions; oncology home-care program, SHC standard home-care program, OC office care program	A significant improvement in FHS was found in ADL, in IADL, in outdoor/indoor walking and in cognition
McCorkle <i>et al.</i> (1989) (USA)	Randomized controlled trial Patients with progressive lung cancer Sample 166 randomly assigned into one of the three groups (6 women and 105 men)	To compare a community support scheme using care attendants with standard aftercare for their effects on independence and morale of elderly patients discharged from hospital and on their use of health and social services. Reach independence	Community based hospital discharge scheme providing support comprising of practical care, rehabilitation and social help	Significant improvement in FHS in the home nursing care groups The office care group indicated significant improved health perception QoL not measured No significant differences in FHS measured as ADL QoL not measured
Townsend <i>et al.</i> (1988) (UK)	Randomized controlled trial Elderly patients discharged from hospital $n = 464/439$ intervention group mean age 82, 25% over 85 (291 women and 173 men)			

Preventive actions and assessments

The preventive assessment programmes comprising the entire process of assessment, recommendations and follow-up proved to be the most effective than those with assessments only. To obtain positive effects, the programme had to comprise the whole process of assessment of functional abilities, recommendations and follow-up. It was obvious that home care in the area of preventive actions and assessments was of great value in reducing and delaying the need for hospital care (Table 3).

Actions and assessments after hospital discharge

Home care after discharge, described as a process of assessment, planning, implementation and follow-up (Table 4), was delivered as home-care rehabilitation programmes or different forms of hospital at home. In the studies about home-care rehabilitation programmes, the authors emphasized the importance of the patients receiving their exercises in their own environments to facilitate the incorporation of the exercises into their usual day-to-day activities. Hospital at home was described as care usually available only in hospital being provided in the patient's home instead. The aim was to prevent admission to acute hospital, to facilitate early admission from acute hospital or to provide care in the home to patients with advanced cancer.

OUTCOMES OF HOME CARE FOR FUNCTIONAL HEALTH STATUS AND QUALITY OF LIFE

All randomized-controlled trials had some aspect of functional health status as an outcome measure, mostly measured as ADL, IADL, cognitive status and social activities. QoL was the outcome measure in 13 of the studies, measured as well-being, feeling of loneliness and/or other aspects of the QoL (Tables 2–4). However, there was an interplay between functional health status and the QoL, which contributed to a difficulty in disentangling cause and effect. Although the outcomes studied in this review mainly focused on the values to the individual, social values of home care were also detected in terms of decreased admission to hospital and a reduction of inpatient hospital days.

Discussion

When interpreting the results of a review some aspects have to be considered. The results may be difficult to translate to other countries due to different health care

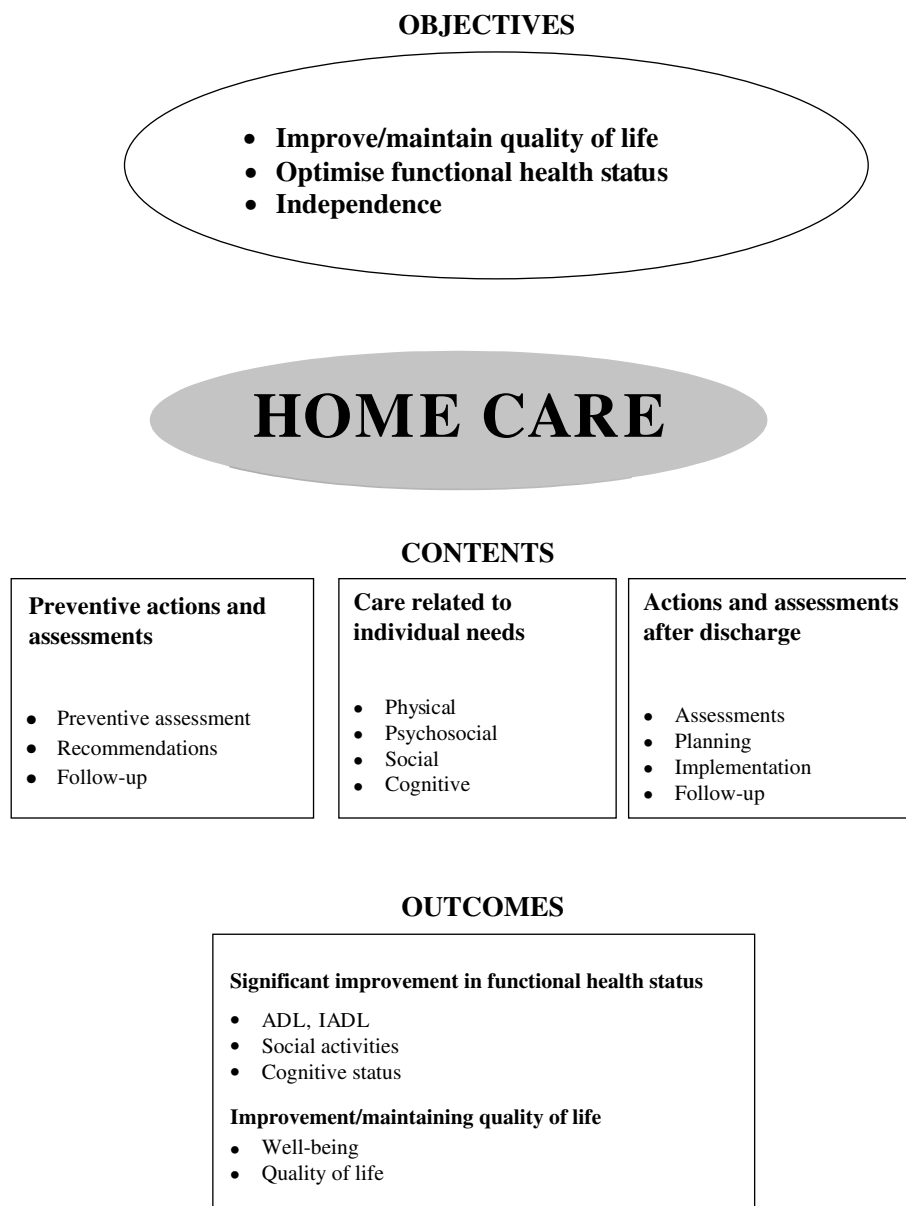


Figure 1 Objectives, contents and outcomes of home care as presented in various empirical studies.

systems and cultures. Furthermore, the population profiles, i.e. older people, were similar in most of the countries. The level of abstraction in the analysis also makes the results more generalized because to a certain degree they are de-contextualized.

The most common care recipients were older people with a predominance of women. The studies can be criticized because old people were treated as a homogeneous group, although the samples were made up of people in ages covering almost 40 years of a lifespan. The needs and the problems of a younger old person are more likely to be different from those of a very old person. There is, for instance, the problem of comorbidity and frailty stemming from age in itself. More detailed age group

analysis is needed besides research focusing on specific age groups among older people and thereby recognizing the different needs within the group of older people in general.

Another important shortcoming in the studies was that no concern was given to the gender perspective, in spite of the dominance of women in the studies (Townsend *et al.*, 1988; Melin & Bygren, 1992; van Rossum *et al.*, 1992; Stuck *et al.*, 1995; Krach *et al.*, 1996; Bernabei *et al.*, 1998; Richards *et al.*, 1998). It is well known that women and men have different needs, problems and living conditions in old age (Steen & Djurfeldt, 1993). For instance, women more often live alone, are more often widowed, and often have a lower economic standard in old

age. Their life situation is therefore quite different from that of men and different from when living as a couple (Statistics Sweden, 2000). There is an obvious need to apply a gender perspective and more age differentiation in future research, especially when it comes to old people.

The aim was to review the literature on home care as a phenomenon and the concept of home care. To conceptualize demands a definition of a phenomenon, which according to Meleis (1997) is an aspect of reality that can be consciously sensed or experienced. Phenomena within a discipline are the aspects that can reflect the domain or territory of a discipline. Concept exploration includes identifying the major components and dimensions of the concept with appropriate questions raised about each component (Meleis, 1997). When discussing the concept home care in this study, concept exploration may concern questions about the content, the outcomes and the underlying objectives.

The content of home care cannot be singled out as focusing on only one aspect. Rather, there were at least three interrelated tasks, care related to individual needs, actions and assessments as prevention, and after hospital discharge (Fig. 1). Thus, home care comprised a variety of activities, ranging from actions preventing decreased functional abilities in old people with the goal of maintaining independence, via palliative care in advanced diseases, to increasing or maintaining patients' QoL and allowing them to die at home. The content described in various studies corresponds to different levels of prevention, i.e. primary prevention provided to act against dependency on care, secondary prevention in terms of early detection of disabilities and diseases, and tertiary prevention as palliative care provided to intervene against lasting side-effects of disease and treatment. This extensive field of actions and assessments indicated that the role of home care is by no means coherent or one-sided. As a concept, it comprises a whole range of activities that may not hang together or cannot be understood or described as one concept. These activities entailed cheaper care and were based implicitly on the idea that being cared for at home is the best alternative. A differentiated description and terminology for home care seems to be appropriate. Referring to Meleis (1997), perhaps home care is best defined as a group of phenomena rather than a single phenomenon or as a multidimensional concept.

The outcomes reported in the studies had two different foci, one on the individual and other on the public health care system. Thus, the term home care indicated multiplicity rather than unity. The benefits for the individual were mainly discussed in terms of life quality and functional health, while the benefits for society were

discussed in terms of minimizing hospital days based on the assumption that being cared for at home increases QoL. Thus, indirectly the benefits for the individual and the society seem to coincide. The aim of this study was not to arrive at any conclusion about the effects from a societal perspective. Although the review did not focus on health-economic outcomes, it seems that home care may be beneficial for the society. The benefits for the individual stood out in the studies as advantages of home care when it came to improving functional status, described as PADL and IADL, and maintaining social and cognitive abilities.

The implicit objectives appeared to be similar in the studies. The objectives for the individual, in improving and maintaining QoL, were related to the possibility of remaining at home in spite of disabilities and illness. In addition maintaining and improving independence could be achieved by optimizing functional health. However, the assumption that being at home is the best mode of care can be questioned. An old person who lives alone may not always prefer to be cared for at home or receive the best care at home. Expressions of positive effects of interventions varied. 'Hospital at home' was considered positive when there were no differences in functional health status and QoL between the hospital at home group and the inpatient group. Effects of preventive actions and assessment, however, had to show significant improvement to be considered as having positive effects. The benefits of home care for patients with advanced cancer remain unclear, as the findings in most of the studies were limited due to subject attrition over the course of investigation and high refusal rates. Smeenk *et al.* (1998) arrived at the same conclusion, in a systematic review of home-care programmes for patients with incurable cancer, that the general belief that home-care programmes are effective for patients with terminal cancer was supported from a scientific perspective mainly because of methodological problems. Thus, the objectives of home care differed.

From this review it becomes obvious that a useful definition of home care claims inclusion of the benefits for the individual and society. The great variety of expressions for home care in the studies reviewed indicates that the authors focused more on describing home care from the present perspective than trying to give a more general definition of the concept. Meleis (1997) suggests that home care, seen as a concept, provides a concise summary of thoughts related to the phenomenon of home care. Home care as a phenomenon seems to be best understood as activities representing the whole span of care activities from primary prevention to palliative care at the end of life. As home care represents a large field of care activities, it might be more appropriate to use home care as an

umbrella concept with different subconcepts describing the level of the activity and objectives in focus. Further, home care based on the implicit definitions in the studies reviewed could be seen as twofold, having the individual at the forefront of health care resources and health-economic benefits. Thus, although the two foci could be conflicting as regards the objectives, they do seem possible to reconcile.

In conclusion, home care as a phenomenon, based on this review, was the care provided by professionals to a person in his/her own home with the ultimate goal being not only to contribute to his/her life quality and functional health status, but also to replace hospital care with care in the home for societal reasons and covering a wide range of activities from preventive visits to end-of-life care. Thus, seen as a group of phenomena, there is a need to develop clearly defined subcontents with home care as an umbrella term. It seems necessary to apply a gender perspective and more age differentiation in future research. As the field of home care seems extensive and the future demands on home care will be even greater, research is needed to elucidate the content valuable to care recipients and society and the health care system, focusing on when and how these goals interact with each other.

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Appendix

The following criteria were used to assess methodological quality of the studies in the review.

A. Internal validity

- operational definitions clearly described?
- sample clearly described (inclusion criteria, exclusion criteria and size)?
- method procedure for sampling described and appropriate?
- comparability of the groups adequate?
- interventions and controls clearly described?
- use of outcome measures and follow-ups appropriate?
- drop out handling adequate?
- presentations of statistical data appropriate?

B. Reliability

- instruments/tests tested for reliability?
- reliability coefficient for used instruments presented?

C. External validity

- Could the outcomes be generalized and to what extent?

D. Critical discussion

- the authors critical assessment of the study?
- the authors discussion of the outcomes compared with other similar studies?

The scores related to each criteria were

1 = high, 2 = moderate, 3 = low methodological quality.
or

1 = low, 2 = moderate, 3 = high risk of bias,

Articles scoring > 8 were included.