

From Centre for Family Medicine,
Department of Neurobiology, Care Sciences and Society,
Karolinska Institutet, Stockholm, Sweden

**DISCHARGED FROM HOSPITAL AND IN
NEED OF HOME CARE NURSING –
EXPERIENCE OF OLDER PERSONS,
THEIR RELATIVES AND CARE
PROFESSIONALS**

IngBritt Rydeman



**Karolinska
Institutet**

Stockholm 2013

All previously published papers were reproduced with permission from the publisher.

Published by Karolinska Institutet.

© IngBritt Rydeman, 2013
ISBN 978-91-7457-893-5

Printed by



www.reproprint.se

Gårdsvägen 4, 169 70 Solna

*I älskat minne av
min käre make ANDERS och goda samtalspartner
jag saknar dig
Mina föräldrar Bror och Eva,
svärföräldrar Gunnel och Åke
Tack för att ni funnits i mitt liv.*

*Till min älskade, älskade son
DANIEL
“nothing’s impossible”*

I denna utsatthet och ensamhet
visar sig tillvarons absurditet.
Den givna formen, världen,
förlorar sin karaktär av självklarhet.
Därmed öppnas möjlighet
att bli mottaglig för något nytt,
okänt och absolut annat än
vad som föreskrivs av den
allmänna ordningen.

S. Kierkegaard

De som har färdats i okänt land
återvänder inte oförändrad

C. S. Lewis

ABSTRACT

Background and aim: The discharge process (DP) is full of well-known risks. The general aim of this thesis was to shed more light into how different stakeholders experience the DP and evaluate the older persons' and their relative's preparedness for life at home after hospital discharge.

Materials and methods: Both qualitative (Studies I, II, IV) and quantitative (Study III) research methods were selected. In Study I different care professionals (n=32) were interviewed in eight focus groups. Study I used a phenomenological method. In Study II older persons with home care nursing (HCN) and their relatives (n=26) were interviewed, and a grounded theory method was used. In Study III data were collected through a questionnaire among older persons and their relatives (n=152) and the questionnaire's psychometric properties were evaluated. Study IV was based on the data in Studies I and II and used an excursive interpretation based on a phenomenological approach and reflective lifeworld research.

Results: The older persons and their relatives, as well as the care professionals, viewed the DP as ambiguous. Care and planning were described as fragmented. Three themes were important for care professionals' cooperation, actions and the outcome of the DP, but also associated with various difficulties and problems. The main concern of the older persons and their relatives was worry about not being sufficiently prepared for life at home. A theoretical model was created that illustrates whether the older persons and their relatives felt prepared or unprepared for life at home at discharge. The care professionals' skills were shown to be of utmost importance to satisfy the preparatory needs of the older persons and their relatives in three significant areas. The questionnaire showed that fifty-three per cent of the older persons and their relatives reported being insufficiently prepared. Factors associated with being insufficiently prepared were poor health at the time of the discharge and not asking for information. The DP is shown to be a critical event with illness making the meaning of life's fragility abruptly explicit and an unpredictable threat to getting on with one's life. The DP is characterised by experiences of being *in-between* that is *contextual*, *bodily* and *existential* for the older persons and the relatives accentuating their vulnerability. The relationship with care professionals and others, bodily conditions and life circumstances influence the *in-between* experience. Without the professional support and cooperation among them in the DP, the older persons run the risk of being lost and powerless throughout the DP.

Conclusions: The DP deeply affects older persons and their relatives. When care professionals use a disease-led approach in their encounter with older patients and follow solely medical routines, they may lose focus on the patients' health processes. The older persons' and their relatives' experiences of exposedness and vulnerability due to illness, bodily, existential or contextual uncertainty indicate a threatening existence in the DP. The older persons and their relatives can easily be lost in an *in-between* experience illuminating the difficulties embedded in the illness, care and the DP in an older person's life. Care professionals need to acknowledge the individual and their everyday world and give follow-up support at home. This would make the DP a strong bridge between the hospital and home. The PPLH questionnaire developed from the theoretical model can be used to provide information that may prove useful in improving the DP from the perspective of older persons and their relatives and also as an assessment tool to identify and satisfy needs among older persons and their relatives both at hospital and at home.

Keywords: discharge process, older persons, relatives, health, home care nursing

CONTENTS

List of publications	7
Abbreviations and definitions	8
Health and living conditions among older persons	9
Growing old	9
The ageing population	9
Health among older persons	9
Living circumstances of older persons	11
Home nursing care for older persons	12
Home care and home care nursing – definitions	12
Policies and organisation in Europe	12
Policies and organisation in Sweden	13
Care utilisation and transition	14
The hospital discharge process	16
Towards a definition of the DP and its regulations in Sweden	16
Return to the home environment	16
Studies of the discharge process	17
Identifying patients’ post-discharge needs	17
Discharge planning models, packages and interventions	18
Patients’ and relatives’ concerns and satisfaction with the discharge process	19
Discharge process questionnaires	19
The rationale for this thesis	21
General and specific aims	22
General aim	22
Specific aims	22
Methods and participants	23
Study Design	23
Study I	24
Study II	25
Study III	27
Study IV	32
Ethical approval	33
Main results	35
Discussion	44
Methodological issues	49
Implications	51
Conclusions	52
Future perspectives	52
Summary in Swedish/ Sammanfattning på svenska	53
Acknowledgements	55
References	56
Appendices	65

LIST OF PUBLICATIONS

This thesis is based on following original articles, referred to in the text by their Roman numbers.

- I Rydeman, I & Törnkvist, L.
The patient's vulnerability, dependence and exposed situation in the discharge process: experiences of district nurses, geriatric nurses and social workers. *Journal of Clinical Nursing* 2006, 15, 1299–1307.
- II Rydeman, I & Törnkvist, L.
Getting prepared for life at home in the discharge process – from the perspective of the older persons and their relatives. *International Journal of Older People Nursing*, 2010, 5 (4) 254–264.
- III Rydeman, I., Szulkin, R., Westerlund, J., Agreus, L. Törnkvist, L.
Self-perceived preparedness for Life at Home among older persons when discharged from hospital – Development and Testing of a Questionnaire. In manuscript.
- IV Rydeman, I., Törnkvist, L., Agreus, L., Dahlberg, K.
Being in-between and lost in the discharge process – An excursus of two empirical studies of older persons', their relatives' and care professionals' experience. *International Journal of Qualitative Studies on Health and Well-being*, 2012, 7, 1–9.

ABBREVIATIONS AND DEFINITIONS

ANOVA	Analysis of variance
DP	Discharge process
EURHOMAP	Mapping professional home care in Europe
GT	Grounded Theory
GP	General practitioner
HCN	Home care nursing
KMO	Keiser-Maier- Olkin measure
NBHW	National Board of Health and Welfare
PAF	Principal axis factoring
PHC	Primary health centre
PPLH	Perceived Preparedness for Life at Home questionnaire
TCM	Transitional Care Model
WHO	World Health Organization

Older persons: persons aged 65 years and over.

Relatives: children, spouses, cohabitants of the older persons.

Ordinary housing: the older person's home where health care is provided via out-patient care.

Special housing: the older person's home, i.e. nursing homes and sheltered housing where health care is provided from the municipalities.

Care professionals: used to describe nurses, district nurses, social workers and physicians at hospitals, municipalities and/or home nursing care.

Home care: professional care provided at home to adult people with formally assessed needs, both health care and social support in daily living.

Home care nursing: healthcare, given by district nurses in the patient's home where the responsibility for care is consistent over time.

HEALTH AND LIVING CONDITIONS AMONG OLDER PERSONS

GROWING OLD

Many who live into advanced age might experience functional decline and dependency on others [1], though chronological age has lost some of its relevance as a marker of old age and care needs. However, frailty, failing health and dependency of others accentuates the older persons' vulnerability. Patients are always somewhat exposed and vulnerable due to their suffering and need of care [2]. Older persons might be especially vulnerable in the discharge process (DP) due to increased likelihood of illness induced limitations and multifaceted care requirements [3]. Despite, these well-known reality the health care system is reported to fail older persons in many European countries [4-6].

THE AGEING POPULATION

The world's population of persons aged 65 years and older is rapidly increasing and is predicted to further rise in the coming decades in the western world [7-10]. Recent decades have seen life expectancy sharply rise in the European Region, which has the highest median age in the world – over 72 years for men and 80 for women [11]. In Sweden the proportion of persons aged 65 years and older was 13.8% in 1970, 18.5% in 2010 and is expected to reach 22.7% by 2030, i.e. every 5th person [12]. In 2007, life expectancy in Sweden was 83 years, making it eighth in the world [8].

The rapidly increasing older population has led to an increase in the number of care-dependent older persons in Europe [7]. For that, WHO in Europe recommends that all countries need to prepare for these demographic trends by adapting their health systems for the ageing population [11]. Moreover, the increasing burden of chronic diseases among the older population requires health promotion and disease prevention intervention at the community level as well as disease management strategies within their health care systems [11].

HEALTH AMONG OLDER PERSONS

Definition of Health

Health is a common concept, but other notions, such as well-being, life quality and life satisfaction is also used. Healthy ageing is high on the agenda of WHO Europe, which is defined as: *the process of optimising opportunities for health, participation and security in order to enhance quality of life as people age. It allows people to realise their potential for physical, social and mental well-being throughout the life course to*

participate in society according to their needs, desires and capacities, while providing them with adequate protection, security and care when they need assistance [11].

Health is complex and multifaceted whose conditions, components and prerequisites are not clearly distinguished [13-15]. The Swedish philosopher Nordenfält [16] stipulates that health is something different from and something more than the absence of diseases, injuries and defects. A new theory on health and nursing care described health as well-being and as “being able to” [15]. Health is an integral feeling of well-being and consequently more than biological health. Well-being is intertwined with the experience of vitality, having power and mood to carry on with one’s minor and major life projects. Other Nordic nursing theoreticians also include concerns embracing the whole person, perceptions of inner balance in relation to other persons as well as life itself [14, 17]

Health of older persons

Older persons are not a homogeneous group and their expectations and perceptions of health are largely individual and may change in various situations. Factors such as deterioration of the older person’s faculties and circumstances that come with ageing, may challenge older persons’ satisfaction with their everyday life and health [18]. Moreover, acute illness, problems with the home environment, a non-active life, lack of close relatives and loneliness has also been reported to decrease quality of and satisfaction with life among older persons [18, 19]. In contrast, important factors for health, satisfaction with life and well-being are physical abilities and mental capacity as well as social support [20]. Drafted in 2009, WHO Europe’s policy brief concerning health care systems for an ageing population summarised that health trends among older persons are complex and vary in different countries [21]. These trends stress the need to provide a suitable and supportive environment for older persons and better coordination across different levels of care and measures to avoid inappropriate hospital care.

By and large, older persons in Sweden have relatively good health and functional abilities [22, 23]. However, it is known that with increasing age the proportion of persons reporting good health decreases. In a recently published report from the National Institute of Public Health, the results from a questionnaire survey of national public health among persons aged 55-84 showed persons aged 75–84 years reported significantly poorer health than the younger age groups [24]. Fifty per cent of those aged 75–84 years also reported reduced mobility and severe physical abilities [24]. Furthermore, in another report from the Institute showed that those who reported poor health were mainly those with low socio-economic status, people living alone, women and foreign-born individuals [25]. Multi-morbidity, i.e. having several diagnoses, is also reported to decrease a person’s physical ability and life quality while increasing the need for health services [20]. Jacobson et al. [26] studied the relationship between care utilisation and psychosocial and life satisfaction factors among 63 frail older persons in southern Sweden over a five-year period. The authors found that those whose use of care mainly involved outpatient care had the highest levels of satisfaction with life. Another study, found that factors leading to a low level of satisfaction with life among 522 older persons with reduced self-care capacity included poor overall health, low

financial status, difficulties in performing activities of daily living, loneliness and anxiety [19].

LIVING CIRCUMSTANCES OF OLDER PERSONS

Most European countries as well as the US and Australia currently support older persons' living at home for as long as possible [9, 27-30]. In Sweden, older persons generally continue living in their homes for a long time [31], regardless of whether or not they need assistance or another living. Reasons for this include unwillingness to move or scarcity of special housing facilities available. Six per cent of the older persons in Sweden live in special housing [31]. The number of older persons with failing health who receive home care is steadily increasing [32-34] and many receive support also from informal caregivers, e.g. their relatives [25, 35]. It is well known that until the end of their life, older persons want to have control and to be independent, respected and autonomous [36, 37] whereas dependency on others may imply vulnerability [15]. Reduced physical ability diminishes older persons' abilities to function in daily life and the more their abilities are reduced the more vulnerable they are to a poorly conforming environment [1]. When the home environment is, thus, unsafe, it becomes threatening for the older persons [1].

HOME NURSING CARE FOR OLDER PERSONS

HOME CARE AND HOME CARE NURSING – DEFINITIONS

Home care is defined by EURHOMAP, i.e. mapping professional home care in Europe, as: *professional care provided at home to adult people with formally assessed needs, which includes rehabilitative, supportive and technical nursing care, domestic aid and personal care, as well as respite as relief to informal caregivers* [4]. The interventions in home care represent an array of support from preventive visits to end-of-life care [38, 39].

Health care at home is mainly described as home care nursing (HCN). According to preparation for the health and medical care act, HCN is defined as healthcare provided in single homes in common housing stock from primary health care to persons in need of long-standing measures. The definition according to the term base by the National Board on Health and Welfare is: *Healthcare, when given in the patients' home where the responsibility for the healthcare is coherent over time. The measures and contributions should proceed from former assessment of the care* [40].

In the Stockholm County Council, HCN is further specified as: *Health care provided in the person's home, the health care does not demand specialised palliative care, inpatient care, or advanced care at home. The person's needs are related to medical or physical conditions and the person's needs for health care support is continuous over time, lasts more than 14 days and is provided at least twice a month* [41, 42].

POLICIES AND ORGANISATION IN EUROPE

European policies stimulate that older persons should continue to live at home for as long as possible, by providing appropriate healthcare and social support when needed [27, 30]. Enabling a greater proportion of older persons to stay healthy and active is key for future sustainable health [11].

Home care could be an answer to the care and social needs among ageing and care-dependent older persons [30]. European general home care policies are mainly a national affair, while the organisation and care services are often decentralised with a tendency towards private providers [4]. The financing policies of home care differ within and between countries and international comparisons are difficult to make due to the limited and incomplete scientific literature in the area. Moreover, medical advances have allowed for health care and advanced care to become part of outpatient care and include a number of home-based solutions [43]. Home-based solutions are important not only for health, social and emotional benefits but also for potentially reducing public expenditures, as home care has been shown to be more cost-effective than institutionalised care [11]. In addition, older persons and their families prefer home care to institutional care [4, 30]. In several European countries, common problems in home care include the coordination and integration of home health care and home help [4].

POLICIES AND ORGANISATION IN SWEDEN

Approximately 250,000 persons in ordinary and special housing receive HCN in Sweden, where 87% are 65 years and older and most are women [43]. Patients receiving HCN also have a greater number of care episodes and hospital days compared to the population in general. Older persons who have both HCN and home help are prescribed the most medicines. In Stockholm County, 17,000 patients aged 65 and older receive HCN, which constitutes an increase of 6% over the last two years [42]. The mean age among them is 80 years, 50% is over 85 years of age; 70% live alone and two-thirds are women. HCN is dominated by persons with complex care needs, reduced autonomy and in great need of support from others [43]. One-third of the patients have been diagnosed with dementia or cognitive failure. Other common diagnoses include heart failure, cancer, conditions post stroke and fractures [42].

Swedish public policy goals stress promoting well-being for older persons, access to good health care and social services, and the possibility of living independently and safely at home [44]. The responsibility for health care is shared by the state, county councils and municipalities. The county councils operate the hospitals, out-patient care and sometimes home care nursing (HCN) in ordinary housing while the municipalities operate in special housing. Outpatient care, such as home-based nursing services, hospital and hospice-at-home care, is seen as central in ensuring the quality of life for older persons. The primary health care in out-patient care is the basis of health care services irrespective of disease, problem and age, and is the biggest part of healthcare services in Sweden. Since 2008 the population has been entitled to freedom of choice of healthcare providers. The concept of choice is high on the political agenda and was recently introduced into social services.

Since 1992 there has been a change from inpatient to outpatient and home-based care for older persons. This has been coupled with a shift of resources from acute and long-stay beds to community care through the healthcare and social service systems. The number of hospital beds and the length of hospital stays has decreased to around half from 1992 to 2008 [34]. Moreover, the number of special housing units in the municipalities has decreased by 20% over the last 30 years. The responsibilities of municipalities include the provision of special housing with integrated health care, i.e. nursing homes, sheltered housing, group homes and places for short-term care, as well as respite care for older persons, giving relief to relatives [45]. The municipalities' responsibilities also include provisions for social and home help for persons living in ordinary and special housing, i.e. support to manage household tasks and personal care in order to satisfy the person's physical, mental and social needs. The support is individually applied based on means.

The healthcare and social care systems are financed by public tax. Fees are charged for both home help and health care, but they are only a fraction of the actual cost. Financing of the provision of health care at the PHC is based on the number of patients who have actively chosen the specific PHC, and increases as the person ages; there is also an amount charged for each home visit [41]. The provision of healthcare should include actions such as health promotion, cooperation, rehabilitative nursing

and other specialised care. However, a recent report of HCN at eight PHC in Stockholm County showed that the financing system did not consider health promotion or the needs of the sickest older persons and that there was poor coordination and cooperation among the care providers in the older persons' chain of care [46].

A reason for such shortcoming may be that HCN in Sweden is not very well defined – not the assignment or the older persons' use of it [33, 43]. Since the older persons might have a great need for support from both home care and specialised care, emphasis the need for continuity of care, well-functioning collaboration and coordination among involved caregivers [32-34]. On behalf of the government, the National Board on Health and Welfare (NBHW) detailed the order and measures of primary health care for the sickest older persons. NBHW states that PHC has a great responsibility for health care, but health care measures for the sickest older persons are not explicitly described [47]. Furthermore, the Board concluded that PHC's chain of care needs to be further developed in close relationship with other caregivers; they question whether the financing system is a sufficient driving force for developing a healthcare system responding to the needs of older persons and stresses that older persons would benefit from person acting as a coordinator of their care. Moreover, older persons are at risk of being disadvantaged due to the free choice of care services unless they have engaged relatives or other help [47].

HCN is district-nurse led and constitutes various kinds of home health care support. The district nurse is the main provider of HCN [39, 41]. HCN is a form of care requiring a holistic view of the patients' needs as well as cooperation among involved caregivers, due to the often complex care needs, including participating in the care planning in the DP [33, 41, 47]. Over the years, Sweden's district nurses in particular have made a considerable contribution to the healthcare of older persons with chronic conditions [48]. The general practitioner (GP) at the PHC is responsible for patients' medical conditions [48]. The most commonly provided measures in HCN in the Stockholm area refer to management of medical treatment for the majority of patients, blood-pressure testing and sample taking for half of them [42]. Approximately half of the patients received support with two or more different measures. Twenty per cent received measures several times a day, 20% once a day and one-third at least once a week. One-third of the patients received visits from the GP one to two times a year and 10% less often. Fifty per cent of the patients visited the GP at the PHC. Home care means that patients cannot attend PHC due to patients' physical or cognitive impairments, according to a mapping of HCN in Stockholm County [49].

CARE UTILISATION AND TRANSITION

International studies have shown that diseases such as chronic obstructive pulmonary disease and heart failure co-vary with high inpatient care utilisation and cause repeated hospitalisation among older persons [50, 51]. However, the high frequency of multi-

morbidity among older persons may indicate that specific diagnoses are uncertain predictors for inpatient care utilisation [52]. Moreover, older persons with a long history as users of inpatient care are reported at risk of remaining high users of both inpatient and outpatient care [50, 53]. In the US, persons aged 65 and older accounted for one-third of all hospitalisations [54] and estimated re-hospitalisation costs are high and associated with gaps in follow-up care [55].

A NBHW mapping of care utilisation among persons aged 65 and older in Sweden found that 50% accounted for half of all the care time and over 50% of the bed-days at hospital [34]. Persons aged 85 years and older, i.e. 2.6% of the population, consumed 13.8% of the total bed-days during 2008. Another study in southern Sweden followed 694 persons aged 65 and older, with long-term care in both ordinary and special housing, who had been hospitalised during the course of one year [56]. Fifteen per cent of them had been hospitalised three or more times during the year; they had more diagnoses and contacts with different care givers than those who had been admitted fewer times. Those who received long-term care in ordinary housing utilised hospital care and outpatient care to a greater extent than those in special housing [56]

After reaching age 80, many people perceive difficulties in managing personal care themselves and at 85 years half of the women and one-third of the men received personal care support [34]. According to reported drafted by the municipalities nearly 211,000 people aged 65 years and older living in ordinary housing received home help service during one day in 2010, which is an increase of 5,000 people compared to former years. Seventy per cent of them also received support from HCN [34].

Effective care management for older persons across the healthcare system and the different social sectors is a key issue for society [11, 30]. Older persons who require transition between care settings and care givers might have different needs than the general population, due to the increased likelihood of multi-morbidity, illness-induced limitations, cognitive impairment and living alone [54]. Other conditions affecting needs in care transition are expectations, knowledge and skills including people's reactions to life changes. Facilitating transition is identified as a central concept for nursing care [57] and attention must be paid on supporting the patient's own control when they have been through a period of health-related turbulence. Learning to live with chronic diseases, illness and disabilities is an ongoing process which requires time and thus appropriate nursing support and education when needed. By accepting a new level of capacity control and self esteem could be strengthened and feelings of well-being and health could be constituted [58, 59] regardless of whether the older persons depend on assistance by others in daily living [60].

THE HOSPITAL DISCHARGE PROCESS

TOWARDS A DEFINITION OF THE DISCHARGE PROCESS AND ITS REGULATIONS IN SWEDEN

The DP is a concern in many countries and the need for improvement has long been emphasised [32, 54, 61-63]. Principally the DP is routine and uneventful, but for persons with complex conditions and in need of continuing care, a comprehensive and well-executed DP is of utmost importance for safe patient care ([34, 64, 65]. A well-executed DP could also be more cost effective.

Different concepts for the DP are used as there is no standardised definition of the DP. A common one is that the DP is a set of actions undertaken by hospital professionals in collaboration with the other involved caregivers to guarantee that patients' transition from hospital to home meet their continued need for follow-up by primary healthcare and/or social services [64, 66]. Discharge planning is also an integral part of healthcare and an accepted nursing intervention aimed at preventing problems after discharge [28, 67, 68]. The patients' transfer from one level of care to another should be conveyed in a smooth and coordinated manner as they cross boundaries of settings and sites [66, 67]. In reality the DP often occurs at the last minute [34, 65] and the information gathering and performance of the DP varies according to local policies at individual hospitals.

In the official directives about the DP, the concerned parties' in-patient and out-patient care and the municipalities have an obligation to develop common guidelines and routines for how the information should be conveyed among them and cooperation should be realised [64]. The DP should commence as soon as the patient is admitted to hospital and be reviewed throughout the hospital stay [64]. According to the directives, the physician authorises the patient's release from the hospital and recognises whether the patient is medically fit and clinically ready for out-patient care [64]. In addition, the patients and their relatives should be involved in the DP. Finally, a care plan should be conjured up for patients continuing care need. The care plan should include how these needs would be met and by whom. The concerned caregivers from outpatient care and municipalities confirm and thus take over the responsibility of the patients' forthcoming care needs. In an overview of HCN in Sweden, an NBHW report states that the ambiguous allocation of responsibility among caregivers worsens cooperation between caregivers [47]. Moreover, the organisation of the healthcare system should also ensure that patients receive the right treatment at the right time, at the right care level to prevent unnecessary readmissions and help patients achieve the best possible health outcome [47].

RETURN TO THE HOME

After older persons are discharged from hospital and back at home again they often have to adjust and cope with possible repercussions due to illness and health problems [62, 69]. Many encounter a variety of problems within the first week back at home, a

particularly vulnerable period [10, 70]. The most commonly reported overall adverse event for older persons in several countries is related to medicine treatment, which also causes a considerable number of readmissions [71-74]. Discrepancies in medication during the hospital to home transition are common [75, 76]. Studies report that many of the medicine-related adverse events could have been prevented [55, 72, 75]. Moreover, patients are also reported to be discharged too early and, thus, a large responsibility for care provision is placed on any informal caregivers [73, 77, 78]. In order to facilitate management at home the informal caregivers, e.g. relatives, are important to include in the DP. For example, a survey in Norway included persons aged 80 years and older, discharged from hospital, showed that the chances for managing well were much greater for those with someone at home than those with no one [79].

STUDIES OF THE DISCHARGE PROCESS

The DP has received attention since 1990 [10, 80-83]. Different factors are reported to negatively influence the patients' discharge: organisational and environmental circumstances such as ambiguities regarding the division of responsibility among caregivers, short length of stay in hospital, unstructured apprehension of patients and lack in discharge routines [32, 82]. Besides, professionals are still reportedly developing discharge plans for patients instead of with them [84].

The result of poorly designed discharge and transition processes is hospital readmission, post-hospital adverse outcomes and unplanned acute measures [78]. In the US nearly one-fifth to one-quarter of recently discharged persons experienced a post-hospital adverse event or hospital readmission within 30 days [55, 85]. Moreover, older persons may be temporarily confused while at hospital [86]. Research demonstrates that any suspect or diagnosed cognitive impairment could worsen during hospitalisation, thus increasing the risk for adverse outcomes [87]. Additional factors associated with adverse outcomes after discharge are advanced age, being a woman, living alone and lack of social support [88, 89].

IDENTIFYING PATIENTS' POST-DISCHARGE NEEDS

A complex step in DP is identifying patients' post-discharge needs [83]. Therefore, competence among involved care professionals has been shown to be of importance [83]. Moreover, collaboration and multidisciplinary approaches are also highlighted [90, 91], as well as communication among professionals [32, 78, 83, 92, 93]. In a recently qualitative study about the DP, stakeholders in five European countries were interviewed regarding aspects of organizational culture [94]. The authors reported following critical aspects; a fragmented hospital to primary care interface, undervaluing administrative tasks relative to clinical tasks and lack of reflection on the DP. In contrast, health care systems enabling information exchange and negotiation between stakeholders is reported to facilitate collaboration and identification of patients' post-discharge needs [95].

DISCHARGE PLANNING MODELS, PACKAGES AND INTERVENTIONS

To facilitate and improve identification of patients in need of support after discharge, and to prevent undesirable outcomes, a number of different screening tools [53, 96, 97] and guidelines have been tested [96, 98]. Specifically, computer-enabled discharge interventions [99] and various other interventions for better coordination of a patient's discharge have been tested [100-102]. Moreover, studies of post-discharge follow-up from, e.g. pharmacists [100-102] advanced practice nurses in the community [103] and nurses and physicians at hospital [104] all reported to reduce hospital readmissions.

Golden and colleagues [105] pointed out that older persons with dementia and multiple health conditions often are excluded in studies of the DP. Growing literature summarises that predicting which patients are at high risk for re-admission is an inexact science mainly due to the fact that DP packages and models are cumbersome and limited when applied to older persons [52]. In the US the Transitional Care Model (TCM) has been developed addressing the health care needs of older adults coping with multiple conditions [28]. The model is nurse-led, and includes an interdisciplinary team approach both at hospital and at home and uses a standardised protocol for identifying persons at high risk of poor health outcomes. The authors picture the TCM as contributing to increasing alignment of the care systems for high-risk individuals and their relatives and reducing health care costs [28].

The most common adverse outcome measured is impact on readmissions, i.e. unplanned readmission within 30 days of hospital discharge, which might reflect deficiencies in DP [106, 107]. Other outcome measures are mortality rate, patient satisfaction, health outcomes and costs [78].

A Cochrane review identified 21 randomised controlled trial studies (RCT) to determine the effectiveness of discharge planning from hospital to home [78]. Patients with various medical conditions were included in the studies. The overall evidence suggested that a structured discharge plan tailored for individual older persons with a medical condition probably brings about a small reduction in hospital length of stay and readmission rates. The authors summarise that the impact of discharge planning remains uncertain on mortality, health outcomes and costs. Patients who are insufficiently informed about their condition and self-care needs are left vulnerable to adverse medical events and unnecessary readmissions. Nevertheless, they state that a comprehensive and reliable discharge plan, coupled with post-discharge support, seems to be vital to ensuring quality transitions, reducing readmission rates, and improving health outcomes [78]. In another review including 18 RCT studies of discharge arrangements for older persons, the authors concludes that arrangements across the hospital and community interface seemed to be safe and to reduce readmissions to 20% [108].

A meta-review of discharge interventions, aimed at reducing problems after the discharge, included 15 studies [70]. In the review the authors reported the studies had heterogeneity in interventions, populations and outcomes. Some evidence was found that intervention with educational components and those combining pre- and post-discharge intervention had some positive impact on patient status, costs and patients'

functioning; however, on the whole they conclude that evidence was limited. Another systematic meta-review of controlled trials of pre and post-discharge interventions included seven studies [106]. The studies targeted high-risk populations, i.e. older persons and those with heart failure. Interventions that included multi-components, i.e. both pre and post-discharge interventions, seemed to be more effective than single component interventions in reducing readmissions [106]. Motamedi and colleagues reviewed the efficacy of computer-enabled discharge communication interventions in 12 studies, of which 8 were RCT studies[109]. Meta-analysis was not possible due to the heterogeneity in measures and outcomes. The authors concluded that computer-enabled discharge communication tools are beneficial and worth implementing due to the evolution of electronic patient information systems despite little evidence.

In summary, since the 1990s, researchers have investigated various approaches and strategies for discharge planning interventions to improve the DP. In general, the results of the reviews showed limited evidence. The interventions were highly heterogeneous and the reported outcomes showed considerable variation and literature does not permit rigid conclusions about which interventions are effective. The available evidence is difficult to analyse and more rigorous trials are needed and suggested.

PATIENTS' AND RELATIVES' CONCERNS AND SATISFACTION WITH THE DISCHARGE PROCESS

Another central aspect in the DP is whether the older persons' and relatives' concerns are met [82, 110]. Patients' satisfaction with the DP is vital to explore, since well-operated DPs are linked to patient satisfaction [103] and their ability to manage at home [111]. The lack of success in improving the DP could indicate a need for measures and instruments that reflect older persons' perspectives [3]. Studies have shown that getting answers to questions is essential for both patients and their relatives [102, 103]. However, older persons are reported to be excluded from the DP [112, 113]. In several studies patients and relatives describe their need to participate in the planning and to receive clear and comprehensive information in order to handle the illness and the situation at home [114-117]. Their desire for participation in their care has been reported in international research [114, 118]. Some studies report that the older persons want to have an active role in their care [114, 119] whereas other reports show them wanting a less active role [118, 120].

Study findings suggest that both older persons' and relatives' lack of knowledge, skills and resources are obstacles to good care and safety at home [121-123] and that relatives are dissatisfied with their level of involvement in the DP [71, 122]. Sahlsten and colleagues [124] showed that professionals also need to be willing to facilitate and encourage patients to take part in the decisions-making.

DISCHARGE PROCESS QUESTIONNAIRES

In part, DP questionnaires measure patient's satisfaction with the services received at hospital among patients with heart failure [103], diabetes and chronic obstructive

pulmonary disease including questions on continuity of care, care management, referrals, conflicting information and continuity of physicians [125] and among orthopaedic patients [126]. Mahoney and Weiss [127] developed a questionnaire to investigate whether the information at hospital met patients' information needs and Grimmer [110] one about the information exchange, medicine management, preparation for coping and control of discharge circumstance. In the US the transitional care measure is endorsed for comparative studies on hospital care [128]. The measure includes items regarding critical understanding, importance of preferences, management preparation and existence of a written and understandable care plan. In Australia a questionnaire has been developed to measure a government-established transition care program targeting older persons who require more time and support following a hospital admission [129]. However, no rigorously tested instruments were found about the DP addressing older persons receiving HCN.

A review of questionnaires of older persons' perspectives of the DP included 10 questionnaires [3]. Four major areas were identified from the literature by the authors to cover older persons' participation in the DP, namely time for discharge, community health care, practical matters and medication. The questionnaires found were developed in the US, Holland and Australia, mainly based on literature reviews and most of them were used only once and not rigorously tested. Three of the questionnaires were developed to capture older patients' perspectives [61, 68, 130] and one captured the patients' desire for participation [67]. The majority of the questionnaires included few items about participation or covered areas that older persons themselves identified as most essential. The main focus was on one-way flow of information, i.e. from care professionals to the patients and the authors conclude that questionnaires and research focusing on older persons' perspectives has been slow to evolve.

THE RATIONALE FOR THIS THESIS

The literature review about the DP showed that the research is extensive and that the DP is a concern in the Western world. The diversity in the research results confirmed that no univocal effect of interventions and in general, the results of the reviews of the DP models showed limited evidence. However, a well executed DP, including follow-ups, seems to increase patient safety and reduce costs to society. Since the proportion of older person increases in population in the Western world, and thus persons with complex health conditions, and several diagnoses who use numerous medicines. They are also often dependent on others to manage daily living activities, needing healthcare and specifically vulnerable in the DP. Any deterioration in health might require hospitalisation. Any deterioration in health might require hospitalisation. During the discharge and transition between levels of care, they are exposed to new organisations, new professionals and new contexts that may lead to unique problems for them. Research focusing on the older persons and their relatives in this area, though vital, is limited. The lack of knowledge about the experiences and perspectives of older persons discharged from hospital and in need of HCN as well as their relatives was the main incentive for this thesis.

GENERAL AND SPECIFIC AIMS

GENERAL AIM

The general aim of this thesis was to shed more light into how different stakeholders experience of the discharge process and evaluate the older persons' and their relative's preparedness for life at home after hospital discharge.

SPECIFIC AIMS

The specific aims of this thesis were:

- To gather and analyse experiences of the discharge process among different care professionals (Papers I & IV)
- To develop a model to understand how older persons in need of home care nursing and their relatives experience the discharge process (Papers II & IV)
- To validate the psychometric properties of a questionnaire that measures perceived preparedness for life at home among older persons and their relatives after discharge from hospital (Paper III)

METHODS AND PARTICIPANTS

STUDY DESIGN

The design of the four studies, carried out between 2001 and 2011, was explorative. The overall aim of the thesis was to deepen the knowledge about the DP from different perspectives. In Study I different care professionals were interviewed in focus groups to achieve a deeper understanding of their experiences of the DP. In Study II older persons with HCN and their relatives were interviewed in order to examine their experiences with the DP and to develop a model explaining their experiences. In Study III a questionnaire was developed to measure older persons' perceptions of preparedness for life at home when discharged from hospital and its psychometric properties were evaluated. The empirical results in study I and II raised new questions that induced the excursus in Study IV aiming to increase knowledge about the DP at a deeper level of understanding. The research methods used in the studies were: phenomenological method (I), grounded theory (II), questionnaire development and psychometric testing (III), and excursive interpretation based on a phenomenological approach and reflective lifeworld research (IV).

The study area encompassed the Stockholm region. Studies I and II were carried out in two municipalities and at one major hospital. Study III encompassed the whole Stockholm region. The studies involved older persons aged 65 years and over, who received regularly HCN at least twice a month from district nurses working at PHC (II, III, IV). The older persons had various medical conditions and support from HCN, municipalities and others. Relatives were also invited to participate (II).

In the thesis the concept of DP is used to include all actions and preparations of an older person's discharge from hospital and transition to home.

Table 1. Overview of research with study focus, participants, data collection and analysis.

Study	Focus	Participants	Data collection	Analysis
I	Experiences of the DP among different care professionals.	District nurses, nurses and social workers (n=31)	Focus groups interviews	Phenomenological method
II	Older persons and their relatives experience with the DP and to develop a model	Older persons and relatives (n= 26)	Individual and groups interviews (n=21)	Grounded Theory
III	Develop a questionnaire and evaluate its psychometric properties	Older persons and relatives (n=152)	Questionnaire	Psychometric testing, ANOVA
IV	Deepen the understanding of the DP among older persons, relatives and care professionals	Study sample, see Studies I and II	From Studies I and II	Excursive phenomenological approach and reflective life world research

Study I

Settings and participants

The study was carried out in two municipalities including units from PHC, special housing social services and geriatric units at one Hospital in the southern part of Stockholm, Sweden. The participants were care professionals who had the most frequent contacts with the DP. Managers at the respective workplaces suggested the names of professionals who were asked to participate in the focus groups. The inclusion criteria were that the professionals had worked regularly with the DP. The professionals received written invitations to the focus-group interview. Thirty-one persons were interviewed in eight focus groups and at two times. The care professional included were district nurses at PHC, district nurses/nurses in special housing, nurses in hospital geriatric- care units and social workers. The professionals had worked for periods varying from nine months to 10 years at their respective workplaces (mean= 3 years).

Data collection

Data were collected through focus-group interviews. The focus group was chosen to enable the care professionals to explore and clarify their views of the phenomenon DP, through group interaction. As stated by others this might have been more difficult in a one-to-one interview [131, 132]. The focus-group interviews were conducted by the same moderator and at the workplaces of the different professionals. Areas of interest included the DP, patient participation, problems and possibilities. The moderator began by giving the same information about the aim of the study to all participants. Without leading the discussion the moderator encouraged the professionals to describe their experiences. An observer also participated and took detailed field notes, including key discussion points and noteworthy quotations. The interviews lasted for 60–90 minutes and were audio taped. Following the interviews, the moderator and the observer summarised and discussed their impressions, which were also audio-taped. The interviews were transcribed verbatim.

Phenomenological method

To obtain an in-depth understanding of the professionals' experiences of the DP, it was necessary to examine their descriptions in detail. The phenomenological method described by Malterud [133] was used. The method made it possible to go beyond common explanations for problems involving this phenomenon, such as lack of time and personnel and technical resources and barriers. Phenomenology is a philosophy as well as a research method, purpose of which is to describe experiences as they are lived [134, 135]. The phenomenology method points explicitly to ideas and assumptions that are hidden and that influence behaviours and actions [136]. It involves bracketing, intuition, analysis and describing. Bracketing means being aware of one's pre-understanding and not letting it guide the analysis. The phenomenon is examined with an open mind in order to grasp its uniqueness and meaning. During analysis, the descriptions are compared and contrasted. Finally, a description of what has been revealed is formulated [133, 134].

Analysis

In the first step in the phenomenological analysis [133, 134], the whole texts were read through to obtain a rough understanding of the whole phenomenon. With this as a basis the texts were re-read and divided into meaning units organised into 16 preliminary themes. Examples of meaning units: *at the hospital they decide that the patient needs to live in the special setting, but we make another assessment. We think she/he can manage at home with more help from us*, organised into preliminary themes: *hospital staff makes decisions without involving other caregivers or the patient. Other caregiver makes another assessment*. Next, the themes were transformed into a disciplinary language; *View of mankind, organisation*. The transformed meaning units were synthesised into a consistent statement of the structure of the phenomenon. During the analysis, the researchers had an ongoing discussion and read the texts repeatedly, so that the meaning was described as experienced by the participants.

Study II

Settings and participants

In order to form a heterogeneous group of older persons with varying medical conditions, situations and needs, patients were selected in a major hospital in a large city. The older person had been hospitalised at; geriatric, orthopaedic, infection, neurologic and rheumatologic units. Patients at seven PHC in two municipalities were included. District nurses (n=32) were informed about the study in a letter. The district nurses identified and asked older persons who satisfied the inclusion criteria. These specified persons at least 65 years of age discharged from hospital within two weeks and under regular HCN, i.e. at least once every two weeks after discharge. The older person's relatives, if any, were also invited to be interviewed.

An eligibility-based selection was made to ensure that the sample of older persons incorporated diversity in terms of age, gender and social situation in order to achieve a broad and in-depth picture of the discharge process. Twenty-one interviews were conducted with 26 persons concerning 17 older persons. Three of the older persons could not participate in the interviews due to their medical condition or mental disorder and an additional two could only partly provided data. The mean age was 79 years. One

of the participants had experience of only one discharge, two were discharged to respite care and this was arranged urgently for one from home. Four participants were readmitted urgently within 1–3 days after discharge from hospital. They received help from the district nurse with, for instance, drug treatment, blood sampling, surveillance, wound care and care of catheters (urine and blood).

Table 2. Characteristics of the older persons (n=17) under study and participants in the interviews on occasion 1 and 2.

Older person's code ¹	Gender ²	Age	Marital status ³	Support from social services	Reason for hospitalisation	Interview 1 participants ⁴	Interview 2 participants ⁴
A	M	84	M	No	Heart problems	O	O
B	M	65	M	No	Infection	S	–
C	M	74	M	No	Infection	O,S	OS
D	F	72	M	Yes	Rheumatic disease	O	–
E	M	81	M	No	Infection	O,S	OS
F	F	73	M	No	Intestinal problems	O,S	O
G	M	75	M	Yes	Intestinal problems	O	–
H	F	87	W	Yes	Dehydration	O,C	–
I	F	70	W	No	Infection	O	–
K	M	81	W	Yes	Heart problems	O	–
L	M	71	M	No	Heart problems	S	–
M	F	85	W	Yes	Fracture	O	–
N	M	82	M	No	Pneumonia	O,S	–
O	M	79	M	Yes	Stroke	S,C	–
P	M	91	M	Yes	Intestinal problems	O,S,C	–
Q	F	77	W	Yes	Intoxication	O	–
R	F	82	M	No	Heart problems	O,S	–

¹ Older person's code: A–R. ² Gender: Male=M, Female=F. ³ Marital status: Married=M. Widow/widower=W.

⁴ Older person=O. Spouse=S. Child=C.

Data collection

Twenty-one in-depth interviews were conducted. Four of the participants were interviewed twice. The interviews took place at the home of the older persons 4–8 weeks after being discharged from hospital. They were audio-taped, lasted 40–90 minutes. The aim of the interviews was to explore the participants' experience of the DP by means of a few introductory questions and to encourage them to talk and clarify the details. The introductory questions focused on: the older persons'/relatives' experience of the interactions with the professionals in the DP, both positive and negative, thoughts and actions taken in different discharge situations and at home; important aspects of quality for the older persons/relatives in connection with the discharge. As the analysis progressed questions became more and more focused.

Grounded theory

The grounded theory (GT) method [137-139] was used to develop a deeper understanding of how older persons and their relatives experience being discharged from hospital to home. GT was chosen because it provides a structured approach to understanding what is happening in the interaction between the older persons their relatives and the care professionals within the DP, i.e. how older patients and their relatives deal with and manage their situation. The method facilitates the development of a theoretical model grounded in empirical data which can illuminate experiences. The research strategy followed classic GT presented in Glaser & Strauss [138], developed in Glaser [140] but also influenced by Strauss & Corbin [141], as outlined in Hylander [142]. GT include the process of constant comparison during throughout collection, selection, coding and analysis of data and memo writing-to assist the analysis.

Analysis

Each interview was transcribed verbatim and carefully read in order to capture the overall substance of its content. A process of constant comparison was carried out throughout collection, selection, coding and analysis of data. Memos were written to assist the analysis and keep track of ideas and hypotheses. Memos covered questions and possible connections, as well as theoretical and methodological considerations.

The analysis started after the first interview. Each interview was analysed line-by-line to identify initial codes that were given names (open coding); the informants' own words were used as much as possible. Comparisons of differences and similarities between the codes were continuously made to ensure that those with similar content were given the same labels. These substantive codes were compared and similar codes were clustered to form descriptive categories. Example of analysis: *when anything happened at home the first few times we didn't know how to handle it and had no one to contact – uncertainty (open coding) – where to turn with questions (category)*. The analysis guided the data collection. The core process “*getting prepared for life at home*” was identified in which all the categories and most of the interaction could be related. The categories were saturated, their properties and dimensions were delineated and subcategories of each category were explored. Conceptual relationships between categories and subcategories were sought and continuously verified in the data (theoretical coding). The content of each category was described and extracts from interviews were selected to illustrate the categories. Finally a substantive theory was outlined.

Study III

Settings and participants

PHCs with at least one hundred patients enrolled in HCN were included, i.e., 53 of 157 in Stockholm County. Two procedures were used to identify persons from the 53 PHCC, representing different geographic areas, see figure 1. First, 17 PHC were asked to submit lists of persons enrolled in HCN, 8 of which agreed to do so. Second, the County Council register of patients enrolled in HCN was used to identify persons from an additional 6 PHC. A total of 1752 persons were identified. In addition, the County Council database of patients who had been hospitalised was used also for length of hospital stay, number of hospitalisations and diagnosis. Information about cognitive

state was not available, but 22 persons had been diagnosed with Alzheimer’s or other dementia and were therefore excluded. The two procedures identified 636 possible persons.

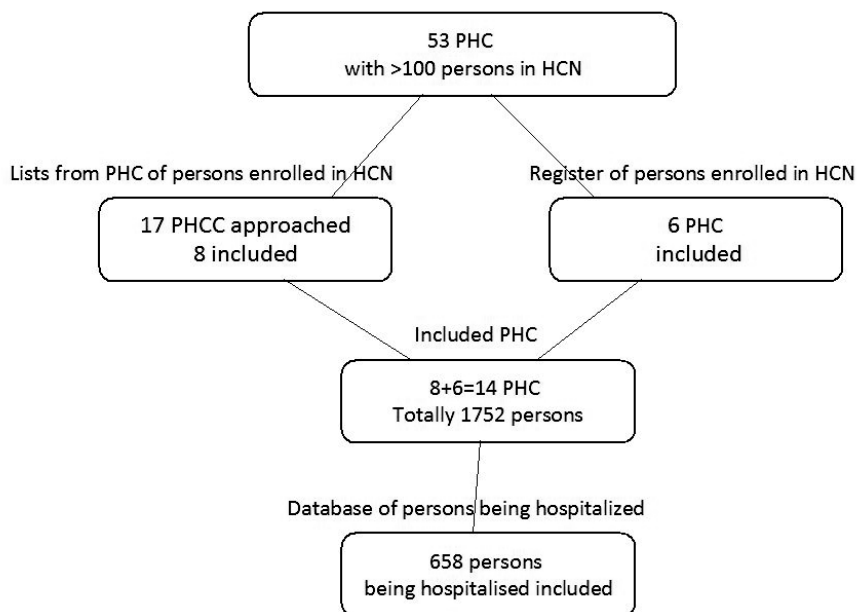


Figure 1. Procedures to identify older persons (n=658) for the study.

The inclusion criteria were older persons who received regularly HCN, were 65 years and over, lived in their home and had been hospitalised for at least two days during the past six months. The questionnaire entitled *Perceived Preparedness for Life at Home* (PPLH) was developed from the theoretical model in study II. The questionnaire, a cover letter about the study and a self-addressed stamped envelope were sent to the 636 persons. Those who had not completed and returned the PPLH or contacted the researcher received a phone call (n=259) or were sent a reminder letter (n=121). One-hundred fifty-six persons did not meet the inclusion criteria or had died. No information was available for 200 persons who did not complete the PPLH. A total of 158 persons returned the questionnaire, 6 of whom were excluded because they had more than 8 missing items out of the 26 concerning preparation. The sample consisted of 152 older persons.

Table 3. Demographic and background data of the 152 older persons.

	n	%
Gender (n=152)		
Female	94	62
Male	58	38
Education (n=148)		
None	3	2
Compulsory school	83	56
Secondary school	38	26
Post-secondary	24	16
Living arrangements (n=149)		
Cohabiting	49	33
Single	100	67
Help from the social services before hospitalisation (n=152)		
Yes	93	61
No	59	39
Help from social services today (n=151)		
Yes	116	77
No	35	23
Help from the district nurse before hospitalisation (n=152)		
Yes	99	65
No	53	35
Who answered the PPLH? (152)		
Older person	79	52
Someone else	10	7
Older person and someone else	63	41
Need for information at discharge (n=146)		
Yes (rated 0)	21	14
No (rated 1–6)	125	86
Health at the time of admission (n=149)		
Poor (rated bad, rather bad)	109	73
Good (rated good, rather good)	40	27
Health at the time of discharge (n=149)		
Poor (rated bad, rather bad)	70	46
Good (rated good, rather good)	79	54
Health the preceding week (n=151)		
Poor (rated bad, rather bad)	65	43
Good (rated good, rather good)	86	57

The respondents had been hospitalised for different reasons, see table 4.

Table 4. Reason for hospitalisation among the older persons (n=137)*.

Problems related to:	n	%
Orthopaedic	32	23
Cardiovascular	29	21
Gastrointestinal	16	11.7
Cerebral	11	8
Infection	10	7
Dermatological	6	4
Urological	5	4
Eye, diabetic, pain, gynaecological, haematological and rheumatologic	5	21.3

*No diagnosis had been registered for 14 of the older persons

The older persons (n=135) reported having received support from the district nurse with medical treatment (73), wound care (35), blood sampling (31), surveillance (10), maintenance of urine catheters (7), injections (6), taking of blood pressure, (4) compression treatment (5) medical devices (2) and infusion (1). Thirty-two per cent of the elderly received support with more than one measure.

Development of the questionnaire Perceived Preparedness for Life at Home

Questionnaire development: The rationale behind the development of the new questionnaire were based on that none were found in the literature that suited our target group. The questionnaire development involved devising relevant items assessing preparation for the included categories of *preparation areas* and *preparation skills*. Appropriate response alternatives and a logical structure were devised, followed by an examination of face- and content validity. The PPLH was devised from the theoretical model *Getting prepared for life at home in the discharge process* (II). An additional 27 items were included to capture socio-demographic and background data, state of health, information about relatives and the initial period at home.

Content validity: The initial draft of the questionnaire and its comprehensibility were first assessed by a researcher with long experience of instrument development and who were judged to have excellent linguistic skills. Eleven healthcare professionals (experts) well acquainted with the DP then tested face and content validity. They assessed the instructions, the relevance of the content and the response alternatives, as well as the formulation and comprehensibility of each item. The validity of each item was assessed on a three-point scale: high, satisfactory and low. The experts deemed all items to have high or satisfactory validity. They also identified similar items and suggested that the statements be rewritten as questions, which was done prior to the next test. Next, five older persons with experience of the discharge process completed the modified questionnaire and were asked to evaluate the comprehensibility of each item on a three-point scale: easy to understand, understandable and difficult to understand. They evaluated all items except for two as either easy to understand or understandable. The

questionnaire was revised after the assessments of the two groups. The final questionnaire included 52 items whereof 27 concerned preparedness.

Analysis

In order to analyse the PPLH's psychometric properties the following tests was involved: factor analysis, ANOVA and reliability tests. Data were computed with SPSS for Windows software, Version 19.0. A significance level of 0.05 was used in all statistical analyses.

Table 5. Statistical tests used in study III.

Purpose/analysis	Statistical test
Describe frequencies and distributions	Mean, range, percent, standard deviations
Assess the differences between two independent groups means, interval, ratio data	T-test
Assess the differences in proportion in two or more independent groups s (nominal data)	Chi ²
Examine correlation between items	Polychoric correlation
Examine correlations among items	Bartlett's test of sphericity
Assess correlations among items	Kaiser Meyer-Olin measure
Extraction method to find underlying structures	Factor analysis, principal axis factoring
Assess number of factors	Eigenvalue, Catell's screeplot, parallel analysis
Assess differences between groups on mean ratings for factors or the total scale.	Analysis of variance ANOVA
Assess the internal consistency of the questionnaire	Cronbach's α
Examine test-retest reliability between ratings on the questionnaire at two occasions	Pearson's r correlation coefficient

Factor analysis Exploratory factor analysis with principal axis factoring (PAF) was used as extraction method to find underlying structures and to reduce the number of items [143, 144]. PAF is recommended for questionnaire development [145]. The factors were assumed to be correlated with each other. Thus, oblique rotation was used to identify the simplest possible structure of the factor loadings [144]. Missing values were excluded pairwise. The selection criteria for the number of factors were based on Kaiser's criteria of eigenvalue >1, Catell's screeplot [146] and parallel analysis [147]. The cut-off point was set at > 0.40 for factor loadings and >0.2 for communality [143, 148, 149].

Predicted group differences Analysis of variance (ANOVA) was used for analysing differences between groups on mean ratings for factors and/or the total scale. In accordance with the findings in the previous study, it was presumed that persons who reported being Sufficiently prepared, Asking for information and Good health at the time of discharge would report higher mean ratings than those who did not. The groups consisted of persons who Asked for information (n=73)/ Did not ask for information (n=57) and perceived themselves as being in Good health (n=70)/Poor health at the time of discharge (n=79). No predictions were made regarding differences between factors or regarding interactions between factors and groups.

Reliability Cronbach's α was estimated in order to test internal consistency and was considered acceptable at 0.70–0.90 for the total scale and > 0.60 for each factor [143]. Pearson's r correlation coefficient was used to establish test-retest reliability between scores on the two occasions that the questionnaire was answered.

Study IV

Settings and participants

The study built upon study I and II. Study I was carried out in two municipalities and included following participants and settings: district nurses in PHC, district nurses/nurses in special housing, nurses in hospital geriatric- care units and social workers in municipalities. In Study II patients were selected in a major hospital in Stockholm. Patients at seven PHC in two municipalities were included. The participants included were: 17 older persons with varying medical conditions, situations and needs. Totally 26 persons were interviewed individually or together.

Analysis

The study is based on an excursus of previously published research (I, II). Data were collected through interviews in focus groups (I) and individually or with 2–3 persons (II).

The foundation of the excursive interpretation is reflective lifeworld research and the analytic principles described by Dahlberg et al.[150] focusing on the world as it is experienced prior to the formulation of any hypothesis in order to explain it. The base is the interview data and the results from two empirical studies, no new data were added. The text units behind the themes (I) and categories (II) as well as the results were re-read to get a sense of the whole. In this new analysis further meanings were displayed. In the common results of the empirical studies the patients and their relatives articulated that they are on their way home but not yet there and that they are at the hospital but have not yet left. Example of a text unit: *it is a chock that you get so seriously affected so fast- and then you are supposed to go home and you are not knowing how it would work out and how you would manage.* With the phenomenological philosophy as a framework, these experiences lead us to an understanding of “*the in-between*”. As another example of the excursive analysis we noticed that the meaning of vulnerability was not explicit in study 2. However, re-reading the data with a lifeworld perspective we found implicitly described vulnerability in expressions of how caregivers were making decisions, “over their heads”, e.g. *it is so hierarchical the physician decides. I distrusted their decision. I did not want it to be like this (relative).* The experience of vulnerability could also be seen in expressions of their frailty and worries of how it will be at home.

All scientific research and not least an excursive understanding of a phenomenon requires a capacity of researching openness in understanding the phenomenon on its own premises, which is called “bridling” [150]. The researcher adopts a reflective stance to prevailing assumptions and theories, as well as to the previously described findings, so that the immediate, spontaneous or taken for granted understanding does not affect the analysis in an uncontrolled way. By bridling the process of understanding the opportunity for seeing something new is strengthened.

Life world theory

Lifeworld theory was originally described by phenomenological inspired philosophers in southern Europe. Husserl [151] is understood as the founder of the phenomenological movement, from which the lifeworld (Lebenswelt) became an important idea in European philosophy. Merleau-Ponty [152], Heidegger [153] and Gadamer [154] took up the thread and describe the same or similar existential themes. The lifeworld theory has ontological as well as epistemological and methodological implications, and in an essential way it characterises humans' existence, our attitude and experience of everything else that we claim to be our world.

Understanding people and their lives in terms of their lifeworlds constitutes the way with which we understand the world. The lifeworld is thus the actual basis and starting point for the everyday world and for a person's understanding. According to Husserl [151] the lifeworld is also the starting-point for scientific work. The lifeworld is the lived world, the world which is "given" in all experience, thought and action. Understanding the lifeworld as the world of experience helps us to understand, explain and describe in a basic way both the everyday world in general and when it is characterised by health, suffering and caring. The lifeworld is at the same time an individual world and a shared world. We live together and interact with others and these relationships influence the subjects' being in the world. For example, patients are essentially affected by their relationships with care professionals and relatives [150, 155, 156].

The lifeworld is an imminent and transcendent world. A person's lifeworld does not have its own existence; it is fundamentally interwoven with and cannot be separated from the person who is described, and is difficult to discern with one's senses. It is characterised both by temporality and by spatiality: the lifeworld is essentially "here and now" but it also involves the movement between the present, past and future, and the different spatial horizons move with the lived body [152].

A central part of the phenomenological philosophy and the lifeworld idea is intentionality. First, intentionality concerns how everything that we think, feel and do in relation to the world around us has its starting point in how this world is experienced by us and, how we observe things in the world around us [157]. Second, it is made clear how we, at a basic level, always experience the world as something, i.e. how everything we see, hear or in other ways perceive always has significance, a meaning for us [150].

Ethical approval

All the studies in this thesis were performed in accordance with the Helsinki Declaration and ethical approval were obtained from the Ethical Committee at Karolinska Institutet at Huddinge University Hospital (I, II) and in Stockholm (III) (registration number 107/01, 311/02, 2008/892-31/5).

For Study I informed consent was obtained from the participants after they had received written and verbal information about the study. In Study II the clinical department heads at the hospital, primary healthcare centres and district nurses were informed about the study in a letter. The district nurses were also informed verbally and asked to identify older persons according the inclusion criteria, to give them verbal and

written information about the study and to ask them to participate. Informed consent was obtained from the participant at the time of the interviews. In Study III approval was obtained from the Chief Medical Officer at Health Care Provision and at the Health Care Registers in Stockholm County. The head of the clinical department and the district nurses at the PHCs were notified by letter. A form was attached with the questionnaire, describing the purpose of the study. The participants consented in writing. The questionnaires were returned in a closed envelope directly to a secretary who had no connection with the project. The list of all names of the participants, including codes, was also kept by the secretary.

All of the study participants were guaranteed confidentiality and that their anonymity would be preserved when the findings were presented. They were reassured that their participation was voluntary and that they could withdraw from the study at any time.

MAIN RESULTS

The main results are presented of respectively study focusing on: the patients' vulnerability, dependence and exposed situation in the DP as described by care professionals (I), getting prepared for life at home in the DP, the main concern of the older persons and their relatives (II), self-perceived preparedness for Life at Home among older persons when discharged from hospital (III) experiences of *being in-between* among the older persons and their relatives in the DP (IV).

Study I

The care professionals reported what worked well, although they mainly described what was frustrating and difficult. They reported about problems regarding: respect for professional knowledge, attitudes among professionals outside their own organisation and workplace, and their varying degree of participation in the DP. They felt that the ambiguity in who was responsible for what in the different organisations involved made collaboration and planning difficult and also seemed to have various negative consequences for the patients.

The overall structure comprised the patient's vulnerability, dependence and exposed situation in the DP and its three themes: Framework, Basic Values and Patient Resources, influencing the professionals' actions in the P. The themes represent different parts of the phenomenon and comprise the phenomenon as a whole. There are no clear boundaries between the themes.

The Framework theme included two subthemes: general and local. The general framework concerned the problems and difficulties of current regulations, resource restraints and comprehensive, written common guidelines constructed for all the organisations. The resource restraints, for example the lack of hospital beds were also experienced as influencing the patient's length of stay and possibility of getting rehabilitation. The local framework concerned problems of routines, the aims of those concerned, the fields of care professional knowledge, and the culture-specific framework within which they worked, i.e. the prevailing norms and assumptions at their own workplaces. Most of them felt that care professionals in other care forms lacked understanding of the conditions and the field of professional knowledge that they themselves worked in. Examples of a culture-specific framework were the hospital environment and the medical language, which were sometimes experienced as negatively influencing the patient's possibility of participating, as well the possibilities of the care professionals acting in the DP.

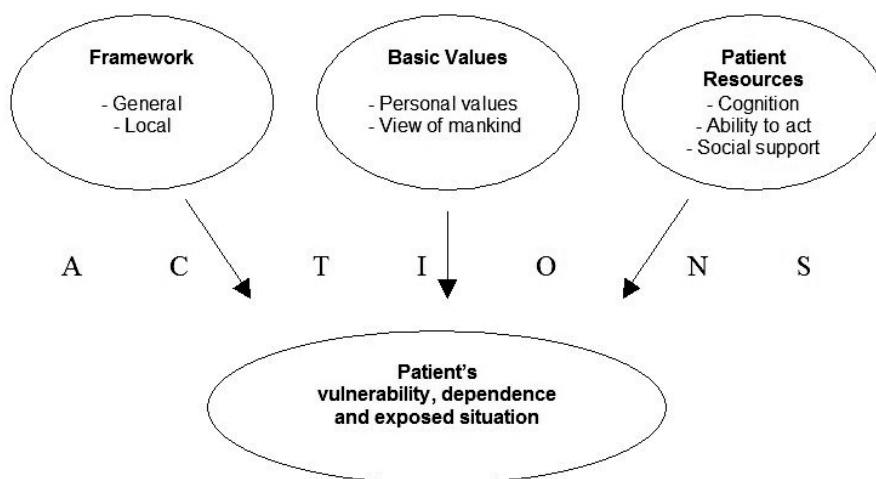


Figure 2. The common essence of different care professionals' experience of the discharge process.

The Basic Values theme included: personal values and view of mankind. The personal values concerned the professionals' views concerning what was right and wrong, as well as their views of mankind. Earlier experiences of problems seemed to influence their expectations and actions both consciously and unconsciously. They described the lack of a holistic view. They experienced a discrepancy between what they themselves judged to be the patient's actual needs and what was planned, which led to frustration and a dilemma. In the care professionals' descriptions their view of the patient was sometimes objective and that the focus was on the medical needs. The majority of them emphasised respect for the patient's integrity and right of self-determination, but felt that this was not always observed. The patient was often regarded as alone and exposed and in a disadvantageous and dependent position in the discharge process. Their Basic Values resulted in the fact that the care professionals were often sceptical towards and questioned one another's assessments, actions and decisions.

The Patient Resources theme included the patient's cognition, ability to act, and his/her social support. The patient's cognition, for example, his/her intellectual and theoretical understanding of the situation, was regarded as important, in order for the patient to participate in the DP. Problems arose when the patient did not understand the purpose of the DP or knew what was planned in the follow up care. The care professionals often felt that there was too much information for the patient to absorb in connection with the DP. The patient's ability to act included both physical abilities, i.e. activities in daily life, and abilities to handle situations based on their preferences. The patient's illness could constitute a threat to the desired life situation, and it was seldom possible for them to have a complete picture of what the situation at home would be like. The participants felt that it was not always obvious that the care professionals took as a starting-point the patient's preferences in the DP and discussed from this point of view. Social support, i.e. family support and any previously received support from outpatient

care and social services seemed to facilitate the DP. Family members were often regarded as a resource that could support the patient and also compensate for the patient's possibly insufficient resources. However, frustrations and disagreements regarding the planning of the patient's discharge sometimes arose among them. Family members sometimes persuaded the patient, but caregivers also talked the patient into something.

Problems in all these factors were felt to influence the care professionals' actions and thereby the patient's possibilities of being involved and participating in the DP. Problems and disagreements arose, especially when the patient's resources and needs were not assessed or discussed or when the care professionals were unsure about whether the patient had the resources to take full responsibility for him- or herself.

Study II

The main concern of the older persons and their relatives was to "feel prepared for life at home" in the DP. They worried about not knowing how they would manage at home. The analysis resulted in a theoretical model, *Getting prepared for life at home in the discharge process*. Feeling prepared meant having a satisfactory conception of how life at home would be. The model explains what determines whether older persons and/or their relatives feel prepared or unprepared for life at home at the time of discharge.

Three significant preparation areas were displayed – caring issues, activities of daily living and where to turn, in which the older persons and their relative had needs in, to various extents. The first preparation area, caring issues, concerned the older person's state of health, treatment and the continuing care: for example, information about the follow-up at home. The second area, activities of daily living, concerned common and necessary aspects of daily life, such as support at home and technical aids: for example, knowing about the arrangements at home for meals and personal hygiene. The third area, where to turn to in case of foreseen or unforeseen needs of caring issues and activities of daily living, concerned, for example, knowing who to contact about new prescriptions and if there was a change for the worse.

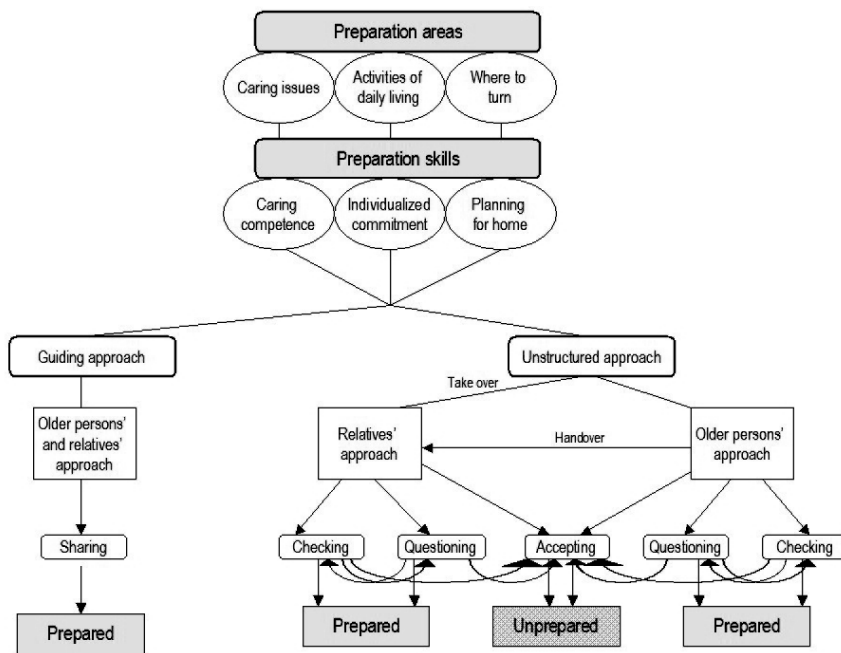


Figure 3. Getting prepared for life at home in the discharge process from the perspective of the older persons and their relatives.

Three significant preparation skills among the professionals were highly valued by the older persons and their relatives; caring competence involving giving quality medical and nursing care; individualised commitment concerning adjustments to meet the need for information and arrangements; planning for life at home including planning and taking care of forthcoming needs.

When the care professionals were skilled in preparation they were perceived as having a guiding approach which supported and satisfied individual needs in the preparation areas. Then the care professionals were perceived as being knowledgeable and committed in their caring functions. When the older persons and their relatives perceived the care professionals as having an unstructured approach, their individual needs risked remaining unsatisfied. The care professionals were then perceived as being, for instance, uncaring, having no insight or interest in their situation and not seeing them as individuals. Moreover, the care professionals could also be perceived as task-oriented, having a medical focus or thinking of the hospital’s best interest.

In addition, the older persons’ and relatives’ own approach was also of importance for satisfying needs. Their approach differed mainly depending on how they reacted to the care professionals’ approach. If the professionals were perceived as being skilled and thus guiding, they reacted with confidence and took a sharing approach. By contrast, they reacted with distrust, disagreement or resignation when the professionals were perceived as being unstructured. If so, they took a checking, questioning or accepting

approach. When they had the strength and interest to actively do something themselves, i.e. checking and/or questioning, their needs had a chance of being satisfied. If this was not sufficient for their needs, they felt unprepared at the time of discharge.

Study III

A questionnaire entitled *Perceived Preparedness for Life at Home (PPLH)* was developed from a theoretical model, *Getting prepared for life at home when discharged from hospital (II)*. A total of 152 persons responded the questionnaire. The mean age was 83 years ($SD = 7.68$, range 65–101), for woman the mean age was 84 years ($SD = 7.96$) and for men 81 years ($SD = 6.9$). The mean number of hospitalisations during the past 6 months was 2 (range 1–10) and the mean length of hospital stay was 8 days (range 2–40). Seventy-seven per cent of the women lived alone and 46 % of the men. Fifty-three per cent answered not being sufficiently prepared for life at home on the question; *Did you feel that you were sufficiently prepared for life at home when discharged from hospital?*

Of those who answered the question about whether they had asked for information prior to discharge ($n=130$), 44% had not asked for any information and 19% had asked for all the information they needed. Thirty-three per cent of the respondents said that they were living with a partner.

The KMO estimate and the Bartlett test supported the use of factor analysis. Extraction of the number of factors based on eigenvalue >1 , screeplot and parallel analysis supported a two-factor solution. The two factors accounted for 54% of the total variance. The final factor solution included 19 items, six items in the original questionnaire were excluded due to deemed not being statistical and clinical relevant. The first factor was labelled *Professional's commitment* represented the care professional's approach and attitude towards the older persons/relatives and their individual needs. The second factor was labelled *Information on how to cope* and reflected different aspects of information on how to manage at home. The results corresponded quite well with the two areas in the theoretical model.

Table 6. Factor solution with factor loadings, communality, dropout, eigenvalue and explained variance for the PPLH questionnaire.

	Factor loadings		Communality	Dropout n (%)
	1	2		
Factor 1 Professional's commitment				
Item				
11 Did healthcare professionals provide explanations in a way that you could understand?	0.92	0.12	0.72	5 (3.2)
13 Did healthcare professionals make plans and arrangements on the basis of your needs?	0.90	-0.15	0.65	2 (1.3)
12 Did healthcare professionals plan your treatment and care together with you?	0.86	-0.15	0.6	2 (1.3)
10 Were healthcare professionals knowledgeable about your health?	0.77	0.10	0.7	3 (1.9)
15 Did you receive information about your health and your disease?	0.77	0.03	0.62	4 (2.6)
9 Did healthcare professionals show interest in you and your needs?	0.77	0.05	0.64	3 (1.9)
29 Did you receive all the information you needed?	0.66	0.27	0.73	8 (5.2)
16 Did you receive information about treatment options?	0.61	0.17	0.53	6 (3.9)
17 Did you receive information about your medication?	0.55	0.03	0.33	2 (1.3)
23 Did you receive information about follow-up care?	0.54	0.25	0.52	4 (2.6)
35 Did healthcare professionals plan and arrange the kind of treatment and care you needed?	0.49	0.31	0.53	8 (5.2)

	Factor loadings		Communality	Dropout n (%)
	1	2		
Factor 2 Information on coping				
Item				
24 Did you receive information about whom to contact with questions about social service agencies?	-0.18	0.85	0.57	0
21 Did you receive information about available support in the home?	-0.03	0.70	0.47	1 (0.6)
25 Did you receive information about whom to contact with questions about your treatment and care?	0.17	0.67	0.62	2 (1.3)
19 Did you receive information about how to use walking aids?	0.06	0.65	0.47	3 (1.9)
22 Did you receive information about who was responsible for your care at home?	0.24	0.60	0.63	4 (2.6)
32 Did healthcare professionals arrange for a district nurse to support you?	0.04	0.59	0.38	9 (5.9)
26 Did you receive information about whom to contact with questions about medical devices?	0.13	0.48	0.33	2 (1.3)
34 Did healthcare professionals arrange for the assisted device you needed?	0.13	0.40	0.24	3 (1.9)
Eigenvalue	9.8	1.8		
Explained variance (%)	45	9		

Reliability tests of internal consistency: Cronbach's α ranged from 0.88 -0.94 for the factor and total scale and test of test-retest reliability ranged from 0.70 and 0.86 (Person correlation) indicating satisfactory reliability for the PPLH questionnaire.

Mean rating

The mean rating for the each respondent was 4.10 (*SD* 1.65) for factor one *Professional's commitment*, 4.85 (*SD* 1.48) for factor two *Information on how to cope* and 4.42 (*SD* = 1.46) for the total scale.

Predicted group differences

A main effect of Preparedness showed that, as predicted, the overall mean rating for respondents who reported being sufficiently prepared was significantly higher than by respondents who reported being Not sufficiently prepared. A Preparedness interaction effect was obtained indicating that the difference between the groups (Sufficiently vs. Not sufficiently prepared) was significantly higher for *Professional's commitment* than for *Information on how to cope*.

Asked for information

The 2×2 mixed ANOVA showed a main effect of Asked for information, that the overall mean rating by respondents who Asked for information was significantly higher than the overall mean rating by respondents who Did not ask for information. A main effect of Type of factor showed once again that the respondents reported significantly higher mean ratings on *Information on how to cope* than on *Professionals commitment*. Finally, a Type of factor \times Asked for information interaction effect was obtained, indicating that the difference between the groups (Asked vs. Did not ask for information) was significantly larger for *Professional's commitment* than for *Information on how to cope*.

Health at the time of discharge, and gender

The $2 \times 2 \times 2$ mixed ANOVA showed a main effect of Health at the time of discharge, as predicted, the overall mean rating by respondents who reported good health was significantly higher than the overall mean rating by respondents who reported poor health. A main effect of Type of factor showed again that the respondents reported significantly higher mean ratings on *Information on how to cope* than on *Professional's commitment*. A Type of factor \times Health interaction effect indicated that the difference between the groups was significantly larger for *Professional's commitment* than for *Information on how to cope*. Women who reported good health at discharge had significantly higher mean ratings on the total scale than women who reported poor health, whereas there was almost no difference between men who reported good health and men who reported poor health.

Study IV

The findings revealed that the hospitalisation and DP are understood as a critical event for the older persons and their relatives, with the illness making the meaning of life's fragility abruptly explicit and an unpredictable threat to getting on with one's life and minor and major life projects. The DP is a phenomenon that is characterised by experiences of being *in-between* and three meaning constituents. The three constituents of the experience of the DP as being *in-between* are not completely separated but intertwined: Vulnerability-lost in the life context; Influencing one's life; Adapting to life circumstances. Contextual, bodily and existential *in-between* experiences are displayed as vulnerability, which relates to the context of being at hospital but on their way home, to the bodily frailty of not being ill but not well enough to manage a life at home and consequently, to a shaky existence. It is important for the older persons to understand the new life situation and to influence their everyday life; here the experience of existential *in-between* is apparent. Living with worsening health, repeated hospitalisations and a fragile body is a reminder of existential fragility, as well as an existential *in-between* situation.

The older persons have to relate to *in between* experiences. The *contextual in-between* implies being part of a hospital context the older persons and their relatives are more or less familiar to and do not fully understand or control. It is a context that they are being controlled and one in which they have to rely on others' expertise. The *bodily in-*

between includes the impact of illness and ageing on body and bodily frailty with aspects such as limited mobility and loss of abilities influencing one's self-perception and independency. The *existential in between* includes being faced with altered life premises including losses and death, and the realisation of life goals one strives to fulfil. The relationship with care professional and others, bodily conditions and life circumstances influence the *in-between* experience.

The DP is marked of bodily and existential diversity intertwined with bodily and existential needs. A decisive factor for how the DP is going to proceed is how the care professionals are able to handle the discharge situation. The care builds upon encounters, relations, perceptiveness and openness toward the patients' and their relatives' needs and awareness of their vulnerability. When the carers treat the older persons and their relatives with respect for their experiences and life coherence, they feel heard, seen and included, and feelings of trust and safety increase. Without the professional support and no cooperation among them in the DP the older persons run the risk of being lost and exposed in the discharge process.

DISCUSSION

Main findings

Study I showed that care professionals overall felt that the patients were vulnerable, dependent and exposed during the DP. Problems occurred in the DP due to different frameworks, rules, values, view and assessment of the patients among the care professional and within different organisations. The results from Study II contributed to new in-depth knowledge about the older persons' and their relatives' experiences of the DP; to get prepared for life at home but also their worry whether or not they can manage at home. The care professionals' approach at hospital could either facilitate or hinder the older persons and their relatives to take part and get prepared. It was often hard for themselves to control or influence the DP. In Study III the initial testing of the new PPLH questionnaire showed it to have satisfactory validity and reliability, capturing self-perceived preparedness for life at home among older persons and their relatives. Half of the respondents reported being insufficiently prepared. Aspects associated with higher degree of preparedness were good health at the time of discharge, specifically for women, and by the patients themselves asking for information. The results from Study IV display the illness and the DP as a course of action where the familiar becomes unfamiliar for the older persons and their relatives, entailing an insecure future existence characterised by the experience of being *in-between*. The *in-between* experiences, i.e. not being ill but not being well enough to manage life at home, are displayed as vulnerability. The older persons have to relate to *in-between* experiences that are *contextual*, *bodily* and *existential*, inducing bodily and existential needs.

The findings raise concerns about whether existing regulations, policies in society and health care and organisational structures support a well-executed DP. How can health care contribute to making the older persons and their relatives feel that they are seen as individuals and that they receive the necessary support to adjust to their often new situation? What are the necessary requirements and needed improvements? The findings will be discussed in relation to the theory of health and well-being as described by Dahlberg and Segesten [15].

Vulnerability in the Discharge Process – “in-between”

Profound understanding of illness and the DP elucidate how the familiar life becomes unfamiliar and how the known transforms into the unknown for the older person and their relatives. Illness signifies the altered access to a good life through a healthy body and the vulnerability in this relationship, though there is a wish to come home again despite being ill. The older person's vulnerability is obvious both in their own descriptions in Study II and in those of the care professionals' about the patients in Study I. Patients are always exposed and vulnerable due to their illness, suffering and need of care as described by Dahlberg and Segesten [150]. The individual reaction to illness and care has particular relevance for their life situation and constitute specific meanings that both illness and care have for their life.

The older persons and their relatives' experiences were characterised by perceptions of being *in-between* in the DP, as revealed in Study IV, entailing an insecure presence and future existence as well as anxiety and worry. The existential *in-between* experiences are displayed as vulnerability, which relates to the bodily frailty of not being ill but not being well enough to manage a life at home. When an older person is confronted with life changes such as illness, self-formulation, creative ways of relating to illness could help give the person access to the existential context [58, 158]. In dealing with the illness and uncertainty, the older persons and their relatives described their need for caregivers to listen to them and to be personally acknowledged for one's needs. However, when their needs were not acknowledged or addressed at hospital, the DP was greatly affected, and the homecoming became distressing and filled with uncertainty.

When the caregivers view the older persons as a "diagnosis", home-goer or a group, they feel like non-persons, which impede their power to create something good from the *in-between* situation, as described in Studies I and II. Studies report that the reductionist view, focusing only on biomedical aspects, impedes a patient's health process [60]. The older persons and their relatives described their need to remain in an existential coherence and to exert influence on their existence as well as having difficulties influencing the DP. The loss of control accentuates their vulnerability and they have to adapt to the prevailing hospital structures. Then the older persons relied on their relatives, if they got any. A review of DP planning models confirms that a large amount of responsibility for care provision is often placed on informal caregivers [78]. Study I shows the difficulties the care professionals experienced, e.g. ambiguities in responsibilities and values within different organisations, making collaboration and planning difficult and implying various negative consequences for the patients.

The older persons' fragility could represent an obstacle, but it is not crucial for the fulfilment of their concerns and goals. According to Summer Meranius [60], interviews with older persons with multi-morbidity showed that their functional abilities did not rule whether they could live a good life or fulfil their goals. In the findings of the thesis the older persons reported being at the hospital but on their way home and how they hoped the situation would improve when they returned home where they at least could regain self-determination. The importance of the home for the older persons' identity and well-being has been described in several studies [60, 159, 160].

Furthermore, in Study II, three preparation areas were shown to be important for the older persons and their relatives – caring issues, activities of daily living and where to turn in case of need of assistance. If the needs in these areas were sufficiently satisfied, they felt prepared for life at home at discharge. These areas are only partly described in other studies, which dealt with receiving adequate information on medical conditions and complications [103, 114, 122] and the availability of community support services [91, 114, 161]. Furthermore, the professionals in Study I found it hard to assess both the patients' needs and their resources, but felt that the medical needs were in focus at hospital implying the patients others needs were not addressed or highlighted.

Factors associated with adverse outcomes among patients after discharge include advanced age, being a woman, living alone, lack of social support and cognitive impairment [88, 89]. In Study II and III, it was shown that older persons experiencing poor health at the time of discharge, and those who did not ask for information, risked feeling insufficiently prepared, implying they were also at risk of adverse outcomes. A reality is that patients are discharged quicker whilst still frail, and thus the risk of adverse outcomes increases [78]. Study II focuses on the importance of that the older persons' relatives' receive the necessary support for reorientation, information and arrangements.

Being dependent and having to rely on care professionals and others, as revealed in Studies II and IV, threatened the older persons' and their relatives' self-dependency, which was essential for their health and well-being. Their care was controlled by others and they had to rely on others' expertise. Health and well-being include to go on with everyday life and its minor and major life projects [15]. The patients' self-dependency needs to be understood in its context by the care as described in other studies [60, 160]. Studies show that if the care is adjusted to the individual, they feel involved and in control of their life [60, 160]. In contrast, when they are excluded from the DP planning, it may lead to loss of control and worry [112, 113]. Despite needing help, older persons could feel independent and realise their life goals but could be impeded if the care professionals do not regard them as individuals or treat them with dignity [60].

The excursive analysis of the DP showed how the illness, care-giving and the DP had particular relevance for the older persons' and relatives' life situation, and constituted specific meanings of loss of one's health and well-being. The loss of health and well-being is essentially related to the life changes and loss of a healthy body as they face unfamiliar circumstances and, not least, when encountering impersonal treatment by care professionals. Both the experience of well-being and the experience of "being able to", which are the essential meanings of health [15] are affected by the existential experience of being "in-between" that characterises the DP. It can be difficult to go on with one's life and fulfil one's important life goals if the DP is not adjusted to the older persons' and their relatives' lifeworld. When the caregivers continue to use a disease-led approach, where medical routines are prioritised, they lose focus on the patients' health processes. The major finding in this thesis highlights the importance of favouring health supportive care as the major focus when older persons are in DP.

Health and well-being in the DP mean that the older person and their relatives among others should be acknowledged as individuals, where one's life context is the central base, as well as engaged and interested care professionals. In Summer Meranius' thesis [60] about older persons living with multi-morbidity, health and well-being are closely linked to perceptions of living in an existential coherence. As Dahlberg and Segesten [15] emphasise, health includes finding ways to live with one's self and in strong interaction with others and the world. All *in-between* situations related to the DP include possibilities as well as risks. The findings show how illness and care giving practices present the older persons and their relatives with an uncertain situation. The DP and its associated care practices may weaken the older persons' life power and may hinder the process of reconciliation. However, being personally acknowledged for

one's potential and supported to re-orientate and establish a new existential context is beneficial for recapturing health and well-being [58, 162]

Vulnerability in the care

Health care needs to match the older persons' and their relatives' life situations, existence and existential coherence in relation to the illness [15, 60, 162]. The thesis results show that care-giving might contribute to older persons' and their relatives' feelings of abandonment, vulnerability and exclusion as well as lack of preparedness for discharge. The care conduces to suffering instead of alleviation a result also supported by other studies [14, 60, 163-166]. Morse [167] described suffering as a fundamental yet normal response to catastrophic loss, Eriksson [168, 169] describes suffering in three forms: as related to illness, as related to care, and as related to life. Berglund et al. [163] reported in a recent study that patients living with long-term and/or life-threatening diseases suffered during care-giving when they felt distrusted or mistreated and when their perspective on illness and health was overlooked. Despite, that the goal of nursing is to improve health and well-being and to alleviate suffering [14, 15].

The older persons' and the relatives' perceptions of an uncertain and shaky existential coherence need to be met and acknowledged by the care professionals – a precondition for good care as described by several researchers [15, 17, 156, 165, 170]. For example, Study II showed that when care professionals were committed and interested, i.e. having a guiding approach, the older persons and their relatives felt safe and implying feelings of preparedness.

Biological health cannot be separated from the existential health experience [15, 156]. However, when a medical approach rules the DP – e.g. older persons are viewed as a “diagnosis”, a fragmented view of them as “older” or “home-goer” – the inequality in care relation became apparent, as described in Study II. Then the DP became controlled by the care professionals. A care relation between the patient and the care professionals is not equal, and is always a dependence relationship. The patient depends highly on the care professionals, which may cause problems due to a power imbalance [15, 17, 171]. Moreover, Study II also showed that the power the caregivers possess could contribute to feelings of exclusions and the *in-between* experiences among the older persons and their relatives.

Studies describe how patients' experiences of non-patient-centred encounters negatively influence patient safety, communication and behaviour [164, 172]. A care ruled by “the way we are used to doing it” impedes the older persons' perceptions of health, excludes their everyday life concerns and diminishes room for individual encounters. Rytterström [173] showed that care in the municipalities was ruled by routines, often task oriented that lacked interpersonal relations with the older persons. Studies also show that the organisational structures and environmental circumstances can restrict or encourage patient participation during hospitalisation [32, 118, 174] consistent with findings described in Paper I.

Assessment of patients' needs requires specialised skills and is a prerequisite for a comprehensive DP [96, 175]. The findings in Study II revealed the three significant preparation skills among care professionals: caring competence, individualised commitment and planning for life at home. A professional approach, including these skills, supported the individuals' needs for satisfaction. In contrast, an unstructured approach – task-oriented, medical focus or thinking of the hospital's best interest, i.e. a fragmented care – complicated satisfying the older persons' and their relatives' needs. The care professionals in Study I saw that it was hard for the older persons and relatives to grasp the DP situation and at the same time they reported how hard it was for them to give the proper support.

Moreover, the role of nurses in the DP is highlighted in several studies, e.g. nurse-led and directed DP models, to improve and prevent adverse outcomes especially for fragile persons [28, 121]. In addition, facilitating transition and discharge planning is also described as central for nursing [68, 97]. Studies also show that multidisciplinary team approaches to the DP bring different perspectives on the needs of older people, and are reported to contribute to a more holistic view of the patient's health processes [103, 176]. Special multidisciplinary assessment instruments may be of help in obtaining a common picture of the patients' resources, preferences and needs [96, 176]. However, awareness about the risk of a reductionist and fragmented view of the individual must be addressed when using such instruments.

Regulations and policies in the discharge process

Patient participation, autonomy and dignity are “soft values” that are highly sought after in health care and societal regulations and policies [177, 178]. However, a gap between reality and legislation has been reported [34] and is further confirmed in this thesis. Thus, bridging the gap calls for improvements. It is important that genuine health care encounters are based on individualisation of the patients, that take account the patient's lifeworld as described [150, 156, 162]. Hence, to increase patient satisfaction with the care system, “soft values” should be widely included in caring practices. However, a poor definition of “soft values” may impede their use and implementation [179, 180].

The health care system seems to contribute to the fact that mostly selective measures are provided and that health care has become a service of solitary fragmented uncoordinated measures [33, 34, 47]. Necessary planning, coordination and follow-up, which the frailest older persons particularly need, seem to fail according to the findings in the thesis. The frailest older persons need well planned and well coordinated health care as is required by policies [32, 64]. Thus, the coordinating of older persons' care is central and it is vital to follow-up on DP decisions and care plans at home. The coordinator's role needs to be further clarified and strengthened, a role and assignment suitable for the district and community nurse working in HCN. Several reviews report that a discharge plan, coupled with post-discharge support, seem to ensure quality transitions, reduce readmission rates, and improve health outcomes [70, 78, 94]. The older person leaves the hospital environment and when back at home, he/she is supposed to manage everyday life; as many of them said, “not until you get home does it become obvious what works and what doesn't.” The DP is supposed to be a health-

promoting bridge between the hospital and the older persons' home, and to support their intentions of going on with their life. However, our results reveal that this DP bridge can be absent or weak. Moreover, healthy ageing is high on the European WHO agenda with such items as optimising opportunities for health, participation and security to enhance quality of life as people age and also to meet the demands of an ageing population [11].

METHODOLOGICAL ISSUES

The research methods used in the thesis were both qualitative and quantitative in order to explore the DP among older persons, their relatives and care professionals. The methods were chosen according to the specific aims of this thesis. Research involving different DP planning packages and models has been performed using a variety of research methods and outcomes which has made it impossible to establish which package and/or model may work best in the DP. The Cochrane reports are based on evidence-based medicine (EBM), grounded in natural science and primarily built upon randomised controlled trials. This research design is used in studies where the biomedical perspective is the predominant one [150, 162]. Research about an individual's life experiences needs other scientific approaches. The DP and its parts are complex and contain a diversity of uncontrollable variables, making the use of a single method impossible. In addition to quantitative research, qualitative research provides the necessary knowledge to develop evidence-based health care.

According to Morse and Niehaus [181] mixed methods could be used for complex aims and questions, e.g. the study has multiple groups of participants. Moreover, mixed methods are useful when the research is explorative and cannot be conducted using a single method. Thus, qualitative and quantitative methods can be combined. The use of both qualitative and quantitative approaches in this thesis improved the process of identifying and monitoring perceptions among older persons and their relatives with respect to the DP as well as among care professionals and refinement of both the PPLH questionnaire and the theoretical model. In addition, the excursive interpretation based on a phenomenological approach and reflective lifeworld research of two empirical studies (Studies I & II) contributed to a more profound understanding of the DP. Despite the fact that interview data were collected and analysed according to different qualitative methods, the studies complemented each other in a useful way that deepened the understanding of the DP.

The thesis addresses older persons with various kinds of medical conditions and can be regarded as representative of older persons in HCN in Sweden. This is also unique since other studies in the area mainly address older persons with one specific medical condition or exclude some conditions [105]. In addition, the older persons' relatives participated in the interviews, all having the major responsibility for the care of the older person. There are some limitations regarding the data collection in the thesis. In Study I, data were collected in focus-group interviews, which is not always thought to be compatible with a phenomenological method due to the individual voices and perceptions that might not be heard [182]. Although the inclusion criteria for Studies I and II were having personal experiences of the DP, there could have been a selection

bias towards persons with an especially strong view about the DP since participation was voluntary. Another limitation is that only one of the interviewees in Study II had a foreign mother tongue. However, the collected data were regarded as rich and the interviewees spoke open-heartedly about their experiences in both Studies I and II.

The reminder procedure in Study III indicated that completing a questionnaire might have been too demanding for several of the older persons. Some of them were not able to complete it, indicating that they represented a vulnerable group. Nevertheless, the number of the respondents required to achieve statistical power was obtained. The rationale behind the development of a new questionnaire was based on that none were found in the literature that suited our target group. The findings from the interviews with older persons and their relatives in Study II i.e. the theoretical model, underpinned the development of the PPLH questionnaire. One strength is that these areas in the model were identified and described by the older persons and their relatives themselves as important. Establishing validity and reliability of the new questionnaire require further testing [183]. The dropout was generally low in this thesis. However, recoding and dichotomisation of some response alternatives and exclusion of some respondents in the test-retest phase might have influenced the findings and need to be taken into account when interpreting the results.

Findings in Study I were presented and discussed at two seminars to which different caregivers involved in the DP were invited. The caregivers confirmed the results and made no contradictory comments. The theoretical model in Study II has been validated by its emergence via the constantly comparing method according to Grounded Theory (GT). Moreover, in order to check on the work and relevance [140], the theoretical model was presented to four older persons and two relatives who had previously experienced the DP. The findings were discussed and confirmed by all of them and they did not add any new data or contradictory comments to the theoretical model. The statistical testing in Study III validated several aspects in the theoretical model. The model thus became further refined and was deemed as both theoretically and clinically relevant. Throughout the qualitative analysis (Studies I, II, IV) the data were constantly assessed by the authors independently to enhance the validity of the findings.

All scientific research, not least an excursive analysis of a phenomenon, requires openness in understanding the phenomenon on its own premises, which is called “bridling” [150]. It can be difficult to be fully aware of one’s pre-conception, as parts of it may be unconscious [150, 184]. However, the researchers tried to keep this in mind and tackled the participants’ descriptions and discussions, with as few pre-conceptions as possible.

Researchers are always challenged with the prevailing understanding of their topic and the risk of conceptualising too early and thus losing the meaning. The researcher adopts a reflective stance towards prevailing assumptions and theories, so that the analysis is performed in a controlled manner. By bridling the process of understanding one strengthens the opportunity for seeing something new. The reflective stance and the practice of “bridling” in Study IV increased openness and gave an opportunity to find something new. Strong theories may easily silence the soft voice of the lifeworld and thus we put extra energy into the effort of thoroughly understanding the experiences of

the informants. Moreover, a colleague who has not been involved in the studies from the very beginning was included in Study IV, contributing to methodological rigour and more valid results. To maintain objectivity, data must be presented without being influenced by one's own thinking [185]. In addition, the theory on health and caring [15] used in the discussion was found to be highly relevant in the DP context and expanded the understanding of the DP.

IMPLICATIONS

The approach taken in carrying out the DP needs to strengthen the older persons' and their relatives' well-being, i.e. their everyday life, existence and ability to manage at home. The problems and deficiencies concerning the DP identified in this thesis require urgent improvements. Based on the literature and the results in this thesis, we believe that efforts are needed to address these issues in the DP. Therefore, it is important that the care-giving contribute to following to the older persons and their relatives:

- perception of genuine individualised encounters at hospital and not fragmented and non-individualised encounters at hospital
- alleviation and not suffering
- feeling sufficiently prepared for life at home at discharge and not perceptions of being insufficiently prepared for life at home at discharge
- receive necessary support and follow-ups at home and not inadequate support and follow-ups at home

Various efforts are needed to improve the DP: a checklist at hospital or at follow-ups at home (e.g. a revised PPLH questionnaire) could be used to assess whether the individual needs of the older persons and their relatives have been met. This could be used inter-professionally as an interface solution and a foundation for co-operation among all care providers involved identifying the older persons and relatives most likely to benefit from follow-up and a basis for referral to primary health care and social services. The suggestion is that the responsibility for follow-ups should be provided by district and community nurses in PHC to promote continuity of care. Moreover, to prevent undesirable expensive and adverse outcomes as well as unnecessary suffering among older persons and their relatives, there are alternatives to the prevailing care practices. Dahlberg et al. [155] suggests an approach to care, lifeworld led care, where caregivers not only have technical and medical knowledge but also knowledge about the freedom people seek in influencing their life and the vulnerability they feel during their journey as they struggle with different health related conditions. Care professionals need to acknowledge the existential impact but also the patients' "expertise" in their own life in order to provide comprehensive care from an expanded view of knowledge. Lifeworld-led care can alleviate their suffering and help patients reconcile with the new situation and find ways to get on with their life projects.

CONCLUSIONS

This thesis highlights the recurring issues in the DP that deeply affect older persons and their relatives. When care professionals use a disease-led approach in their encounter with older patients and follow solely medical routines, they may lose focus on the older persons' health processes. The older persons' and their relatives' experiences of exposedness and vulnerability due to illness, bodily, existential or contextual uncertainty indicate a threatening existence in the DP. The older persons and their relatives can easily be lost in an *in-between* experience that illuminates the difficulties embedded in the illness, care and the DP in an older person's life. Health and well-being in the DP mean that the older person and their relatives, among others, must be regarded as individuals, where the patient's existence and life context is the central base and that care professionals must be engaged and interested. There is a desire among the older persons to return home, but they need and long for the DP to become a strong bridge between the hospital and their home. To be personally acknowledged for one's potential and supported to re-orientate and establish existential coherence is beneficial for recapturing health and well-being.

The PPLH questionnaire developed from the theoretical model "Getting prepared for life at home in the DP" showed satisfactory validity and reliability, and had the potential to capture aspects of perceived preparedness among older persons and their relatives when discharged from hospital. The questionnaire can be used to provide information that may prove useful in improving the DP from the perspective of older persons and their relatives and also as an assessment tool to identify and satisfy needs among older persons and their relatives both at hospital and at home.

FUTURE PERSPECTIVES

The DP and its deficiencies enhance the need for supporting older persons' transitions between different care levels as well as their health processes. The findings in this thesis raise further questions:

- How can the different care givers and organisations cooperate in the patients' care planning and transition in the DP?
- What are the older persons' and their relatives' experiences of the first time at home after the discharge from hospital?
- How can HCN support the older persons and their relatives back at home?
- Could reorganising HCN and outpatient care improve continuity of care, prevent unnecessary re-admissions and contribute to safety for the older persons?

SUMMARY IN SWEDISH/ SAMMANFATTNING PÅ SVENSKA

BAKGRUND

En välfungerande utskrivning från sjukhus till hemmet, utskrivningsprocessen, är av stor betydelse för äldre personer med fortsatta behov av vård. Trots det påvisas brister år efter år i studier. Sviktande hälsa och olika funktionsnedsättningar förstärker den äldre personens sårbarhet. Utskrivningsprocessen är då central och ska bidra till en trygg och sammanhållen vård för de äldre.

MÅLSÄTTNING

Den övergripande målsättningen med denna avhandling var att fördjupa kunskapen om utskrivningsprocessen från sjukhuset till hemmet utifrån äldre personers, deras närståendes och vårdpersonals perspektiv samt att utveckla en enkät som mäter om de äldre och närstående känner sig förberedda för livet hemma vid utskrivningen från sjukhus.

MATERIAL OCH METOD

Avhandlingen består av fyra delstudier: tre kvalitativa (studie I, II, IV) och en kvantitativ (studie III). I den första studien intervjuades 31 personer (sjuksköterskor och biståndshandläggare i kommunen, distriktssköterskor i primärvården samt sjuksköterskor inom geriatrisk vård) om sina erfarenheter av utskrivningsprocessen i fokusgrupp intervjuer. Intervjuerna analyserades med hjälp av fenomenologisk metod. I studie II intervjuades äldre personer och deras närstående om sina erfarenheter av utskrivning från sjukhus. Totalt intervjuades 26 personer individuellt eller i grupp. Grundad teori användes vid datainsamling och analys. I studie III utvecklades en enkät utifrån den teoretiska modellen i studie II. Enkäten besvarades av 152 personer, svaren bearbetades med psykometriska metoder och varians analys. Studie IV baseras på en fördjupad analys, exkurs, av intervjudata och resultat i studie I och II. En reflekterande livsvärldsansats och fenomenologisk metod användes som analys metod.

RESULTAT

Utskrivningsprocessen upplevdes ofta som komplicerad och problematisk av vårdpersonalen i studie I. Faktorer som påverkade personalens agerande och gjorde patienten utsatt och sårbar var att de hade olika regelverk, rutiner, värderingar och syn på patienten. Den teoretiska modellen i studie II bidrar med ny kunskap utifrån äldre personer och deras närståendes perspektiv av utskrivningsprocessen och faktorer av betydelse för att bli förberedd för livet hemma vid utskrivningen från sjukhus. Den första testningen av enkäten visade tillfredsställande validitet och reliabilitet samt att enkäten fångar aspekter av att känna sig förberedd för livet hemma. Drygt hälften som

besvarade enkäten uppgav att de inte kände sig tillräckligt bra förberedda. Faktorer av betydelse för att känna sig förberedd var god hälsa vid utskrivningen, speciellt för kvinnor, och att de själva efterfrågade information. I studie IV:s framkom att sjukdom och utskrivningsprocessen är en händelse där det kända förändras till det okända för de äldre och deras närstående, vilket medför en osäker framtida existens och kan innebära en känsla av att befinna sig i ett ”mellanrum”. De äldre och de närstående har att förhålla sig till detta ”mellanrum” som är kontextuellt, kroppsligt och existentiellt, vilken innebär kroppsliga och existentiell behov. Att vara i ”mellanrum”, att inte vara sjuk men inte heller tillräckligt frisk för att klara sig hemma, innebär att den äldre blir sårbar och vilsen i utskrivningsprocessen.

SLUTSATSER

Avhandlingen visar att utskrivningsprocessen har stor inverkan på de äldre och deras liv. De äldre känner sig utsatta och sårbara beroende på sjukdom, kroppslig skörhet, osäker livssituation samt att man befinner sig i en sjukhusmiljö som man är mer eller mindre bekant med. När vårdpersonalen har sjukdomsfokus och följer medicinska rutiner dvs. ett fragmenterat förhållningssätt, tappar de lätt fokus på de äldres hälsoprocesser. De äldre och de närstående kan lätt hamna i ett ”mellanrum” vilket utmärker de svårigheter sjukdom och utskrivningsprocessen medför, i vilken hela deras existens kan hotas och medför osäkerhet om de kan fullfölja sina livsprojekt. Hälsa och välbefinnande innebär att bli sedd som den individ man är, i sin existens och i sitt livssammanhang vilket bör vara utgångspunkten i utskrivningsprocessen. Vårdpersonalens förhållningssätt är av stor betydelse för att de äldre och de närstående, de behöver visa intresse och engagemang för de äldre och deras närstående och inte förhålla sig till dem som en ”diagnos” eller en grupp ”äldre”. De äldre vill hem men önskar att utskrivningsprocessen ska vara den bro som de behöver mellan sjukhuset och hemmet. Tvärtom, så visade avhandlingen att denna bro kan saknas eller vara svag. Att bli sedd som den individ man är utifrån sina resurser och att få stöd att orientera sig i livet är av största betydelse för att återfå hälsa och känna välbefinnande.

Enkäten som är framtagen utifrån äldre personers och närståendes egna erfarenheter av utskrivningsprocessen visade vid den första testing ha tillfredställande validitet och reliabilitet. Den har potential att fånga aspekter av betydelse för att känna sig förberedd för livet hemma vid utskrivningen från sjukhuset. Enkäten kan vara användbar som ett underlag för att förbättra utskrivningsprocessen men också som ett bedömningsinstrument endera på sjukhuset inför utskrivningen eller vid uppföljning i hemmet för att identifiera och tillgodose de äldres och de närståendes behov.

ACKNOWLEDGEMENTS

First, I would like to express my sincere gratitude to Lena, director of further training, Jan and Lars, former and current heads at the Centre for Family Medicine, who supported and encouraged me to go on with and fulfil this thesis. To all of the “older” persons, relatives and care professionals who took time to participate and share your experiences in interviews and in answering the questionnaire. My warm thanks!

Lena Törnkvist, my main supervisor and co-author for our long journey in the scientific world, for encouragement and believing in me despite turbulence.

Lars Agreus, my co-supervisor, for valuable support and quantitative contributions.

Karin Dahlberg, for great inspiration and your admirable skills and intellectual standpoint in the lifeworld, for introducing and guiding me into it, for broadening my skills, for believing in me and for supporting me

Ingrid Hylander, for sharing your knowledge, qualitative seminars and valuable guidance in GT

Sven-Erik Johansson, for your lectures, guidance and good advice in statistics

Robert Szulkin, for our struggle in the psychometrics, “parametrics vs. non-parametrics, that is the question”

Joakim Westerlund, for saying yes and for all the valuable advice and great support in the statistical analysis

Jenny Stollo, my mentor for so many valuable times, for your wisdom, consideration and listening to me. You have become more than a mentor, a real friend.

Linda and Jennifer Evans, for revising my manuscripts.

All colleagues and friends at CeFAM; district nurses at further training, administration, IT support, English clubs, academic seminars.

Thanks to my family and all of my friends. My sister Ulla and her husband Helge for taking care of me when I needed it. Margareta, for patiently listening to me, encouraging me, for never fading enthusiasm and for all our good times. Not the least my beloved Lars, for your love and patience with me and who helped me find the sun again.

Financial support

The study was conducted with support from the Purchasing Office Stockholm County Council and the Centre for health Care Science, Karolinska Institutet, Sweden,

REFERENCES

1. Hallberg, I.R., *Äldres boende ur ett vård- och omsorgsperspektiv. (Older persons living environment)*. Statens Offentliga Utredningar. 2006.
2. Lindenberger, U. and Baltes, P.B. *Intellectual functioning in old and very old age: cross-sectional results from the Berlin Aging Study*. Psychol Aging, 1997. 12(3): p. 410–32.
3. Foss, C. and Askautrud, M. *Measuring the participation of elderly patients in the discharge process from hospital: a critical review of existing instruments*. Scand J Caring Sci, 2010. 24 Suppl 1: p. 46–55.
4. Genet, N., et al., *Home care in Europe: a systematic literature review*. BMC Health Serv Res, 2011. 11: p. 207.
5. Tingle, J., *Improving quality of care for older people*. Br J Nurs, 2012. 21(6): p. 368–9.
6. Socialstyrelsen, *Lägesrapport – Hälso- och sjukvård och socialtjänst. National Board of Health and Welfare*. 2011.
7. Eurostat. Available from: <http://epp.eurostat.ec.europa.eu/portal/page/portal/eurostat/home>.
8. OECD. Available from: <http://www.oecd.org/>.
9. Masters, S., et al., *Development and testing of a questionnaire to measure older people's experience of the Transitional Care Program in Australia*. Australian Journal on Ageing, 2010. 29(4): p. 172–178.
10. Naylor, M. and Keating, S.A. *Transitional care*. Am J Nurs, 2008. 108(9 Suppl): p. 58–63; quiz 63.
11. WHO, *Active Ageing: Good health adds life to years*. 2012, WHO Europe.
12. Statistics Sweden, *Sveriges framtida befolkning 2009–2010*. Available from: <http://www.scb.se/Pages/ProductTables.aspx?id=25795>.
13. Sarvimaki, A. and Stenbock-Hult, B. *Quality of life in old age described as a sense of well-being, meaning and value*. J Adv Nurs, 2000. 32(4): p. 1025–33.
14. Eriksson, K., *Theories of caring as health*. NLN Publ, 1994(14–2607): p. 3–20.
15. Dahlberg, K. and Segesten, K. *Hälsa och vårdande i teori och praxis (Health and caring)*. 2010, Stockholm: Natur & Kultur.
16. Nordenfält, L., *Hälsa och värde. studier i hälso- och sjukvårdens teori och etik (Health and Value)*. 1991, Stockholm: Thales.
17. Gustafsson, B., *Bekräftande omvårdnad: SAUK-modellen för vård och omsorg*. 2004, Lund: Studentlitteratur.
18. Vaarama, A., Pieper, R. and Sixsmith, A. *Care-related Quality of Life in Old Age: Concepts, Models, and Empirical Findings*. 2007, New York: Springer Verlag Inc.
19. Borg, C., Hallberg, I.R. and Blomqvist, K. *Life satisfaction among older people (65+) with reduced self-care capacity: the relationship to social, health and financial aspects*. J Clin Nurs, 2006. 15(5): p. 607–18.
20. Ho, S.C., et al., *Life satisfaction and associated factors in older Hong Kong Chinese*. J Am Geriatr Soc, 1995. 43(3): p. 252–5.
21. Rechel, B., et al., *How can health systems respond to population ageing? 2009*, World Health Organization Europe.
22. Larsson, K. and Thorslund, M. *Chapter 8: old people's health*. Scand J Public Health Suppl, 2006. 67: p. 185–98.
23. Parker, M.G. and Thorslund, M. *Health trends in the elderly population: getting better and getting worse*. Gerontologist, 2007. 47(2): p. 150–8.

24. Statens Folkhälsoinstitut. *Hälsa bland 55–84-åringar enligt den nationella folkhälsoenkäten Hälsa på lika villkor (HLV) (Health among persons aged 55–84)*. 2012.
25. Statens Folkhälsoinstitut. *Äldres hälsa: Kunskapsunderlag för folkhälsopolitisk rapport 2010 (Health of the elderly: Knowledge base for the Public Health Policy Report 2010)*. 2010.
26. Jakobsson, U., et al., *Psychosocial perspectives on health care utilization among frail elderly people: an explorative study*. Arch Gerontol Geriatr, 2011. 52(3): p. 290–4.
27. Tarricone, R. and Tsouros, A. *Home care in Europe*, WHO Europe. 2008.
28. Bergmark, A., Parker, M.G. and Thorslund, M. *Priorities in care and services for elderly people: a path without guidelines?* J Med Ethics, 2000. 26(5): p. 312–8.
29. Naylor, M.D., *Advancing high value transitional care: the central role of nursing and its leadership*. Nurs Adm Q, 2012. 36(2): p. 115–26.
30. Webster, C. and K. Bryan, *Older people's views of dignity and how it can be promoted in a hospital environment*. J Clin Nurs, 2009. 18(12): p. 1784–92.
31. Abramsson, M. and Niedomysl, T. *Äldre personers flyttningar och boendepreferenser (Delegation on older people's housing)*. 2008.
32. Rydeman, I. and Törnkvist, L. *Utskrivningsplanering för äldre – samverkan och samordning i vårdkedjan (Discharge planning for older persons – cooperation in the care chain)*. 2006.
33. Törnkvist, L. and Wänell, S. *Basal hemsjukvård för äldre personer med långvariga vårdbehov – hur kan vården förbättras? (Home care nursing for older persons in need of long term care)*. 2008.
34. National Board of Health and Welfare, *Lägesrapport 2011 – Hälsa- och sjukvård och socialtjänst 2011*: Stockholm, Sweden.
35. Hellstrom, U.W. and Sarvimaki, A. *Experiences of self-determination by older persons living in sheltered housing*. Nurs Ethics, 2007. 14(3): p. 413–24.
36. Hallberg, I.R. and Kristensson, J. *Preventive home care of frail older people: a review of recent case management studies*. J Clin Nurs, 2004. 13(6B): p. 112–20.
37. Andersson, L., *Ageism (Ageing)*. 2008, Lund, Sweden: Studentlitteratur.
38. Thome, B., Dykes, A.K. and Hallberg, I.R. *Home care with regard to definition, care recipients, content and outcome: systematic literature review*. J Clin Nurs, 2003. 12(6): p. 860–72.
39. Rydeman, I., Törnkvist, L. and Gustafsson, B. *Patient/relative power in home-care-nursing: a study of involvement and influence from district nurses' point of view*. Theoria, Journal of Nursing Theory, 2005. 14(2): p. 5–18.
40. National Board of Health and Welfare, *Socialstyrelsens termbank*. Available from: <http://app.socialstyrelsen.se/termbank/QuickSearchBrowse.aspx>.
41. Stockholm County Council. *Regelbok för husläkarverksamhet med basal hemsjukvård 2011*. 2011; Available from: <http://www.uppdragsguiden.sll.se/upload/Avtal/Auktorisering/Regelbocker%202011/Regelbok%202011%20hlm%20slutversion%20m%20ankar.pdf>.
42. Stockholm County Council. *Basal hemsjukvård – vad har hänt sedan 2008? Resultat från undersökning hösten 2010*. 2010; Available from: http://www.sll.se/upload/HSNf/FHS/Rapport_hemsjukvard_2010.pdf.
43. National Board of Health and Welfare. *Hemsjukvård i förändring En kartläggning i Sverige och förslag till indikatorer* 2008: Stockholm, Sweden
44. Government of Sweden *Mål för äldreomsorgen*. Available from: <http://www.regeringen.se/sb/d/14929/a/170338>.

45. SFS. *Socialtjänstlagen (Social Services Act), 2001:453*. 2001.
46. Hagman, L. and Österman, J. *Organiseringen av hemsjukvården vid åtta husläkarmottagningar (The organisation of home care nursing at eight primary health care centres)*. 2011.
47. National Board of Health and Welfare. *Organisering av vård och omsorg för de mest sjuka äldre – en kartläggning av översikter 2012*: Stockholm, Sweden.
48. Lupari, M., et al., 'We're just not getting it right' – how should we provide care to the older person with multi-morbid chronic conditions? *J Clin Nurs*, 2011. 20(9–10): p. 1225–35.
49. Törnkvist, L., *Grunder för hembesök (Reasons for home care nursing)*. 2005, Centre for Family Medicine: Stockholm, Sweden.
50. Condelius, A., et al., *Utilization of medical healthcare among people receiving long-term care at home or in special accommodation*. *Scand J Caring Sci*, 2010. 24(2): p. 404–13.
51. Timms, J., et al., *Documentation of characteristics of early hospital readmission of elderly patients. A challenge for inservice educators*. *J Nurses Staff Dev*, 2002. 18(3): p. 136–43; quiz 144–5.
52. Greenwald, J.L. and Jack, B.W. *Preventing the preventable: reducing rehospitalizations through coordinated, patient-centered discharge processes*. *Prof Case Manag*, 2009. 14(3): p. 135–40; quiz 141–2.
53. Hegney, D., et al., *Nurse discharge planning in the emergency department: a Toowoomba, Australia, study*. *J Clin Nurs*, 2006. 15(8): p. 1033–44.
54. Bobay, K.L., et al., *Age-related differences in perception of quality of discharge teaching and readiness for hospital discharge*. *Geriatr Nurs*, 2010. 31(3): p. 178–87.
55. Jencks, S.F., Williams, M.V. and Coleman, E.A. *Rehospitalizations among patients in the Medicare fee-for-service program*. *N Engl J Med*, 2009. 360(14): p. 1418–28.
56. Condelius, A., Hallberg, I.R. and Jakobsson, U. *Medical healthcare utilization as related to long-term care at home or in special accommodation*. *Arch Gerontol Geriatr*, 2010. 51(3): p. 250–6.
57. Meleis, A.I., et al., *Experiencing transitions: an emerging middle-range theory*. *ANS Adv Nurs Sci*, 2000. 23(1): p. 12–28.
58. Stabell, A. and Lindström, U. *Mot opplevelse av integritet og verdighet – en streben og strid (towards experience of integrity and dignity)*. *Vård i Norden*, 2003(4): p. 29–34.
59. Kralik, D. and van Loon, A. *Understanding transition in chronic illness*. *Aust Nurs J*, 2007. 15(2): p. 29.
60. Summer Meranius, M., *Era delar är min helhet: En studie om att vara äldre multisjuk*. (Dissertation). Växjö: Department of Caring Science. Linnaeus University. 2010.
61. Coleman, E.A. and Berenson, R.A. *Lost in transition: challenges and opportunities for improving the quality of transitional care*. *Ann Intern Med*, 2004. 141(7): p. 533–6.
62. Forster, A.J., et al., *Reliability of the peer-review process for adverse event rating*. *PLoS One*, 2012. 7(7): p. e41239.
63. Foust, J.B., Vuckovic, N. and Henriquez, E. *Hospital to home health care transition: patient, caregiver, and clinician perspectives*. *West J Nurs Res*, 2012. 34(2): p. 194–212.
64. SOSFS, *Samverkan vid in- och utskrivning av patienter i slutenvården (Co-operation at admission and at discharge of inpatients)*, National Board of Health and Welfare. Stockholm: Sweden. 2005.

65. Weurlander, I. and Wånell, S. *Sköra länkar i vårdkedjan: En studie om gränsytor i vården och omsorgen om de mest sjuka äldre*. Stockholm, Sweden. 2011.
66. Coleman, E.A., Mahoney, E. and Parry, C. *Assessing the quality of preparation for posthospital care from the patient's perspective: the care transitions measure*. *Med Care*, 2005. 43(3): p. 246–55.
67. Huber, D.L. and McClelland, E. *Patient preferences and discharge planning transitions*. *J Prof Nurs*, 2003. 19(4): p. 204–10.
68. Mistiaen, P., et al., *Predictive validity of the BRASS index in screening patients with post-discharge problems. Blaylock Risk Assessment Screening Score*. *J Adv Nurs*, 1999. 30(5): p. 1050–6.
69. McKeown, F., *The experiences of older people on discharge from hospital following assessment by the public health nurse*. *J Clin Nurs*, 2007. 16(3): p. 469–76.
70. Mistiaen, P., Francke, A.L. and Poot, E. *Interventions aimed at reducing problems in adult patients discharged from hospital to home: a systematic meta-review*. *BMC Health Serv Res*, 2007. 7: p. 47.
71. Pearson, P., et al., *The process of hospital discharge for medical patients: a model*. *J Adv Nurs*, 2004. 46(5): p. 496–505.
72. Pirmohamed, M., et al., *Adverse drug reactions as cause of admission to hospital: prospective analysis of 18 820 patients*. *BMJ*, 2004. 329(7456): p. 15–9.
73. Rytter, L., et al., *Comprehensive discharge follow-up in patients' homes by GPs and district nurses of elderly patients. A randomized controlled trial*. *Scand J Prim Health Care*, 2010. 28(3): p. 146–53.
74. von Euler, M., et al., *Adverse drug reactions causing hospitalization can be monitored from computerized medical records and thereby indicate the quality of drug utilization*. *Pharmacoepidemiol Drug Saf*, 2006. 15(3): p. 179–84.
75. Setter, S.M., Corbett, C.F. and Neumiller, J.J. *Transitional care: exploring the home healthcare nurse's role in medication management*. *Home Healthc Nurse*, 2012. 30(1): p. 19–26.
76. Corbett, C.F., et al., *Nurse identified hospital to home medication discrepancies: implications for improving transitional care*. *Geriatr Nurs*, 2010. 31(3): p. 188–96.
77. Bauer, M., et al., *Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence*. *J Clin Nurs*, 2009. 18(18): p. 2539–46.
78. Shepperd, S., et al., *Discharge planning from hospital to home*. *Cochrane Database Syst Rev*, 2010(1): p. CD000313.
79. Bragstad, L.K., et al., *Factors predicting a successful post-discharge outcome for individuals aged 80 years and over*. *Int J Integr Care*, 2012. 12: p. e147.
80. Jackson, M.F., *Discharge planning: issues and challenges for gerontological nursing: a critique of the literature*. *J Adv Nurs*, 1994. 19(3): p. 492–502.
81. Waters, K., et al., *Sources of support for older people after discharge from hospital: 10 years on*. *J Adv Nurs*, 2001. 33(5): p. 575–82.
82. Anthony, M.K. and Hudson Barr, D. *Successful patient discharge: a comprehensive model of facilitators and barriers*. *Journal of Nursing Administration*, 1998(28): p. 48–55.
83. Bull, M.J. and Roberts, J. *Components of a proper hospital discharge for elders*. *J Adv Nurs*, 2001. 35(4): p. 571–81.
84. Connolly, M., et al., *Systems and people under pressure: the discharge process in an acute hospital*. *J Clin Nurs*, 2009. 18(4): p. 549–58.

85. Forster, A.J., et al., *Adverse events among medical patients after discharge from hospital*. CMAJ, 2004. 170(3): p. 345–9.
86. Merriman, M.L., *Pre-hospital discharge planning: empowering elderly patients through choice*. Crit Care Nurs Q, 2008. 31(1): p. 52–8.
87. Inouye, S.K., et al., *Risk factors for hospitalization among community-dwelling primary care older patients: development and validation of a predictive model*. Med Care, 2008. 46(7): p. 726–31.
88. Aminzadeh, F. and W.B. Dalziel, *Older adults in the emergency department: a systematic review of patterns of use, adverse outcomes, and effectiveness of interventions*. Ann Emerg Med, 2002. 39(3): p. 238–47.
89. Witherington, E.M., Pirzada, O.M. and Avery, A.J. *Communication gaps and readmissions to hospital for patients aged 75 years and older: observational study*. Qual Saf Health Care, 2008. 17(1): p. 71–5.
90. Carroll, A. and Dowling, M. *Discharge planning: communication, education and patient participation*. Br J Nurs, 2007. 16(14): p. 882–6.
91. Naylor, M.D., *Transitional care for older adults: a cost-effective model*. LDI Issue Brief, 2004. 9(6): p. 1–4.
92. Bull, M.J., *Elders' and family members' perspectives in planning for hospital discharge*. Appl Nurs Res, 1994. 7(4): p. 190–2.
93. McKenna, H., et al., *Discharge planning: an exploratory study*. J Clin Nurs, 2000. 9(4): p. 594–601.
94. Hesselink, G., et al., *Organizational Culture: An Important Context for Addressing and Improving Hospital to Community Patient Discharge*. Med Care, 2012.
95. Allen, J., Ottmann, G. and Roberts, G. *Multi-professional communication for older people in transitional care: a review of the literature*. Int J Older People Nurs, 2012.
96. Bowles, K.H., *Patient problems and nurse interventions during acute care and discharge planning*. J Cardiovasc Nurs, 2000. 14(3): p. 29–41.
97. Naylor, M.D., *Transitional care: a critical dimension of the home healthcare quality agenda*. J Healthc Qual, 2006. 28(1): p. 48–54.
98. Tomura, H., et al., *Creating an agreed discharge: discharge planning for clients with high care needs*. J Clin Nurs, 2011. 20(3–4): p. 444–53.
99. Graumlich, J.F., et al., *Patient and physician perceptions after software-assisted hospital discharge: cluster randomized trial*. J Hosp Med, 2009. 4(6): p. 356–63.
100. Jack, B.W., et al., *A reengineered hospital discharge program to decrease rehospitalization: a randomized trial*. Ann Intern Med, 2009. 150(3): p. 178–87.
101. Maramba, P.J., et al., *Discharge planning process: applying a model for evidence-based practice*. J Nurs Care Qual, 2004. 19(2): p. 123–9.
102. Payne, S., et al., *The communication of information about older people between health and social care practitioners*. Age Ageing, 2002. 31(2): p. 107–17.
103. Bull, M.J., Hansen, H.E. and Gross, C.R. *Predictors of elder and family caregiver satisfaction with discharge planning*. J Cardiovasc Nurs, 2000. 14(3): p. 76–87.
104. Naylor, M.D., et al., *High-value transitional care: translation of research into practice*. J Eval Clin Pract, 2011.
105. Golden, A.G., et al., *Care management's challenges and opportunities to reduce the rapid rehospitalization of frail community-dwelling older adults*. Gerontologist, 2010. 50(4): p. 451–8.
106. Scott, I.A., *Preventing the rebound: improving care transition in hospital*

- discharge processes*. Aust Health Rev, 2010. 34(4): p. 445–51.
107. Kansagara, D., et al., *Post-discharge intervention in vulnerable, chronically ill patients*. J Hosp Med, 2012. 7(2): p. 124–30.
 108. Parker, L. *Do Current discharge arrangements from inpatient hospital care for elderly reduce readmission rates, the length of inpatient stay or mortality, or improve health status?* World Health Organization Europe. 2005.
 109. Motamedi, S.M., et al., *The efficacy of computer-enabled discharge communication interventions: a systematic review*. BMJ Qual Saf, 2011. 20(5): p. 403–15.
 110. Grimmer, K. and Moss, J. *The development, validity and application of a new instrument to assess the quality of discharge planning activities from the community perspective*. Int J Qual Health Care, 2001. 13(2): p. 109–16.
 111. Weiss, M.E., et al., *Perceived readiness for hospital discharge in adult medical-surgical patients*. Clin Nurse Spec, 2007. 21(1): p. 31–42.
 112. Efraimsson, E., et al., *Expressions of power and powerlessness in discharge planning: a case study of an older woman on her way home*. J Clin Nurs, 2003. 12(5): p. 707–16.
 113. Roberts, K., *Exploring participation: older people on discharge from hospital*. J Adv Nurs, 2002. 40(4): p. 413–20.
 114. Grimmer, K., Moss, J. and Falco, J. *Experiences of elderly patients regarding independent community living after discharge from hospital: a longitudinal study*. Int J Qual Health Care, 2004. 16(6): p. 465–72.
 115. Rutten, F.H., et al., *Recognising heart failure in elderly patients with stable chronic obstructive pulmonary disease in primary care: cross sectional diagnostic study*. BMJ, 2005. 331(7529): p. 1379.
 116. Rydeman, I. and Tornkvist, L. *Getting prepared for life at home in the discharge process – from the perspective of the older persons and their relatives*. Int J Older People Nurs, 2010. 5(4): p. 254–64.
 117. Shepperd, S., et al., *Discharge planning from hospital to home*. Cochrane Database Syst Rev, 2004(1): p. CD000313.
 118. Doherty, C. and Doherty, W. *Patients' preferences for involvement in clinical decision-making within secondary care and the factors that influence their preferences*. J Nurs Manag, 2005. 13(2): p. 119–27.
 119. Bastiaens, H., et al., *Older people's preferences for involvement in their own care: a qualitative study in primary health care in 11 European countries*. Patient Educ Couns, 2007. 68(1): p. 33–42.
 120. Say, R., Murtagh, M. and Thomson, R. *Patients' preference for involvement in medical decision making: a narrative review*. Patient Educ Couns, 2006. 60(2): p. 102–14.
 121. Bradway, C., et al., *A qualitative analysis of an advanced practice nurse-directed transitional care model intervention*. Gerontologist, 2012. 52(3): p. 394–407.
 122. Driscoll, A., *Managing post-discharge care at home: an analysis of patients' and their carers' perceptions of information received during their stay in hospital*. J Adv Nurs, 2000. 31(5): p. 1165–73.
 123. Forster, A.J., et al., *Patient-level factors associated with methicillin-resistant Staphylococcus aureus carriage at hospital admission: A systematic review*. Am J Infect Control, 2012.
 124. Sahlsten, M.J., et al., *An analysis of the concept of patient participation*. Nurs Forum, 2008. 43(1): p. 2–11.
 125. Bull, M.J., Luo, D. and Maruyama, G.M. *Measuring continuity of elders' posthospital care*. J Nurs Meas, 2000. 8(1): p. 41–60.

126. Hadjistavropoulos, H., et al., *Patient perceptions of hospital discharge: reliability and validity of a Patient Continuity of Care Questionnaire*. Int J Qual Health Care, 2008. 20(5): p. 314–23.
127. Maloney, L.R. and Weiss, M.E. *Patients' perceptions of hospital discharge informational content*. Clin Nurs Res, 2008. 17(3): p. 200–19.
128. Parrish, M.M., et al., *Implementation of the care transitions intervention: sustainability and lessons learned*. Prof Case Manag, 2009. 14(6): p. 282–93; quiz 294–5.
129. Masters, S., et al., *Policy and Updates Development and testing of a questionnaire to measure older people's experience of the Transitional Care Program in Australia*. Australian Journal on Ageing, 2010. 29(2): p. 172–178.
130. Clare, J. and Hofmeyer, A. *Discharge planning and continuity of care for aged people: indicators of satisfaction and implications for practice*. Aust J Adv Nurs, 1998. 16(1): p. 7–13.
131. Krueger, R. and Casey, M. *Focus groups: A practical guide for applied research*. 3rd ed. 2000, London: Sage Publications, Inc.
132. Barbour, R. and Kitinger, J. *Developing Focus Group Research: Politics, Theory and Practice*. 2001, London: Sage Publications Ltd.
133. Malterud, K., *Kvalitativa metoder i medicinsk forskning (Qualitative Methods in Medical Research)*. 1998, Lund: Studentlitteratur
134. Giorgi, A., in *Phenomenology and Psychological Research* Giorgi. A, Editor. 1985, Duquesne University Press Pittsburgh. p. 8–25.
135. Husserl, E., *Cartesianska meditationer: En inledning till fenomenologin (Cartesian Meditations: An Introduction in to Phenomenology)*. 1992 (first published 1950) Gothenburg: Daidalos.
136. Hall, E.O.C., *Phenomenological methodologies in the service of health in Fridlund, B. Hildingh, C. (eds) Qualitative Research Methods in the Service of Health*. 2000, Lund: Studentlitteratur.
137. Glaser, B., *Theoretical sensitivity: advances in methodology of grounded theory*. 1978, Mill Valley: Sociology press.
138. Glaser, B. and A. Strauss, *The discovery of Grounded Theory: Strategies for Qualitative Research*. 1967, New York Aldine de Gruyter.
139. Strauss, A. and J. Corbin, *Basic of Qualitative Research Techniques and Procedures for Developing Grounded Theory*. second ed, ed. S. Publications. 1998, London: Sage Publications
140. Glaser, B., *Theoretical Sensitivity: Advances in Methodology of Grounded Theory*. 1978, Mill Valley CA: Sociology Press.
141. Strauss, A. and J. Corbin, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 1998, London, UK: Sage Publications.
142. Hylander, I., *Towards a grounded theory of the conceptual change process in consultee-centred consultations*. Journal of Educational and Psychological Consultation, 2003. 14: p. 263–280.
143. Streiner, D.L. and Norman, G.R. *Health measurement scales: a practical guide to their development and use*. 4th ed. 2008, Oxford: Oxford University Press.
144. Prett, M., Lackey, N. and Sullivan, J. *Making sense of Factor Analysis The use of Factor Analysis for Instrument Development in Health Care Research*. 2003, London and Thousand Oaks: Sage Publications.
145. Floyd, F. and Widaman, K. *Factor Analysis in the Development and Refinement of Clinical Assessment Instruments*. Psychological Assessment, 1995. 7(3): p. 286–299.
146. Cattell, R.B., *The scree test for the number of factors*. Multivariate Behavioral

- Research, 1966. 1: p. 245–276.
147. Dinno, A. *Gently Clarifying the Application of Horn's Parallel Analysis to Principal Component Analysis Versus Factor Analysis*. 2010; Available from: http://doyenne.com/Software/files/PA_for_PCA_vs_FA.pdf.
 148. Gorsuch, R.L., *Factor Analysis* 1983, New Jersey: Lawrence Erlbaum Associates, Hillsdale.
 149. Tabachnick, B.G. and Fidell, L.S. *Using multivariate statistics* 4th ed. 2001, Boston: Allyn and Bacon
 150. Dahlberg, K., Dahlberg, H. and Nyström, M. *Reflective lifeworld research*. 2nd ed. 2008, Lund, Sweden: Studentlitteratur.
 151. Husserl, E., *The crisis of European sciences and transcendental phenomenology* 1970/1936 Evanston: North Western University Press.
 152. Merleau-Ponty, M., *Phenomenology of perception*. 1995/1945, London Routledge.
 153. Heidegger, M., *Being and Time* 1998/1927, Oxford Blackwells.
 154. Gadamer, H.-G., *Truth and method*. J. Weinsheimer & D. Marshall, Trans. 2nd ed. 1995/1960, New York: The Continuum Publishing Company.
 155. Dahlberg, K., Todres, L. and Galvin, K. *Lifeworld-led healthcare is more than patient-led care: an existential view of well-being*. Med Health Care Philos, 2009. 12(3): p. 265–71.
 156. Todres, L., Galvin, K. and Dahlberg, K. *Lifeworld-led healthcare: revisiting a humanising philosophy that integrates emerging trends*. Med Health Care Philos, 2007. 10(1): p. 53–63.
 157. Cavalcante Schuback, M., *The knowledge of attention*. International Journal of Qualitative Studies on Health and Well-being, 2006. 1(133–140).
 158. Mayan, M., Morse, J.M. and Eldershaw, L. *Developing a concept for self-reformulation*. International Journal of Qualitative Studies on Health and Well-being, 2006. 1(20–26).
 159. Hinck, S.M., *The meaning of time in oldest-old age*. Holist Nurs Pract, 2007. 21(1): p. 35–41.
 160. Borglin, G., et al., *Older people in Sweden with various degrees of present quality of life: their health, social support, everyday activities and sense of coherence*. Health Soc Care Community, 2006. 14(2): p. 136–46.
 161. Efraimsson, E., et al., *How to get one's voice heard: the problems of the discharge planning conference*. J Adv Nurs, 2006. 53(6): p. 646–55.
 162. Todred, L., Galwin, K. and Holloway, I. *The humanization of healthcare: A value framework for qualitative research*. International Journal of Qualitative Studies on Health and Well-Being, 2009. 4 p. 68 –77.
 163. Berglund, M., et al., *Suffering caused by care – patients' experiences from hospital settings*. Int J Qual Stud Health Well-being, 2012. 7: p. 1–9.
 164. Nyström, M., Dahlberg, K. and Carlsson, G. *Non-caring encounters at an emergency care unit – a life-world hermeneutic analysis of an efficiency-driven organization*. Int J Nurs Stud, 2003. 40(7): p. 761–9.
 165. Sveneus, F., *Sjukdomens mening det medicinska mötets fenomenologi och hermeneutik (The meaning of illness)*. 2003, Stockholm: Natur & Kultur.
 166. Ozolins, L., *Beröringens fenomenologi i vårdssammanhang*. (Dissertation) Växjö: Department of Caring Science. Linnaeus University. 2011.
 167. Morse, J.M., *Toward a praxis theory of suffering*. ANS Adv Nurs Sci, 2001. 24(1): p. 47–59.
 168. Eriksson, K., *Understanding the world of the patient, the suffering human being: the new clinical paradigm from nursing to caring*. Adv Pract Nurs Q, 1997. 3(1): p. 8–13.

169. Eriksson, K., *Caring science in a new key*. Nurs Sci Q, 2002. 15(1): p. 61–5.
170. Toombs, K., *The meaning of illness a phenomenological account of different perspectives of physician and patient*. Philosophy & Medicine 42. 1993, Boston: Kluwer Academic Publisher.
171. Stenbock-Hult, B. and Sarvimaki, A. *The meaning of vulnerability to nurses caring for older people*. Nurs Ethics, 2011. 18(1): p. 31–41.
172. Wessel, M., et al., *When do patients feel wronged? Empirical study of sick-listed patients' experiences with healthcare encounters*. Eur J Public Health, 2012.
173. Rytterstrom, P., Arman, M. and Unosson, M. *Aspects of care culture in municipal care for elderly people: a hermeneutic documentary analysis of reports of abuse*. Scand J Caring Sci, 2012.
174. Abramson, J. *Participation of elderly patients in discharge planning: is self-determination a reality?* Social Work, 1998(33): p. 443–448.
175. Huby, G., et al., *Capturing the concealed: interprofessional practice and older patients' participation in decision-making about discharge after acute hospitalization*. J Interprof Care, 2007. 21(1): p. 55–67.
176. Ross, F., C. O'Tuathail, and D. Stubberfield, *Towards multidisciplinary assessment of older people: exploring the change process*. J Clin Nurs, 2005. 14(4): p. 518–29.
177. SFS. *Socialtjänstlagen (Social Welfare Act)*. Stockholm, Sweden. 2001.
178. SFS. *Hälso- och sjukvårdslag (Health and Medical Care Act)*. Stockholm, Sweden. 1982.
179. Holland, D.E. and Harris, M.R. *Discharge planning, transitional care, coordination of care, and continuity of care: clarifying concepts and terms from the hospital perspective*. Home Health Care Services Quarterly 2007. 26: p. 3–19.
180. Huby, G., et al., *Capturing the concealed: Interprofessional practice and older patients' participation in decision-making about discharge after acute hospitalization*. Journal of Interprofessional Care, 2007. 21: p. 55–67.
181. Morse, J.M. and Niehaus, L. *Mixed Methods Design Principles and procedures*. 2009, US: Left Coast Press Inc.
182. Webb, C. and Kevern, J. *Focus groups as a research method: a critique of some aspects of their use in nursing research*. J Adv Nurs, 2001. 33(6): p. 798–805.
183. Streiner, D. and Norman, G. *Health measurement scales: a practical guide to their development and use*. 4th ed. 2008, Oxford: Oxford University Press.
184. Hallberg, I., *The core category of Grounded Theory*. International Journal of Qualitative Studies on Health and Well-being, 2006(1): p. 141–148.
185. Kvale, S. and Brinkman, S. *Intervjuer (Interviews)*. 2009, Lund: Studentlitteratur.