

Indispensable intermediaries

The role of informal caregivers in the discharge process of older relatives

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Contents

| | |
|--|------|
| Contents..... | III |
| Acknowledgements..... | VII |
| Abstract..... | IX |
| Terms and abbreviations..... | XI |
| List of publications..... | XIII |
| 1 Introduction..... | 1 |
| 1.1 Overall aim..... | 1 |
| 1.2 Outline of the dissertation..... | 2 |
| 2 Background..... | 5 |
| 2.1 The Norwegian health care setting..... | 5 |
| 2.1.1 Increasing pressure on care delivery in the community..... | 6 |
| 2.2 Informal care..... | 8 |
| 2.2.1 The interface between formal and informal care..... | 8 |
| 2.2.2 The informal caregivers' contributions..... | 10 |
| 3 Participation..... | 12 |
| 3.1 Taxonomy of patient involvement and participation..... | 13 |
| 3.1.1 Levels of involvement and participation..... | 14 |
| 3.2 Participation as a legal right..... | 15 |
| 3.3 Participation as a consumer right..... | 16 |
| 4 Discharge process for older patients..... | 17 |
| 4.1 Discharge planning..... | 18 |
| 4.2 Informal caregivers' participation in the discharge process..... | 19 |
| 4.2.1 Information as a precursor to participation..... | 19 |
| 5 Aims and research questions..... | 23 |
| 5.1.1 Aim and research question of Paper I..... | 23 |
| 5.1.2 Aim and research questions of Paper II..... | 23 |
| 5.1.3 Aim and research questions of Paper III..... | 23 |
| 6 Material and methods..... | 25 |
| 6.1 Design..... | 25 |
| 6.2 Setting and sample..... | 27 |

| | | |
|-------|---|----|
| 6.2.1 | Recruitment of participants | 27 |
| | Phase One: Recruitment for the main study | 28 |
| | Phase Two: Recruitment for the follow-up study | 30 |
| 6.2.2 | Characteristics of the patient sample | 32 |
| 6.2.3 | Characteristics of the informal caregiver sample | 34 |
| 6.2.4 | Characteristics of the informal caregiver sample in the follow-up study | 35 |
| 6.3 | Data collection | 36 |
| 6.3.1 | Development of the discharge questionnaire | 36 |
| 6.3.2 | Data collection for the main study | 37 |
| 6.3.3 | Interview guide for follow-up study | 38 |
| 6.3.4 | Data collection for follow-up study | 38 |
| 6.3.5 | Preparation of the data material for analyses | 39 |
| | Preparation of the questionnaire data | 39 |
| | Preparation of the qualitative interview data | 40 |
| 6.4 | Statistical analyses | 40 |
| 6.4.1 | Paper I | 40 |
| | Descriptive statistics | 40 |
| | Guttman scale | 41 |
| | Multivariate logistic regression | 41 |
| 6.4.2 | Paper II | 42 |
| | Descriptive statistics | 42 |
| | Multivariate logistic regression | 42 |
| | Content analysis | 43 |
| 6.5 | Qualitative analysis | 44 |
| 6.5.1 | Paper III | 44 |
| | Inductive thematic approach | 44 |
| | Coding procedure | 44 |
| | Categorization and development of themes | 44 |
| 6.6 | Ethical considerations | 46 |
| 6.6.1 | The main study | 46 |
| 6.6.2 | Follow-up interviews | 47 |
| 7 | Results | 48 |

| | | |
|-------|---|-----|
| 7.1 | Informal caregivers' participation when older adults in Norway are discharged from the hospital | 48 |
| 7.2 | Factors predicting a successful post-discharge outcome for individuals aged 80 years and over | 49 |
| 7.3 | The indispensable intermediaries: a qualitative study of informal caregivers' struggle to achieve influence at and after hospital discharge | 50 |
| 8 | Discussion | 51 |
| 8.1 | General discussion of the findings..... | 51 |
| 8.1.1 | Informal caregivers' participation | 51 |
| | The advantages of the younger generation caregivers | 52 |
| 8.1.2 | Successful transitions back to their home | 54 |
| 8.1.3 | The changing roles of informal caregivers..... | 56 |
| | Caregiver burden | 58 |
| | Summarizing comments..... | 58 |
| 8.2 | Methodological considerations..... | 60 |
| 8.2.1 | Mixed methods design | 60 |
| 8.2.2 | Sampling procedures and representativeness | 60 |
| | The sample of informal caregivers in the qualitative follow-up study | 63 |
| 8.2.3 | Reliability, validity, and trustworthiness..... | 64 |
| | Quantitative approach | 64 |
| | Qualitative approach | 65 |
| 9 | Conclusions | 67 |
| 9.1 | Future perspectives | 69 |
| 10 | References | 71 |
| | Errata | 89 |
| | Original papers | 91 |
| | Appendices | 133 |

Figures

| | |
|---|----|
| Figure 1 Thompson’s levels of involvement..... | 14 |
| Figure 2 Mixed methods design with a sequential explanatory approach | 25 |
| Figure 3 Timeline of recruitment and data collection | 27 |
| Figure 4 Flow chart of inclusion of respondents and discharge cases covered in the study | 30 |
| Figure 5 Flow chart of inclusion of informal caregivers in the follow-up interviews | 31 |

Tables

| | |
|--|----|
| Table 1 Overview of the three sub-studies of the dissertation I..... | 2 |
| Table 2 Overview of the three sub-studies of the dissertation II | 26 |
| Table 3 Characteristics of the sample of patients recruited during Phase One | 33 |
| Table 4 Self-reported cause for hospitalization..... | 34 |
| Table 5 Characteristics of the sample of informal caregivers | 35 |
| Table 6 Demographic characteristics of caregivers and the patients they care for | 36 |
| Table 7 Content analysis, number of statements from free text comments | 43 |
| Table 8 Examples of codes, categories, and main themes of the qualitative analysis | 45 |

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Abstract

Background: Research has shown that frail, older individuals are especially vulnerable in the discharge process due to complex continuing care needs. Informal caregivers can play an important role in securing patients' autonomy in their encounter with the health care services and in supporting their older relative during the discharge process. Shorter hospital stays, which has become a key characteristic in the contemporary health care services, put pressure on formal and informal care delivery in the municipalities. Contemporary policy initiatives emphasize active participation by the patients themselves and their informal caregivers to strengthen the emphasis on the users' individual needs. Recent research calls for involving the informal caregivers in the decision-making process to ensure successful post-discharge outcomes for the patient and the informal caregivers. However, while the existing research is predominantly concerned with information exchange, there is a scarcity of research on the informal caregivers' actual participation in the discharge planning.

Aims: The general aim of this dissertation was to describe and explore the role of informal caregivers in the discharge process when older relatives, 80 years and older, were discharged from the hospital to community care. The specific aims were: to describe the participation reported by informal caregivers in the discharge planning, to describe which factors contributed to a successful post-discharge outcome, and to explore the informal caregivers' experiences of influencing decision-making at and after hospital discharge for home-dwelling older relatives.

Methods: The dissertation was designed to address participation in the discharge process from the perspectives of patients and informal caregivers using a mixed methods design with a sequential explanatory approach. Recruitment of participants and data collection for this PhD study was carried out in two phases. In Phase One, between October 2007 and May 2009, a cross-sectional study using structured questionnaire interviews with a consecutive sample of 254 patients and 262 caregivers was conducted. In Phase Two a follow-up qualitative interview study with 19 informal caregivers was conducted between March 2010 and July 2010. Bivariate cross-tabulations and Chi-square tests for association and trend were conducted with the nominal and ordinal variables from Phase One. Multivariate logistic regression analysis was performed to describe the informal caregivers' participation in discharge planning (Paper I) and to describe predictors of a patient-reported successful post-

discharge outcome (Paper II). Free text comments from the questionnaire were analyzed using a content analysis (Paper II), while the qualitative data from the follow-up study of Phase Two were analyzed using an inductive thematic approach (Paper III).

Results: The younger generation caregivers, mainly adult children, appear to be better informed and they engage in dialogue and cooperate with the personnel at the hospital to a greater degree than the older generation caregivers, mainly consisting of spouses. However, only half of all the informal caregivers reported participation in planning the patient discharge (Paper I). The findings highlight that having someone at home upon homecoming from the hospital and having adequate formal home-care services are significantly associated with patient-reported success in managing well in the early post-discharge period (Paper II). The informal caregivers wanted to actively participate, but gaining influence was often perceived to be complicated and required a great deal of resourcefulness. The informal caregivers described an ongoing struggle that was not always resolved until the situation became unbearable for the informal caregivers. The informal caregivers appeared to be indispensable as intermediaries between the patient and the health care services (Paper III).

Conclusion: The importance of informal caregivers as intermediaries was supported by findings from both methodological approaches. The informal caregivers appear to be indispensable intermediaries without whom the patients become even more vulnerable in the discharge process. The findings underline how the different generations of caregivers experience the discharge process differently and that the younger generation caregivers seem to have better chances of participation. This study shows that focusing on informal caregivers and their participation is an investment toward better patient outcomes, and that more research is required to explore how informal caregivers can be actively included in the discharge process.

Terms and abbreviations

| | |
|--------------------|---|
| Aging in place | Contemporary health care policy enabling older adults to remain living in the community, with a level of independence, supported by home health care services and informal caregivers, rather than receiving institutional care. |
| Community care | Care provided to patients in a nursing home or care provided by formal home health care personnel in the patient's home. |
| Discharge planning | The process of identifying and preparing for a patient's anticipated health care needs after discharge from the hospital. The goal is to reduce hospital length of stay and unplanned readmission to hospital and encourage the coordination and continuity of health care as patients transfer across care settings. |
| Discharge process | The process of patient discharge from the hospital, including the discharge planning at the hospital and the first 3-5 weeks after discharge. |
| Informal caregiver | Family members, members of the extended family, friends and neighbors that the older patients have named as their next of kin and who provide help and support without being paid to do so. |
| Next of kin | Family members with a legal kinship tie to the patient |
| DEQ | The Discharge of Elderly Questionnaire |
| IADL | Instrumental activities of daily living |
| NGO | Non-governmental organization |
| PADL | Personal activities of daily living |

List of publications

- I. Bragstad, LK., Kirkevold, M., Hofoss, D. & Foss, C. (2014) Informal caregivers' participation when older adults in Norway are discharged from the hospital. *Health & Social Care in the community*, Vol. 22(2): 155–168.
- II. Bragstad, LK., Kirkevold, M., Hofoss, D. & Foss, C. (2012) Factors Predicting a successful post-discharge outcome for individuals aged 80 years and over. *International Journal of Integrated Care*, Vol. 12, 10. Feb. 2012.
- III. Bragstad, LK., Kirkevold, M. & Foss, C. (2014) The indispensable intermediaries: A qualitative study of informal caregivers' struggle to achieve influence at and after hospital discharge. *BMC Health Services Research*, **14**:331

1 Introduction

The main objective of this dissertation is to describe the informal caregivers' participation in the discharge process when relatives 80 years and older are discharged from the hospital to community care.

The discharge process and care transitions between hospitals and community care are a critical point in the trajectory of care [1-3]. The care planning during the discharge process is described by patients and their informal caregivers as fragmented [3, 4]. This adds to the challenges for older individuals who are often especially vulnerable during the transition and require support throughout the discharge process [4-6].

Informal caregivers can play an important role in securing patients' autonomy in their encounter with the health care services [7, 8] and in supporting their older relative during the discharge process [4]. Informal caregivers' participation in the discharge process has been found to increase satisfaction with discharge planning and the continuity of care across settings [9]. However, previous research indicates that informal caregivers' involvement in discharge planning is limited [10-14]. Family members rarely get to participate despite their potential as important resources in the discharge process and not least as important sources of support for the patients in the first post-discharge period [1, 4, 8, 9, 15-17].

Contemporary policy initiatives emphasize active participation by the patients themselves and their informal caregivers to strengthen the emphasis on the users' individual needs [18, 19]. Thus, informal caregivers' participation during the discharge process is not only an important user right but more importantly, there is reason to believe that informal caregivers' participation can be an important factor contributing to an improved discharge process for frail older individuals [20].

1.1 Overall aim

The overall aim of the dissertation is to describe and explore the participation of informal caregivers in the discharge process when older relatives, 80 years and older, were discharged from the hospital to community care.

The main assumption underpinning this research is the belief that encouraging informal caregivers to actively participate in the discharge process will improve the post-discharge outcome for older individuals. There are, however, many gaps in our knowledge about the informal caregivers' experiences with participation in the transition from hospital to community care. Table 1 provides an overview of the titles, aims, and research questions of the three sub-studies.

Table 1 Overview of the three sub-studies of the dissertation I

| | PHASE ONE | | PHASE TWO |
|---------------------------|--|--|---|
| | Study I | Study II | Study III |
| Title of paper | Informal caregivers' participation when older adults in Norway are discharged from the hospital | Factors predicting a successful post-discharge outcome for individuals aged 80 years and over | The indispensable intermediaries: a qualitative study of informal caregivers' struggle to achieve influence at and after hospital discharge |
| Aim | Describe the participation reported by informal caregivers in discharge planning when their older family member was discharged from the hospital | Describe which factors contributed to a successful post-discharge outcome, as the patients themselves reported it | Explore the informal caregivers' experiences of influencing decision-making at and after hospital discharge for home-dwelling older relatives |
| Research questions | <p>What level of participation did informal caregivers experience in the discharge planning?</p> <p>Were there differences in involvement and participation among the younger generation and the older generation of informal caregivers?</p> <p>Did caregivers' and patients' demographic factors influence the self-reported participation of informal caregivers in the discharge-planning process?</p> | <p>How do the patient-reported discharge process, formal home-care, informal care, and state of health influence the patients' self-reported post-discharge outcome?</p> | <p>How do informal caregivers describe their role as participants in the decision-making concerning the health care services their older relative receives?</p> <p>How do informal caregivers describe their approach to influencing the care of their older relatives?</p> |

1.2 Outline of the dissertation

The dissertation consists of three sub-studies describing and exploring participation in the discharge process drawing on the experiences of patients and informal caregivers. Each sub-study is presented in published original research papers (I–III), which are included at the end

of this dissertation. The dissertation as a whole consists of 10 chapters including the reference list.

The study was undertaken in a Norwegian health care services setting in the interface between specialist health care services in the hospital and home health care services in the community. The process of patient discharge from the hospital is the broad focus of the study. The experiences of informal caregivers who provide unpaid help and support to older relatives during and after the discharge process are the specific focus of the dissertation. The theoretical perspective that has been chosen is the concept of participation.

The first four chapters of the dissertation start with a broad overview of the context and gradually narrowing attention toward the specific focus of this dissertation. Chapter 2 starts by providing a brief overview of the Norwegian health care setting and describing key factors contributing to an increased pressure on care delivery in the community. A broad overview of informal care in the community and the interface between formal and informal care delivery follows, and is considered a part of the context for this study. The chapter ends with a summary of why this dissertation has identified the role of informal caregivers as the focus of the study. Chapter 3 starts by delineating why the concept of participation has been chosen as the theoretical perspective of the dissertation. Subsequently, Thompson's taxonomy of involvement and participation is described as this is the operationalization of the concept of participation that is used in this dissertation. Chapter 3 ends by outlining the perspective of participation as a legal and a consumer right. In Chapter 4 the focus of the study is described starting with the broad focus of the discharge process of older patients. A literature review on the specific focus of the dissertation follows in section 4.2 where the existing research on informal caregivers' participation in the discharge process is emphasized. Chapter 5 presents the aims of the three sub-studies of this dissertation. Chapter 6 contains the description of the material and methods used in this dissertation. The chapter starts with the design of the study and continues with a description of the setting and sample, sample characteristics, an account of the data collection and analysis. Chapter 6 concludes with the ethical considerations of the study. Chapter 7 presents the results of the three separate sub-studies. In Chapter 8 there is a general discussion of the findings of the study and also a description of methodological considerations. The conclusions are summarized in Chapter 9 supplemented with implications of the findings and some future perspectives. Following the references in Chapter 10, the three original papers of this dissertation are enclosed in a separate section. Lastly, the

Discharge of Elderly Questionnaire (DEQ) and the interview guide from the follow-up interviews are attached at the end of the dissertation.

2 Background

The health care services in Norway are a part of the context framing this study and are briefly outlined in this background chapter of the dissertation to provide an overview of the setting of the study.

2.1 The Norwegian health care setting

In the Nordic welfare state model, health care is predominantly a public responsibility and the state is the preferred and dominant provider of care [21, 22]. The Norwegian health care services provide universal health care, which involves providing services across all municipalities and counties in a model that incorporates all citizens in one universal system [21, 23, 24]. This model of health care delivery is not dependent on personal wealth or individual health insurances; all citizens have access to the same level of services [21, 25].

The health care services are organized in a two-tier model that consists of the specialist health care services at one tier and primary health care services at the other tier. This tier organization of the health care services is an important part of the context framing this study. Typically, the care of older patients with complex and sometimes interrelated disorders involves multiple settings (e.g., in-patient hospitalization and home-health care services). Patient transitions between hospitals and primary health care are consistently described in international and Nordic literature as a critical point where the potential for care fragmentation and poor coordination is especially apparent [26-30]. These transitions warrant particular attention due to the potential adverse events and poor post-discharge outcomes. The hospitals are a part of the specialist health care services managed by regional health enterprises. Primary health care services are managed by local municipalities and include community care provided to patients living at home or in nursing homes. And it is in the transitions between the specialist health care services in the hospitals and community care in the municipalities we find the focus of this study. The home health care services and nursing homes are important providers of care in the post-discharge period. Care provided by community care services significantly impacts on the role of informal caregivers. A focus on policy developments within the health care services is outlined in this background chapter to give an overview of the context of the study and to highlight how these changes impact the role of informal caregivers in the transitions of care.

Since the 1980s, Norway has gone through a series of reforms to modernize both tiers of the health care services [31, 32]. Reforms of the specialist health care services attempted to solve the waiting list problem by increasing the number of treated patients in hospitals and to introduce more modern management principles based on activity-dependent budgets [32]. These reforms contributed to shorter hospital stays and patients being discharged earlier than before to make room for new patients [32]. This development has significantly impacted the way health care is delivered in the community. The modernization of the primary health care sector, including the municipal home health care reform in 1984 and the nursing home reform in 1988, involved decentralization to the lowest administrative levels, thereby assigning responsibility for primary care to the municipalities [33]. This development led to an increased emphasis on community care and care delivery in the home, while reducing the number of beds in institutional care [34-37]. To compensate for the retrenchment of institutional care that accompanied the earlier reforms, there has been an expansion of the municipal home-care services in Norway [35]. Although this municipal home-care expansion has been essential in achieving the policy of aging in place, the informal caregivers correspondingly assume essential responsibilities in assisting older individuals living at home before and after hospitalization.

2.1.1 Increasing pressure on care delivery in the community

In 2007-2009, when the data collection for this study was carried out, individuals 80 years and older made up 4.5% of the Norwegian population and individuals in this age group generated more than 20% of all bed-days in somatic hospitals [38, 39]. Simultaneously, the average length of hospital stay has decreased over the last decade throughout the Western world [40]. Norway has the second shortest length of stay of all the European countries and has seen a decrease from six to four and a half days in the period from 2000 to 2010 [40]. Shorter hospital stays result in patients being discharged “quicker and sicker” than ever before and, thus, at an earlier stage of the rehabilitation process [16, 41, 42].

Population projections show a significant increase of the older population in the European countries over the next 40 years [43]. Although the increase is not as dramatic in Norway [44] as in some of the other European countries [18, 43], 13% of the Norwegian population was aged 67 and over in 2009, and this proportion is projected to rise to 17% in 2030 and 21% in 2050 [44]. With an aging population there is cause for concern for the old age dependency ratio with regards to accommodating the increasing need for health care services [18, 19, 43].

In Norway, the old age dependency ratio amounted to 22 older dependents per 100 working-age population in 2009 and the number of dependents is steadily rising and amounted to 24 dependents in 2013 [45]. These population projections are accompanied by an anticipated shortage of health care personnel to care for the aging population [19, 33, 46]. Even if the older population remains as healthy as or even healthier than today, it may prove difficult to meet the increasing demand for personnel in the municipal health care services when the proportion of the population 80 years and older starts increasing from 2020 [47].

Today, community care for older individuals in Norway is mainly provided at home or in sheltered housing by the municipal home-care services and in nursing homes in the local municipalities. The municipal home-care services in Norway provide home-help services and round the clock home-nursing care. Service hours are allocated depending on the patient's need for assistance and can be adjusted if individual needs change over time. Compared to other European countries, home-care delivery in Norway is viewed as generous [43, 48]. The overall number of home-care recipients in Norway has increased as a result of the aforementioned primary care reforms [49]. This home-care services expansion has not, however, only benefitted the oldest individuals living at home. Although there has been a substantial increase of care recipients aged 80 and over, the fastest growing patient group in the municipal home-care services has been adults under the age of 67 [35]. The municipal home-care services are caring for people with long-term, complex disorders, and severe disabilities regardless of the age of the recipient [18, 35]. This contributes to increasing demands and increased competition for the resources of the municipal home health-care services.

The aging population, substantial growth in care-dependent younger patients now living in the community rather than in institutions, and hospital reforms resulting in shorter hospital stays, earlier discharge and subsequent increased needs for follow-up care in the community, have contributed to increasing pressure on the service provision in the municipal home-care services [35]. Thus, policy makers are suggesting alternative measures to accommodate the care needs of older individuals such as reorganizing and redistributing formal responsibilities for care to the primary health care services in the community [50] and finding ways to utilize informal care resources (family members and volunteers) to a greater degree than today [18, 19, 51]. Consequently, the increased pressure on care delivery in the community is gradually shifting toward informal caregivers.

2.2 Informal care

Informal care or informal caregiving is in this dissertation defined as unpaid help and assistance provided to older individuals by their family members, members of the extended family, friends, or neighbors. Estimates show that in Norway informal caregivers provide approximately 40%–50% of the care for home-dwelling older individuals [25, 47, 52, 53]. In other Western countries with less developed formal home-care services, however, it is estimated that informal caregivers provide 80% of the care delivered in the community [25, 52-55]. In Norway, informal caregiving to home-dwelling older relatives has been consistent over the past 20 to 30 years [18, 56, 57]. Estimates showed that approximately 15% of the adult population provided informal care to a relative outside their household in 2008; simultaneously, one in five older individuals living at home received regular help and support from an informal caregiver [47].

Informal care has become an issue of particular current interest due to proposed policy changes intending to develop a modern policy for informal care in Norway [18]. The policy documents acknowledge that in order to maintain the level of support provided by informal caregivers today, the public policy needs to acknowledge informal caregivers' substantial contribution and find ways to support their caregiving efforts. However, challenges due to changing family structures and increased mobility within and across country borders puts pressure on the availability of informal care in the community [18, 58, 59]. Family and work conflicts between gainful employment and caring for children may put additional pressure on the informal caregiving ability [59]. Consequently, the proposed modern policy for informal care includes providing professional support, respite options, and guidance for family members who perform demanding caregiving tasks [18]. This proposed policy recognizes the informal caregivers' efforts as important contributions toward a sustainable model of care in which formal and informal caregivers need to work together.

2.2.1 The interface between formal and informal care

A substantial number of older individuals in the Nordic countries who receive informal care from family and friends simultaneously receive formal care from the home-health care services [47, 56, 60, 61]. Consequently, the interface between formal and informal care in the community is an important relation that has elicited a considerable amount of research [56, 62-65]. Particular interest has been devoted to exploring how and if informal and formal care substitute for or complement each other [56, 62, 64, 65]. Seen from the health care services'

viewpoint, the interface between formal and informal caregivers is an important factor that may impact the expending of care resources. While for the informal caregivers, the relationship with the formal care services may be an important source of respite and a sharing of care responsibilities [56].

The substitution theory, which argues that when formal service levels are high, informal care is low, has been challenged [56]. Formal caregivers have been found to perform personal activities of daily living (PADL-activities), while informal caregivers often provide help with instrumental activities of daily living (IADL-activities) [61, 66, 67]. Importantly, research has also shown that patients receiving extensive formal care from the municipality continue to receive informal care [56, 60, 61]. Formal and informal caregivers in Norway appear to complement each other and often provide help with different tasks rather than substitute each other [56, 57, 60, 61].

It has been suggested that we are now seeing a “reverse” substitution effect in that informal caregivers match the decline of formal services, and effectively substitute for the lack of formal care [62]. In a study exploring long-term care in Europe, informal care was found to decrease home help services (mainly help with IADL-activities) while it complemented home nursing care services [65]. This suggests that the substitution effect vanishes for older individuals with more extensive care needs [65]. It is possible that the substitution theory carried greater weight before the modernization of the primary care sector, when care for an older individual was mainly carried out in institutions. At that time institutional care (formal care) could potentially replace informal care; however, that is no longer the case in today’s system where community care and aging in place is emphasized and older individuals continue living at home despite being dependent on care [57]. The deinstitutionalization has contributed to care efforts being shared between the families and formal care providers to a greater extent [57]. And we are now in a situation where informal care may be a substitute for formal care. Bonsang [65], however, suggests that this kind of substitution between informal and formal care only occurs if the older individual has limited care needs. This has implications for informal caregivers’ potential to substitute for formal care if care needs increase proportionately with the aging population.

2.2.2 The informal caregivers' contributions

Research on informal care in Nordic countries has been concerned with a number of different aspects ranging from the particulars of describing who the informal caregivers are, whom they care for, and which tasks they perform [66, 68, 69]. Internationally, caregiver burden is perhaps the most commonly investigated caregiving outcome [70], often with a particular focus on how the caregiving experience influences informal caregivers' quality of life and overall health condition [70-73].

Previous research concerned with *who* provides informal care has showed that spouses are often the first to assume caregiving responsibilities for older adults when care needs arise. Adult children and members of the extended family often take the caregiver role if no spouse is available or able to care for a frail older individual [68]. Romøren [66] found that four out of five informal caregivers were members of the older person's close family (spouse, children, son-/daughter-in-law, grandchildren, or siblings). Furthermore, research has found that informal caregivers were predominantly females and particularly wives and daughters [53, 66, 69, 74, 75]. However, contemporary research has shown that men, sons in particular, are more involved in informal care in Northern Europe than in any other part of Europe [53].

Jegermalm [67] explored informal caregiving and developed a typology of care and caregiving. In his study Jegermalm identified four typologies of caring and concluded that the typical caregiver on the "heavy end" of caring (providing personal care) was typically a woman, usually an elderly wife caring for a spouse in her household or a daughter caring for an elderly mother in a separate household [67]. The findings from Jegermalm's study support earlier studies in describing traditional gender roles in caregiving, namely that female informal caregivers are often involved in personal care tasks and IADL-activities, whereas male informal caregivers often help with IADL-activities, such as grocery shopping, shoveling snow, and gardening [61, 66]. However, Jegermalm's work also showed that it is common for both women and men to be involved as informal helpers in the sense of providing help and support on the lighter end of the spectrum, keeping company and providing practical help (not personal care) [67]. Estimates from Statistics Norway [47] corroborate these findings and highlight that sons help older relatives with grocery shopping and other practical tasks whereas daughters to a greater degree take responsibility for cleaning and personal care. Sons and daughters appear to be equally involved, however, in providing support and help in interaction and negotiation with formal home-care services [47].

Informal caregivers provide help with a wide variety of practical tasks; however, social and emotional support is perhaps the most common form of support provided by adult children to their older parents [74]. In addition to practical and emotional support, informal caregivers play an important role in supporting their older relative in health care consultations [7, 76, 77], managing information [78], and in negotiating formal care in the community [79, 80] by ensuring high-quality services when patients are not able to demand this for themselves [81].

It is the informal caregivers' experiences in the discharge process that is the specific focus of the dissertation. By limiting the scope of this study to the discharge process, we have not explored other issues regarding informal caregiving. Exploration of the wide range of tasks and responsibilities traditionally positioned in the realm of informal caregivers will remain on the outskirts of the study.

3 Participation

A literature review conducted prior to this study showed a thorough documentation of the importance of participation for older individuals during the discharge process [82].

Participation is encouraged not only through an increasing awareness in public policy but also because earlier research has showed that participation may benefit the patients' post-discharge outcomes [2, 82]. The concept of participation adopted in the questionnaire developed for this study was operationalized using the work of Thompson [83]. Thompson's taxonomy conceptualizes participation as more than merely exchanging information, including in addition a dimension of cooperation with health care personnel and having one's opinions heard. This is a central assumption underpinning the study in this dissertation. Consequently, the theoretical perspective that has been chosen in this dissertation is the concept of participation.

The concept of participation in the health care services has received increasing attention on the health policy agenda in the economically developed world, including Norway during the last several decades [83-86]. Debates about participation tend to reflect a growing unease with the paternalistic philosophy underpinning the health care services [86]. The relationship between patients and health care personnel traditionally relies on a paternalistic model whereby the patient is a passive recipient of care, while the health care personnel make the decisions based on their expert knowledge [87]. I argue that the relationship between informal caregivers and health care personnel has also traditionally relied on a paternalistic model. This paternalistic model is universally challenged by the idea of participation. Thus, a redefinition of the patient/informal caregiver role is a key characteristic of the concept of participation [87]. The redefinition of roles lies in encouraging patients and informal caregivers to take an active participatory role moving away from the traditionally paternalistic hierarchy.

Participation can, thus, be seen as a process of empowerment of the individual and as a tool to ensure the individual's autonomy [83, 88]. Participation grants users influence in the decision-making processes with regards to individual service provision.

The policy and the ideology of participation have been the subject of international research since the early 1980s [89]. The concept lacks clarity and is poorly defined and open to interpretation despite abundant literature [8, 87, 90, 91]. There is an extensive range of similar and related terms often used interchangeably with participation such as: collaboration,

consultation, user/patient participation, shared decision-making, and partnership [8, 83, 87, 90, 92-94]. This ambiguous terminology may contribute to an unintended obscurity in the definition of the concept of participation.

My understanding of the concept of participation has emerged through deliberations in the research team and after reviewing the literature. It became clear that the concept is contextually changeable. This may explain why it is a concept that is so difficult to clearly define in the literature. Participation is perhaps best understood as a process. In line with my understanding I have found that Thompson's taxonomy of involvement and participation is a useful operationalization. This taxonomy was developed to offer conceptual clarity, which had been lacking [83].

This PhD study is limited to participation in the discharge process and with a particular view of participation as a consumer and democratic right regulated through legislation. Furthermore, it is presumed that the essential characteristics of participation also apply to the participation of informal caregivers as representatives of the patient.

3.1 Taxonomy of patient involvement and participation

Thompson identified five levels of patient-determined involvement based on empirical studies of patients' involvement in health care consultations. In his model these patient-determined levels were aligned with five parallel levels of professional-determined involvement gleaned from existing theories of patient involvement [83]. In Thompson's taxonomy, participation can only occur when patients desire to be involved in dialogue and shared decision-making and when professionals simultaneously reciprocate the wish for dialogue and shared decision-making. In this sense, participation is co-determined by patients and professionals and can only occur in reciprocal relationships of dialogue and shared decision-making (Figure 1) [83]. Participation requires an exchange of information/knowledge between users and professionals narrowing the competence gap [83] and consequently enabling a dialogue and the sharing of decisions. This indicates that health care personnel must surrender some of their decision-making power to enable and empower users to participate in the decision-making [91]. However, Thompson emphasizes that while dialogue underpins the possibility of shared decision-making, the patient may sometimes prefer the professional (as agent) to make the decision based on knowledge of his or her preferences. Participation does not, therefore,

necessarily include the actual sharing of decisions or even consensus as long as the patient has made his or her preferences known through previous dialogue with the professionals [83].

| Patient-Desired Level | Patient-Determined | Co-Determined | Professional-Determined |
|-----------------------|-------------------------------|------------------------|--------------------------|
| 4 | Autonomous decision-making | [PARTICIPATION] | Informed decision-making |
| 3 | | Shared decision-making | Professional-as-agent |
| 2 | Information-giving | Dialogue | Consultation |
| 1 | Information-seeking/receptive | | Information-giving |
| 0 | Non-involved | | Exclusion |

* Figure from Thompson 2007, p 1306 (reproduced with permission from Elsevier Ltd.)

Figure 1 Thompson’s levels of involvement

3.1.1 Levels of involvement and participation

“Level 0” of Thompson’s taxonomy is non-involvement or exclusion. “Level 1” involves professionals supplying the information they consider necessary and/or patients seeking and receiving information. At “Level 2,” there is a dialogue between patients and professionals and an exchange of information, implying that the patient him- or herself supplies information to the professionals. “Level 3,” marked by shared decision-making, is the level at which patients and professionals cooperate, and the patient’s opinions and preferences are incorporated before the professionals make a decision. At “Level 4” of the taxonomy, patients are autonomous in decision-making, and professionals offer their expertise to patients to enable them to make autonomous informed decisions.

Thompson’s taxonomy [83] offers a necessary simplification in a linear model progressing from non-involvement toward participation, while simultaneously acknowledging the complex and multi-faceted, dynamic nature of the concept of participation (Figure 1). Contextual dimensions such as the nature of the illness (acute/chronic), characteristics of the patient (active/passive) and the patient-professional relationship (high/low level of trust) appears to influence the demand for involvement, which also impacts the potential for moving between the levels of involvement [83]. Generally, Thompson [83] suggests that there is reduced demand for involvement when the illness is acute, the patient appears to be passive, and has a high level of trust in the health care professionals. Conversely, there is increased demand for involvement if the illness is chronic, the patient appears to be active, and has a low level of trust in the health care professionals [83]. The aforementioned simplification lies in establishing a seemingly linear model, while simultaneously acknowledging that the phenomenon is complex and dependent on a number of contextual factors. This model,

however, is useful for the purpose of academic exploration and research. Thus, this understanding of the levels of participation was used in the development of the discharge questionnaire for this study as well as in the statistical analyses.

Within this PhD study, we propose that the taxonomy of involvement and participation developed by Thompson [83] also applies to the participation of informal caregivers as representatives of the patients.

3.2 Participation as a legal right

Health care policy and legislation throughout the economically developed world has consistently advocated opportunities for patients and informal caregivers to take an active part in health care delivery [83, 86]. Participation as a legal right formally established in the legislation is an example of participation as a democratic right. It is customary to conceptualize participation on two levels, the system level and the individual level. Participation at the system level has been described as collective or indirect participation in formulation of policy [8, 92]. This entails including user representatives (often representing non-governmental voluntary organizations [NGOs]) in the process of reaching the goal of high-quality care and equality for service users. Indirect participation emphasizes the democratic dimension of quality requiring a developmental process of engagement over time [83].

At the individual level, every patient has a legally established right to influence and participate in decisions regarding his or her own medical treatment in primary and specialist health care services [95, 96]. The active participation in decision-making regarding their own personal care, at the individual level, has been described as direct participation [8, 92]. Similarly, the involvement of informal caregivers in relation to individual care decisions is viewed as direct participation [8]. It is participation at the individual level, direct participation, which is the concern of this dissertation.

In Norway, the patient's next of kin has the right to be present when medical treatment is administered when the patient requests it [95]. In the event that the patient is cognitively impaired, the right to influence and participate in decisions regarding medical treatment is transferred to the patient's next of kin or is shared between the patient and his or her kin [95]. The Norwegian Patient's Rights Act [95] also mandates the right of patients and their next of

kin to access information about the patient's health condition and medical treatment when the patient consents to this or when the situation calls for it. Consequently, informal caregivers are granted direct participation on behalf of the patient when the patient requests it.

3.3 Participation as a consumer right

The concept of participation has gained momentum with the increasing marketization of health care, which has led to a view of the health service user as a consumer [97]. Within this consumerist model, participation has become a tool to improve the quality and efficiency of the services [98]. Thus, participation can be understood as a market tool, where the market is the health care services, and where the patient (or their informal caregiver) is expected to take an active, responsible role [88]. The logic of participation within this model is predicated on the understanding of the health care services as a quasi-market where market forces regulate the service provision by encouraging the individual freedom to make choices [88]. As in other markets, this conceptualization implies that different providers “compete” for users by allowing them to choose the service that suits them best, where their individual needs are recognized. Participation, thus, becomes a way to make the system responsive to individual needs and preferences by giving decision rights to those who benefit from and experience the service [83, 98]. Patients and their informal caregivers are free to use their consumer power to demand high-quality services and to lodge complaints when services are not satisfactory [87]. Within this model, participation functions as an incentive for service providers to provide high-quality services [87], and it increases public accountability and democratic control by giving decision rights to the users [98].

However, older patients in particular may find it difficult to act as consumers, and they often practice participation in a subtle and discrete way [99]. Furthermore, as is often the case in small local communities, there may not be several providers to choose from, thus, the logic of leaving the current provider for a new one if you are not content is not always realistic. The only practical choice is to express discontent with a provider to possibly negotiate higher quality care [81, 83]. However, older patients who often experience limited or weak consumer sovereignty depend on others, mainly their family, to represent them and to complain when the quality of care is not satisfactory [81]. Unfortunately, little is known about how the patients delegate these responsibilities and how the informal caregivers manage this role representing the patients.

4 Discharge process for older patients

The process of patient discharge from the hospital is the broad focus of the study and, thus, a review of this process is relevant. The experiences of informal caregivers who provide unpaid help and support to older relatives during and after the discharge process are the specific focus of the dissertation.

The discharge process includes discharge planning at the hospital and the first three to five weeks after discharge, as this is found to be the most critical post-discharge phase when the majority of adverse events occur [100, 101].

Older patients with continuing care needs and multifaceted care requirements due to complex and interrelated health problems are especially vulnerable in the discharge process [4, 5, 26, 102, 103]. This vulnerability at discharge has been shown to be an important predictor of readmissions [16, 101, 104-107] and/or hastened transition into a nursing home [16, 108]. A relatively short length of hospital stay and living at home rather than in sheltered accommodation have been found to increase the probability of readmission [109]. Approximately 20% of the oldest patients have been found to experience preventable adverse events leading to subsequent re-hospitalization [100, 101, 110-112].

The adverse events patients experience after discharge are often related to discontinuities of care when patients are transferred across settings [28, 100, 111, 113-115]. The most frequent adverse event that patients experience is related to medication information and management of new medications [26, 110, 113, 116-118]. In particular, changes and discrepancies in the preadmission and post-discharge medication regimen pose significant challenges and are potential threats to patient safety during transitions. A new medication regimen can be challenging for patients and their caregivers to manage if they are not provided sufficient information and education prior to discharge [28, 101, 111, 113]. Other issues that have proven to be challenging after discharge are how to manage housework and other activities of daily living with an acquired functional limitation [2, 42, 106, 116, 119, 120] and securing sufficient and well-adapted community health care ensuring continuity of care across settings [42, 120, 121].

4.1 Discharge planning

The substantial challenges and discouraging consequences of hospital discharge for older adults has encouraged a significant increase in research efforts into discharge planning in the international research community [2, 6, 106, 120, 122, 123]. In this dissertation, discharge planning is defined as the process of identifying and preparing for a patient's anticipated health care needs after discharge from the hospital [122]. The expressed goal of discharge planning is to reduce hospital length of stay and unplanned readmission to hospital and improve the coordination and continuity of health care as patients transfer across care settings [6, 26, 124]. Discharge planning is a complex process incorporating patient assessment, developing a discharge plan, providing information and education to patients and their informal caregivers, and planning (follow-up) care post discharge [122].

Much of the research on discharge planning has been targeted toward information exchange between the health care personnel across the different settings of care, i.e., looking at safe transfer of accurate and complete clinical information [28, 118, 124, 125] including developing tools to transfer discharge information electronically from one setting to the next [26, 126-129]. In recent years, there has been an increased effort in research on discharge planning with the specific goal of preventing re-hospitalizations [130-132] and increasing patient safety across settings [100, 106, 133]. In particular, there has been an emphasis on developing interventions to make transitions across settings as efficient and safe as possible [26, 102, 113, 131, 134-137]. It has also been recognized that in order to secure continuity of care there is a need to include the patients in the discharge planning [10, 15, 16, 102, 119, 138-143].

In spite of this, studies show that patients report a lack of opportunities to communicate their wishes and perceptions to the hospital staff [8, 15, 103, 141, 143-145]. In a series of case studies, Efraimsson et al. explored the participation of older women and their family members in discharge planning conferences at the hospital [139, 141, 145, 146]. In the discharge planning conferences, it became evident that the decisions were in fact made beforehand, before the patients and their family members were included [141]. Moreover, most of the discussions centered on the issues the professionals were concerned with, such as placement, medical issues, and routine administrative protocols [139]. The patients felt insecure and powerless as the professionals dominated the discussions [139, 145] and ultimately the patients felt excluded, despite being encouraged to participate [141]. Almborg et al. [143]

explored patients' participation in discharge planning after acute stroke, and found that less than 40% of the patients had participated in the development of their discharge plan. The patients reported that they had been adequately informed; however, this was not enough to ensure participation in goal setting and identifying post-discharge needs [143].

Several literature reviews have identified factors influencing the discharge process and post-discharge outcomes [2, 6, 120, 122]. Coffey found that despite substantial efforts to improve information management and information transfer across settings, difficulties persist and this is still an area that needs improvement [2]. Poor communication between professionals across settings and between professionals and informal caregivers will increase the vulnerability of the patients and may lead to unsuccessful discharge. The needs and concerns of patients and caregivers in transition from hospital to home require further exploration [2]. Importantly, reviewing the existing literature has led to consistent recommendations for more active involvement of caregivers and patients in the discharge process [2, 120, 122].

4.2 Informal caregivers' participation in the discharge process

Research suggests that the role of the family is one of the most significant factors of the discharge planning for frail older individuals [122]. Informal caregivers' involvement in the discharge process is found to increase satisfaction with discharge planning, continuity of care, feelings of preparedness, and acceptance of the caring role [9] and to increase the well-being of patients and their informal caregivers [10]. Involving family members has also been shown to improve the patient's participation in the decision-making process [2, 7, 8]. Moreover, it is recognized that informal caregivers' satisfaction with the discharge process influences the patients' satisfaction and even influences the patient outcome positively [122]. However, research indicates that informal caregivers' participation in discharge planning is limited [10-14].

4.2.1 Information as a precursor to participation

A study from South Australia highlighted that informal caregivers often felt unprepared for the caregiving role after discharge and felt they had no choice whether or not to take on the role of caregiver due to a lack of involvement in the discharge planning [13]. The informal caregivers' perspectives and concerns were often overlooked in the discharge planning, thus,

leaving the caregivers unprepared for their role after discharge [147]. A study exploring the perspectives of patients, caregivers, and clinicians on the hospital to home transition in an urban area of the USA also highlighted that informal caregivers were inadequately prepared for the patient discharge [148]. The informal caregivers in this study perceived themselves to be in a peripheral role during discharge planning at the hospital and felt they had to initiate efforts and negotiate the complex hospital system to elicit information [148].

A Swedish study exploring how the patients and their informal caregivers experience the discharge planning process further highlights significant areas of preparation to accommodate their post-discharge needs [149]. Three important areas of preparation were uncovered in this study: caring issues, ADL-activities, and where to turn in case of unforeseen needs [149]. It was important for informal caregivers to be prepared with regards to the patients' state of health, treatment, and arrangements for continuing care after discharge. Regarding the issue of ADL-activities, it was important to have sufficient arrangements for support at home and technical aids. Lastly, it was important to know who to contact in case of unforeseen events. The relatives reported feeling prepared if their needs had been met in the three significant preparation areas [149].

Two Canadian studies exploring care coordination for older hip fracture patients across settings from the perspectives of the patients, their informal caregiver, and health care personnel found several factors that threaten continuity of care [150, 151]. Breakdowns in communication about care between the informal caregivers and the formal caregivers led to ambiguity in information sharing and a limited flow of information. Unclear roles and responsibilities contributed to blurred boundaries between the individuals involved, and this contributed further to the poor information exchange across settings. Informal caregivers felt like they were sometimes a burden to the formal caregivers when they required information [150]. The previous studies have been concerned with informal caregiver's participation as a means of preparing for discharge. There is, however, a lack of research describing the informal caregivers' access to information and participation from the perspective of the informal caregivers.

Research exploring the collaboration between relatives of frail older patients and nurses in acute hospital wards in Sweden [152] supports the notion that treating relatives as partners in decision-making rather than as passive recipients of information is important for ensuring the quality of care for the older patient. In this study, the collaboration was explored in relation to

the relatives' reported level of satisfaction with the care provided throughout the hospital care trajectory. Low satisfaction with care was significantly associated with a low level of collaboration, indicating that relatives who were more involved in collaboration with nurses were more satisfied with the care provided [152]. The study reinforces the importance of sharing information with relatives and highlights that in addition to sharing information, involving relatives in decision-making is fundamental to the care quality. This entails a new role for relatives as active partners with nurses in managing care, rather than being passive recipients of information [152].

These studies highlight some of the challenges informal caregivers face in the discharge process. In particular, these studies corroborate Thompson's [83] assertion that a lack of sufficient information in the discharge process hampers participation, not only for patients but also for informal caregivers. These previous studies have explored information exchange; however, we need further knowledge about the informal caregivers' actual degree of participation in the discharge process.

A Swedish study exploring the relatives of stroke patients' perceptions of participation found that the majority of the relatives reported receiving information about the patients' illness; however, only about half of the relatives reported receiving information about care, medication, rehabilitation, and support [153]. Furthermore, four out of five reported that they did not at all participate in assessing goals and anticipating needs after discharge [153]. However, longer duration in the hospital, higher education level among patients, and patients and relatives being female were factors positively associated with greater reported involvement by relatives [153]. This study explicitly addresses the participation of relatives of stroke patients in a Swedish health care setting. However, there is a lack of knowledge from a Norwegian health care setting. An exception is a contemporary Norwegian study exploring the informal caregivers' perceptions of participation when their older relative underwent hemodialysis, which found that the informal caregivers had no dialogue with the health care personnel [154]. The informal caregivers reported struggling for involvement to be able to participate in decision-making. They felt forgotten or excluded, which corresponds to the lowest level of involvement in Thompson's taxonomy [154]. This study was a qualitative study conducted with a particular focus on involving informal caregivers in decision-making in dialysis units. There is still a lack of knowledge from a broader Norwegian health care context including a wider range of hospital wards. Furthermore, we need more knowledge

about the level of participation of informal caregivers conducted in a larger scale through a quantitative approach.

Recent research highlights the importance of including informal caregivers in the discharge process, but there is a lack of studies describing whether or not informal caregivers in fact participate and how they experience the participation or lack thereof. There are some indications that informal caregivers struggle to be involved [154] despite the considerable literature advocating informal caregiver participation in the discharge process. Furthermore, informal caregivers are a diverse group of individuals with a range of kinship ties to the patients. There is reason to believe that spouses, children, and children-in-law caregivers have different needs and may struggle with different issues as informal caregivers [155]. The research on informal caregivers described above does not distinguish between spouses and adult children and children-in-law in describing the experiences with participation, although Lindhardt et al. [152] do explore this as a factor in their analysis. There is a need for research exploring the potential differences between the different generations of informal caregivers also when it comes to experiences of participation in the discharge process.

Contemporary development of the health care services puts pressure on formal and informal care delivery in the community after hospital discharge. As the brief overview of literature on informal care shows, we already know quite a lot about the burden of prolonged informal caregiving for family members living in the community. However, pertaining to informal caregiving for patients at and after hospital discharge in the transition from the hospital to community care, we need more knowledge. Participation in discharge planning is encouraged to ensure continuity of care and care delivery in accordance with the wishes and needs of patients and informal caregivers. However, while the existing research is predominantly concerned with information exchange as though information in itself constitutes participation, there is an apparent scarcity of research on the informal caregivers' actual participation in the discharge planning. We simply do not know enough about the experiences of informal caregivers and their participation in the discharge process of older adults. There are a number of specific gaps in our current knowledge of informal caregivers' participation in the discharge process that this study aims to fill.

5 Aims and research questions

5.1.1 Aim and research question of Paper I

The aim of Paper I was to describe the participation reported by informal caregivers in discharge planning when their older family member was discharged from the hospital. There are no previous studies describing the informal caregivers' participation from the Norwegian health care services setting. The three specific research questions for this paper were as follows:

- What level of participation did informal caregivers experience in the discharge planning?
- Were there differences in involvement and participation among the younger generation and the older generation of informal caregivers?
- Did caregivers' and patients' demographic factors influence the self-reported participation of informal caregivers in the discharge-planning process?

5.1.2 Aim and research questions of Paper II

The aim of Paper II was to describe which factors contributed to a successful post-discharge outcome, as the patients themselves reported it. Several hypotheses regarding factors that may influence the post-discharge outcome were derived from earlier research and were tested in this study. Four groups of factors related to how the patients perceived the discharge process, how they perceived the formal support they received after discharge, the involvement of informal caregivers and the patient's state of health at discharge were tested. The specific research question in this study integrated the four separate hypotheses that were tested:

- How do the patient-reported discharge process, formal home-care, informal care, and state of health influence the patients' self-reported post-discharge outcome?

5.1.3 Aim and research questions of Paper III

The aim of Paper III was to explore the informal caregivers' experiences of influencing decision-making at and after hospital discharge for home-dwelling older relatives. In this sub-

study, we intended to explore the experiences of informal caregivers in greater depth than structured survey interviews allowed, by using qualitative interviews with informal caregivers. The specific research questions in this study were as follows:

- How do informal caregivers describe their role as participants in the decision-making concerning the health care services their older relative receives?
- How do informal caregivers describe their approach to influencing the care of their older relatives?

These specific questions form the rationale for conducting this PhD study and are explored in this dissertation.

6 Material and methods

6.1 Design

The dissertation was designed to address participation in the discharge process from the perspectives of patients and informal caregivers using a mixed methods design with a sequential explanatory approach [156]. This type of design involves collecting and analyzing quantitative data during the first phase of the research followed by collecting and analyzing qualitative data during the second phase of the research (Figure 2) [156, 157]. The second phase of data collection is informed by the first phase of data collection and analysis, which makes the two forms of data separate but connected.

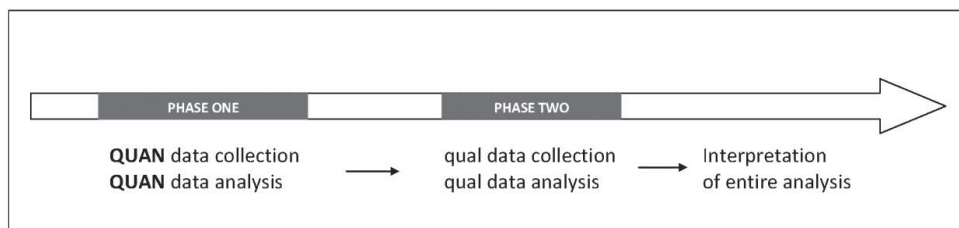


Figure 2 Mixed methods design with a sequential explanatory approach

The emphasis in this study's sequential explanatory design lies on the quantitative data collection and analysis, implying an approach that gives weight to the quantitative data. The qualitative data collected and analyzed in the second phase contributes to explaining the results from phase one.

The three sub-studies of the dissertation have two different designs and have drawn upon three samples of participants. An overview of the design, sampling procedure, and method of data collection in the three sub-studies is presented in Table 2.

Table 2 Overview of the three sub-studies of the dissertation II

| | PHASE ONE | | PHASE TWO |
|----------------------------------|---|--|--|
| | Study I | Study II | Study III |
| Study design | Cross-sectional design | Cross-sectional design | Exploratory qualitative design |
| Sampling procedure | Consecutive | Consecutive | Purposive sampling |
| Sample | Informal caregivers (n = 262) | Patients (n = 142) | Informal caregivers (n = 19) |
| Method of data collection | Structured, in-person interviews, questionnaires, self-report | Structured telephone interviews, questionnaires, self-report | Semi-structured, follow-up, telephone interviews |

Mixed methods research has emerged over the past 20 years and is by some described as a third methodological movement [157] and as an alternative and a supplement to the quantitative and qualitative research traditions [158]. However, mixed methods research is a contested concept wherein a commonly agreed upon definition is lacking [157-159].

Despite being a contested area, the mixing of methods is increasingly common in contemporary medical and health care research [160], and it is even emerging as a dominant paradigm in health care research [157]. Teddlie and Tashakkori [158, p. 31-32] define mixed methods research as “the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches for the purpose of breadth of understanding or corroboration.” This definition suggests that mixed-methods research is a means to expand the breadth of understanding of a particular research question or to corroborate findings from one approach with findings from the other. This perspective establishes the mixed methods approach as a research activity where the qualitative and quantitative approaches are seen as complementary. It involves determining whether the findings confirm, refute, extend, or modify each other.

Quantitative approaches, such as the cross-sectional survey design that is used in this study (Paper I and II), are well suited for describing relationships and associations between phenomena at a fixed point in time [161]. Qualitative methods can help answer questions that quantitative research may not be able to provide in-depth answers to, such as exploring patients’ motivations, perceptions, and expectations in greater depth than what is possible

through structured questionnaires [162]. In this study, the choice of mixed approaches is consistent with the aim of the dissertation in that the findings from the questionnaire and the qualitative interviews both tap the experiences of the patients and the informal caregivers.

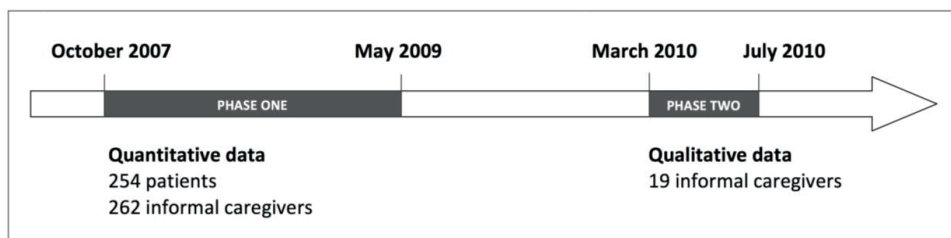
In this dissertation, the interpretation connecting the results from both phases occurs in the discussion chapter. Results from the qualitative approach are explored to determine if they challenge, refute, confirm, or corroborate the findings from the quantitative approach and vice versa. Thus, the sequential explanatory mixed methods approach used in the dissertation is intended to enable a more in-depth understanding of the overall research aim by connecting the results from the two separate phases.

6.2 Setting and sample

This PhD dissertation is part of a multicenter study that explored transitions from hospital care to community care in Norway. The main study aimed to investigate transitions in three steps describing patient flow, inter-agency barriers, and user perspectives. The multicenter study focused on the transitions from somatic hospitals into home-care and nursing home care in the municipalities for patients aged 80 and over. This dissertation explores the user perspectives on the discharge process from the perspective of the patients, aged 80 and over, and their informal caregivers.

6.2.1 Recruitment of participants

Recruitment of participants and data collection for this PhD study was carried out in two phases (Figure 3). In Phase One, data were collected in quantitative self-report survey interviews with patients and their informal caregivers. In Phase Two, qualitative telephone interviews were carried out with a sample of informal caregivers.



* Figure from Bragstad, Kirkevold, & Foss, 2014, p

Figure 3 Timeline of recruitment and data collection

Phase One: Recruitment for the main study

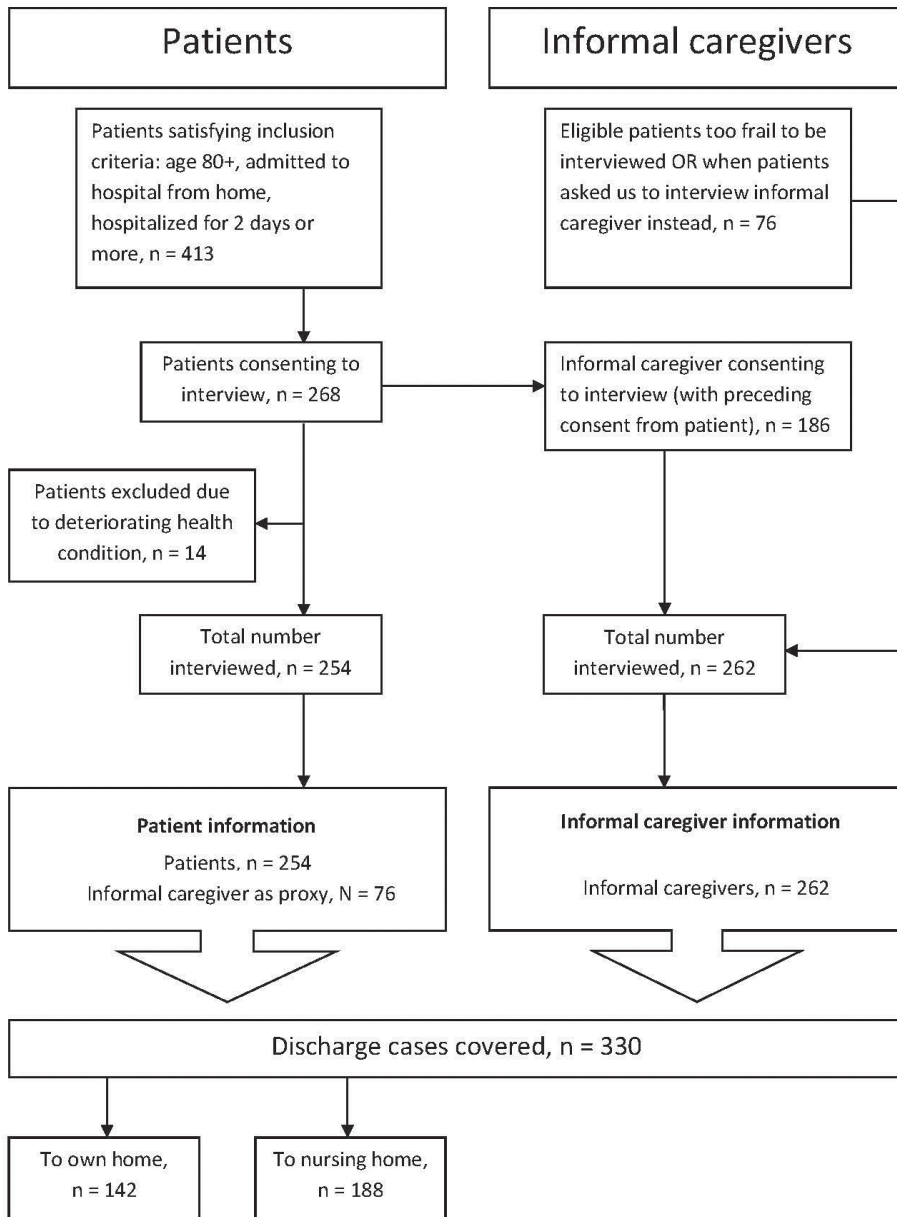
In 2007 all 434 municipalities in Norway were stratified by size into three strata: small municipalities (< 4000 inhabitants), medium-sized (4000–13000 inhabitants), and large (> 13000 inhabitants).¹ A proportionately stratified sample of 67 municipalities was drawn from the three strata [161]. All regions of Norway, except for the region of Western Norway, were represented in our sample of municipalities. To obtain a representative sample of the Norwegian population of home-dwelling persons aged 80 and over who had been discharged from hospital back to the community, we chose a consecutive sampling procedure intending to recruit all eligible patients discharged from the hospital to the selected municipalities during our recruitment period of 20 months [161]. Between October 2007 and May 2009, charge nurses in the 67 municipalities in our sample were asked to consecutively identify and recruit all eligible patients for our study. The local recruiters, the charge nurses, were thoroughly informed about the inclusion criteria for the study through training seminars, detailed written instructions, and conversations with the research assistants at regular intervals throughout the study. The recruiters identified 413 eligible patients recently discharged from 14 different hospitals (Figure 4). Inclusion criteria were:

- Aged 80 and over
- Admitted to hospital from home
- Hospitalized for at least two days
- Discharged home with assistance from the formal home health care services or to a nursing home
- Adequate physical and cognitive capacity (as assessed by the recruiting nurse) to participate in the planning of their own discharge

Between the time of recruitment, at discharge, and the time for the interview, two to three weeks after discharge, some patients experienced deteriorating health conditions and some even passed away. Due to the expected fluctuating health conditions of patients of this age, the interviewers were required to assess the physical and cognitive capacity of the patients before commencing the interview. At the time of the interview, 76 of the patients were found to be too physically frail or cognitively impaired to be interviewed; in those cases, their informal caregiver was asked, with the consent of the patient, to participate as a proxy for the patient and to provide information on the patient's perceptions.

¹ The main reason why the research team chose to stratify municipalities by size was to ensure a representative sample of patients in the study to be able to explore potential macro-level differences between municipalities of different sizes for the two parts of the multicenter study investigating patient flow and inter-agency barriers.

Each recruited patient was asked to identify his or her closest informal caregiver to be asked to participate in the study. The patient thus chose the sample of informal caregivers included in the study. There were no exclusion criteria for the informal caregivers, and the number of informal caregivers recruited to the study followed from the number of patients recruited to the study.



* Modified version of flowchart in Bragstad, Kirkevold, Hofoss, & Foss, 2014, p 158

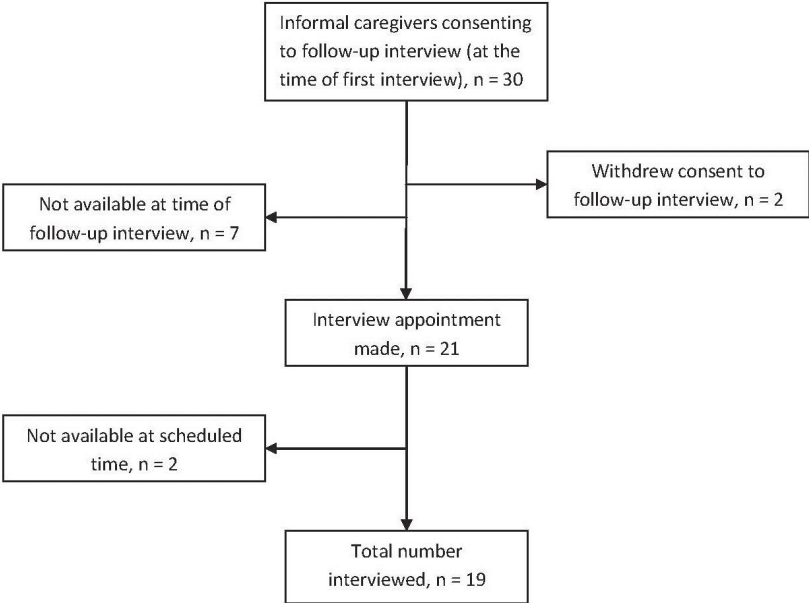
Figure 4 Flow chart of inclusion of respondents and discharge cases covered in the study

Phase Two: Recruitment for the follow-up study

The follow-up study was not initially planned as a part of the main study. However, during the data collection, the research team encountered many interesting accounts of the informal

caregivers’ experiences that were not captured by the pre-designed questionnaires. The research team decided to include a follow-up study to be able to explore the stories of the informal caregivers in greater depth. A qualitative approach was chosen for the follow-up study. Sampling in qualitative research is different from quantitative research in that qualitative studies commonly use small, nonrandom samples [161]. The sampling procedure in the follow-up study aimed to select informal caregivers representing a wide range of experiences, kinship ties, and backgrounds; it can be described as a purposive sampling [161]. During the last months of the regular data collection, interviewers in 17 different municipalities asked informal caregivers of home-dwelling patients to participate in a follow-up telephone interview. This means that the informal caregivers had already been included in the sample of informal caregivers participating in the quantitative study, where their older relative named him or her as their closest informal caregiver.

A total of 30 informal caregivers gave preliminary consent to participate in the follow-up interview at a later time. Between March 2010 and July 2010, during Phase Two of the data collection, the informal caregivers were contacted for the follow-up interview (Figure 2). At that time, 18 to 24 months after their initial interview, 19 informal caregivers gave definitive consent to participate in the follow-up study (Figure 5).



* Figure from Bragstad, Kirkevold, & Foss, 2014, p 4.

Figure 5 Flow chart of inclusion of informal caregivers in the follow-up interviews

Two hundred and fifty-four patients and 262 informal caregivers were recruited in Phase One of the main study, altogether supplying information regarding 330 discharge cases (Figure 4). The response rate for the patients was 61.5% and for informal caregivers, it was 79.4%. Nineteen informal caregivers were recruited in Phase Two of our study.

6.2.2 Characteristics of the patient sample

Patient statistics in Norway consistently confirm that overall more women than men are treated in somatic hospitals [38]. In 2006, when recruitment for this study started, patients aged 80 and over constituted 16.2% of all in-patient hospital admissions in somatic hospitals in Norway [39]. The population of in-patients aged 80 and over consisted of 61.1% females and 39.9% males in 2006 [39]. The sample of patients recruited in Phase One consisted of 224 (68%) women and 106 (32%) men (Table 3).

The average length of stay for the patients in this study was 12.1 days. This is significantly longer than the average length of stay for the overall patient population in somatic hospitals in Norway, which was approximately 5 days in 2006 [163]. However, due to the age group included in this study, a longer length of stay is to be expected.

The patients were discharged either to a nursing home 57% (188) or back to their home with home nursing care 43% (142). The average age for the patients was 85.8 years old with a median of 85 years. Almost 63% (205) of the patients were widowed, and of the patients discharged home, only 33.8% (47) lived with someone; the rest lived alone.

Table 3 Characteristics of the sample of patients recruited during Phase One

| | Total sample |
|---|-----------------------|
| | Mean [SD] or n (%) |
| <i>Characteristics of hospital stay and discharge destination</i> | |
| Length of hospital stay (n = 330) | 12.1 [10.5] |
| Discharge destination (n = 330) | |
| Home | 142 (43) |
| Nursing home | 188 (57) |
| <i>Demographic characteristics</i> | |
| Age (years) (n = 329) | 85.8 [4.7] |
| Gender: (n = 330) | |
| Female | 224 (67.9) |
| Male | 106 (32.1) |
| Civil status (n = 326) | |
| Never married | 15 (4.6) |
| Married or cohabiting | 94 (28.8) |
| Divorced | 12 (3.7) |
| Widowed | 205 (62.9) |
| Level of education (n = 324) | |
| Basic | 168 (51.9) |
| High School | 134 (41.4) |
| College or university | 22 (6.8) |
| Living arrangements (n = 139*) | |
| Live alone | 92 (66.2) |
| Live with someone | 47 (33.8) |

* This question was posed exclusively to patients discharged back to their home.

The patients and their informal caregivers were asked about the cause of hospitalization. We categorized the causes reported by the patients and in cases of missing information we supplied it using information reported by their informal caregivers. The primary cause for hospitalization in our sample was fractures after falls in the home and other issues with the muscular and skeletal systems, followed by issues with the lungs and respiratory system and circulatory failure or heart disease (Table 4). According to the patients and their informal caregivers, 85% (280) of the patients had additional health problems besides the disease they were admitted for, which indicates that there is a substantial need for formal as well as informal care after discharge.

Table 4 Self-reported cause for hospitalization

| <i>Cause for hospitalization</i> | <i>n (%)</i> |
|-----------------------------------|--------------|
| Muscular and skeletal systems | 100 (30.3) |
| Lungs and respiratory system | 48 (14.5) |
| Circulatory failure/heart disease | 47 (14.2) |
| Bowel and urinary tract disease | 31 (9.4) |
| Stroke | 31 (9.4) |
| Miscellaneous | 31 (9.4) |
| Cancer | 25 (7.6) |
| Reduced general condition | 8 (2.4) |
| Diabetes | 6 (1.8) |
| Don't know | 3 (0.9) |
| Total | 330 (100) |

6.2.3 Characteristics of the informal caregiver sample

The sample of informal caregivers recruited in Phase One consisted of family members, with a variety of kinship ties with the patient. Adult children and children in-law constituted 71.8% (188) of the sample while almost 18% (47) were the patients' spouses (Table 5). The informal caregivers who were recruited were those that the patients indicated as their closest informal caregiver. The patient thus chose whom to recruit as informal caregivers. The sample consisted of 63% (165) females and 37% (97) males. Overall, 62.2% (163) of the informal caregivers were gainfully employed in a part-time or full-time position. Thirty-one percent (33) of the informal caregivers lived with the patient after discharge.

Table 5 Characteristics of the sample of informal caregivers

| <i>Demographic characteristics</i> | Total sample Mean [SD] or n (%) |
|--------------------------------------|--|
| Age (years) (n = 262) | 59.9 [12.1] |
| Kinship tie to the patient (n = 262) | |
| Spouse | 47 (17.9) |
| Children and Children in-law | 188 (71.8) |
| Extended family or other | 27 (10.3) |
| Gender (n = 262) | |
| Female | 165 (63.0) |
| Male | 97 (37.0) |
| Civil status (n = 262) | |
| Never married | 13 (5.0) |
| Married or cohabiting | 221 (84.3) |
| Divorced | 20 (7.6) |
| Widowed | 8 (3.1) |
| Level of education (n = 262) | |
| Basic | 130 (49.8) |
| High School | 43 (16.5) |
| College or university | 88 (33.7) |
| Gainfully employed (n = 262) | |
| Yes | 163 (62.2) |
| No | 99 (37.8) |
| Live with the patient now (n = 106*) | |
| Yes | 33 (31.1) |
| No | 73 (68.9) |

* This question was posed exclusively to informal caregivers of patients discharged back to their home.

6.2.4 Characteristics of the informal caregiver sample in the follow-up study

Thirteen women and six men were recruited and interviewed in Phase Two. The informal caregivers included two spouses, thirteen sons/daughters, two daughter-in-laws, and two nephews (Table 6). At the time of the interview, the informal caregivers were between 45 and 83 years of age with an average age of 60 years. Eleven were gainfully employed in a part-time or full-time position, and the remaining eight were retired or on disability benefits.

During the interview process, some patients were admitted to hospital and discharged again, some several times, and six of the patients had passed away at the end of the interview process. Eight of the patients were living independently in their private home, however, still receiving formal home health care services. Three of the patients lived in sheltered housing provided by the municipality and two had moved to a nursing home.

Table 6 Demographic characteristics of caregivers and the patients they care for

| <i>Demographic characteristics</i> | Caregivers | Patients |
|---|--------------------|--------------------|
| | Mean [SD] or n (%) | Mean [SD] or n (%) |
| Age (years) | 60 [10.2] | 88.5 [5.5] |
| Gender: | | |
| Female | 13 (68.4) | 16 (84.2) |
| Male | 6 (31.6) | 3 (15.8) |
| Patient's current living arrangement | | |
| Independent, private home | | 8 (42.1) |
| Sheltered housing, municipal | | 3 (15.8) |
| Nursing home | | 2 (10.5) |
| Passed away since previous interview | | 6 (31.6) |
| Civil status | | |
| Never married | 2 (10.5) | |
| Married | 14 (73.7) | |
| Divorced | 1 (5.3) | |
| Widowed | 2 (10.5) | |
| Kinship tie to patient | | |
| Spouse | 2 (10.5) | |
| Child | 13 (68.4) | |
| Extended family (daughter-in-law, nephew) | 4 (21.1) | |
| Gainfully employed | | |
| Yes | 11 (57.9) | |
| No | 8 (42.1) | |

6.3 Data collection

6.3.1 Development of the discharge questionnaire

The Discharge of the Elderly Questionnaire (DEQ) was developed by the research team for the purpose of this study. A literature review revealed that despite a thorough documentation of challenging issues in the discharge process of older individuals, few questionnaires existed [82]. Furthermore, the literature review showed that despite thorough documentation of the importance of participation for the older individuals, existing questionnaires measured degrees of information rather than participation [82]. Qualitative interviews and the literature review revealed four areas of substantial importance for the older individuals: timing of the discharge, factors related to the municipal home health care services, medication information and handling, and how practical issues should be resolved [82, 99].

The research team decided to focus on the whole discharge process, including the first post-discharge period, to acquire a broad picture of the issues of importance to the patients and their informal caregivers. The DEQ was developed with a broader focus on medical and practical issues than earlier developed questionnaires. Most importantly, the concept of participation adopted in the DEQ was operationalized using the work of Thompson [83] and incorporated participation conceptualized as more than merely exchanging information, including in addition a dimension of cooperation with hospital staff and having one's opinions heard.

The DEQ was constructed in two versions, one for patients and one for informal caregivers (Appendix 1–4). The two versions were constructed with the same content with a few target questions adjusted depending on the interviewee and the location to which the patient was discharged (home or nursing home). The questionnaires were designed to elicit data on the perceptions of the patient and the informal caregiver regarding the discharge process and the challenges after discharge. The questionnaire was tested in pilot interviews to ensure that the questions were understandable and that the questionnaire covered areas that the respondents felt were significant. The patient questionnaire (Appendix 1–2) is described in Paper II [164], while the informal caregiver questionnaire (Appendix 3–4) is described in detail in Paper I [165].

6.3.2 Data collection for the main study

The patients were interviewed face-to-face and the informal caregivers were interviewed by telephone, with the exception of informal caregivers co-residing with the patients who were sometimes interviewed face-to-face when the interviewer visited their home. The research team enlisted local interviewers to carry out the questionnaire interviews. The interviewers were trained to administer the questionnaire in an identical manner in every interview, and all the participants were asked the exact same questions administered in the same order. The initial interviews were carried out within two to three weeks of the patient's discharge from the hospital. The telephone interviews with informal caregivers were conducted within four weeks of the patient's discharge. The interviewer could help by clarifying ambiguous or confusing questions and help the respondents grade their answers by supplying a visual grading scale. The interviewers helped ensure that all questions were understood and answered, thus, minimizing the amount of missing data [161].

6.3.3 Interview guide for follow-up study

The aim of the follow-up study was to explore the informal caregivers' experiences of influencing decision-making at and after hospital discharge for home-dwelling older relatives. The qualitative approach made it possible to delve deeper into the informal caregivers' experiences than the structured questionnaire interviews allowed. The follow-up study, thus, added an important breadth to the collective data material of the PhD study. The follow-up interviews were designed to be open and exploratory because we wanted to explore the answers the informal caregivers gave and be open to following any new directions that the participants might suggest. For the qualitative follow-up study, we developed a thematic interview guide based on topics that emerged in the preceding structured questionnaire interviews with informal caregivers (Appendix 5). The interview guide outlined topics to be covered and some suggested questions and possible follow-up probing questions [166].

6.3.4 Data collection for follow-up study

In the main study, the interviews with the informal caregivers were conducted as highly structured telephone interviews. Telephone interviews are especially suitable for carrying out structured interviews where the goal is reducing interviewer effects, strengthening interviewer uniformity, and promoting standardization of questions and where time- and cost-efficiency is paramount [167]. In the follow-up interviews, we did not want the same rigidity in terms of structure and sequencing of questions. However, given the widespread geographic location² of the participants, it proved too costly and time consuming to choose in-person interviews, particularly as all the interviews were conducted by only one interviewer. By way of introduction and to counteract some of the disadvantages associated with the inability to perform in-person interviews, the interviewer started the interviews by providing information about the project developments since their last interview (18–24 months earlier). Furthermore, the goal of the follow-up interviews was clarified and the informal caregivers were asked to confirm their consent to participate. In most cases the interviewer spoke with the participants on two separate occasions, first to introduce the follow-up study and to make an interview appointment, then, to conduct the interview itself. This approach gave the informal caregivers the opportunity to decide whether or not to confirm their consent to participate, to ask questions, or express other concerns before starting the interview.

² The participants lived in 13 different municipalities in four regions in Norway (Southern Norway, Eastern Norway, Middle Norway, and Northern Norway).

We chose an active approach to the follow-up interviews, viewing both parties in the interview as active in the construction of meaning [168, 169]. This approach has implications for the interview itself and the analysis of the empirical material and calls for reflexivity in terms of the researcher's influence [170]. The informal caregivers' stories and experiences were given priority during the interviews and the thematic interview guide merely served as a reminder of topics to cover and had suggested phrasings for questions.

6.3.5 Preparation of the data material for analyses

Preparation of the questionnaire data

We performed initial statistical analyses to inspect the data as a means to ensure the accuracy of the data file and to check for consistency [161, 171]. When dealing with large surveys it is often impossible to proofread the entire data file [171]; however, as a measure of quality assurance of the data file, we chose to proofread the entire sample of 516 questionnaires against the SPSS data file. During the proofreading, inconsistencies in the coding practice were corrected, and we completed a thorough cleaning of the data file [161, 171]. Missing data analyses were conducted to uncover any potential systematic patterns of missing data [171]; no such patterns were found. However, in preparing the variables for the logistic regression analysis in Paper II, we uncovered between two and nine missing values on seven of the variables we intended to include in the logistic regression analysis. Two to nine missing values on each separate variable is not necessarily cause for concern when looking at the big picture. However, when performing analyses with listwise deletion of cases, missing values on any of the included variables excludes that case from all analyses and, thus, there is a risk of decreased sample size and loss of statistical power [161]. We therefore imputed missing values on four variables with information from the informal caregivers' questionnaires. We used the sub-group mean imputation method and imputed the mean age of home-bound women and men in the three cases where age was missing [161].

Missing values on the patient-reported variables measuring PADL-function and IADL-function were imputed from the informal caregivers' answers. This method of imputation gave us variables without any missing values, and we were able to calculate the sum score. We are aware that patients and informal caregivers may sometimes disagree regarding their assessment of the patient's functional ability [172]. However, we argue that imputing the

score reported by the informal caregiver resulted in a more trustworthy value than imputing the mean score of all the other patients' scores on the variable.

Preparation of the qualitative interview data

The process of transcribing interviews can be viewed as a kind of translation process, translating the spoken language into written text [162, 166]. Within this process of transcription it is argued that some of the context of the interview can disappear; it is simply not possible to translate all the nuances of the spoken language into written text [166], and it is furthermore argued that non-verbal markers are lost in this translation [166]. This is inherent in the nature of transcribing interviews and is dealt with in different ways by different researchers. Our interviews were conducted as telephone interviews; thus, we didn't have access to body language or gestures to aid our interpretation of their intended meanings. We chose to transcribe the interviews verbatim and write them out in their entirety to ensure that the transcripts were as detailed as possible [162].

6.4 Statistical analyses

6.4.1 Paper I

Descriptive statistics

A descriptive data analysis was conducted on all variables to obtain frequency distributions of all categorical variables and means and standard deviations for continuous variables. Bivariate cross tabulations and Pearson's Chi-Square test for association were conducted with the participation variables to identify differences in participation by generation of caregiver and by gender. Bivariate cross tabulations and Chi-Square tests for trend were conducted with the participation variables to investigate the informal caregiver's perceptions of how they were treated at the hospital by level of caregiver education. The Chi-Square test for trend was used when one of the variables in the bivariate cross tabulation had several categories with a natural order, such as level of education, while the other variable was dichotomous. The Chi-square test for trend takes order into account and is a more sensitive test than the Pearson's Chi-Square test for association when dealing with ordinal variables, as it assesses whether there is an increasing (or decreasing) trend in proportions over the ordinal categories [173, 174].

For the questions measuring Thompson's participation at Level 1, Level 2, and Level 3, the categories "to a high degree" and "to some degree" were interpreted as participation, whereas the other two categories, "to a minor degree" and "not at all," were interpreted as non-participation.

Guttman scale

An analysis of the cumulative scaling [175-177] of the response pattern across the questions in our questionnaire measuring Thompson's [83] levels of participation was carried out on the patient and the informal caregiver material. Our understanding of Thompson's taxonomy of participation was that receiving and providing information was a precondition for patients and informal caregivers to be able to cooperate with the hospital personnel and influence decision-making in the discharge process.

Our analyses presented a Guttman reproducibility coefficient of 0.85, for both groups of informants. The Guttman coefficient calculated from our data supports Thompson's idea that participation can be operationalized into the following hierarchically organized levels:

- Level 1: Receives information
- Level 2: Provides input (dialogue)
- Level 3: Cooperates with the health care personnel

The deterministic nature of a Guttman scale means that an individual's response to an item can be predicted from their cumulative score [176] in our data material with an 85% probability of being right. Furthermore, the Guttman reproducibility coefficient of 0.85 for both groups of informants lends support to our assertion that the older patients are just as consistent in their responses as their mostly younger informal caregivers.

Multivariate logistic regression

A multivariate logistic regression analysis was performed to assess the impact of a number of predictors, controlled for each other, on the likelihood that informal caregivers would report participation at Thompson's Level 3 [83]. The dependent variable in the analysis was self-reported cooperation with the hospital staff, dichotomized into participation and non-participation, as described above. In line with findings from earlier research on relatives' involvement in hospital discharge, we chose to include the following covariates in our logistic

regression model: the patient's hearing ability [178], the caregiver's generation [155], the caregiver's and patient's gender and education level, and the length of the hospital stay [143].

Coefficients with a p-value lower than 0.05 were considered statistically significant. The p-value of the Hosmer and Lemeshow model goodness-of-fit statistic was $p = 0.398$. Data were analyzed using IBM SPSS Statistics 19.

6.4.2 Paper II

Descriptive statistics

A descriptive data analysis was conducted on all variables to obtain frequency distributions of categorical variables and means and standard deviations for continuous variables.

Multivariate logistic regression

Logistic regression analysis was performed to assess the impact of a number of factors³ on the odds of the patients reporting that they managed well after being discharged home from hospital. The dependent variable in this analysis was a question posed only to patients discharged to their home. The dependent variable "self-reported post-discharge outcome" was dichotomized for the purpose of the logistic regression analysis. The value 0 was given to the response categories, "The first 2–3 weeks after discharge from hospital were difficult in the beginning, but ok after a while"/"both difficult and ok all along"/"difficult all along and still difficult" while the value 1 indicated the response category "ok all along." The PADL and IADL-variables were added together constructing two individual sum scores, which were included in the model.

Several literature reviews have identified factors influencing the transition process and post-discharge outcomes [2, 6, 120, 122, 179]. Professional/service factors, informal caregiver factors, personal factors [179], and factors related to discharge planning [6] have been found to be crucial to the transition process between hospitals and home. Based on earlier research we developed the logistic regression model to explore these four groups of factors. The independent variables "adequate help from the municipal home health care," "someone was

³ Initially we wanted to include the informal caregiver's reported participation as a factor in the logistic regression model. However, due to the listwise deletion of cases in this analysis it proved to be impossible to mix data reported by patients and informal caregivers in the same logistic regression model. Thus, we were forced to build the model with the patient-reported variables exclusively.

present when I came home,” “I live alone,” “I receive help from family now,” “there was a discharge planning conference,” “I was surprised by the timing of my discharge from hospital,” and PADL sum and IADL sum were included in the logistic regression model.

The analysis was controlled for age, gender, and length of hospital stay. The p-value of the Hosmer and Lemeshow model for goodness of fit was $p = 0.894$. Coefficients with a p-value lower than 0.05 were considered statistically significant. Data were analyzed using IBM SPSS Statistics 18.

Content analysis

In addition to the statistical analyses we used the free text comments from the structured interviews to broaden our understanding of the findings in Paper II. The free text comments associated with the dependent variable and three of the independent variables included in the logistic regression model were assembled in a text file, organized by question. All comments were read and organized according to the content they conveyed, dividing the comments into groups of contrasting sentiments for three of the questions while the comments of the last question were organized according to their manifest content (Table 7).

Table 7 Content analysis, number of statements from free text comments

| Question | Number of statements | |
|--|-----------------------------|----|
| <i>How have you managed at home since your discharge?</i> | <i>Well</i> | 19 |
| | <i>Not well</i> | 20 |
| <i>If you came home to an empty house, how was that experience for you?</i> | <i>Good</i> | 8 |
| | <i>Bad</i> | 7 |
| <i>Did the timing of the discharge surprise you?</i> | <i>No</i> | 9 |
| | <i>Yes</i> | 12 |
| <i>If the formal help you receive is insufficient, what would you want done differently?</i> | | 24 |

A sample of the comments from each of the questions was presented in Table 3 of Paper II. This content analysis of the free text comments contributed to understanding what the patients intended to convey when they answered the questionnaire. The comments were used in the text of Paper II to broaden our understanding of the experiences of the patients.

6.5 Qualitative analysis

6.5.1 Paper III

Inductive thematic approach

The qualitative analysis was inspired by an inductive thematic approach [162]. The initial stage of the qualitative analysis started with the transcription of the data material.

Subsequently, the research team read all the interview transcripts to obtain a general content overview of the material. This is the common starting point of most approaches to qualitative data analysis [161, 162].

Coding procedure

The coding procedure was supported by using the qualitative analysis software HyperRESEARCH to keep track of all codes and coded passages of text from the transcripts [180]. A coding manual was compiled inductively on the basis of the empirical data [161, 162]. We read through the transcripts a second time when all the codes were created and added later codes where appropriate to ensure a consistent coding practice across all 19 interviews. All the codes in the codebook were inspected and matching codes were grouped together. The codebook consisted of 52 unique codes.

Categorization and development of themes

The range of codes was categorized and grouped together in thematic categories. We read the interview text, the codes, and categories several times in an iterative process in which we developed the main themes. The research question and the purpose of the study guided our selection of codes and categories to prioritize in the analysis. In this process, some of the codes and themes from the interviews were pushed in the background while others were brought to the foreground and given emphasis [162]. In the iterative process of analysis, two main themes emerged in our interpretation of the empirical data material: “taking an active role” and “struggling to gain influence.” Several codes and categories were incorporated within these two themes as exemplified in Table 8.

Table 8 Examples of codes, categories, and main themes of the qualitative analysis

| Transcribed text ⁴ | Code ⁵ | Category | Main theme |
|---|--|---|-------------------------------------|
| <p>“My mother can’t pick up the phone to inquire about anything these days, so I’m the one who has to take over these tasks that she managed herself earlier. Because I am the only one capable of letting them [the municipality] know when something is not right.” (IC-10)</p> | <p>Being an informal caregiver involves looking after the older relative’s needs</p> | <p>Emerging dependence</p> | <p>Taking an active role</p> |
| <p>“It is important that I can act as a spokesperson, because she is not able to herself. [. . .] Being an intermediary sort of lies within the role, I think. It is part of the responsibility of [family members]” (IC-31)</p> | <p>Being an informal caregiver involves being the older relative’s spokesperson</p> | <p>Feelings of responsibility</p> | |
| <p>“It’s difficult for them [the home nurses] too; they may communicate our wishes, but their directives are not necessarily supported or acted upon. [...] They understand our situation and are attentive toward us, but ultimately they don’t make the decisions.” (IC-10)</p> | <p>The decisions are not made by the home nursing providers</p> | <p>Working with the “gatekeepers” of the health care services</p> | <p>Struggling to gain influence</p> |
| <p>“After her breast surgery they wanted to send her home on a Friday. Her surgical wound was still open and it was . . . well, I outright declined. I said: ‘I am leaving town for the weekend, I will not be home if she is discharged’ . . .” (IC-19)</p> | <p>You have to be resourceful to be heard</p> | <p>Strategies used when participating on behalf of the care recipient</p> | |

*Table from Bragstad, Kirkevold & Foss, 2014, p 6.

⁴ The quotes used as examples here are quotes used in Paper III.

⁵ The codes represent the quoted text in the context it appeared in the transcripts: the modified quote used in Paper III does not incorporate the full context that the codes refer to.

6.6 Ethical considerations

6.6.1 The main study

This study was designed in accordance with the ethical principles for medical research involving human subjects as stated in the World Medical Association's Declaration of Helsinki [181]. Approval for the study was obtained from the South-East Norway Regional Ethics Committee for Medical Research (reference number: 1.2007.1250), and it was reported to the Data Protection Official for Research (NSD) (project number: 17078). All municipalities involved in the process of recruiting respondents consented to participate in the study. We obtained informed written consent from each patient before interviews were initiated. When patients consented to include their informal caregiver in the study, the informal caregivers were contacted and asked if they would agree to be interviewed. The informal caregivers received written information describing the study and gave their informed (oral) consent for the interviews.

Considering the frailty of the patient group we wanted to recruit to our study, a number of issues were taken into consideration prior to their recruitment. The research team wanted to make sure the patients' health condition would not be compromised due to inclusion in our study. In the recruitment process the research team invited the recruiters and local interviewers in each municipality to attend a daylong seminar where ethical issues in the recruitment and interview process were addressed. To avoid alienating the informants by initiating each interview with a formal assessment of their cognitive abilities, the research team decided, in agreement with the South-East Norway Regional Ethics Committee for Medical Research, that the recruiting nurse would make an assessment of the patient's cognitive ability based on the nurse's medical experience and knowledge of the patient. The recruiters were instructed to exclude patients who were cognitively impaired and not able to give their informed consent; however, they were instructed to ask the patient's close relative to participate as a proxy in those cases. Additionally, as a second quality assurance of the cognitive ability of the included patients, the interviewers were asked to indicate their assessment of the patient's cognitive ability in the questionnaire for each of the patients recruited for the study. The local recruiters and interviewers were health care personnel, mainly nurses and geriatric nurse students, and all had experience of working with older patients. Furthermore, the interviewers were instructed to terminate the interview if the

patients' health condition was threatened in any way during the interview. All of the local recruiters and interviewers were required to sign a professional confidentiality agreement.

6.6.2 Follow-up interviews

When the informal caregivers were approached for the follow-up interviews, they were informed about the purpose of the follow-up interviews and assured that they would remain anonymous throughout the research process. Each informal caregiver was assigned an anonymous identifying number that was used throughout the research process, in all transcripts of the interviews, and for the quotes in the manuscript. They were informed about their right to withdraw their consent at any time for any reason. Lastly, they were asked to renew their previous consent for participation and asked to consent for audio recording of the interview. All 19 informants gave their consent.

During the initial stages of the follow-up interviews, we were, in six cases, made aware that the patient had passed away since our last interview. In each case we informed the family member again that they were free to terminate the interview and withdraw their consent at any time, especially if they felt the interview was too stressful with regards to their relatively recent loss. None of the informal caregivers wished to terminate the interview, in fact, they expressed gratitude to be able to talk about the events leading up to their loved one's death.

7 Results

In this chapter of the dissertation, the main findings from each of the sub-studies will be summarized.

7.1 Informal caregivers' participation when older adults in Norway are discharged from the hospital

Sub-study one found that informal caregivers of older hospitalized relatives consistently expressed a clear preference to influence and participate in decision-making regarding medical treatment, time of discharge, and how practical issues should be resolved. In other words, the informal caregivers wished to participate and be able to influence decision-making at the hospital during the discharge process. Furthermore, we found differences between groups of informal caregivers demonstrating that the younger generation informal caregivers expressed a significantly stronger wish to influence the timing of the discharge than the older generation caregivers.

Exploration of the different levels of participation, operationalized through Thompson's (2007) taxonomy of participation, revealed differences between the two generations of caregivers on all three levels of participation. The younger generation caregivers consistently reported receiving information (Level 1) and providing information to the health care personnel (Level 2) to a higher degree than the older generation caregivers. Overall, half of the informal caregivers reported that they felt they cooperated with the health care personnel at the hospital (Level 3). The multivariate logistic regression analysis showed that "generation of informal caregiver" was a significant predictor of participation at Level 3. Controlled for the other factors in the model, the younger generation informal caregivers had higher odds than the older generation informal caregivers of participation at Level 3 (OR = 2.121, $p = 0.045$). In addition, the patient's hearing ability was a significant predictor of informal caregiver participation at Level 3. This finding showed that the odds of participation at Level 3 was more than one and a half times as high (OR = 1.722, $p = 0.049$) for informal caregivers of patients with reduced hearing ability than for informal caregivers of patients who had no problems with hearing.

The study concluded that the two generations of informal caregivers had markedly different experiences with participation at Level 1, 2, and 3 of Thompson's taxonomy. The younger

generation caregivers consistently reported participation to a higher degree and a higher level than the older generation caregivers. These findings indicate that older patients who are assisted by informal caregivers in the younger generation have better chances of participation in the discharge process.

7.2 Factors predicting a successful post-discharge outcome for individuals aged 80 years and over

Multivariate logistic regression analysis was performed to assess the impact of a number of factors on the likelihood that the patients would report that they managed well after discharge. Four groups of predictors suggested by earlier research were explored. Two of the explanatory variables in our model predicted a successful post-discharge outcome: having someone present at homecoming and receiving adequate formal help from the municipality. We interpreted the first explanatory variable as representing the informal caregivers, as family members or other informal caregivers were most commonly present at homecoming. The second explanatory variable represents the formal home health care. Controlling for the other variables in the model, the odds of managing well after discharge were more than four times higher (OR = 4.75, $p = 0.022$) for patients reporting that someone was present at homecoming than for those who came home to an empty house. Patient statements showed that some of the patients were prepared for coming home to an empty house and did not experience this as a problem. However, some patients felt lonely and abandoned, and others shared experiences of difficulties managing on their own. Our findings suggest that it is imperative for a successful post-discharge outcome that the patient does not come home to an empty house.

In our sample, all patients received formal home-help and/or home-nursing care. However, 28.4% of the patients found the formal help insufficient. Patients who reported receiving adequate help from the municipality had odds four times (OR = 4.18, $p = 0.006$) higher of reporting that everything went well after discharge than those who stated the help was inadequate. Statements made by the patients strongly suggested that the need for social support in addition to practical help with instrumental activities of daily living is a requirement not commonly met by formal caregivers.

Our findings emphasize the importance of both the informal and formal caregivers at homecoming. Having someone at home upon return from hospital and having adequate

formal home-care services are important factors that might contribute to a successful post-discharge outcome for the patients.

7.3 The indispensable intermediaries: a qualitative study of informal caregivers' struggle to achieve influence at and after hospital discharge

The first two sub-studies showed that informal caregivers actively wanted to influence the decision-making during the discharge process. The third sub-study further corroborates these findings showing that informal caregivers go to great lengths to be able to help their older relative receive appropriate formal care in the community. The informal caregivers described how they took an active role when their older relative became dependent on help. The importance of and need for taking an active role was the first main theme of the informal caregivers' experiences. Informal caregivers stepped up to participate on the patient's behalf. However, gaining influence was especially challenging when the informal caregivers did not know the health services very well. Even informal caregivers who described themselves as knowledgeable about the health care services struggled to gain influence.

The struggle to gain influence was the second main theme of the experiences of the informal caregivers. Several informal caregivers described how they tried to negotiate with and work with the gatekeepers of the health care services. In this struggle the informal caregivers described using different strategies to gain influence. Some took on a supervisory role, and acted only when they felt their older relative was not getting proper care. However, the most common strategy was being actively involved throughout the process. Taking an active approach was, however, no easy success at first. The informal caregivers described an ongoing struggle that was not always resolved until the situation became unbearable for the informal caregivers. In those cases the informal caregivers felt forced to demonstrate that the patient safety was being compromised and sometimes took desperate actions to gain influence.

The study concluded that the informal caregivers were indispensable intermediaries between the patient and the health care services. The informal caregivers wanted to participate, but gaining influence was often complicated and required resourceful informal caregivers. The findings accentuate the need to discuss how frail older individuals and their informal caregivers can be enabled to participate in decision-making at and after hospital discharge.

8 Discussion

In the first section the findings from this PhD study will be discussed in light of the research questions and the overall aim of the dissertation. In the second section of this chapter, methodological considerations of the study will be discussed.

8.1 General discussion of the findings

The aim of this dissertation was to describe and explore the role of informal caregivers in the discharge process when older relatives, 80 years and older, were discharged from the hospital to community care.

In the following sections, I will discuss the informal caregivers' participation and the advantages of the younger generation caregivers. Furthermore, I will discuss factors contributing to successful transitions and the changing roles of informal caregivers. I will connect the findings from the quantitative studies with findings from the qualitative approach to contribute to a broader understanding of the aim of the PhD study.

8.1.1 Informal caregivers' participation

The literature review presented in section 4.2 revealed that there is a scarcity of research on the informal caregivers' participation in the discharge process. In our study, Thompson's taxonomy of involvement and participation has served as a catalyst for our understanding of participation as a concept [83]. As shown in the literature review, the existing research is primarily concerned with information exchange and shows clearly that informal caregivers are generally poorly informed, and consequently their participation is hampered. Shared decision-making is not common, and the informal caregivers often report being poorly prepared for the discharge of the patient. This lends support to our and Thompson's assumption that information in itself is not participation but it is a precondition for participation. As the literature review showed there was a need for research conducted in a broader range of hospital wards and with a larger sample than the previous research. The research of this study is founded on data from a wide range of somatic hospital wards in Norway and the patients were admitted for a variety of medical disorders. To our knowledge, this is the first study with a sample as large as ours exploring the participation of patients aged 80 and over and the participation of their informal caregivers in a Norwegian health care services context. Our

findings have shown that the informal caregivers have expressed clear wishes for participation in the discharge process at the hospital and after discharge (Paper I & III). At the hospital, the informal caregivers most markedly wanted to influence how practical problems should be solved, and, they also expressed a clear preference to influence the time of discharge and to influence medical treatment (Paper I). The qualitative follow-up interviews (Paper III) revealed that the informal caregivers unanimously wanted to participate in the discharge process and this lends support to the findings from the quantitative study. However, there is no universal approach employed by all of the informal caregivers. Some chose a passive approach in taking on a supervisory role where they keep an eye on things from a distance, while others take a more active approach seeking information, establishing dialogue, and demanding participation.

The advantages of the younger generation caregivers

There were differences between the younger generation informal caregivers and the older generation caregivers on the preference to influence the time of discharge; the younger generation caregivers wanted to influence the timing to a greater degree than the older generation. The younger generation of caregivers mainly included adult children living in a separate household from the older patient whereas the older generation was mainly spouses living in the same household. Given that adult children and other informal caregivers provide support and help their older relatives with numerous tasks after discharge [60, 61, 74, 182, 183] and in light of the fact that individuals in the younger generation are often employed and live separately [184], it is to be expected that they desire influence over decisions made in the discharge process to be able to plan their efforts. Discharge decisions affect not only the patient's situation but also the caregiver's situation to a high degree.

Our findings showed that the two generations of informal caregivers perceived information practices at the hospital differently (Paper I). In the Norwegian health care services, the right of patients and caregivers to be informed about a patient's health condition is clearly articulated in the form of legislation [95]. However, the older generation caregivers reported feeling less informed than the younger generation caregivers did. There were differences between the generations, in favor of the younger generation, with regard to receiving information about the patient's health condition at Level 1 of Thompson [83]. The younger generation also reported participation at Level 2 more frequently than the older generation. This finding may suggest that staff members engaged in dialogue with younger caregivers

more than with caregivers of the same generation as the patient. In Paper I, our findings showed that overall half of the caregivers reported achieving participation at Level 3. This means that only half of the caregivers reported that they cooperated with the hospital staff during the discharge process. The multivariate logistic regression of Paper I showed that the younger generation caregivers had higher odds of reporting participation at Level 3. This means that the younger generation caregivers have consistently experienced higher levels of participation than the older generation caregivers. In our study, participation at Level 3 was also predicted by the patient's hearing ability, demonstrating that when the patient was hearing impaired, informal caregivers took on a supportive role and cooperated with hospital staff. This finding suggests that informal caregivers must be especially persistent in seeking participation to compensate for the patient's sensory loss and must ensure participation that supports the patient's interests. This finding is supported by findings from the qualitative interviews. The informal caregivers describe the patients' deteriorating health and declining self-care capacity as a starting point in their caregiver trajectory (Paper III).

Our findings from the qualitative interviews (Paper III) suggest that the younger generation caregivers may be more active in establishing a dialogue and thus more actively seeking participation. This may have implications for our understanding of the differences in participation between the generations. Previous research on older patients and participation [99, 185] has shown that older patients do not participate in a direct and outspoken manner, and their communication differs from what is expected in the efficient modern hospital. This means that another possible interpretation is that the older generation caregivers were less proactive in establishing a dialogue than the younger generation caregivers, thus, experiencing lower levels of participation.

Younger caregivers may be more attuned to the type of involvement that allows them to engage in dialogue with the staff and to be heard [186]. Furthermore, staff members may be more comfortable communicating with caregivers of their generation who exhibit a more active and empowered attitude [187]. Communication with older individuals can be more time consuming and arduous than communication with younger individuals, which may have detrimental effects on communication with caregivers in a busy hospital setting where the hospital staff is pressed for time. Knowing that older patients are more reluctant to actively initiate cooperation with staff [99], the responsibility for initiating cooperation should lie with

the hospital staff. However, our findings from Papers I and III showed that the hospital staff was not always perceived, by informal caregivers, as initiators of cooperation.

In combination with the complexities of the health care services, the extensive frailty effectively prevents patients from taking the mandated active role in handling their practical care arrangements in cooperation with formal care service providers. This is when the informal caregivers describe that they step up to participate on behalf of their older relative and sometimes take over tasks the older relative used to manage themselves (Paper III). In doing so, the informal caregivers can contribute to a more favorable outcome for their older relative by taking care of and advocating for the patient's rights and wishes in the discharge process. However, the lack of communication or poor communication between informal caregivers and the health care providers [150, 151, 154, 188] and inadequate preparation of the informal caregivers [73, 148, 149] are unanimously described in recent research as key challenges. This may lead to a further hampering of informal caregivers' participation. Seen in context with our findings, it appears to be important to provide information and support according to the informal caregivers' individual needs. Considering the legislation and professional ideals of enabling active participation, the level of participation reported in this study is low: hospital staff and the health care services should not be satisfied with only half of the caregivers achieving participation where this is a legally established patient and caregiver right.

8.1.2 Successful transitions back to their home

In our study, having someone at home upon returning from hospital was an important predictor for the patients' self-reported successful post-discharge outcome (Paper II). Our findings suggest that it is imperative for a successful post-discharge outcome that the patient does not come home to an empty house. However, as some informal caregivers described (Paper III), it is not always possible to be present when the patient comes home, due to short notice prior to discharge. And the situation can be further exacerbated when the formal home-care services are not able to be present either, as is sometimes the case. In those cases in which the informal caregivers take on the responsibility, they do not always trust the system to take the appropriate responsibility. The informal caregivers in our study expressed anxieties with regard to the patients being discharged too early. They described how they went to extreme measures to be heard by decision makers in the discharge process; implicitly, they did not perceive themselves to be included in the decision-making (Paper III). They

removed house keys from the patient's handbag or claimed to be leaving town to prevent their older relative from being discharged too early or to an empty house. This is an example of how some informal caregivers interpret their responsibility; they use whatever means necessary to make their point known and to be heard. Informal caregivers caring for patients living at home described a similar approach in negotiating with the formal home-care services. They went outside the chain of command, appealing to the administrative leader of the municipality for their older relative to gain access to nursing home placement. We have interpreted these actions as desperate measures to force the decision makers or the gatekeepers to hear their arguments. A previous study has shown that it was possible to negotiate for more flexible service provisions and individual solutions [189], and a recent study suggests that this flexibility is still possible when the health care personnel choose to disregard the formal contracts of care to create flexibility in individual cases [190]. However, a recent study exploring the participation of the informal caregivers of older people undergoing hemodialysis in the hospital setting [154] and our findings from Paper I illustrate how the informal caregivers' attempts at negotiations failed due to scarce opportunities for direct communication with the decision makers in the system. The informal caregivers report that they had limited dialogue with the health care team, and they struggled to be included in the decision-making [154]. In our study, the only real chance of opposition is to claim serious deficits in patient safety, which is the only strategy that informal caregivers have found effective in communicating their disagreement with the care decisions.

Another important predictor for a self-reported successful post-discharge outcome was having adequate formal home health care (Paper II). Consistent with other European studies, the caregivers in our study describe a constant struggle to gain influence in the health care services [154, 191] and to participate in the care decision-making process for their older relatives [192, 193]. According to our findings this struggle intensifies when an older family member experiences greater functional decline and his or her care needs increase (Paper III). According to the informal caregivers, some patients experience a rapid decline, increasing the need for 24-hour supervision and attention. That kind of monitoring is only available through institutional care in a nursing home, and the family is no longer able to provide the needed amount of care. According to a study of the balance between formal and informal care [194], the welfare state takes over the caregiving when the care needs of the patients increase. Contrary to these findings, our informants described substantial challenges to navigating the system to acquire the needed care for their older relative. Descriptions presented in earlier

research and policy studies give the impression that this transition is seamless and without resistance from the system and that a sufficient number of nursing home beds are available. However, the development of the municipal care sector in recent decades has challenged this perception [34, 195]. The current policy of aging in place, enabling the older person to live at home longer than before, coupled with an aging population and retrenchment of institutional care in the community, although accompanied by expansion of the municipal home health care sector, puts pressure on the municipal resources [196] and on the informal caregiver resources.

Informal caregivers describe desperately trying to negotiate and fight the system to obtain the next level of formal community care (Paper III). Our results suggest, contrary to the claims that informal caregivers experience fewer burdens in the Nordic welfare state [25], that informal caregivers see their roles as demanding. This is consistent with a report on participation in the health and care sector that shows that patients and their informal caregivers may experience incongruity between their formal rights and the actual access to services provided by their local municipality [197]. In essence, the expectations of informal caregivers and patients are not always met with respect to the help they are mandated to receive, which is formally stated within the legislation.

8.1.3 The changing roles of informal caregivers

As a consequence of the complexity of the system, the comprehensiveness of the roles informal caregivers assume is virtually unlimited. The informal caregivers describe their roles as encompassing that of hands-on caregiver, spokesperson, intermediary, and advocate — and often a combination of several roles simultaneously. This complexity of the informal caregivers' role is supported by a contemporary study exploring decisions made at discharge [123]. In particular, it turned out to be a complex task to accommodate all perspectives of the discharge planning including enduring the stress of staying vigilant to advocate for the needs of their older relative while at the same time encouraging the older relative to stay independent and to communicate all the relevant details of the discharge planning [123]. Despite universal health care coverage in the Nordic countries, including public provision of long-term care, the family has always contributed to patient care [22, 61, 62, 64] and has continued to provide the same care levels following the introduction of formal health care services [24, 56, 61, 198, 199]. The political rhetoric surrounding the role of informal caregivers in Norway is new. Contemporary white papers more explicitly express that the

policy makers want to develop a modern policy of informal care whereby informal caregivers are expected to provide care and take (greater) responsibility for the care of older family members living in the community [18, 19, 51].

The informal caregivers convey an overwhelming sense of responsibility for the well-being of their older relatives. This is a sentiment that is further underlined by contemporary research [123, 150, 200]. In a Danish study exploring relatives' experiences of the patients' recovery after discharge, the relatives experienced a profound sense of responsibility for the patients' well-being and their adherence to the rehabilitation regimen [200]. Some informal caregivers in our study (Paper III) act as a supervisory authority, ensuring the provision of high-quality health care services for their older relatives. Consistent with policy developments in other Nordic and European countries [57], the modernization schemes to strengthen the primary care sector in Norway contributes to blurring the boundaries between the private and public sectors [201], thus, making the boundaries between informal and formal caregivers' responsibilities unclear.

The informal caregivers express the responsibility they feel in a variety of ways and most prominently in the way they devote time and energy to making sure that their loved ones receive formal services. Informal caregivers do not always trust the system to take the appropriate responsibility [202], thus, the informal caregivers find themselves in a position of trying to mitigate the consequences of inadequate levels of care provided by the formal caregivers. The informal caregivers describe how they are sometimes overwhelmed by the responsibility. Similarly, a study exploring the feasibility of integrated transitional care in Canada found that the discharge planning did not adequately account for the division of roles and responsibility between the formal and informal caregivers, leading to unclear roles and role strain for the informal caregivers due to system constraints [150]. Contemporary policy initiatives in Norway [19, 50] place more responsibility on the families of older patients and on the volunteer sector to solve the challenges of limited formal resources as the older population increases. This is an example of how the boundaries between formal and informal caregivers are blurred. Moreover, the often indistinguishable boundaries can contribute to the informal caregivers' overwhelming sense of responsibility resulting in their caregiving responsibilities superseding everything else in their life.

Caregiver burden

It is widely recognized that informal caregiving can be challenging on several different levels, not only in managing the practical tasks of caregiving but also in coping with the burden of the caregiving role [25, 70, 72, 155, 203]. The concept of caregiver burden is multifaceted and lacks a consistent definition across the abundant literature [70]. Zarit et al. suggested the following definition: “the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative” [204, p. 261]. This definition emphasizes the multidimensional nature of the concept and acknowledges that burden is an individualized experience [203].

The extensive research on caregiver burden over the past decades has documented the diversity and complexity of the caregiving experience [25, 72, 155]. The study in this dissertation has not directly examined the caregiver burden of informal caregivers. However, it may be useful to look at the experiences of the informal caregivers as an expression of the burden they have experienced in the role as informal caregivers. A study examining caregiver burden among spouses and adult children suggests that it is not the workload (objective burden) per se that causes the caregiver’s distress, rather the interpretation that caregivers apply to the caregiving activities (subjective burden) [72]. The findings of our study (Paper III) support this notion. The informal caregivers emphasized the feelings of responsibilities as their primary concern rather than the actual caregiving tasks.

There is a limited amount of European and Nordic studies examining the phenomenon within the setting of more developed welfare-state models where the caring responsibilities are shared between the family and the formal health care services. An exception is a Norwegian study examining psychosocial well-being among adult children and children-in-law providing regular personal care to a parent(/-in-law) [25]. This study suggests that the current nature and level of parental caregiving in Norway does not jeopardize the informal caregivers’ well-being [25]. The authors, however, emphasize that a reduction in formal care and a stronger reliance on informal caregivers may create more caregiver distress.

Summarizing comments

In looking at the findings from this study in light of previous research, a few significant characteristics emerge. The capacity in the Norwegian home-care sector is under pressure [37, 196], and the findings from our study indicate that both informal care and formal home health

care are vital elements for older patients discharged from hospital. For older patients, hospitalization is often the beginning of a functional decline resulting in frequent re-hospitalization and initiating the transition from living independently to becoming care-dependent and in need of nursing home placement. Informal caregivers can contribute to a smoother discharge process by cooperating in the discharge planning. Caregivers often possess important information about the patient's functional ability, ability to manage independently at home, and the environment in which the patient lives. Our findings of the experiences of informal caregivers with information practices and participation in hospitals highlight important challenges that must be taken seriously to ensure cooperation between families and hospitals when older patients are discharged. A recent British study [205] has shown how the role of the informal caregivers changes across different care settings. At home, caregivers take responsibility for the coordination of informal and formal care in a "conductor" capacity, while in institutional care settings, informal caregivers are relieved of their responsibilities and, thus, take the role of "second fiddle" [205]. This resembles the experiences of the informal caregivers in our study in that they express how they have to take charge after discharge, to make sure all arrangements are made, and to remain vigilant in following up with the formal caregivers to ensure they take responsibility for their share (Paper III).

The patients become dependent on assistance from their informal caregivers, which is consistent with findings from a Swedish study in which patients became dependent on their families for negotiating help arrangements [80]. These findings accentuate the need to discuss how frail patients and their informal caregivers can be supported and enabled to achieve care arrangements that meet the patients' needs. This has the potential for becoming a serious deficit in our future care systems, which is especially daunting when we recognize that informal caregivers are paramount in securing high-quality care arrangements for their older relative [81]. The seriousness of this finding is further supported by a Norwegian study exploring the provision of fair nursing care, which showed that services are provided primarily to patients and families who have enough resources to advocate for their care [206]. This highlights the desperate situation of frail patients lacking informal caregivers or with an informal caregiver of the older generation, who in turn may find that they are greatly lacking the needed support to be able to advocate for appropriate care and lacking someone to act on their behalf.

8.2 Methodological considerations

In the following I will discuss the methodological considerations regarding design, sampling procedures and representativeness followed by a discussion of the reliability, validity, and trustworthiness of the findings of this dissertation.

8.2.1 Mixed methods design

This PhD study has had a mixed methods design with a sequential explanatory approach [156]. The main challenge of this type of design is the length of time involved in data collection in two separate phases [156]. At the same time, a significant strength of this approach, compared to other mixed methods designs, is that it is easy to implement due to the clear and separate stages of data collection. Clear, separate phases of data collection can also be a strength in describing and reporting the research conducted within this design [156]. A cross-sectional survey design, which is the quantitative design used in Phase One of this study (Paper I and II), is appropriate for describing the status of phenomena or for describing relationships between phenomena at a fixed point in time [161]. This assumption rests on the requirement that the sample is representative of the population [173] and that the sample is large enough to achieve statistical power [161].

8.2.2 Sampling procedures and representativeness

We arranged to have recruiters in 67 municipalities recruit patients to the study; however, we were unable to recruit patients from 15 of the municipalities. We suspect that some recruiters may not have been able to follow the consecutive sampling procedure, despite extensive efforts made by the research assistants in the team diligently calling the recruiters every other week throughout the recruitment period to answer any questions they might have had and to remind them to keep an eye out for new patients who might fit the inclusion criteria. It is possible that the pressures of facilitating the recruitment of patients in addition to taking care of their regular responsibilities may have been too demanding for some of the recruiters. However, we believe the municipalities we were unable to recruit patients from were a random sample mainly due to insufficient personnel resources in the recruiting municipalities. There are no indications that the lack of recruitment from these 15 municipalities has introduced a bias due to a skewed hospital selection or an overrepresentation of small-, medium-, or large-sized municipalities. We have no reason to believe that the 15 municipalities not yielding any participants share other specific characteristics.

Earlier research has shown that it may be difficult to recruit older adults to research studies [207], sometimes due to a lack of trust in the health care personnel, transportation obstacles, caregiver burden, medical concerns, sensory and cognitive limitations, and frail health [208]. Taking into consideration the advanced age of the target population for our study, the research team went to great lengths to achieve an acceptable response rate in the study. The recruitment scheme and the sampling procedure, as well as the choice of enlisting interviewers in each municipality to conduct the structured interviews face-to-face, were tools intended to enhance the response rate and the quality of the data material. Response rates tend to be higher in face-to-face interviews compared to, for example, postal or internet surveys because people are less likely to decline participation when solicited in person [161]. Furthermore, we wanted to avoid the known issues of non-response bias often encountered in postal surveys [173]. The response rate for the patients was 61.5%. Many of the advantages of face-to-face interviews also apply to telephone interviews, which was the method chosen to carry out the interviews with the informal caregivers. The response rate of the informal caregivers was 79.4%.

A weakness in our design was the lack of distinction between patients who were discharged to short-term rehabilitation stays at the nursing home and those discharged to permanent nursing home placement. All patients who were discharged to nursing homes were registered in the same manner regardless of their subsequent destination after rehabilitation. The lack of traceability of the patients who eventually returned to their home after two to three weeks of rehabilitation introduces uncertainty with regards to the actual functional ability of the studied patients. It also introduces uncertainty with regards to the objective caregiver burden experienced by their informal caregivers, as it is probable that caregivers of nursing home patients experience less physical burden and are less restricted by their caregiving responsibilities. Consequently, the sample of home-bound patients for Paper II was smaller than we have reason to believe it could have been had we been able to follow the patients throughout their transition. Additionally, we have not performed analyses comparing patients discharged home and patients discharged to a nursing home, because assignment to the two groups is uncertain.

Another weakness in the study was the lack of information about the patients and informal caregivers who declined to participate. The recruiters in the municipalities were instructed to keep lists of all eligible individuals, whether or not they declined or consented to participate

in the study; however, we have found the information about the persons who declined participation to be inadequate. Only in 53% of the cases do we have information about the patients who declined to participate. Consequently, we were not able to compare the included and the excluded individuals and have not been able to fully ascertain potential nonresponse bias [161]; we just do not know enough about the non-responders to ascertain whether or not they were significantly different from the participants in terms of demographic characteristics, health status, or satisfaction with the discharge process. In all the documented cases, the patient declined to participate due to their health condition or they felt too sick or too tired to participate in the interview. Several of the patients asked us to interview their informal caregiver in their place, indicating to us that the topic of the interviews and the topic of our study were important to them, and their reason for not taking part was strictly a matter of not having the stamina to be interviewed.

Another factor that can influence the generalizability of our findings is our inclusion criteria. The recruiting nurses were instructed to assess the patients' cognitive ability based on their knowledge of the patient and their professional experience. The interviewer did a second assessment of cognitive function at the time of the interview. Persons with cognitive impairment were excluded from the study. Consequently, our sample is probably less cognitively impaired than the general population aged 80 and over, especially if the nursing home population is included. The prevalence of dementia in Norway in the population age group 80–84 years is estimated to be 17.6%, and the prevalence severely increases in the older age groups. In the age group 85–89 years the prevalence is 31.7% and in the age group 90 and older it is 40.7% [209]. The prevalence of cognitive impairment of the home-dwelling older population of Norway is unknown, but in the nursing home population it has been estimated that as much as 80% have dementia or another form of severe cognitive impairment [210]. Our sample of patients was admitted to hospital from home, indicating that their health before hospitalization was such that they could live on their own. Furthermore, the sample of patients in Paper II consists of patients who were discharged back to their home after hospitalization. By excluding the patients who were discharged to nursing homes in our analysis we have implicitly included patients with relatively lower functional decline at discharge compared to the complete sample included in the main study.

The first and foremost self-reported cause for hospitalization in our sample was fractures after falling at home, followed by lung and respiratory system problems, and circulatory failure or

heart disease (Table 4). In the general Norwegian population 80 and older who were admitted to general hospital the most frequent cause for hospitalization was circulatory issues or heart disease, followed by fractures and problems with lung and respiratory system closely followed by cancer [38]. In our study, based on the self-reported cause for hospitalization, it seems that a larger proportion was admitted due to less serious conditions than in the general population. This means that it is likely that patients who were admitted for more serious conditions were not asked to participate due to their health condition or declined to participate in our study.

In light of these issues, it is possible that the patients included in our study were in relatively good health compared to the general population of recently discharged patients aged 80 and over. As for the informal caregivers included in the study, they differ from the general population in that they provide larger amounts of help to their older relative, which is to be expected when they were recruited because they were named by the patient as the informal caregiver.

Although there are few, if any, studies with a sample as large as our sample exploring the participation of patients aged 80 and over and the participation of their informal caregivers, we encourage caution in generalizing our findings to other populations due to the relatively moderate sample size. Furthermore, we caution generalization due to the probability that our sample was less functionally impaired than the population. This may in fact indicate that the situation is more serious than our research has uncovered because the frailest individuals are not included.

The sample of informal caregivers in the qualitative follow-up study

The participants' motivation for taking part in the research can be an important consideration when examining the trustworthiness of the results of the study. Research has shown that people have a wide range of motivations for taking part in qualitative research, including subjective interest in the focus of the study, to satisfy one's curiosity, enjoyment of participation, individual empowerment, being able to explore their own thoughts and feelings and expressing that to an interested party, therapeutic interest, and material and economic interest [211]. The informants in our study did not receive any material or economic incentives to participate, but several did express that they enjoyed the opportunity to share their thoughts and experiences with an interested party. Also, it is reasonable to assume that

the informants have a subjective interest in the topic of the study, seeing as they within the last 12–18 months experienced their older relative’s discharge process. It is possible that informal caregivers with unique experiences were recruited. A unique story may have prompted the interviewer to ask for their participation in the follow-up interview, and the informal caregivers may have wanted to share their unique story, especially if they felt they contributed to a positive outcome for their older relative or if they had had to face difficulties and may have wanted to express their criticism of the system. Nevertheless, our findings correspond very well with other, similar studies.

8.2.3 Reliability, validity, and trustworthiness

Quantitative approach

The literature review that was conducted at the start of the multi-center study revealed that there were no existing questionnaires that capture the full range of participation, and furthermore, the existing questionnaires do not cover those areas of the discharge process identified by the older patients themselves as the most essential [82]. Consequently, the research team developed The Discharge of Elderly Questionnaire for the purpose of conducting structured interviews with patients and their informal caregivers. The questionnaire was tested in pilot interviews to ensure that the questions were understandable and that the questionnaire covered areas that the respondents felt were significant. The questionnaire was used in the two quantitative sub-studies within this dissertation (Paper I and II).

We have evaluated the questionnaire to assess whether or not it measures what it is supposed to measure and if it actually provided answers to the research questions in this dissertation. Each proposed question arose from deliberations of the research team and from literature searches. Thereafter every question was formulated and critically evaluated on the basis of the team members’ experiences with this type of research. Finally the research team evaluated the complete questionnaire with regard to the content of the questions, formulations, and order.

During the literature review and the subsequent development of the questionnaire, the research team developed a hypothesis that patients and informal caregivers find participation to be important and that they want to participate. This was consistently confirmed through the interviews with both groups of respondents. Another hypothesis was that participating in

decision-making regarding the practical issues in and after the discharge was important to the respondents. This hypothesis was also confirmed. This underlines the importance of including these kinds of questions in the questionnaire.

With regards to the concept of participation, we have conducted an analysis of the cumulative scaling of the response pattern across the questions in our questionnaire measuring Thompson's [83] levels of participation. A Guttman reproducibility coefficient of 0.85 calculated in our material supports Thompson's idea that participation can be operationalized in these hierarchically organized levels, and it supports our hypothesis that the participation of patients and informal caregivers follows this logic. With the data material collected in this cross-sectional study, although quantitative and subjected to statistical analyses, the inferences made are solely based on associations between the variables [161, 174]. Thus, we are not suggesting that there is a causal relationship between participation and the other variables included in our logistic regression analyses [161, 174].

The assessments we have made indicate that the questionnaire gave us relevant information on the participation of patients and informal caregivers and that it was suitable for this study.

Qualitative approach

To ensure the trustworthiness of the findings reported in Paper III, we focused on addressing a number of criteria determining the quality of qualitative research [162]. We have aimed for transparency in reporting our data analysis procedures [162], accounting for the use of HyperRESEARCH [180] in our coding process and supplying examples of how the interviews were coded and categorized into main themes exemplified in a table showing examples of statements, codes, categories, and main themes (Table 4).

We acknowledge that the data transcripts may have multiple readings. To maximize the validity of our interpretations, all members of the research team took part in reading the transcripts, identifying the main themes, and discussing the emerging results until a consensus was reached on the interpretation of our findings [162]. The interpretations we present are influenced by the experiences of the research team. Our reading of the empirical data material is inextricably linked to our perceptions as researchers. We assert that the collective effort to analyze the empirical material serves to counteract individual biases and strengthens the credibility of our interpretations. Furthermore, the quotes used in Paper III are intended to illustrate our interpretations of the informants' statements and lend support to the

trustworthiness of our analysis [212]. The use of quotes in our paper has another purpose besides illustrating interpretations; it is also a way of introducing transparency to our analyses. We have attempted to account for the role of the researchers by reflexivity regarding our roles as co-creators of the data and the meaning presented in our results [162]. Altogether, these efforts were undertaken to ensure the trustworthiness of our findings and the conclusions made in this study.

9 Conclusions

The three sub-studies of this dissertation have explored the experiences of informal caregivers from different points of view drawing from the empirical data material collected at different points in the discharge process. By combining the findings from the three sub-studies it has become clear that the role of an informal caregiver is a complex and at times especially challenging role to take on in their pursuit of the best possible care for their older relative.

The cooperation between informal caregivers and health care personnel is brought to the forefront, and consequently, the role of the informal caregiver is unmistakably often a role of an intermediary between the patient and the health care services. The findings underline how the different generations of caregivers experience the discharge process differently. The younger generation caregivers, mainly adult children, perceive themselves to be better informed and they engage in dialogue and cooperate with the personnel at the hospital to a greater degree than the older generation caregivers, mainly consisting of spouses. The importance of having someone at home at homecoming and receiving sufficient formal home health care was underlined. Family members are most often the person present at the homecoming after discharge. However, for patients without close relatives or with relatives living far away, personnel from the formal health services in the municipality may sometimes be present at homecoming. The importance of informal caregivers as intermediaries was supported by findings from both methodological approaches showing that informal caregivers take on the responsibility to seek information and establish dialogue with the formal health services in the municipality to negotiate sufficient formal services for their older relative. Informal caregivers willingly take on the role as an intermediary between the patient and the health care services. They recognize that the patients are prevented from taking the active participating role that is needed, and in essence the informal caregivers participate on behalf of the patient and negotiate with the formal home health services to ensure that the patient is provided with the best possible care.

Cooperation with the health care personnel is generally described as challenging for informal caregivers. When only half of the informal caregivers reported they were able to cooperate with the hospital staff in planning the patient discharge, it is evident that the informal caregivers are struggling to be included in the process. Findings from the qualitative study support this notion and further illuminate the extent of this struggle. The informal caregivers

describe how they exert a great deal of resourcefulness to be able to actively participate and facilitate cooperation with health care services. The caregivers utilize different strategies and their key strategy is to collaborate with the gatekeepers to be able to influence decision-making in the discharge process. The success of informal caregivers depends on several elements. First, informal caregivers must be willing to participate on behalf of their older relatives. Second, they have to devote relentless efforts and persistence to manage the complexities of the health care services. Last, they have to be able to choose appropriate strategies in order to be heard.

Older patients who are not assisted by younger generation informal caregivers may be perceived to be at risk of missing the participation needed for a smooth transfer to their own home or to a nursing home. Inherently, frail older individuals may receive different care quality, whereas patients with strong, resourceful informal caregivers receive qualitatively better care than patients without caregivers or those with informal caregivers not strong enough to advocate and negotiate on their behalf. The patients' extensive frailty and increasing dependence on their families coupled with the complexity of the health care services contribute to the perception of the informal caregivers' indispensable role as intermediaries in the health care services.

The findings of this PhD study highlight how all-consuming and extensive the responsibilities are that the informal caregivers experience toward the well-being of their older relatives. The study accentuates the extensive vulnerability of older patients and their informal caregivers, and several groups appear to be especially vulnerable:

1. Older patients without informal caregivers to help them appear to be especially vulnerable in these discharge processes.
2. Older patients with caregivers of the same generation as themselves seem to be more vulnerable than older patients with younger caregivers.
3. Informal caregivers with limited resources to take an active part in seeking information, dialogue, and cooperation with the health personnel appear to be particularly vulnerable and have a hard time gaining influence on behalf of their older relative and may be insufficiently prepared for discharge.

4. Informal caregivers who initially saw themselves as resourceful and wanted to participate on behalf of their old relative but were overwhelmed by the complexity of the services and, subsequently, gave up their quest to participate, find themselves in a helpless position.
5. Informal caregivers who experience the boundaries between informal and formal caregivers' responsibilities to be unclear appear to struggle more with their role.

This study shows that focusing on informal caregivers and their participation is an investment toward better patient outcomes, and that more research is required to explore how informal caregivers can be actively included in the discharge process. Furthermore, the study supports the need for a modern policy for informal care; however, a new policy is required to explicitly address the needs of informal caregivers and not just the needs of the formal health care services.

9.1 Future perspectives

In this study we have explored the perspectives of the patients and the informal caregivers. However, the next logical step might be to include the formal caregivers' perspectives as well, in a study exploring experiences with participation from all three perspectives. It would be interesting to know how the formal caregivers view this issue and if they recognize the challenges identified by patients and informal caregivers.

Data for this study were collected prior to the implementation of the Coordination Reform in Norway. This reform introduced new financial structures in the formal health care services; municipalities are now required to co-finance the hospital stay for a patient from their municipality [50]. This has encouraged further expansion of the primary care in the municipalities with the establishment of intermediary units with skilled nursing facilities equipped to handle patients who are too sick to stay at home or in a nursing home, but not sick enough to warrant hospital care. These intermediary units, often located in a nursing home with a few designated beds, are often used when patients are discharged if they are not well enough to return home. There are substantial efforts evaluating the reform; however, statistics from the specialist health care services indicate that when patients are deemed by hospital personnel to be ready for discharge, they are discharged quicker than before, further shortening the hospital stays in Norway [213]. It would be interesting to explore if the

challenges that we have discovered in this PhD study with regards to the informal caregivers' participation are further amplified in today's reformed system. All the research suggesting that shorter stays hamper participation would imply this. And in that case, we should continue the efforts to find new ways of including the informal caregivers in the discharge planning. How can we make arrangements to encourage their participation, and what kinds of participation do informal caregivers prefer?

We need more research to find ways to support the most vulnerable patients and informal caregivers in care transitions. How can we safeguard the needs of the most vulnerable individuals identified in this dissertation? I believe there is a particular need for intervention studies looking at interventions tailored to the Norwegian health care setting. Preferably, patients, informal caregivers and health care professionals should participate in the development of an effective intervention addressing the needs of all parties in care transitions.

10 References

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Errata

Doctoral candidate: Line Kildal Bragstad

Dissertation title: *Indispensable intermediaries. The role of informal caregivers in the discharge process of older relatives*

Changes:

Page XI – Terms and abbreviations

To ensure consistency I ask for permission to delete the abbreviation “*MeSH Medical Subject heading*” because this abbreviation is not used in the text.

To ensure consistency between the running text and text in tables I ask for permission to make the following changes:

Page 2 – Table 1

Aim – Study II: Change the word explore to describe.

Aim – Study III: Change the word describe to explore.

Page 34 – Table 4

Change Muscular and skeletal system to Muscular and skeletal systems.

Original Papers

- I. Bragstad, LK., Kirkevold, M., Hofoss, D. & Foss, C. (2014) Informal caregivers' participation when older adults in Norway are discharged from the hospital. *Health & Social Care in the community*, Vol. 22(2): 155–168.
- II. Bragstad, LK., Kirkevold, M., Hofoss, D. & Foss, C. (2012) Factors Predicting a successful post-discharge outcome for individuals aged 80 years and over. *International Journal of Integrated Care*, Vol. 12, 10. Feb. 2012.
- III. Bragstad, LK., Kirkevold, M. & Foss, C. (2014) The indispensable intermediaries: A qualitative study of informal caregivers' struggle to achieve influence at and after hospital discharge. *BMC Health Services Research*, 14:331

Original papers

Paper 1

Paper II

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Research and theory

Factors predicting a successful post-discharge outcome for individuals aged 80 years and over

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Abstract

Introduction and background: The early post-discharge period is a vulnerable time for older patients with complex care requirements. This paper identifies factors predicting a self-reported successful post-discharge outcome for patients aged 80 years and over by exploring factors related to the discharge process, the provision of formal home-care services, informal care and characteristics of the patients.

Methods: The study reports results from survey interviews with patients admitted from home to 14 hospitals in Norway and later discharged home. Logistic regression analysis was performed to assess the impact of a number of factors on the likelihood that the patients would report that they managed well after discharge.

Results: The odds of managing well after discharge were more than four times higher (OR=4.75, p=0.022) for patients reporting that someone was present at homecoming than for those who came home to an empty house. Patients who reported receiving adequate help from the municipality had an odds four times (OR=4.18, p=0.006) higher of reporting that everything went well after discharge than those who stated the help was inadequate.

Conclusions: Having someone at home upon return from hospital and having adequate formal home-care services are significantly associated with patient-reported success in managing well.

Keywords

post-discharge outcomes, family caregivers, care transitions, aged 80 and over

Introduction

Older patients with multiple and often complex care requirements are being discharged from hospital to

home 'quicker and sicker' than ever before, and thus at an earlier stage of the rehabilitation process [1–3]. The early post-discharge period is an especially vulnerable phase which involves significant transitions for older

patients and their family caregivers [4–6]. Furthermore, today's health-care systems have an objective to ensure that older persons are able to live at home as long as possible [7] and to reduce the need for admission to care institutions.

During the last 20 years we have seen a substantial change in policy resulting in a general downscaling of care institutions in Norway and other European countries [8, 9]. To compensate for this deinstitutionalization there has been an expansion of the municipal home-care services in Norway [7] and a steady increase in the overall number of formal home health-care recipients [10]. However, taking into account the population growth over the same period, there was a proportional decrease from 41% of the 80 and over age group receiving home-care services in 1992 to 37% in 2006 [7, 10]. Furthermore, patients aged 80 and over are on average granted fewer service hours than patients aged 67 and under [11]. These contemporary changes in the primary and secondary health-care services call for further exploration. This paper identifies factors that may predict a self-reported successful post-discharge outcome for patients aged 80 and over.

Theory

Several literature reviews have identified factors influencing the transition process and post-discharge outcomes [5, 12–15]. Professional/service factors, informal/family caregiver factors, personal factors [5] and factors related to discharge planning [13] were found to be crucial to the transition process between hospital and home. As shown in Figure 1, these four groups of factors are assumed to influence the post-discharge outcome.

The discharge process

Hospital professionals are commonly in charge of discharge planning; however, participation by professionals

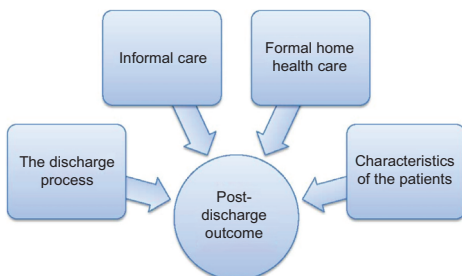


Figure 1. Four groups of factors assumed to influence post-discharge outcome in the transition process from hospital to home for patients aged 80 years and over.

from the primary health-care services jointly with family caregivers is required to make transitions from hospital to home as efficient and safe as possible [9]. The goal of discharge planning is to prepare patients and their family caregivers for life at home following hospitalization [15]. In order to feel prepared to return to their homes, patients express a need for information and arrangements regarding care issues, activities of daily living and where to turn if unforeseen events arise [16]. During the early post-discharge period, defined as the first three to five weeks, approximately 20% of the oldest patients experience adverse events [17, 18]. This may be indicative of unsuccessful discharge and could potentially lead to re-admission to hospital or transfer to a nursing home. Studies have shown that a relatively short length of hospital stay [19] and living at home rather than in sheltered accommodation [19, 20] increases the probability of readmission. Discharge planning combined with additional post-discharge support can reduce unplanned readmission [13].

Characteristics of the patients

Essential personal factors include readiness for discharge [5, 16], level of disability and subsequent need for post-discharge support [5]. Difficulties with activities of daily living tend to increase with advancing age. Old age is associated with a high prevalence of multimorbidity, chronic illness, as well as sensory and functional impairment and a general decline in health [2, 18, 21–24]. Physiological changes associated with ageing predispose older patients to serious complications at the time of hospital discharge and following it [24]. Frailty of patients or significant deterioration in functional status, as well as the presence of cognitive problems, can be predictive of unsuccessful post-discharge outcomes [3, 25, 26]. Most patients experience increased functional dependency post-discharge and hence require formal post-hospital home-care [27], often in conjunction with extensive informal care from unpaid carers [28].

Formal home-care services

Coming home from hospital, older patients need emotional support and require assistance with personal and instrumental activities of daily living [2]. In Norway and other Nordic countries the welfare state holds the main responsibility for the care of older people [29, 30]. The municipal home-care services in Norway provide both formal home-help services and round the clock home-nursing care. Allocation of home-care services in Norway is not limited to a set time period, but is based on individual needs assessments. Service hours are allocated depending on the patient's

needs, and can be adjusted when necessary. On average, patients aged 80 and over were allocated 4.65 hours per week in 2010 [11]. Home-care assistants in the home-help services usually provide assistance with personal care activities, such as bathing, dressing, feeding and instrumental activities of daily living. Administering medication, giving injections and changing wound dressings, on the other hand, are examples of tasks carried out by home nurses. Formal home-care delivery in Norway is viewed as generous compared to other countries [31]. However, studies from countries with comparable health-care systems—Canada [2] and the UK [32]—have shown that home-care services may be inadequate in meeting the full range of the patient's post-discharge needs.

Informal care

Family members, neighbours and friends are essential informal care providers when older patients return home after hospitalization [6, 12, 28, 29, 32–35]. Patients receiving extensive formal care from the municipalities in Norway continue to receive informal care from family caregivers [29, 36, 37]. Estimates show that close to 80% of the home care in Norway [35] and the UK [32] is provided by family members and other informal caregivers. Formal and informal caregivers complement each other and provide help with different tasks [29]. Formal caregivers have been found to perform personal activities of daily living, while family caregivers or other informal caregivers offer help with instrumental activities of daily living [29]. Family caregivers have always had a leading role in helping older people at home [6]. However, in Norway the welfare system is built on the premise that public health care should be sufficient, and older people should not have to rely on informal caregivers to manage. The deliberate shift away from hospital care towards home-care has intensified the pressures on families and increased their role in supporting older people after discharge [15, 32].

Research question

A clear emphasis on the importance of recognising patients as experts with a unique knowledge of their own health and preferences has emerged through the policy initiatives and health-care legislation of recent years [38, 39]. Surveys to ascertain patients' views serve as tools to elicit information that contributes to improved practices [40]. Research also supports the notion that seeking patients' views and preferences in the discharge process is of vital importance for a successful discharge [41]. The specific research question we seek to answer in this study is therefore:

How do the patient-reported discharge process, formal home-care, informal care and state of health influence the patients' self-reported post-discharge outcome?

Methods

Background and sample

The study is part of a research project funded by the Norwegian Research Council, in which self-reported questionnaire results for patients admitted from home to 14 hospitals in Norway and discharged home to long-term community care are reported. The charge nurses at home-care offices in 67 Norwegian municipalities identified potential participants and introduced the study to patients who met the inclusion criteria. Inclusion criteria were: aged 80+, admitted to hospital from home, hospitalized for 2 days or more and adequate cognitive performance (as assessed by the recruiting nurse) to take part in the planning of their own discharge and to give written informed consent to participate in the study. Three hundred and thirty respondents were recruited to the main study (Figure 2).

At the time of the interview, 43% (142) of the 330 respondents in this study lived at home while 57% (188) were nursing-home residents. The sample in this paper consists of the 142 home-dwelling patients.

The questionnaire

The Discharge of Elderly Questionnaire was developed by the research team. It was designed to elicit data about the patients' experiences regarding their discharge and the management of their health problems after discharge. There was no existing questionnaire covering these dimensions [42]. The questionnaire was organized in four main parts: 'Here-And-Now', 'At the Hospital', 'Summary' and 'Demographic Background'. The 'Here-And-Now' section contains questions about how the patient manages after discharge. 'At the Hospital' is divided into six subcategories: 'Information about the hospital stay', 'the discharge process', 'received information and training', 'participation in the discharge planning', 'communication' and 'the role of family caregivers'. In the 'summary' part of the questionnaire patients were asked concluding questions about their general assessment of the help received during their hospital stay. The last section of the questionnaire concerns the patients' demographic background, previous and current care arrangements and present functional status. Functional status was measured by four ADL-measures (dressing, bathing, transferring and feeding) [43] and three IADL-measures (shopping, light household chores and heavier

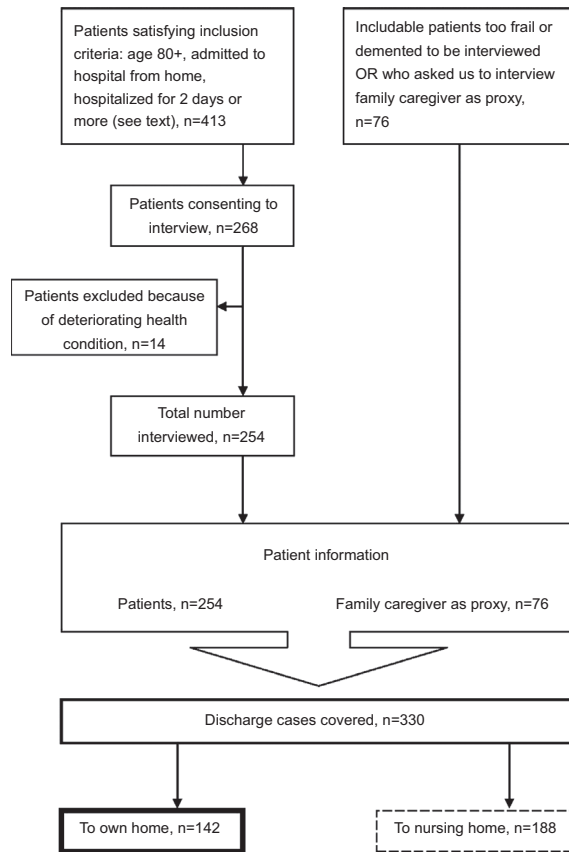


Figure 2. Flow chart of inclusion of respondents and discharge cases covered in the study.

household chores) [44]. Performance was graded as independent, partly dependent or dependent.

Data collection

Geriatric nurses or geriatric nurse students carried out structured face-to-face interviews with the patients during the first two weeks following discharge from hospital. Family caregivers interviewed as proxy were interviewed by telephone. Interviewers were trained to clarify the questions in a uniform way, and to help respondents grade their answers [45].

Data analysis

Logistic regression analysis was performed to assess the impact of a number of factors on the likelihood that the patients would report that they managed well after being discharged home from hospital. The

independent variables ‘adequate help from the municipal home health care’, ‘someone was present when I came home’, ‘I live alone’, ‘I receive help from family now’, ‘there was a discharge planning conference’, ‘I was surprised by the timing of my discharge from hospital’, ADL sum and IADL sum were included in the logistic regression model (Figure 3).

The analysis was controlled for age, gender and length of hospital stay. The p-value of the Hosmer and Lemeshow model for goodness of fit was $p=0.894$. An α -level of 0.05 was used in all statistical tests. Data were analysed using PASW Statistics 18.

Ethical considerations

The study was designed in accordance with the World Medical Association’s Declaration of Helsinki [46]. Approval for the study was obtained from East Norway Regional Ethics Committee for Medical Research

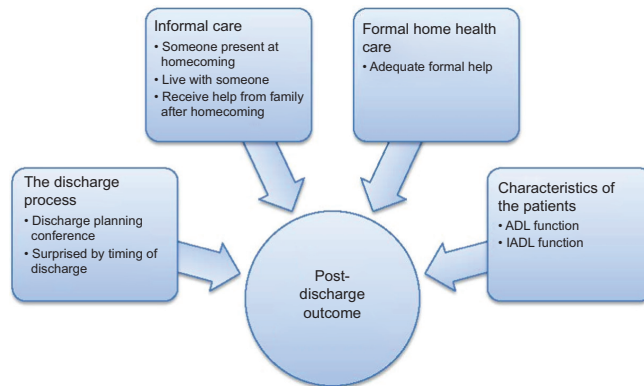


Figure 3. Variables in our data material organized in four groups of factors assumed to influence post-discharge outcome in the transition process from hospital to home for patients aged 80 years and over.

(project number: 17078) and all the municipalities involved. Informed written consent was obtained from each patient before the interviews were initiated.

Results

Characteristics of the sample

In our sample of 142 home-dwelling patients with a mean age of 85.9 years, 70.4% (100) were women (Table 1).

Thirteen (9.4%) of the patients had been in education beyond upper secondary school. While 29.1% (41) of the patients were married, 62.4% (88) were widows or widowers. At the time of the interview 66.2% (92) of the patients lived alone.

Managing after discharge

As shown in Table 2, 54.1% (66) of the patients reported that they had managed well after their homecoming. This response is interpreted as a self-reported successful post-discharge outcome.

In 91.2% (93) of the cases, no discharge planning conference was held. Furthermore, 20% (24) reported that the timing of their discharge from hospital surprised them. Statements made by the patients (Table 3) suggest that some were surprised because they thought they were discharged too early and they wanted to stay in hospital until they felt strong enough to return home.

A family member was present at the patient's homecoming in 57.7% (71) of the cases. In 12.2% (15) of the cases someone from the home-care services was

present, yet 15.4% (19) of the patients came home to an empty house (Table 4). Thirteen (10.6%) of the patients reported that they did not require any assistance at homecoming. Patient statements (Table 3) show that some of the patients were prepared for coming home to an empty house, and did not experience this as a problem. However, some patients felt lonely and abandoned, and others shared experiences of difficulties managing on their own.

At the time of the interview 80.3% (114) of the patients reported that they received help from their family. In our sample 93.7% (133) of the patients received home-nursing care. In addition, 67.6% (96) of the patients received home-help. Despite this, 28.4% (35) of the patients reported that they felt the help they received from the municipality was not adequate. Patient statements (Table 3) suggest that the feeling of inadequacy stems from what they feel is an insufficient allocation of service hours and a need for more help with IADL tasks like grocery shopping and house cleaning.

As shown in Table 5, two of the independent variables made a unique statistically significant contribution to the logistic regression model.

Controlled for the other factors in the model, the odds of managing well after discharge were more than four times higher (OR=4.75, p=0.022) for patients reporting that someone was present when they came home than for those who came home to an empty house. Patients reporting that they thought the help they received from the municipality was adequate had an odds four times (OR=4.18, p=0.006) higher of reporting that everything went well after discharge than those who thought the help was inadequate. The patients' age, gender, length of stay, ADL and IADL function, whether they received help from family and friends, lived alone,

Table 1. Characteristics of the sample

| Discharged to own home, 43% (n=142/330) | |
|--|--------------|
| Length of hospital stay | |
| Mean | 10.4 days |
| Median | 7 days |
| Time since discharge | |
| Mean | 16.7 days |
| Median | 14 days |
| ADL-sum ¹ (S.D.) | |
| Mean | 10.5 (1.79) |
| Median | 11 |
| IADL-sum ² (S.D.) | |
| Mean | 4.9 (1.83) |
| Median | 5 |
| Age | |
| Mean | 85.9 years |
| Median | 85 years |
| | % (n) |
| Gender | |
| Women | 70.4 (100) |
| Men | 29.6 (42) |
| Marital status | |
| Married | 29.1 (41) |
| Widow/widower | 62.4 (88) |
| Divorced | 3.5 (5) |
| Cohabiting | 0.7 (1) |
| Unmarried | 4.3 (6) |
| Level of education | |
| Primary school | 46 (64) |
| Lower secondary/vocational school | 38.8 (54) |
| Upper secondary school | 5.8 (8) |
| University or college degree | 9.4 (13) |
| Living status | |
| Alone | 66.2 (92) |
| With someone | 33.8 (47) |
| Type of residence | |
| Private, not adapted | 42.8 (59) |
| Private, adapted | 26.8 (37) |
| Municipal housing, adapted | 29 (40) |
| Other | 1.4 (2) |

¹ADL-sum ranges from 4—dependent in all activities to 12—dependent in all activities.

²IADL-sum ranges from 3—dependent in all activities to 9—dependent in all activities.

Table 2. Self-reported post-discharge outcome

| How have you managed since coming home from hospital? | % (n) |
|--|--------------|
| It has been okay all along | 54.1 (66) |
| It was difficult at first, but okay after a while | 18.9 (23) |
| It has been mixed (difficult and okay) all along | 16.4 (20) |
| It has been difficult all along, and I still find it difficult | 9.8 (12) |
| My experience does not fit in any of the categories | 0.8 (1) |
| Total ¹ | 100 (122) |

¹Total number of patients discharged to own home were 142. For various reasons family caregivers were interviewed as proxy for 19 of the patients. Proxies were not asked to answer this question, thus, the total number of respondents who were asked this question was 123. One person did not answer the question, resulting in a total number of 122 answers.

reported being surprised by the timing of the discharge or whether they reported that there was a discharge planning conference were not statistically significant predictors in this model.

Discussion

In our study, having someone at home upon returning from hospital was an important predictor for a self-reported successful post-discharge outcome. The patients were met at their home by family members in 57.7% of the cases and by others in 16.3% of the cases. The family's involvement commences early in the transition process, preparing and assisting in the homecoming for the patients. Our findings suggest that it is imperative for a successful post-discharge outcome that the patient does not come home to an empty house.

Another important predictor for a self-reported successful post-discharge outcome was having adequate formal home health care. In our sample all patients received formal home-help and/or home-nursing care. However, 28.4% of the patients found the formal help insufficient. Earlier research has pointed towards the inadequacy of municipal home-care services [2, 32]. In our study we are unable to pinpoint precisely what the patients found insufficient. But statements made by the patients suggest that the need for social support in addition to practical help with instrumental activities of daily living is perhaps the one need not commonly met by formal caregivers in today's 'stopwatch service' provision. To promote a feeling of well-being and mastery after coming home, it seems to be important for the municipality to perform an assessment of the patients' needs for services that correspond to the patients' own expectations.

As earlier research has shown, informal help from family and friends is an important supplement to the formal home help provided by the municipality [6, 12, 28, 32–35]. In our sample 80.3% of the patients received help from family and friends. Our findings, supported by patients stating 'it would not have gone this well without my daughter' and 'the home nurses and my wife are helping me' (Table 3), highlights the importance of both the informal and formal caregivers at homecoming.

In our logistic regression model ADL and IADL function were not statistically significant with regard to the dependent variable. That is not to say that the patient's functional status does not affect the post-discharge outcome, it probably just means that the patient's functional dependency was compensated for by the amount of formal and informal help received post-discharge.

Despite the fact that 91.2% of the patients reported that there was no discharge planning conference and

Table 3. Examples of patient statements

| Question | Typical statements—patient quotes | |
|--|-----------------------------------|---|
| How have you managed at home since your discharge? | Well | “I have received a lot of help, my son is visiting” “It has been okay all along thanks to the home nurses” “The home nurses and my wife are helping me” “It would not have gone this well without my daughter” |
| | Not well | “I have not been well, very dizzy and powerless” “I feel tired and weak, and the home nurses are not here long enough” “I think I was discharged too early considering my health status” “I have had some pain, it has been difficult to walk” “I feel lonely after coming home” |
| If you came home to an empty house, how was that experience for you? | Good | “It was okay, I didn’t need someone there” “It was okay, I had my telephone and TV. I have always lived alone, so I’m used to it” “I knew I would be on my own at home, it was okay” |
| | Bad | “No one was there. No one was there to say, “welcome home”. The mailbox was full. But the home care aide came and helped me to bed” “I was too tired to “feel anything”, I fell asleep in my chair. The taxi driver helped me to my living room” “I felt lonely and abandoned. I had a dream that the home care aide would be there ready with a cup of coffee” “It was very difficult. I had great pain in my hip, and I had to walk the stairs to my house. Luckily, a neighbor came to my assistance” “On account of a misunderstanding the hospital’s discharge notice failed to reach my family. That’s why I came to an empty house. I was able to reach my family, and they came shortly after.” |
| If the formal help you receive is insufficient, what would you want differently? | | “I would like to exercise more” “I could use some more physical therapy” “It is not enough and the job they do is often unsatisfactory” “I need more help with laundry and window cleaning. I am lonely” “I wish someone could do my grocery shopping” “I need help with house cleaning” “I only get help with one shower per week” “I wish I could get more than two hours per week now that I am ill” |
| Did the timing of the discharge surprise you? | No | “I was prepared” “I was told the same day, but felt prepared” “No, I was prepared they wouldn’t let me stay long, despite me feeling weak and weary” |
| | Yes | “I felt I was too ill to go home” “I thought they would run more tests and that the stay would be longer. I was very ill” “I wanted to stay at the hospital longer” “I had not been told what was wrong with me, I was surprised. They took our beds in the morning, and I had to sit on a chair waiting for the taxi until 5 pm. It was horrible” “Yes, and because of that I asked to stay longer, but my request was declined” |

Table 4. Homecoming

| Was someone present when you came home from the hospital? | % (n) |
|---|-----------|
| Not necessary, I can manage on my own | 10.6 (13) |
| No, I came home to an empty house | 15.4 (19) |
| Yes, my next of kin was present | 57.7 (71) |
| Yes, someone from the formal home health services was present | 12.2 (15) |
| Someone else was present | 4.1 (5) |
| Total ¹ | 100 (123) |

¹Total number of patients discharged to own home was 142. For various reasons family caregivers were interviewed as proxy for 19 of the patients. Proxies were not asked to answer this question, thus, the total number of respondents who were asked this question was 123.

that 20% reported being surprised by the timing of their discharge, the logistic regression model did not confirm our assumption that these variables are significant

predictors of a successful post-discharge outcome. However, these findings raise questions that need further exploration concerning the quality of the discharge planning and the cooperation between formal and informal caregivers regarding the patient’s discharge.

The capacity in the Norwegian home-care sector is under pressure [9] and the findings from this study indicate that both informal care and formal home health care are vital elements for older patients discharged from hospital.

Conclusion

Our findings show that having someone at home upon returning from hospital and having adequate formal home-care services are significantly associated with patient-reported success in managing well in the long-term after returning home from hospital.

Table 5. Logistic regression model

| | B (S.E.) | p-Value | Odds ratio (95% CI) |
|---|-----------------|----------------|----------------------------|
| Gender (0=female) | 0.396 (0.514) | 0.411 | 1.486 (0.543–4.070) |
| Age | –0.090 (0.056) | 0.110 | 0.914 (0.819–1.021) |
| Length of stay | –0.026 (0.025) | 0.298 | 0.974 (0.927–1.024) |
| ADL-sum ¹ | –0.246 (0.166) | 0.140 | 0.782 (0.565–1.084) |
| IADL-sum ² | 0.076 (0.149) | 0.608 | 1.079 (0.806–1.446) |
| Adequate help from municipality (0=no) | 1.430 (0.518) | 0.006 | 4.177 (1.514–11.526) |
| Someone present when I came home (0=no) | 1.558 (0.682) | 0.022 | 4.749 (1.248–18.078) |
| Live alone (0=yes) | 0.525 (0.520) | 0.313 | 1.690 (0.610–4.682) |
| Help from family now (0=no help) | –0.885 (0.600) | 0.140 | 0.413 (0.127–1.337) |
| Discharge planning conference (0=no) | 0.513 (0.995) | 0.606 | 1.671 (0.238–11.752) |
| Surprised by discharge (0=yes) | 0.903 (0.576) | 0.117 | 2.467 (0.797–7.634) |
| Constant | 7.736 (5.350) | 0.148 | 2288.178 |

*The dependent variable: self-reported post-discharge outcome (0=the first 2–3 weeks after discharge from hospital were difficult in the beginning, but ok after a while/both difficult and ok all along/difficult all along and still difficult, 1=ok all along).

¹ADL-sum ranges from 4—dependent in all activities to 12—independent in all activities.

²IADL-sum ranges from 3—dependent in all activities to 9—independent in all activities.

(Hosmer and Lemeshow model goodness of fit p=0.894) (n=122).

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Paper III

RESEARCH ARTICLE

Open Access

The indispensable intermediaries: a qualitative study of informal caregivers' struggle to achieve influence at and after hospital discharge

Line Kildal Bragstad*, Marit Kirkevold and Christina Foss

Abstract

Background: The care policy and organization of the care sector is shifting to accommodate projected demographic changes and to ensure a sustainable model of health care provision in the future. Adult children and spouses are often the first to assume care giving responsibilities for older adults when declining function results in increased care needs. By introducing policies tailored to enabling family members to combine gainful employment with providing care for older relatives, the sustainability of the future care for older individuals in Norway is more explicitly placed on the family and informal caregivers than previously. Care recipients and informal caregivers are expected to take an active consumer role and participate in the care decision-making process. This paper aims to describe the informal caregivers' experiences of influencing decision-making at and after hospital discharge for home-bound older relatives.

Methods: This paper reports findings from a follow-up study with an exploratory qualitative design. Qualitative telephone interviews were conducted with 19 informal caregivers of older individuals discharged from hospital in Norway. An inductive thematic content analysis was undertaken.

Results: Informal caregivers take on comprehensive all-consuming roles as intermediaries between the care recipient and the health care services. In essence, the informal caregivers take the role of the active participant on behalf of their older relative. They describe extensive efforts struggling to establish dialogues with the "gatekeepers" of the health care services. Achieving the goal of the best possible care for the care recipient seem to depend on the informal caregivers having the resources to choose appropriate strategies for gaining influence over decisions.

Conclusions: The care recipients' extensive frailty and increasing dependence on their families coupled with the complexity of health care services contribute to the perception of the informal caregivers' indispensable role as intermediaries. These findings accentuate the need to further discuss how frail older individuals and their informal caregivers can be supported and enabled to participate in decision-making regarding care arrangements that meet the care recipient's needs.

Keywords: Informal caregivers, Family, Consumer participation, Aged 80+, Informal help, Formal help, Home health care services

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Background

Population projections show a significant increase of the older population in the European countries over the next 40 years [1]. Although the increase is not as dramatic in Norway [2], which is the setting of this study, as in some of the other European countries [1,3], the old age dependency ratio is cause for concern with regards to accommodating the increasing need for health care services in the aging population [1,3].

During the last 20 years we have seen a substantial change in primary care policy resulting in a retrenchment of institutional care in the municipalities in Norway and other European countries [4-6]. To compensate for this downscaling of care institutions, there has been an expansion of the municipal home-care services [1,7,8]. These home-care service developments coincide with the increased policy emphasis on aging in place seen in Norway and throughout the Western world [1,9].

The care policy and organization of the care sector is shifting to accommodate projected demographic changes [1,8] and to ensure a sustainable model of health care provision in the future [3,10,11]. When welfare states are under pressure and are obliged to discuss potential prioritizing and rationing of welfare services, the growing interest in informal care is noticeable [8,12].

Contemporary policy documents acknowledge that in order to maintain the level of support provided by informal caregivers today, a new "modern policy for informal care" that looks closely at the relationship between employment and caregiving in a more future-oriented manner is required [3,10,11]. By introducing policies tailored to enabling family members to combine gainful employment with providing care for older relatives, the sustainability of the future care for older individuals in Norway is more explicitly placed on the family and informal caregivers than previously [3,10,11].

Formal health care services

The premise that health care is a public responsibility has traditionally been a core element of the Nordic welfare state [13]. This welfare state model differs from other models in that the arrangements between the state, market, and family strongly favor placing the responsibility with the welfare state [13]. This means that the state is established as the preferred and dominant provider of care, a model that is collectively supported by the Norwegian population [14]. The public services in Norway are based on the principle of universalism, which involves a uniform standard of services across all municipalities and counties in a model that incorporates all citizens in one universal system [13]. A central tenet of the Nordic welfare state model is to ensure provision of health care services and institutional care according to the citizens' needs, independent of personal wealth, availability of

family members to deliver informal care, or place of residence [13,15]. Nevertheless, the substantial welfare state expansion in the post-war era has not eroded filial obligations in Norway [14]. Despite placing the primary responsibility with the formal health care services, the adherence to filial obligation norms is expressed in a resilient belief that the family has a responsibility to support their older relatives [13,14,16]. This belief is demonstrated through the consistently high levels of care provided by informal caregivers of home-bound older relatives over the past 20 to 30 years [3,16,17], although it is significantly higher in countries with less developed formal home care services [1].

In Norway, the formal health care services are primarily public services organized in a two-tier model that consists of the specialist health care services at one tier and primary health care services at the other tier. The hospitals are a part of the specialist health care services. Hospitals are owned and financed by the Ministry of Health and Care Services and managed by regional health enterprises. Long-term care is part of the primary health care services, which are owned, financed, and managed by local municipalities.

Informal care

In the Nordic countries, research on informal care has received less attention compared to the amount of research on formal care [16,18]. However, this trend changed during the 1990s [16,18]. In the international research community, research on informal care has been concerned with who provides informal care [19,20] and what kind of help and support informal caregivers provide [21-23]. Another perspective has been on what motivates family members to provide informal care to older relatives [24-27]. It is widely recognized that informal caregiving can be challenging on several different levels, thus, a significant amount of research concerns the caregiver burden of informal caregivers [28-31].

Research has shown that, traditionally, spouses, adult children, and extended family members are the first to assume caregiving responsibilities for older relatives when care needs arise [32]. The family assumes an important role in providing practical assistance and providing essential emotional support during hospitalization and after discharge [17,33]. In addition, informal caregivers play an important role in supporting their older relative in health care consultations [23,34], managing information [35], and in negotiating formal care in the community [36,37] by ensuring high-quality services when patients are not able to demand this for themselves [38]. However, changing family structures and increased mobility in and across country borders [8] pose challenges to the availability of informal care for older individuals living in the community.

Consumer participation

The concept of patients as consumers has gained momentum in the health care services during recent decades [39]. Consumer participation has become a way to make the health care services responsive to individual needs and preferences by giving decision rights to those who receive medical care [40]. This shift has challenged the paternalistic model that traditionally dominated the relationship between patients and health care services, in which the patient is a passive recipient of care, while the health care personnel make decisions based on their expert medical knowledge [41]. This shift toward increased patient autonomy entails redefining the patient role from passive recipient to active participant [41]. The concept of increased autonomy and consumer participation has become an established ideal in the health care legislation, providing patients and his or her family a legal right to participate in the decision-making process to influence the choice of available treatment options and how treatment and care is provided [42]. Care recipients and their informal caregivers are encouraged to use their consumer influence to request high-quality services and are able to lodge complaints when services are not satisfactory [41]. However, this may not always work in practice, because older patients in particular may find it difficult to act as consumers, and they often practice participation in a subtle and discrete way [43]. Thus, older individuals come to depend on others, mainly their family, to represent them when the quality of care is not satisfactory [38].

Informal caregiver participation in the discharge process

Informal caregivers' involvement in the discharge process is found to increase their satisfaction with discharge planning, continuity of care, feelings of preparedness, and acceptance of the caring role and to increase the well-being of patients and their informal caregivers [44,45]. Involving family members has also been shown to improve the care recipient's participation in the decision-making process [46,47]. Moreover, it is recognized that informal caregivers' satisfaction with the discharge process influences the patients' satisfaction and even influences the patient outcome positively [45]. However, research indicates that informal caregivers' involvement in discharge planning is limited [48]. Family members are rarely consulted despite their potential as important resources in the discharge process and not least as important sources of support for the patients in the first post-discharge period [49,50].

Research on the transition between the home and hospital has emphasized the importance of collaboration between relatives of older patients and formal caregivers, indicating the need for a new, more active role for relatives as partners in decision-making at admission and discharge [51]. In the hospital setting, informal caregivers struggle to be more involved [52]; however, participation

can be hampered by a lack of dialogue between formal and informal caregivers [52,53]. Furthermore, research has shown that informal caregivers can act as a "bridge" between the patient and formal care, facilitating formal care [54] by initiating the process of acquiring formal help for their home-bound older relatives [37].

Rationale of the study

The contemporary demographic changes put pressure on formal and informal care delivery in the municipalities after hospital discharge. Consumer participation in discharge planning is encouraged to ensure continuity of care and care delivery in accordance with the wishes and needs of care recipients and informal caregivers. However, there is an apparent scarcity of research on the informal caregivers' participation in the discharge planning. Current research underscores the importance of involving the informal caregivers early in the discharge process and encourages communication and information exchange between formal and informal caregivers. Research has identified a need to involve informal caregivers in the decision-making process to ensure successful post-discharge outcomes for the patient and the informal caregivers. However, we do not know enough about the specific roles of informal caregivers and their participation at and after the discharge process of older adults. This has become an issue of particular current interest due to proposed policy changes intending to develop a modern policy for informal care, more explicitly placing greater responsibility for a sustainable model of care on informal caregivers.

Purpose

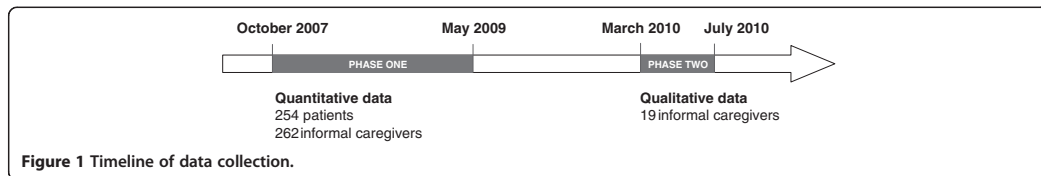
The purpose of this study is to describe the informal caregivers' experiences of influencing decision-making at and after hospital discharge for home-bound older relatives. The specific research questions in this study were as follows: How do informal caregivers describe their role as participants in the decision-making concerning the health care services their older relative receives? How do informal caregivers describe their approach to influencing the care of their older relatives?

Methods

Setting and sample

This exploratory, qualitative interview study is part of a larger research study that explored patients' and informal caregivers' participation in the discharge process during the transition from hospital to long-term primary health care in Norway. Recruitment of participants and data collection was carried out in two phases (Figure 1).

During Phase One, between October 2007 and May 2009, 254 patients and 262 informal caregivers from 52 municipalities were recruited to the study. Data were collected in structured self-report (face-to-face [patients] and



telephone [informal caregivers]) interviews. The results from Phase One of the main study have been reported elsewhere [53,55,56].

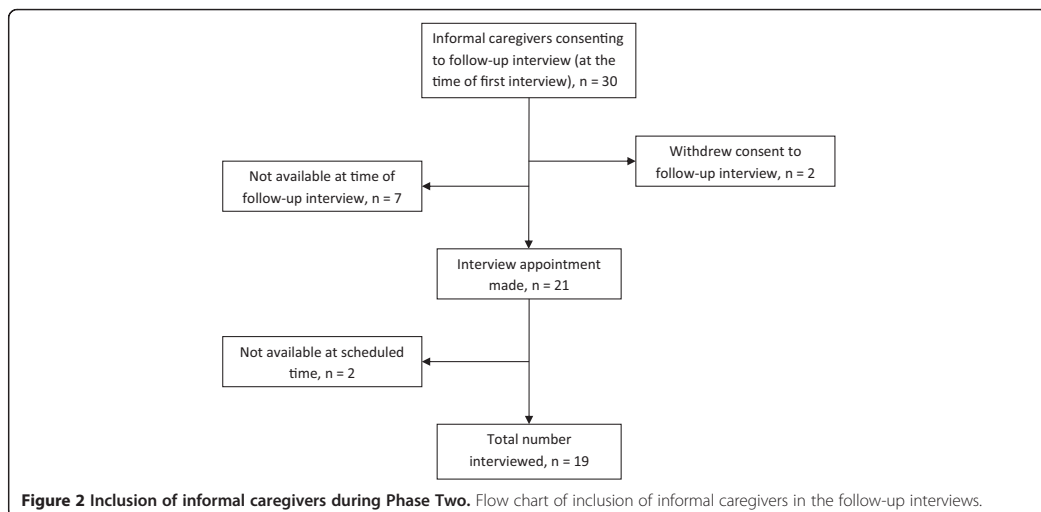
During the last months of the data collection in Phase One, a sample of 30 informal caregivers of home-bound patients were asked for a preliminary consent to participate in follow-up interviews to be carried out at a later stage (Phase Two). The sample was chosen through a purposive sampling for maximum variation with the goal of selecting informal caregivers representing the range of experiences, kinship ties, and backgrounds [57]. During Phase Two, between March 2010 and July 2010, 19 informal caregivers gave their definitive consent to participate in the follow-up study (Figure 2). Qualitative telephone interviews were carried out with the 19 informal caregivers during Phase Two of the data collection.

Interview guide preparation and data collection

A semi-structured interview guide was developed based on topics that emerged in the preceding structured interviews with informal caregivers [53]. In preparing the interview guide, audio recordings of a sample of 15 of the 262 previous interviews were utilized. The format of the structured interviews and the answers recorded in

the questionnaires did not do justice to the stories of the informal caregivers; the audio recordings revealed their stories in greater detail. Thus, the research team decided to delve deeper into the experiences of the informal caregivers in the follow up study and encouraged the informal caregivers to express their experiences more freely in qualitative interviews. The three main themes of the interview guide were: (1) The role of the informal caregivers at and after discharge, (2) individual experiences of being an informal caregiver for an older relative, and (3) trust in the health care services.

At the beginning of the interviews, the informal caregivers were asked to talk about their experiences within the time frame from discharge up until the time of the follow-up interview. The initial question was: “Can you tell me what happened when your relative was discharged from the hospital?” This question allowed caregivers to start by telling their stories in their own words. Then, the interviewer continued by asking questions such as: “How would you describe your participation in the discharge process?”, “How would you describe your involvement with the formal caregivers in the municipality for follow-up care post discharge?”, “Did you experience any dilemmas as a caregiver in this process?”, and



"In retrospect, what has been the most prominent experience?" The interview guide served as a reminder of the topics to cover and had suggested phrasings of questions but was not binding and did not structure the interviews in a uniform way. The purpose of the non-binding and semi-structured interview guide was to promote openness to follow the informal caregivers' stories and explore their experiences. By choosing an open approach, we position the interviewer as an active participant in the construction of meaning in the interview [58,59]. The kinds of questions and follow-up prompts the interviewer used were influenced by her pre-understanding of the field of inquiry, consequently, the interviewer influenced the shared meaning production in the interview through her questions. The interviews lasted between 11 and 36 minutes with an average length of 24 minutes.

Data analysis

All interviews were audio recorded, transcribed verbatim, and written out in their entirety in a normalized Norwegian language (not transcribing the informants' dialect). Standardizing speech can make the informant's meaning clearer; however, it can also eliminate elements that convey the distinctiveness and emotionality of the speaker [60]. We have strived to be faithful to what the person speaking wanted to convey; however, the transcription process is the first stage of interpretation, and this process is influenced by the researchers' perception. The written representation of each interview has been filtered through our perception and our interpretation of the informant's dialect and interpretation of what they wanted to convey. The text went through a second translation process from Norwegian to English for use in this article, again filtered through our perception and with our interpretation of the intended meaning and with our translation from Norwegian to English.

We selected a qualitative analysis inspired by an inductive thematic content analysis [57]. The initial stage of the qualitative analysis started with the transcription of the data material, and we completed this stage by reading through all transcripts and obtaining a general content overview of the material [57,61]. In the following description of our coding procedure and accounting for how categories and main themes were developed, we have strived to enhance transparency by accounting for the procedures we have used and the choices we have made.

Coding procedure

We imported all interview transcripts into the qualitative analysis software HyperRESEARCH [62] and started the coding procedure. We developed codes inductively on the basis of the empirical data [57]. The HyperRESEARCH software program was used in this process of developing and keeping track of all the codes and coded passages of

text from each of the interviews. To ensure a consistent coding practice in all 19 interviews, regardless of in what stage of the coding process the interview appeared, we read through the transcripts a second time when all the codes were created and added later codes where appropriate. As a conclusion of this step of the analysis we inspected all the codes in our codebook to determine if any of the codes overlapped and captured the same concepts and could be grouped together; we ended up with 52 unique codes in our codebook. This process concluded the code development, and the use of HyperRESEARCH software was discontinued at this stage of the analysis.

Categorization and development of themes

Based on the codes, we grouped similar codes together in categories. We read the interview text, the codes, and categories several times in an iterative process through which we developed the main themes [57,61]. During these discussions, we reached a consensus about which codes and themes should be given priority in the subsequent analysis. At this point, the research question and the purpose of the study contributed to guiding our selection of codes and categories to prioritize. In the process of analyzing the interviews we emphasized an exploration of the categories and themes most prominently accentuated by our informants. Thus, some categories introduced by the researcher during the interview were not explored further because the empirical data did not support these categories as substantial concerns to our informants [57]. In the iterative process of analysis for this article, two main themes emerged in our interpretation of the empirical data material (Table 1). The first theme was "taking an active role." The categories "emerging dependence" and "feelings of responsibility" were examples of the categories contained in this theme. Several codes were incorporated in these two categories, and two examples are presented in Table 1. The second main theme was "struggling to gain influence" (Table 1). In this main theme, categories such as "Working with the 'gatekeepers' of the health care services" and "strategies used when participating on behalf of the older relative" were included.

Ethical considerations and informed consent

This study was designed in accordance with the ethical principles for medical research involving human subjects as stated in the World Medical Association's Declaration of Helsinki [63]. Approval for the study was obtained from the South-East Norway Regional Ethics Committee for Medical Research (reference number: 1.2007.1250) and all municipalities involved in the process of recruiting respondents. The study was reported to the Data Protection Official for Research (NSD) (project number: 17078). When the informal caregivers were approached for the follow-up interviews, all were informed about the

Table 1 Examples of codes, categories, and main themes of the qualitative analysis

| Transcribed text | Code ¹ | Category | Main theme |
|---|---|--|------------------------------|
| "My mother can't pick up the phone to inquire about anything these days, so I'm the one who has to take over these tasks that she managed herself earlier. Because I am the only one capable of letting them [the municipality] know when something is not right." (IC-10) | Being an informal caregiver involves looking after the older relative's needs | Emerging dependence | Taking an active role |
| "It is important that I can act as a spokesperson, because she is not able to herself. [...] Being an intermediary sort of lies within the role, I think. It is part of the responsibility of [family members]" (IC-31) | Being an informal caregiver involves being the older relative's spokesperson | Feelings of responsibility | |
| "It's difficult for them [the home nurses] too, they may communicate our wishes, but their directives are not necessarily supported or acted upon. [...] They understand our situation and are attentive towards us, but ultimately they don't make the decisions." (IC-10) | The decisions are not made by the home nursing providers | Working with the "gatekeepers" of the health care services | Struggling to gain influence |
| "After her breast surgery they wanted to send her home on a Friday. Her surgical wound was still open and it was ... well, I outright declined. I said: 'I am leaving town for the weekend, I will not be home if she is discharged'..." (IC-19) | You have to be resourceful to be heard | Strategies used when participating on behalf of the care recipient | |

¹The codes represent the quoted text in the context it appeared in the transcripts; the modified quotes used in this paper do not incorporate the full context that the code refers to.

status of the project and the progress since their initial interview. They were informed about the purpose of the follow-up interviews and assured that their data would be treated with confidentiality. During the process of transcribing the interviews, all names of municipalities, hospitals, and persons were removed and the informal caregivers were given anonymized identifying numbers that were used throughout the research process in all transcripts of the interviews and for the quotes used in this manuscript. They were informed about their right to withdraw their consent at any time for any reason. Lastly, they were asked to confirm their preliminary consent for participation and asked to consent for audio recording of the interview. All 19 informants gave their consent.

Trustworthiness

To ensure the trustworthiness of the findings reported in this article, we focused on addressing a number of criteria determining the quality of qualitative research [57,58]. The research team's experiences as health care personnel, informal caregivers to older family members, and as researchers conducting the preceding quantitative study have influenced our pre-understanding of the field of research. We have aimed for transparency in reporting our data analysis procedures [57], accounting for the use of HyperRESEARCH in our coding process and supplying examples of how the interviews were coded and categorized into main themes exemplified in a table showing examples of statements, codes, categories, and main themes (Table 1). We acknowledge that the data transcripts may have multiple readings. To maximize the legitimacy of our interpretations, all members of the research team took part in reading the transcripts, identifying the main themes, and discussing the emerging results until a consensus was reached on the interpretation of our findings [57,61]. The interpretations we present are influenced by the experiences of the research team and are inextricably

linked to our perceptions as researchers. We assert that the collective effort to analyze the empirical material serves to counteract individual biases and strengthens the credibility of our interpretations. Furthermore, the quotes used in the article are intended to illustrate our interpretations of the informants' statements and lend support to the trustworthiness of our analysis [60]. The use of quotes is also a way of introducing transparency to our analyses. We have attempted to account for the role of the researchers by reflexivity regarding our roles as co-creators of the data and the meaning presented in our results [57,58]. Altogether, these efforts were undertaken to ensure the trustworthiness of our findings and the conclusions made in this study.

Results

Participants

Thirteen women and six men were interviewed for this study. The informal caregivers included two spouses, thirteen sons/daughters, two daughter-in-laws and two nephews. At the time of the interview, participants were between 45 and 83 years of age with an average of 60 years. Eleven were gainfully employed in a part- or full-time position, and the remaining eight were retired or on disability benefits. During the time since our initial interview, some older relatives were admitted, sometimes more than once, to the hospital and discharged again, and six of them had passed away. Eight of the older relatives were now living independently in their private homes but were still receiving formal home health care services. Three of the relatives lived in sheltered housing provided by the municipality, and two had moved to a nursing home.

Taking an active role

Emerging dependence and feelings of responsibility

The informal caregivers describe the older relative's deteriorating health and declining self-care capacity as a

starting point in their caregiver trajectory. One daughter explains that she was forced to take over tasks her mother previously managed due to her mother's steadily declining function and increased frailty:

"My mother can't pick up the phone to inquire about anything these days, so I'm the one who has to take over these tasks that she managed herself earlier. Because I am the only one capable of letting them [the municipality] know when something is not right". (IC-10)

The informal caregivers convey that older relatives become dependent on help from their families:

"It is important that I can act as a spokesperson, because she is not able to herself. [...] Being an intermediary sort of lies within the role, I think. It is part of the responsibility of [family members]" (IC-31)

These accounts highlight how the informal caregivers feel it's necessary for them to take an active role to be able to influence the decision-making on behalf of their older relative. By taking on a role as spokesperson and intermediary they seek to ensure the needs of their older relative are heeded in the decision-making process.

A recurring feature of the informal caregivers' descriptions is their extensive feelings of responsibility for the older relative's well-being. Some convey that the feelings of responsibility are a natural part of what can be expected from family members, while other caregivers express the responsibility as a sense of duty toward their older relatives:

"Of course you feel the pressure, maybe not pressure exactly, but more that it is your duty to do the best you can. And that is part of your responsibilities, so to speak, as long as you have an old kin..." (IC-8)

In their adherence to filial obligation norms, where the ideal of reciprocity is a central tenet, the informal caregivers communicate their moral values, sense of duty, and emotional motives as strongly contributing to taking on the caregiving responsibility.

The complexity of the health care services

The caregivers expressed their perception of the health care services as multi-faceted, hierarchical, and unpredictable and sometimes too complex to grasp. The informal caregivers view understanding the health care services as essential to taking an active part on behalf of their older relative. One daughter-in-law described herself as resourceful and knowledgeable about the organizational tiers of the health care services and

usually capable of finding the right authority for her questions. She summarized her experiences:

"Me, I had, in a way, information about where to turn for help and sort of enquired in places where I could get more information and where I could turn for help and such. (...) It was very clear to me after a while that you have to be well informed as an informal caregiver to be able to make it through. You have to be quite resourceful. (...)" (IC-12)

Some informal caregivers found it difficult to participate in and influence care arrangement decisions because they did not know the services well enough:

"The challenge was all the things I didn't know, things my wife could have received assistance with [from the municipality], but I didn't know what to ask for (...)" (IC-19)

Despite apparent expectations to the contrary, some informal caregivers felt that it became their responsibility to monitor and assess the older relative's health care needs and subsequently initiate contact with the health care services when formal care was needed:

"You can say that we felt that the informal caregiver sort of needs to be active. No one will seek you out to provide services. No one! Unfortunately, you have to take action yourself". (IC-12)

This clearly shows that if the informal caregiver does not understand the services or know where to obtain assistance when the older relative's health declines, the older individual and the informal caregiver are vulnerable. However, when the caregivers understand the services and have the resources to take an active role, the outlook is better:

"You know, you have to be very strong to make it, actually to be able to follow through with it. Yes, you have to! You can talk... and nothing happens, but we did it. [...] They [the municipality] thought everything was fine. Until we put our foot down [...]. It all worked out in the end". (IC-23)

The older relative's widespread dependency emerges through the informal caregivers' descriptions. Through their accounts, it becomes clear that the health care services can be too complex if you are not able to be an active care recipient. The informal caregivers have to take the care recipient's place and act as an intermediary between the relative and the health care services. In essence, the informal caregivers take the role of the active participant on behalf of their older relative.

Struggling to gain influence

Working with the "gatekeepers" of the health care services

Many caregivers in our study expressed that they are at the mercy of individual health care personnel and case workers or contact persons. They described the health care personnel working in the purchaser unit of the municipality, and sometimes the personnel at the hospital, as "gatekeepers" guarding access to highly sought-after services. This widespread perception was expressed by several caregivers explaining how they felt they needed the goodwill of the case worker to participate in the process and that they were dependent on the case worker's skills and willingness to advocate for the care recipient's and caregiver's wishes:

"Yes, absolutely, I feel that my opinions were heard [by our case worker]. She was a good person, she was very good at following up [...] and I do think she did the best she could... But, of course she was no magician! She could only do so much". (IC-12)

Statements like this further support the perception that caregivers and care recipients are at the mercy of the personnel in the health care services:

"It's difficult for them [the home nurses] too. They may communicate our wishes, but their directives are not necessarily supported or acted upon. [...] They understand our situation and are attentive toward us, but ultimately they don't make the decisions". (IC-10)

The informal caregivers were aware that the authority of the case workers was limited, acknowledging that the case workers were just a "cog in the machinery":

"Yes, we had to fight. Because... well actually, I think the communication between the hospital and the municipality was greatly lacking. The hospital was clear on the fact that she had no business being discharged to her home in her condition, but at the nursing home they evaluated her situation differently and thought she was in excellent condition to manage at home with a bit of supervision". (IC-12)

The informal caregivers try to make sense of the decisions that are made, which are not always predictable and can be the opposite of the agreements negotiated with the "gatekeepers". The unpredictable outcome of decisions is reported as frustrating. However, the informal caregivers are careful to not be too openly critical of the services and the health care personnel working there because they are dependent upon the provided services; they do not wish to aggravate the service providers and risk losing the support. Several informal caregivers expressed

this notion. One daughter explained that she had to restrain her critique toward the representatives from the municipality:

"Because, you know, I have to stay in their good graces because I am dependent on their help". (IC-13)

Despite a widespread feeling of a personal responsibility for their spouses, elderly parents or extended family members, the informal caregivers expressed apprehension with being dependent on goodwill from the municipal health care services in their struggle to influence care decisions.

Strategies used when participating on behalf of the older relative

All of the informal caregivers in our study took their responsibilities seriously. However, the informal caregivers chose different approaches to positioning themselves for gaining influence and they handled the ensuing challenges in different ways. One son describes what we have interpreted as a passive strategy of participation:

"I feel that it is important to participate, but I feel it is important to participate in a withdrawn way and rather contact the formal services if I discover that something is wrong or that they are neglecting to do certain things. I feel it is better to let them take the responsibility. Then, I can initiate dialogue if things are not working". (IC-8)

This strategy is an example of the informal caregivers taking on a supervisory role, keeping tabs on the formal services, and reacting only when they uncover threats to what they consider to be the appropriate care for their older relative.

A daughter described a more active approach toward gaining influence. She and her husband fought a difficult battle with the municipality to have her mother placed in a nursing home following her hospitalization. The daughter describes an exhausting process of unsuccessfully advocating for her mother's well-being during a period of frequent re-hospitalizations. Her attempts at establishing a dialogue with the municipality failed, and their applications for a nursing home placement were denied several times. The daughter finally resorted to stepping outside the chain-of-command in the municipality, contacting the administrative leader of the municipality directly:

"It all worked out in the end. But it is a pity that you have to go through all this before you are heard...It was terrible. I felt it was degrading that I had to fight with [the municipality]. I cried when I talked to those people, because I felt it was a terrible situation that

we had to struggle with... all I wanted was for Mother to be properly cared for in her last years". (IC-23)

When the informal caregivers reach a point where the situation is perceived as unbearable and all attempts at reaching agreements by dialogue fail, they resort to desperate strategies. One husband described how he resorted to making himself unavailable, knowing that the hospital could not safely discharge his wife if they knew she was on her own:

"After her breast surgery they wanted to send her home on a Friday. Her surgical wound was still open and it was... well, I outright declined. I said: "I am leaving town for the weekend, I will not be home if she is discharged"..." (IC-19)

A daughter used a similar strategy:

"I simply said "this will not work!" and I removed her keys and everything to prevent them from discharging her and sending her home in a taxi". (IC-13)

These desperate actions are expressions of the informal caregivers' struggle to gain influence and demonstrate that the care recipient's safety is compromised without their cooperation. We found that some of the approaches toward participation and gaining influence were the result of exhausting all other options and resorting to measures that would force the services to acknowledge their strongly held opinions. Achieving the goal of the best possible care for the care recipient seem to depend on the ability of the informal caregivers to manage a complex reality, relentlessly and persistently navigating the health care services on behalf of their older relatives and having the resources to choose appropriate strategies for gaining influence over decisions.

Discussion

Taking an active role

The informal caregivers describe their older relatives' deteriorating health and declining self-care capacity as a starting point in their caregiver trajectory. In combination with the complexities of health care services, the extensive frailty prevents older care recipients from taking an active role in handling their practical care arrangements in cooperation with formal care service providers. This is when the informal caregivers describe that they step up to actively participate on behalf of their older relative. These findings are consistent with findings from a Swedish study in which older relatives became dependent on their families for negotiating help arrangements [37]. Current research, corroborated by findings from this study, has shown that informal caregivers can contribute

to a more favorable outcome for their older relative by taking care of and advocating for their rights and wishes in the discharge process [45]. By taking an active role as participants in decision-making the informal caregivers demonstrate their willingness to assume responsibility for their older relative.

Despite universal health care coverage in the Nordic countries, including public provision of long-term care, family members have historically played a central role in negotiating and providing care and has continued to provide the same care levels following the introduction of formal health care services [17]. The findings from this study shows that the informal caregivers currently shoulder substantial responsibilities and that they are willing and able to cooperate with the formal health care services to make sure their older relatives is adequately cared for. The comprehensiveness of the roles informal caregivers assume is virtually unlimited. The informal caregivers describe their roles as encompassing that of hands-on caregiver, spokesperson, intermediary, and advocate. Contemporary white papers more explicitly than before acknowledge that informal caregivers have important roles in supporting older relatives [3,10,11]. The intention to develop a modern policy of informal care including caregiver support services and respite care to enable informal caregivers to combine caregiving responsibilities with gainful employment and other responsibilities [3,10,11] may be a step toward formal recognition of the vital roles informal caregivers play.

Struggling to gain influence

Consistent with other European studies, the caregivers in our study describe a constant struggle to gain influence [52,64] and to participate in the care decision-making process for their older relatives [26] despite the explicit expectation of their involvement. In our study, the informal caregivers express that this struggle intensifies when an older family member experiences greater functional decline and his or her care needs increase. According to the informal caregivers, some older individuals experience a rapid decline, increasing the need for 24-hour supervision and attention rather acutely. That kind of monitoring is only available through institutional care in a nursing home, and the family is no longer able to provide the needed amount of care. Ideally, the welfare state takes over the caregiving by providing formal services when the care needs of the care recipient reach this point [27]. However, the development of the municipal care sector in recent decades has challenged this perception [15,65]. Accordingly, our informants described substantial challenges to navigating the health care services to acquire the needed care for their older relative. The current policy of aging in place coupled with an aging population and retrenchment of institutional care in the community puts pressure on the

municipal resources and on the informal caregiver resources. Informal caregivers describe desperately trying to negotiate and fight the system to obtain the next level of formal community care. Our results suggest, contrary to the claims that informal caregivers experience fewer burdens in the Nordic welfare state [31], that informal caregivers see their roles as demanding. As long as they struggle with gaining access to what they feel is appropriate help for their older relatives, it is unlikely that the formal rights to access services in the welfare state mitigates their feelings of responsibility. This is consistent with a report on user participation in the health and care sector that shows that care recipients and their informal caregivers may experience incongruity between their formal rights to participate and the actual participation in decision-making they experience in their local municipality [66]. In essence, the expectations of informal caregivers and care receivers are not always met with respect to their anticipated participation in decision-making, despite being formally stated in rules and legislation.

The informal caregivers in our study felt the need to resort to extreme measures to be heard by decision makers in the municipalities. They removed house keys or claimed to be leaving town to prevent their elderly relative from being discharged too early or to an empty house. They went outside the chain of command, appealing to the administrative leader of the municipality for their elderly relative to gain access to nursing home placement. These actions are desperate measures to force the decision makers or the gatekeepers to hear their arguments. In line with earlier research [52,53], our informants' attempts at negotiations seemingly failed due to scarce opportunities for direct communication with the decision makers in the health care services. The only real chance of opposition is to claim serious deficits in patient safety, which is the only strategy that informal caregivers have found effective in communicating their disagreement with the care decisions. The informal caregivers express the responsibility they feel for the well-being of their older relative in a variety of ways and most prominently in the way they devote time and energy to making sure that their loved ones receive appropriate formal services. Informal caregivers do not always trust the formal health care services to take the appropriate responsibility [67], thus, the informal caregivers find themselves in a position of trying to mitigate the consequences of inadequate levels of care provided by the formal caregivers.

Limitations of this study

This study is based on individual telephone interviews with a purposive sample of informal caregivers who have provided help and support to older relatives at and after discharge from somatic hospitals in Norway. The study is part of a larger study in which the research team have

developed a questionnaire that patients and informal caregivers have answered through structured interviews. Based on past experiences and research in the preceding sub-studies, our assumption was that the role of informal caregiver would be important and complex, and that their experiences of participation would vary. These elements are parts of the authors' pre-understanding of the field of research, which has in turn influenced the findings of this study. We encourage caution in generalizing the results from this study to other populations or other countries. The participants' potential motivation for taking part in the study can be an important consideration when examining the trustworthiness of the results of the study. The informants in our study did not receive any material or economic incentives to participate, but some did express that they enjoyed the opportunity to share their thoughts and experiences with an interested party. Also, it is reasonable to assume that the informants have a subjective interest in the topic of the study, seeing as they within the last 12–18 months experienced their older relative's discharge process. It is possible that informal caregivers with unique experiences were recruited. A unique story may have prompted the interviewer to ask for their participation in the follow-up interview, and the informal caregivers may have wanted to share their unique story, especially if they felt they contributed to a positive outcome for their older relative or if they faced difficulties and may have wanted to express their criticism of the system.

Conclusions

Informal caregivers willingly take on the role as an intermediary between the care recipient and the health care services. This study shows that they take on the responsibility to seek information and establish dialogue with the formal health services in the municipality to negotiate sufficient formal services for their older relative. They recognize that their older relatives are unable to take the active participatory role that is needed, and in essence the informal caregivers actively participate on behalf of the care receiver and negotiate with the formal home health services to ensure that the best possible care is provided.

The informal caregivers describe how they exert a great deal of resourcefulness to be able to actively participate in and facilitate cooperation with health care services. The caregivers utilize different strategies and they identify establishing cooperation with the gatekeepers as a key strategy to be able to influence decision-making at and after discharge. The success of informal caregivers depends on several elements. First, informal caregivers must be willing to actively participate on behalf of their older relatives. Second, they have to devote relentless efforts and persistence to managing the complexities of the health care services. Last, they have to be able to choose appropriate

strategies in order to gain influence. The care recipients' extensive frailty and increasing dependence on their families coupled with the complexity of health care services contribute to the perception of the informal caregivers' indispensable role as intermediaries.

Implications

These findings accentuate the need to further discuss how frail older individuals and their informal caregivers can be supported and enabled to participate in decision-making regarding care arrangements that meet the care recipient's needs. Failing to do so has the potential for becoming a serious deficit in our future care services, which is especially daunting when we recognize that informal caregivers are paramount in securing high-quality care arrangements for their older relative. The profound responsibility informal caregivers feel for the well-being of their older relative and how indispensable they appear to be when their older relative becomes dependent upon their support raises the question whether care recipients with strong, resourceful informal caregivers may receive qualitatively better care than recipients without caregivers or those with informal caregivers not strong enough to advocate and negotiate on their behalf?

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

LKB, MK and CF participated in the study conception and design. LKB performed the majority of the data acquisition, analysis and interpretation in addition to drafting the manuscript. MK and CF contributed to the analysis, interpretation of the data and manuscript revisions. All authors read and approved the final manuscript.

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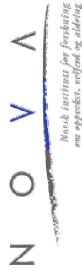
Appendices

1. Questionnaire – Patients discharged home
2. Questionnaire – Patients discharged to nursing home
3. Questionnaire – Caregivers of patients discharged home
4. Questionnaire – Caregivers of patients discharged to nursing home
5. Interview guide – Follow-up interview with caregivers of patients discharged home

Appendices

Appendix 1

Questionnaire – Patients discharged home



**Eldre på flyttefot
-overgang fra sykehus til kommunale pleie- og omsorgstjenester**

INTERVJUSKJEMA –

PASIENTER UTSKREVET TIL KOMMUNALE

HJEMMETJENESTER

Kommune.....

Kommune-nr.....

Pasientens nummer.....

Er pårørende intervjuet?

Ja, pårørende nr.....

Nei

Intervjuers navn.....

Tilstede under intervjuet.....

Del I – Her og nå

1a. Hvordan har du hatt det etter at du kom hjem?

- Jeg synes det har gått fint hele tiden 1
- Det var vanskelig i begynnelsen, men ordnet seg etter hvert 2
- Blandet (både vanskelig og fint) hele tiden 3
- Det har vært vanskelig hele tiden, og jeg har ennå problemer 4
- Passer ikke inn i noen av alternativene 5

1b. Kan du si litt mer om det:.....
.....
.....

2. Hvis du har fått ny/endret hjelp, hvem var det som sørget for dette?

- Det ble ordnet fra sykehuset 1
 - Familien ordnet det 2
 - Jeg ordnet det selv 3
 - Hjemmetjenesten ordnet det 4
 - Vet ikke 5
 - Ikke aktuelt (har ikke fått ny/endret hjelp) 6
 - Annet 7
- Spesifiser:.....

3a. Måte du vente for å få den hjelpen du trenger?

- Nei, det var i orden da jeg kom hjem fra sykehuset 1
 - Ja, jeg måtte vente 2
 - Vet ikke 3
- Antall dager:.....

3b. Hvis du måtte vente på hjelp, hvilken betydning mener du det har hatt for helsestanden din slik den er nå?

- Ingen betydning 1
- Førte til at jeg ble dårligere 2
- Det var bra, for det førte til at jeg ble bedre 3

Eventuell kommentar:.....
.....

4a. Hva får du av hjelp nå?

4b. Hva av dette er kommet til etter siste sykehusopphold?

(Her kan intervjuer sette flere kryss)

- a) Får nå:
- Hjemmehjelp 1
 - Hjemmesykepleie 2
 - Privat hjelp av familie/venner 3
 - Privat betalt hjelp 4
- b) Begynt med/endret etter siste sykehusopphold:
- 1
 - 2
 - 3
 - 4

4c. Fikk du tildeelt hjemmefjeneste som nå er avsluttet?

- Nei 1
 - Ja 2
- Spesifiser:.....

5. Hvis du får privat hjelp av familie/venner, hvem er det som hjelper deg mest?

- Ektefelle 1
 - Sønn 2
 - Datter 3
 - Ikke aktuelt (får ikke privat hjelp) 4
 - Andre 5
- Spesifiser:.....

6. Er den hjelpen du får nå fra kommunen tilstrekkelig?

- Ja, det er tilstrekkelig 1
- Nei, det er noe for lite 2
- Nei, det er alt for lite 3
- Nei, det er mer enn jeg selv føler jeg trenger 4
- Ikke aktuelt (får ikke hjelp) 5

7. Hvis hjelpen ikke er tilstrekkelig, hva ville du hatt annerledes?

Svar:

.....

.....

8a. Lovet sykehuset deg tilbud etter utskrivelsen som ikke ble innfridd?

| | | | | |
|--------------|-----------------|------------------|--------------------|------------------|
| 1 - Høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|--------------|-----------------|------------------|--------------------|------------------|

8b. Hva ble evt. ikke innfridd?

.....

.....

Del - II Selve sykehusoppholdet

| |
|--------------------------------|
| Noen opplysninger om oppholdet |
|--------------------------------|

9. Sykehusets navn:

10. Hva slags avdeling ble du skrevet ut fra?

- En medisinsk avdeling 1
 - En kirurgisk avdeling, ikke ortopedisk 2
 - En ortopedisk avdeling 3
 - Annet 4
- Spesifiser:.....

11. Hvor lenge lå du på sykehuset under det siste oppholdet?

12. Hvilken sykdom ble du innlagt for?

13. Har du andre plager i tillegg?

Nei 1
Ja 2 Spesifiser.....

14. Innleggesen var

Planlagt 1
Akutt 2

15. Hvor lenge siden er det du kom hjem fra sykehuset denne gangen?..... dager

16. Reiste du rett hjem fra sykehuset, eller har du vært et annet sted først?

Rett hjem 1
Til familie 2
Annet 3 Spesifiser.....

17a. Hvis du ikke dro rett hjem fra sykehuset, hvor lenge var du annet sted?..... dager

17b. Hvis du ikke dro rett hjem, hva var årsaken til det?

Svar:.....

18. Hvor lenge siden er det forrige gang du var innlagt i sykehus?

Svar:.....

Hvis dette var mindre enn en måned siden:

19. Var dette for de(n) samme sykdommen(e) som nå sist du var innlagt?

Ja 1
Nei 2
Vet ikke 3

Litt om utskrivningen

20a. Når fikk du vite at du skulle reise hjem?

Rett for jeg skulle reise 1
Samme dag 2
Dagen før 3
Flere dager før 4
Visste på forhånd omtrent hvor langt oppholdet skulle vare 5
Annet 6 Spesifiser.....

20b. Ble utreisedagen utsatt i forhold til det som først var planlagt?

Ja 1
Nei 2
Hvis ja, spesifiser bakgrunnen:.....

21. Hvem informerte deg om at du skulle skrives ut?

Min behandlende lege på sykehuset 1
En mindre kjent lege på sykehuset 2
(Syke) Pleier 3
Pårørende 4
Andre 5 Og det var:.....
Vet ikke 6

Evt. kommentar:.....

22. Hvis du ble informert av personalet, hvordan fikk du vite at du skulle skrives ut?

- Under stell 1
- På visit 2
- Ime på legens kontor 3
- Ingen spesiell anledning, det kom bare en og ga beskjed om at jeg kunne reise hjem 4
- I et planlagt møte med flere tilstede (uskrivningssamtale) 5
- Annnet 6 Spesifiser.....

23. Hvis det var et eget møte for å planlegge tiden etter utskrivning, hvem deltok? (flere kryss er mulig)

- Jeg (pasienten) 1
- Legen 2
- Pleier(e) fra sykehuset 3
- Pleiere fra kommunen 4
- Pårørende 5
- Andre 6 Spesifiser.....

For pasienter som reiste rett hjem fra sykehuset:

24. Hvordan kom du deg hjem fra sykehuset?

- Drosje 1
- Privatbil 2
- Ambulanse 3
- Annnet 4 Spesifiser.....

25. Hvem ordnet med transporten?

- Sykehuset 1
- Pårørende 2
- Hjemmetjenesten 3
- Vet ikke 4
- Andre 5 Spesifiser.....

26. Var det avtale at noen skulle være hos deg når du kom hjem (andre enn en evt. ektefelle/samboer)?

- Ja 1
- Nei 2
- Vet ikke 3

27. Hvis ja, hvem gjorde avtale om dette?

- Sykehuset 1
- Pårørende 2
- Hjemmetjenesten 3
- Jeg selv 4
- Vet ikke 5

28a. Var det noen hjemme hos deg når du kom hjem?

- Ikke aktuelt å ha noen der, jeg klarer meg selv 1
- Nei, jeg kom til tomt hus 2
- Ja, pårørende var der 3
- Ja, hjemmetjenesten var der 4
- Noen andre var der 5 Og det var:.....

28b. Hvis du kom til tomt hus, hvordan opplevde du det? Svar:.....

.....

.....

.....

| |
|------------------------------|
| Informasjon/opplering |
|------------------------------|

29. Fikk du den informasjonen du trengte for å reise fra sykehuset om

- sykdommen din?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

- hva du kan gjøre/ikke kan gjøre etter utreise?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

- hvordan medisiner skal tas?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

- hvilken virkning og bivirkning dine medisiner har?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

Annet Og det er:

30a. Når ble informasjonen i hovedsak gitt?

- Under stell/behandling 1
- I en egen samtale 2
- Fikk ingen informasjon 3

30b. Hvis du mottok informasjon, hvordan ble informasjonen gitt?

- Bare muntlig 1
- Både muntlig og skriftlig 2

31. Fikk du informasjon gjennom dine pårørende under sykehusoppholdet?

- Nei 1
- Ja 2 Om hva?

32a. Er det noe det er nødvendig at du gir/er selv i forbindelse med sykdommen din (som særstell, øvelser, trening, diett osv)?

- Nei 1
- Ja 2 Og det er:

32b. Hvis ja: Fikk du nok opplæring for å gjøre dette før du reiste fra sykehuset?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

33. Fikk du de hjelpemidlene du trenger hjemme etter utskrivelsen?

| | | | | |
|----------------|-----------------|------------------|--------------------|--------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Iaktuelt |
|----------------|-----------------|------------------|--------------------|--------------|

Evt. kommentar

34. Har du problemer etter hjemkomst som du ikke var blitt forberedt på?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Hvis ja, kan du utdype dette?

Din rolle i planleggingen av utskrivelsen

35. Kom utskrivelsen overraskende på deg?

- Ja 1
- Nei 2

Evt. kommentar:

36. I hvilken grad synes du at de følgende utsagnene beskriver din deltagelse i uskrivingen?

Jeg fikk informasjon om hva jeg kom til å få av hjelp/oppløring

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Jeg fikk fortalt om hvordan min hjemmessituasjon var

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Vi samarbeidet om hvordan ulike problem kunne løses

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

37a. Var personalet opptatt av det samme som deg i forbindelse med planleggingen av utreisen?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

37b. Kan du si litt mer om det?

38. Fikk du fortalt personalet det du selv mente var viktig for å klare deg bra hjemme?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

39. Erfarte du at dine meninger ble tatt hensyn til?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

40. Hvor viktig var det for deg å ha innflytelse på

Undersøkelse og behandling?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Når du skulle reise?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Howdan praktiske problemer skulle løses hjemme?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

41. Er det noe du ville ha tatt opp, men som du ikke sa noe om?

Nei 1

Ja 2 Og det var:

42. Hvis ja – hvorfor sa du ikke noe?

Svar:

47. Syntes du legen hadde tid nok til at du kunne snakke om det som var viktig for deg?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

48. Syntes du pleierne hadde tid nok til at du kunne snakke med dem om det som var viktig for deg?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

Pårørendes rolle

49. Var din nærmeste pårørende med når du fikk informasjon/opplæring fra personalet?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Fikk ingen info fra personalet |
|----------------|-----------------|------------------|--------------------|------------------------------------|

Evt. kommentar

50. Sparte personalet deg om du ønsket å ha pårørende med under informasjon/opplæring?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Fikk ingen info fra personalet |
|----------------|-----------------|------------------|--------------------|------------------------------------|

Evt. kommentar

43. Tror du at det er viktig for personalet å få vite hva du mener?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

Kommunikasjon

44. Snakket personalet høflig og respektfullt til deg?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

45. Snakket personalet høyt nok til at du hørte hva de sa?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

46. Snakket personalet et språk du forsto?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

51a. Foretrekker du å få informasjon på sykehuset alene, eller sammen med nærmeste pårørende?

- Alene 1
Spiller ingen rolle 2
Sammen med pårørende 3

51b. Hvorfor?

.....

Del III - Oppsummerende

52. Når du ser tilbake, hva mener du er viktig for at tiden etter et sykehusopphold skal bli så god som mulig?

Svar

.....

.....

.....

53. Fikk du så god hjelp med dine problemer som du forventet på sykehuset?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

.....

54. Har du tillit til helsevesenet?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

.....

55. Er det tilbudet du mottar nå, det du ønsket deg?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Spesifiser:

.....

.....

56. Er det noe vi ikke har snakket om som du mener det er viktig å få sagt?

Svar

.....

.....

.....

.....

Del IV – Bakgrunnsopplysninger

57. Når er du født?

Fødselsår

58. Kjønn

- Kvinne 1
Mann 2

59. Hva er din sivilstand?

- Gift 1
Enke/enkemann 2
Skilt/separert 3
Samboer 4
Ugift (aldri vært gift) 5

60. Hvilken utdanning har du?

- Grunnskole (folkeskole) 1
- Framhaldsskole/Yrkeskole/Realskole/husmorskole etc. 2
- Gymnas (Atrium/økonomisk gymnas etc) 3
- Universitets-/høgskoleutdanning 4

61a. Var du i inntektsgivende arbeid da du ble pensjonist?

- Ja 1
- Nei 2

61b. Omtrent hvor mange år har du hatt inntektsgivende arbeid?år

62. Hvordan bor du?

- Privat, ikke tilrettelagt 1
- Privat, tilrettelagt 2
- Kommunal tilrettelagt (service-, trygde-, omsorgsbolig) 3
- Annet 4 Spesifiser:.....

63. Bor du alene eller sammen med andre (dvs. i samme bolig med felles kost)?

- Alene 1
- Sammen med andre 2

Hvis du bor sammen med noen i hjemmet:

64. Hvem bor sammen med deg?

- Ektefelle 1
- Datter 2
- Sønn 3
- Søster/Bror 4
- Annen familie/slekt 5
- Andre 6 Og det er

65. Er den som bor sammen med deg

- en som vanligvis hjelper deg? 1
- en som vanligvis trenger din hjelp? 2
- ingen av delene 3
- begge deler (hjelper hverandre) 4

Evt kommentar

66. Har du problemer med synet?

- Ja 1
- Nei 2

67. Kan du uten problemer lese teksten i en avis?

- Ja (evt. med hjelpemidler) 1
- Nei 2

68. Har du problemer med hørselen?

- Ja 1
- Nei 2

69. Kan du uten problemer føre en samtale med en annen person som snakker med normal stemme?

- Ja (evt. med høreapparat) 1
- Nei 2

70. Kan du ringe i telefonen?

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

71. Kan du handle?

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

72. *Kan du gjøre lettere husarbeid som å vaske opp, tørke støv eller re opp senger?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

73. *Kan du gjøre tyngre husarbeid som å støvsuge, skure gulv eller flytte møbler?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

74. *Kan du dusje eller vaske deg?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

75. *Kan du kle på deg?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

76. *Kan du bevege deg fra seng til stol?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

77. *Kan du spise oppskåret mat?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

78. *Intervjuers vurdering av hukommelse*

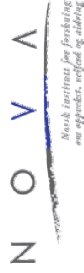
- Normal hukommelse 1
- Lett hukommelsestap 2

79. *Intervjuers vurdering av orienteringsevne*

- Orientert for tid, sted, egen person og situasjon 1
- Noen vansker med å orientere seg 2

Appendix 2

Questionnaire – Patients discharged to nursing home



**Eldre på flyttefot
-overganger fra sykehus til kommunale pleie- og omsorgstjenester**

INTERVJUSKJEMA –

PASIENTER UTSKREVET TIL SYKEHJEM

Kommune.....

Kommune nr.....

Sykehjemets navn.....

Pasientens nummer.....

Er pårørende intervjuet?

Ja, pårørende nr.....

Nei

Intervjuers navn.....

Tilstede under intervju

Del I – Her og nå

1. *Hvordan har du hatt det etter at du kom hit?*

.....

2. *Hvem var det som tok initiativ til at du skulle flyttes over hit til sykehjemmet?*

- Det ble ordnet fra sykehuset 1
- Familien ordnet det 2
- Jeg ordnet det selv 3
- Hjemmefjenseten ordnet det 4
- Vet ikke 5
- Annet 6 Spesifiser.....

3a. *Måtte du vente for du kunne flytte hit?*

- Nei, måtte ikke vente 1
- Ja, jeg måtte vente 2 Antall dager:.....
- Vet ikke 3

3b. *Hvis du måtte vente på å komme hit, hvilken betydning mener du det har hatt for helsestanden din slik den er nå?*

- Ingen betydning 1
- Førte til at jeg ble dårligere 2
- Det var bra, for det førte til at jeg ble bedre 3

Eventuell kommentar.....

4a. Er den hjelpen du får nå tilstrekkelig?

- Ja, det er tilstrekkelig 1
Nei, det er noe for lite 2
Nei, det er alt for lite 3
Nei, det er mer enn jeg selv føler jeg trenger 4

4b. Hvis hjelpen ikke er tilstrekkelig, hva ville du hatt annerledes?

Svar:

.....

.....

5. Hvor ofte mottok du hjelp fra hjemmehjelpensten for siste sykehusinnleggelse?

- Flere ganger daglig 1
En gang daglig 2
Flere ganger i uken 3
En gang i uken 4
Ca. hver 14. dag 5
Sjeldnere 6
Uaktuelt (hadde ikke hjelp) 7

6a. Lovet sykehuset deg tilbud eller utskrivelsen som ikke ble innfridd?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

6b. Hva ble ent. ikke innfridd?

.....

.....

.....

.....

Del - II Selve sykehusoppholdet

Noen opplysninger om oppholdet

7. Sykehusets navn:

8. Hva slags avdeling ble du skrevet ut fra?

- En medisinsk avdeling 1
En kirurgisk avdeling, ikke ortopedisk 2
En ortopedisk avdeling 3
Annet 4 Spesifiser:

9. Hvor lenge lå du på sykehuset under det siste oppholdet?

10. Hvilken sykdom ble du innlagt for?

11. Har du andre plager i tillegg?

- Nei 1
Ja 2 Spesifiser:

12. Innleggelsen var:

- Planlagt 1
Akutt 2

13. Hvor lenge er det siden du reiste fra sykehuset denne gangen? dager

14. Reiste du rett hit til sykehjemmet, eller har du vært et annet sted først?

- Rett til sykehjem 1
Først hjem 2
Til familie 3
Annet 4 Spesifiser:

15. Hvis du reiste til et annet sted først, hvor lenge er det siden du kom til dette sykehjemmet?.....dager

16. Hvis du reiste hjem først, hva er grunnen til at du nå er på sykehjem?

17. Hvor lenge siden er det forrige gang du var innlagt i sykehus?

Svar:

Hvis dette var mindre enn en måned siden:

18. Var dette for de(n) samme sykdommen(e) som nå sist?

- Ja 1
- Nei 2
- Vet ikke 3

Litt om utskrivningen

19a. Når fikk du vite at du skulle reise til sykehjemmet?

- Rett før jeg skulle reise 1
- Samme dag 2
- Dagen før 3
- Flere dager før 4
- Visste på forhånd omirent hvor langt oppholdet skulle være 5
- Annet 6 Spesifiser:.....

19b. Ble uretsvedagen utsatt i forhold til det som først var planlagt?

- Ja 1
- Nei 2

Hvis ja, spesifiser bakgrunnen:.....

.....

20. Hvis informerte deg om at du skulle skrives ut til sykehjemmet?

- Min behandelende lege på sykehuset 1
- En mindre kjent lege på sykehuset 2
- (Syke) Pleier 3
- Pårørende 4
- Andre 5
- Og det var:..... 6

Evt. kommentar

21. Hvis du ble informert av personalet, hvordan fikk du vite at du skulle skrives ut til sykehjemmet?

- Under stell 1
- På visitt 2
- Inne på legens kontor 3
- Ingen spesiell anledning, det kom bare en og ga beskjed om at jeg kunne reise hjem 4
- I et planlagt møte med flere tilstede (utskrivningssamtale) 5
- Annet 6 Spesifiser:.....

22. Hvis det var et eget møte for å planlegge tiden etter utskrivning, hvem deltok? (flere

kryss er mulig)

- Jeg (pasienten) 1
- Legen 2
- Pleier(e) fra sykehuset 3
- Pleiere fra kommunen 4
- Pårørende 5
- Andre 6 Spesifiser:.....

Informasjon/opplæring

23. Fikk du den informasjonen du trengte for å reise fra sykehuset om

- sykdommen din?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

- hva du kan gjøre/ikke kan gjøre etter utreise?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

- hvordan medisiner skal tas?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

- hvilken virkning og bivirkning dine medisiner har?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

Annet Og det er:

24a. Når ble informasjonen i hovedsak gitt?

Under stell/behandling 1

I en egen samtale 2

Fikk ingen informasjon 3

24b. Hvis du mottok informasjon, hvordan ble informasjonen gitt?

Bare muntlig 1

Både muntlig og skriftlig 2

25. Fikk du informasjon gjennom dine pårørende under sykehusoppholdet?

Nei 1

Ja 2 Og det var:

Din rolle i planleggingen av utskrivelsen

26. Kom utskrivelsen overraskende på deg?

Ja 1

Nei 2

Evt kommentar:

27. I hvilken grad synes du at de følgende utsagnene beskriver din deltagelse i utskrivningen:

Jeg fikk informasjon om hvor jeg skulle flyttes

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Jeg fikk fortalt om hva jeg selv ønsket

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Vi samarbeidet om hvordan ulike problem kunne løses

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt kommentar:

28 a. Var personalet oppnått av det samme som deg i forbindelse med planleggingen av utreisen fra sykehuset?

| | | | | |
|----------------|-----------------|------------------|--------------------|--------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Vet ikke |
|----------------|-----------------|------------------|--------------------|--------------|

28 b. Kan du si litt mer om det?

29. Fikk du fortalt personalet det du selv mente var viktig i forbindelse med uskrivningen hit?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar.....

30. Erfarte du at dine meninger ble tatt hensyn til?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar.....

31. Hvor viktig var det for deg å ha innflytelse på
Undersøkelse og behandling?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Når du skulle reise?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Hvordan praktiske problemer skulle løses?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar.....

32a. Er det noe du ville ha tatt opp, men som du ikke sa noe om?

Nei 1

Ja 2 Og det var.....

32b. Hvis ja – hvorfor sa du ikke noe?

Svar.....

33. Troer du at det er viktig for personalet å få vite hva du mener?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar.....

Kommunikasjon

34. Snakket personalet høflig og respektfullt til deg?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar.....

35. Snakket personalet høyt nok til at du hørte hva de sa?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar.....

36. *Strakket personalet et språk du forsto?*

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

37. *Synes du legen hadde tid nok til at du kunne snakke om det som var viktig for deg?*

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

38. *Synes du pleierne hadde tid nok til at du kunne snakke med dem om det som var viktig for deg?*

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

Pårørendes rolle

39. *Var din nærmeste pårørende med når du fikk informasjon/opplæring av personalet?*

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Fikk ingen info fra personalet |
|----------------|-----------------|------------------|--------------------|------------------------------------|

Evt. kommentar

40. *Spurte personalet deg om du ønsket å ha pårørende med under informasjon/opplæring?*

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Fikk ingen info fra personalet |
|----------------|-----------------|------------------|--------------------|------------------------------------|

Evt. kommentar

41. *Foretrekker du å få informasjon på sykehuset alene, eller sammen med nærmeste pårørende?*

- Alene 1
- Spiller ingen rolle 2
- Sammen med pårørende 3

41b. *Hvorfor?*

Del III - Oppsummerende

42. *Fikk du så god hjelp med dine problemer som du forventer på sykehuset?*

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

43. *Har du tillit til helsevesenet?*

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

44. Er det tilbudet du mottar nå, det du ønsket deg?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Spesifiser:.....
.....
.....

45. Er det noe vi ikke har snakket om som du mener det er viktig å få sagt?

Svar
.....
.....
.....
.....

49. Hvilken utdanning har du?

- Grunnskole (folkeskole) 1
- Framhaldskole/Yrkesskole/Realskole/husmorskole etc. 2
- Gymnas (Artium/økonomisk gymnas etc) 3
- Universitets-/høgskoleutdanning 4

50a. Var du i inntektsgivende arbeid da du ble pensjonist?

- Ja 1
- Nei 2

50b. Omtrent hvor mange år har du hatt inntektsgivende arbeid?år

51. Har du problemer med synet?

- Ja 1
- Nei 2

Del IV – Bakgrunnsopplysninger

46. Når er du født?

Fødselsår

47. Kjønn

- Kvinne 1
- Mann 2

48. Hva er din sivilstand?

- Gift 1
- Enke/enkemann 2
- Skilt/separert 3
- Samboer 4
- Ugift (aldri vært gift) 5

52. Kan du uten problemer lese teksten i en avis?

- Ja (evt. med hjelpemidler) 1
- Nei 2

53. Har du problemer med hørselen?

- Ja 1
- Nei 2

54. Kan du uten problemer føre en samtale med en annen person som snakker med normal stemme?

- Ja (evt. med høreapparat) 1
- Nei 2

55. Kan du ringe i telefonen?

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

56. *Kan du handle om du skulle trenge det?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

57. *Kan du gjøre lettere husarbeid som å vaske opp, tørke støv eller re opp senger?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

58. *Kan du gjøre tyngre husarbeid som å støvsuge, skure gulv eller flytte møbler?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

59. *Kan du dusje eller vaske deg?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

60. *Kan du kle på deg?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

61. *Kan du bevege deg fra seng til stol?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

62. *Kan du spise oppskåret mat?*

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3

63. *Intervjuers vurdering av hukommelse*

- Normal hukommelse 1
- Lett hukommelsestap 2

64. *Intervjuers vurdering av orienteringsevne*

- Orientert for tid, sted, egen person og situasjon 1
- Noen vansker med å orientere seg 2

Appendix 3

Questionnaire – Caregivers of patients discharged home



**Eldre på flyttefot
-overganger fra sykehus til kommunale pleie- og omsorgstjenester**

INTERVJUSKJEMA –

PÅRØRENDE TIL PASIENTER UTSKREVET TIL

KOMMUNALE HJEMMETJENESTER

Kommune.....

Kommune nr.....

Pårørende nr.....

Er pasienten intervjuet?

Ja, pasient nr.....

Nei

Intervjuers navn.....

Først vil vi gjerne ha noen opplysninger om din tilknytning til den eldre

1. Hvilket tilknytningsforhold har du til den eldre?

- Ektefelle 1
- Barn 2
- Søsken 3
- Annet 4 Spesifiser:

2. Bor du sammen med den eldre (dvs. felles husholdning)?

- Ja 1
- Nei 2

Evt. kommentar

Så noen opplysninger om deg selv

3. Når er du født? Fødselsår.....

4. Kjønn

- Kvinne 1
- Mann 2

5. Hva er din sivilstand?

- Gift 1
- Enke/enkemann 2
- Skilt/separert 3
- Samboer 4
- Ugift (aldri vært gift) 5

6. Hvilken utdanning har du?

- Grunnskole (folkeskole) 1
- Framhaldsskole/Yrkeskole/Realskole/Husmorskole etc. 2
- Gymnas (Artium/økonomisk gymnas etc) 3
- Universitets-/høgskoleutdanning 4

7. Har du inntektsgivende arbeid?

- Ja 1
Nei 2

Noen opplysninger om den eldres siste sykehusopphold

8a. Sykehusets navn:

8b. Hva slags avdeling ble hun/han skrevet ut fra?

- En medisinsk avdeling 1
En kirurgisk avdeling, ikke ortopedisk 2
En ortopedisk avdeling 3
Annet 4 Spesifiser:

9. Hvor lenge var din pårørende innlagt på sykehus?

10. Hvilken sykdom ble hun/han innlagt på sykehuset for?

11. Har han/hun andre plager i tillegg?

- Nei 1
Ja 2 Spesifiser

12. Innleggelsen var

- Planlagt 1
Akutt 2

13. Hvor lenge er det siden hun/han kom hjem fra sykehuset denne gangen? dager

14. Reiste hun/han rett hjem eller til et annet sted først?

- Rett hjem 1
Til familie 2
Annet 3 Spesifiser:

15. Hvis din pårørende ikke dro rett hjem, hvor lenge var hun/han annet steds? dager

16. Hvis din pårørende ikke dro rett hjem, hva var årsaken til det?

Svar:

17a. Hvor lenge siden er det forrige gang hun/han var på sykehus?

Hvis dette var mindre enn en måneds tid siden:

17b. Var dette for de(n) samme sykdommen(e) som nå sist?

- Ja 1
Nei 2
Vet ikke 3

Din rolle i planleggingen av utskrivelsen

18. Erfarte du at personalet tok initiativ til samarbeide med deg som pårørende?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

Evt. kommentar:

19. Erfarte du at dine meninger ble tatt hensyn til?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

Evt. kommentar:

20. Ønsket den eldre at du skulle være tilstede når informasjon eller opplæring ble gitt?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

Evt. kommentar:

21. Mener du at det var nødvendig at du var til stede når informasjon eller opplæring ble gitt?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

Evt. kommentar:

22. Var utreisetagen avtalt med deg som pårørende?

- Ja 1
 Nei, men det var ventet 2
 Nei, og den kom overraskende 3

Evt. kommentar:

23a. Når fikk du vite at din pårørende skulle reise hjem?

- Reitt før den eldre skulle reise 1
 Samme dagen 2
 Dagen før 3
 Flere dager før 4
 Jeg visste omtrent hvor lenge oppholdet skulle vare 5
 Fikk ingen beskjed 6
 Annet 7

Spesifiser:

23b. Ble utreisetagen usatt i forhold til det som først var planlagt?

- Ja 1
 Nei 2

Hvis ja, spesifiser bakgrunnen:

24. Mener du at det var tilstrekkelig tilrettelegg for hjemreise ved utskriving?

- Ja 1
 Nei 2

Evt. kommentar:

25. Hvem informerte deg om at din pårørende skulle skrives ut?

- Hans/hennes behandlende lege på sykehuset 1
 En mindre kjent lege på sykehuset 2
 (Syke) Pleier 3
 Pasienten selv 4
 Andre 5
 Uaktuelt (fikk ikke beskjed) 6

Evt. kommentar:

26. Hvor viktig var det for deg å ha innflytelse på

Undersøkelse og behandling?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Når din pårørende skulle reise?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Hvordan praktiske problemer skulle løses hjemme?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Annet som var viktig:

.....

27. Er det noe du ville ha tatt opp, men som du ikke sa noe om?

Nei Ja

Ja Og det var

.....

28. Hvis ja – hvorfor sa du ikke noe?

Svar:

.....

29a. Var personalet opptatt av det samme som deg i forbindelse med planlegging av utreisen?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

29b. Kan du si noe mer om dette?

.....

30. Ble du behandlet med høflighet og respekt av personalet når du som pårørende ville delta i avgjørelser knyttet til uskrivningsprosessen?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

Evt. kommentar

.....

31. I hvilken grad synes du at de følgende utsagnetene beskriver din deltagelse i uskrivningen.

Jeg fikk informasjon om hva min pårørende kom til å få av hjelp/oppfølging

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Jeg fikk fortalt om hvordan min pårørendes hjemmesituasjon var

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Vi samarbeidet om hvordan ulike problem kunne løses

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

.....

32a. Fikk du tilstrekkelig informasjon knyttet til din pårørendes sykdom?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

32b. Erfarte du at din pårørende fikk tilstrekkelig informasjon knyttet til sin egen sykdom?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

.....

Etter at den eldre kom fra sykehuset etter siste opphold

33a. Hva får din pårørende av hjelp nå?

33b. Hva av dette er kommet til etter siste sykehusopphold?

(Her kan intervjuer sette flere kryss)

a) Får nå: b) Begynt med/endret etter siste sykehusopphold:

- Hjemmehjelp 1 2
- Hjemmesykepleie 1 2
- Privat hjelp av familie/venner 3 4
- Privat betalt hjelp? 3 4

33c. Fikk din pårørende tildelt hjemmetjeneste som nå er avsluttet?

- Nei 1
- Ja 2

Spesifiser:.....

34. Koordinering av hjelp til den eldre blir nå i hovedsak ivarettatt av

- Den eldre 1
- Meg 2
- Hjemmetjenesten 3

35. Koordinering av hjelp ble for sykehusoppholdet i hovedsak ivarettatt av:

- Den eldre 1
- Meg 2
- Hjemmetjenesten 3
- Den eldre hadde ikke hjelp fra hjemmetjenesten 4

36. Hvor ofte hjelper du din pårørende nå?

- Flere ganger daglig 1
- En gang daglig 2
- Flere ganger i uken 3
- En gang i uken 4
- Ca. hver 14. dag 5
- Sjeldnere 6

37. Hvor ofte mottok din pårørende hjelp fra familien for siste innleggelse på sykehus?

- Flere ganger daglig 1
- En gang daglig 2
- Flere ganger i uken 3
- En gang i uken 4
- Ca. hver 14. dag 5
- Sjeldnere 6

38. Hvor ofte mottok din pårørende hjelp fra hjemmetjenesten for siste innleggelse?

- Flere ganger daglig 1
- En gang daglig 2
- Flere ganger i uken 3
- En gang i uken 4
- Ca. hver 14. dag 5
- Sjeldnere 6
- Uaktuelt (fikk ikke hjelp) 7

39. Hvor ofte mottar din pårørende hjelp fra hjemmetjenesten nå?

- Flere ganger daglig 1
- En gang daglig 2
- Flere ganger i uken 3
- En gang i uken 4
- Ca. hver 14. dag 5
- Sjeldnere 6

40. Er den hjelpen din pårørende får nå fra kommunen tilstrekkelig?

- 1
Ja, det er tilstrekkelig
 2
Nei, det er noe for lite
 3
Nei, det er alt for lite
 4
Nei, det er mer enn han/hun trenger
 5
Ikke aktuelt

41. Hvis hjelpen ikke er tilstrekkelig, hva ville du hatt annerledes?

Svar

.....

.....

.....

| | | | | |
|---------------|--|--|--|--|
| Oppsummerende | | | | |
|---------------|--|--|--|--|

42a. Erfarte du at sykehuspersonaler lovet din pårørende tilbud etter utskrivelse, som ikke har blitt innfridd?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

42b. Hva ble evt. ikke innfridd?

.....

.....

.....

43. Fikk din pårørende så god hjelp med sine problemer som du forventet?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

.....

.....

.....

44. Har du tillit til helsevesenet?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

.....

.....

45a. Hvordan fungerte samarbeidet mellom sykehuset og hjemmehjelpen ved denne utskrivelsen?

| | | | | |
|----------------|----------------|------------------|------------------|--------------|
| 1 - Svært godt | 2 - Nokst godt | 3 - Nokst dårlig | 4 - Svært dårlig | 5 - Vet ikke |
|----------------|----------------|------------------|------------------|--------------|

45b. Hva ville du eventuelt ha ønsket deg annerledes?

Svar

.....

46. Er det tilbudet din pårørende mottar nå, det du ønsket deg?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Spesifiser.....

.....

.....

.....

47. Når du ser tilbake, hva mener du er viktig for at tiden etter et sykehusopphold skal bli så god som mulig?

.....

.....

.....

.....

48. Er det ellers noe som du mener det er viktig å få sagt?

.....
.....
.....
.....
.....

FØLGENDE SPØRSMÅL STILLES NÅR PASIENTEN IKKE ER INTERVJUBAR

| Bakgrunnsopplysninger |
|-----------------------|
|-----------------------|

49. Når er din pårørende født?

Fødselsår

50. Kjønn

- Kvime 1
Mann 2

51. Hva er din pårørendes sivilstand?

- Gift 1
Enke/enkemann 2
Skilt/separert 3
Samboer 4
Ugift (aldri vært gift) 5

52. Hvilken utdanning har din pårørende?

- Grunnskole (folkeskole) 1
Framhaldsskole/Yrkesskole/Realskole/husmorskole etc. 2
Gymnas (Atrium/økonomisk gymnas etc) 3
Universitets-/høgskoleutdanning 4

53a. Var hun/han i inntektsgivende arbeid da vedkommende ble pensionist?

- Ja 1
Nei 2

53b. Omtrent hvor mange år har din pårørende hatt inntektsgivende arbeid?år

54. Hvordan bor din pårørende?

- Privat, ikke tilrettelagt 1
Privat, tilrettelagt 2
Kommunal tilrettelagt (service-, trygde-, omsorgsbolig) 3
Annet 4 Spesifiser:

55. Bor din pårørende alene eller sammen med andre (dvs. i samme bolig med felles kost)?

- Alene 1
Sammen med andre 2

Hvis din pårørende bor sammen med noen i hjemmet:

56. Hvem bor sammen med din pårørende?

- Ektefelle 1
Datter 2
Sønn 3
Søster/Bror 4
Annen familie/slekt 5
Andre 6 Og det er

57. Er den som bor sammen med din pårørende

- en som vanligvis hjelper han/henne? 1
- en som vanligvis trenger hans/hennes hjelp? 2
- ingen av delene? 3
- begge deler (hjalp hverandre) 4

Kommentar.....

.....

.....

Under og etter sykehusoppholdet

58. Hvis det var et eget møte for å planlegge tiden etter utskrivning, hvem deltok? (flere kryss er mulig)

- Legen 1
- Pleier(e) fra sykehuset 2
- Pleiere fra kommunen 3
- Pasienten 4
- Pårørende (meg) 5
- Vet ikke 6
- Andre 7 Og det var

For pasienter som reiste rett hjem fra sykehuset:

59. Hvordan kom pasienten hjem fra sykehuset?

- Drosje 1
- Privatbil 2
- Ambulansse 3
- Vet ikke 4
- Annet 5 Spesifiser.....

60. Hvem ordnet med transporten?

- Sykehuset 1
- Jeg 2
- Hjemmesykepleien 3
- Pasienten selv 4
- Andre 5 Og det var:.....
- Vet ikke 6

61. Hvis din pårørende har fått ny/andret hjelp, hvem var det som sørget for dette?

- Det ble ordnet fra sykehuset 1
- Hun/han ordnet det selv 2
- Jeg ordnet det 3
- Hjemmesjenssten ordnet det 4
- Andre ordnet det 5 Spesifiser.....
- Vet ikke 6

62. Måtte din pårørende vente for å få den hjelpen hun/han trenger?

- Nei, det var i orden da hun/han kom hjem fra sykehuset 1
- Ja, hun/han måtte vente 2 Antall dager:.....
- Vet ikke 3

Evt. kommentar

.....

Litt om hvordan den eldre fungerer

63. Har din pårørende problemer med synet?

- Ja 1
- Nei 2
- Usikker/Vet ikke 3

64. Kan din pårørende uten problemer lese teksten i en avis?

- Ja (evt. med hjelpemidler) 1
- Nei 2
- Usikker/Vet ikke 3

70. Kan din pårørende gjøre yngre husarbeid som å støvsuge, skure gulv eller flytte møbler?

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3
- Usikker/Vet ikke 4

71. Kan din pårørende dusje eller vaske seg?

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3
- Usikker/Vet ikke 4

72. Kan din pårørende kle på seg?

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3
- Usikker/Vet ikke 4

73. Kan din pårørende bevege seg fra seng til stol?

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3
- Usikker/Vet ikke 4

74. Kan din pårørende spise oppskåret mat?

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3
- Usikker/Vet ikke 4

75. Din vurdering av din pårørendes hukommelse

- Normal hukommelse 1
- Lett hukommelsestap 2
- Stor hukommelsestap 3
- Usikker/Vet ikke 4

65. Har din pårørende problemer med hørselen?

- Ja 1
- Nei 2
- Usikker/Vet ikke 3

66. Kan din pårørende uten problemer føre en samtale med en annen person som snakker med normal stemme?

- Ja (evt. med høreapparat) 1
- Nei 2
- Usikker/Vet ikke 3

67. Kan din pårørende ringe i telefonen?

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3
- Usikker/Vet ikke 4

68. Kan din pårørende handle?

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3
- Usikker/Vet ikke 4

69. Kan din pårørende gjøre lettere husarbeid som å vaske opp, tørke støv eller re opp senger?

- Ja, uten hjelp 1
- Trenger noe hjelp 2
- Nei, kan ikke 3
- Usikker/Vet ikke 4

76. Din vurdering av din pårørendes orienteringsevne

- Orientert for tid, sted, egen person og situasjon 1
- Noen vansker med å orientere seg 2
- Desorientert 3
- Usikker/Vet ikke 4

Appendix 4

Questionnaire – Caregivers of patients discharged to nursing home



**Eldre på flyttefot
-overganger fra sykehus til kommunale pleie- og omsorgstjenester**

INTERVJUSKJEMA –

PÅRØRENDE TIL PASIENTER SOM ER UTSKREVET TIL SYKEHJEM

Kommune.....

Kommune nr.....

Sykehjemmets navn.....

Pårørende nr.....

Er pasienten intervjuet?

Ja, pasient nr.....

Nei

Intervjuers navn.....

Først vil vi gjerne ha noen opplysninger om din tilknytning til den eldre

1. Hvilket tilknytningsforhold har du til den eldre?

Ektefelle 1

Barn 2

Søsken 3

Annet 4 Spesifiser:

2. Bodde du sammen med han/hun før sykehjemsinntillegelsen (dvs. felles husholdning)?

Ja 1

Nei 2

Evt. kommentar.....
.....

Så noen opplysninger om deg selv

3. Når er du født? Fødselsår.....

4. Kjønn

Kvinne 1

Mann 2

5. Hva er din sivilstand?

Gift 1

Enke/enkemann 2

Skilt/separert 3

Samboer 4

Ugift (aldri vært gift) 5

6. Hvilken utdanning har du?

Grunnskole (folkeskole) 1

Framhaldsskole/Vikesskole/Realskole/husmorskole etc. 2

Gymnas (Artium/økonomisk gymnas etc) 3

Universitets-/høgskoleutdanning 4

7. Har du innlekksgivende arbeid?

- Ja 1
Nei 2

Noen opplysninger om den eldre/siste sykehusopphold

8 a. Sykehusets navn:

8 b. Hva slags avdeling ble hun/han skrevet ut fra?

- En medisinsk avdeling 1
En kirurgisk avdeling, ikke ortopedisk 2
En ortopedisk avdeling 3
Annet 4 Spesifiser:

9. Hvor lenge var din pårørende innlagt på sykehus?

10. Hvilken sykdom ble hun/han innlagt på sykehuset for?

11. Har han/hun andre plager i tillegg?

- Nei 1
Ja 2 Spesifiser:

12. Innleggelsen var

- Planlagt 1
Akutt 2

13. Hvor lenge er det siden hun/han kom til sykehjemmet? dager

14. Reiste hun/han rett til sykehjemmet eller til et annet sted først?

- Rett til sykehjemmet 1
Hjem først 2
Til familie 3
Annet 4 Spesifiser:

15. Hvis din pårørende reiste til et annet sted først, hvor lenge er det siden han/hun kom til dette sykehjemmet? dager

16. Hvis din pårørende reiste hjem først, hva er grunnen til at hun/hun nå er på sykehjem?

Svar

17 a. Hvor lenge siden er det forrige gang hun/hun var på sykehus?

Hvis dette var mindre enn en måned tid siden:

17b. Var dette for de(n) samme sykdommen(e) som nå sist?

- Ja 1
Nei 2
Vet ikke 3

Din rolle i planleggingen av utskrivelsen

18. Erfarte du at personalet tok initiativ til samarbeide med deg som pårørende?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - 1 høy grad | 2 - 1 noen grad | 3 - 1 liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

Evt. kommentar:

19. Erfarte du at dine meninger ble tatt hensyn til?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - 1 høy grad | 2 - 1 noen grad | 3 - 1 liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

Evt. kommentar:

20. Ønsket den eldre at du skulle vere tilstede når informasjon eller opplæring ble gitt?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

Evt. kommentar:

21. Mener du at det var nødvendig at du var til stede når informasjon eller opplæring ble gitt?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

Evt. kommentar:

22. Var utreisedagen avtalt med deg som pårørende?

- Ja 1
 Nei, men det var ventet 2
 Nei, og den kom overraskende 3

Evt. kommentar

23a. Når fikk du vite at din pårørende skulle reise til sykehjemmet?

- Retts for den eldre skulle reise 1
 Samme dagen 2
 Dagen før 3
 Flere dager før 4
 Jeg visste omtrent hvor lenge oppholdet skulle vare 5
 Fikk ingen beskjed 6
 Annet 7

Spesifiser:

23b. Ble utreisedagen usatt i forhold til det som først var planlagt?

- Ja 1
 Nei 2

Hvis ja, spesifiser bakgrunnen:

24. Hvem informerte deg om at din pårørende skulle skrives ut til sykehjemmet?

- Hans/hennes behandlende lege på sykehuset 1
 En mindre kjent lege på sykehuset 2
 (Syke) Pleter 3
 Pasienten selv 4
 Andre 5
 Uaktuelt (fikk ikke beskjed) 6

Evt. kommentar

25. Hvor viktig var det for deg å ha innflyvelse på

Undersøkelse og behandling?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Når din pårørende skulle reise?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Hvordan praktiske problemer skulle løses?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Annet som var viktig:

26. Er det noe du ville ha tatt opp, men som du ikke sa noe om?

Nei 1

Ja 2

Og det var.....

.....

.....

27. Hvis ja – hvorfor sa du ikke noe?

Svar.....

.....

28a. Var personalet opptatt av det samme som deg i forbindelse med planlegging av utreisen?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

28b. Kan du si noe mer om dette?

.....

.....

.....

29. Ble du behandlet med hoflighet og respekt av personalet når du som pårørende ville delta i avgjørelser knyttet til utskrivingsprosessen?

| | | | | |
|----------------|-----------------|------------------|--------------------|------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke | 5 - Ikke aktuelt |
|----------------|-----------------|------------------|--------------------|------------------|

Evt. kommentar

.....

.....

30. I hvilken grad synes du at de følgende utsagnetene beskriver din deltagelse i utskrivningen.

Jeg fikk informasjon om hva min pårørende kom til å få av hjelp/oppfølging

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Jeg fikk fortalt hvordan min pårørendes hjemmesituasjon var

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Vi samarbeidet om hvordan ulike problem kunne løses

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

.....

.....

.....

.....

31a. Fikk du tilstrekkelig informasjon knyttet til din pårørendes sykdom?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

31b. Erfarte du at din pårørende fikk tilstrekkelig informasjon knyttet til sin egen sykdom?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

.....

.....

Etter at den eldre kom fra sykehuset etter siste opphold

32. Hvor ofte besøker du din pårørende nå?

- Flere ganger daglig 1
- En gang daglig 2
- Flere ganger i uken 3
- En gang i uken 4
- Ca. hver 14. dag 5
- Sjeldnere 6

33. Hvor ofte mottok din pårørende hjelp fra familien for siste innleggelse på sykehus?

- Flere ganger daglig 1
- En gang daglig 2
- Flere ganger i uken 3
- En gang i uken 4
- Ca. hver 14. dag 5
- Sjeldnere 6

34. Hvor ofte mottok din pårørende hjelp fra hjemmesjестen for siste innleggelse på sykehus?

- Flere ganger daglig 1
- En gang daglig 2
- Flere ganger i uken 3
- En gang i uken 4
- Ca. hver 14. dag 5
- Sjeldnere 6
- Uaktuelt (fikk ikke hjelp) 7

35a. Er den hjelpen din pårørende får nå tilstrekkelig?

- Ja, det er tilstrekkelig 1
- Nei, det er noe for lite 2
- Nei, det er alt for lite 3
- Nei, det er mer enn han/hun trenger 4
- Ikke aktuelt 5

35b. Hvis hjelpen ikke er tilstrekkelig, hva ville du hatt annerledes?

Svar

.....

.....

.....

Oppsummerende

36a. Erfarte du at sykehuspersonalet lovet din pårørende tilbud etter utskrivelse, som ikke har blitt innfridd?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

36b. Hva ble evt. ikke innfridd?

.....

.....

.....

37. Fikk din pårørende så god hjelp med sine problemer som du forventet?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

.....

.....

38. Har du tillit til helsevesenet?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Evt. kommentar

.....

.....

39a. Hvordan fungerte samarbeidet mellom sykehuset og kommunen i forbindelse med at din pårørende skulle flytte til sykehjemmet?

| | | | | |
|----------------|-----------------|-------------------|------------------|--------------|
| 1 – Svært godt | 2 – Nok så godt | 3 – Nok så dårlig | 4 – Svært dårlig | 5 – Vet ikke |
|----------------|-----------------|-------------------|------------------|--------------|

39b. Hva ville du eventuelt ha ønsket deg annerledes? .

Svar

.....

.....

40. Er det tilbudet din pårørende mottar nå, det du ønsker deg?

| | | | |
|----------------|-----------------|------------------|--------------------|
| 1 - I høy grad | 2 - I noen grad | 3 - I liten grad | 4 - Overhodet ikke |
|----------------|-----------------|------------------|--------------------|

Spesifiser:.....

.....

.....

41. Når du ser tilbake, hva mener du er viktig for at tiden etter et sykehusopphold skal bli så god som mulig?

.....

.....

.....

.....

.....

.....

.....

.....

42. Er det ellers noe som du mener det er viktig å få sagt?

.....

.....

.....

.....

.....

.....

.....

FØLGENDE SPØRSMÅL STILLES NÅR PASIENTEN IKKE ER INTERVJUBAR

Bakgrunnsopplysninger

43. Når er din pårørende født?

Fødselsår

44. Kjønn

Kvinne 1

Mann 2

45. Hva er din pårørendes sivilstand?

Gift 1

Enke/enkemann 2

Skilt/separert 3

Samboer 4

Ugift (aldri vært gift) 5

46. Hvilken utdanning har din pårørende?

Grunnskole (folkeskole) 1

Framhaldsskole/Yrkesskole/Realskole/husmorskole etc. 2

Gymnas (Artium/økonomisk gymnas etc) 3

Universitets-/høgskoleutdanning 4

47a. Var hun/han i inntektsgivende arbeid da vedkommende ble pensjonist?

Ja 1
Nei 2

47b. Om trent hvor mange år har din pårørende hatt inntektsgivende arbeid? år

48. Hvordan bodde din pårørende før hun/han kom til dette sykehjemmet?

Privat, ikke tilrettelagt 1
Privat, tilrettelagt 2
Kommunal tilrettelagt (service-, trygde-, omsorgsbolig) 3

49. Bodde din pårørende da alene eller sammen med andre (bvs. i samme bolig med felles kost)?

Alene 1
Sammen med andre 2

Hvis din pårørende bodde sammen med noen i hjemmet:

50. Hvem bodde sammen med din pårørende?

Ektefelle 1
Datter 2
Sønn 3
Søster/Bror 4
Annens familie/slekt 5
Andre 6 Og det er
Kommentar

51. Var den som bodde sammen med din pårørende

- en som vanligvis hjalp han/henne? 1
- en som vanligvis trengte hans/hennes hjelp? 2
- ingen av delene? 3
- begge deler (hjalp hverandre) 4

Kommentar

Under og etter sykehusoppholdet

52. Hvis det var et eget møte for å planlegge tiden etter utskrivning, hvem deltok? (Jere kryss er mulig)

Legen 1
Pleier(e) fra sykehuset 2
Pleiere fra kommunen 3
Pasienten 4
Pårørende (meg) 5
Vet ikke 6
Andre 7 Og det var

53. Måtte din pårørende vente før hun/han kunne flytte hit?

Nei, målte ikke vente 1
Ja, han/hun måtte vente 2 Antall dager:.....
Vet ikke 3

Evt. kommentar

Litt om hvordan den eldre fungerer

54. Har din pårørende problemer med synet?

Ja 1
Nei 2
Usikker/Vet ikke 3

55. Kan din pårørende uten problemer lese teksten i en avis?

Ja (evt. med hjelpemidler) 1
Nei 2
Usikker/Vet ikke 3

56. Har din pårørende problemer med helsen?

- Ja 1
Nei 2
Usikker/Vet ikke 3

57. Kan din pårørende uten problemer føre en samtale med en annen person som snakker med normal stemme?

- Ja (evt. med høreapparat) 1
Nei 2
Usikker/Vet ikke 3

58. Kan din pårørende ringe i telefonen?

- Ja, uten hjelp 1
Trenger noe hjelp 2
Nei, kan ikke 3
Usikker/Vet ikke 4

59. Kan din pårørende om nødvendig handle?

- Ja, uten hjelp 1
Trenger noe hjelp 2
Nei, kan ikke 3
Usikker/Vet ikke 4

60. Kan din pårørende gjøre lettere husarbeid som å vaske opp, tørke støv eller re opp senger?

- Ja, uten hjelp 1
Trenger noe hjelp 2
Nei, kan ikke 3
Usikker/Vet ikke 4

61. Kan din pårørende gjøre tynge husarbeid som å støvsuge, skure gulv eller flytte møbler?

- Ja, uten hjelp 1
Trenger noe hjelp 2
Nei, kan ikke 3
Usikker/Vet ikke 4

62. Kan din pårørende dusje eller vaske seg?

- Ja, uten hjelp 1
Trenger noe hjelp 2
Nei, kan ikke 3
Usikker/Vet ikke 4

63. Kan din pårørende kle på seg?

- Ja, uten hjelp 1
Trenger noe hjelp 2
Nei, kan ikke 3
Usikker/Vet ikke 4

64. Kan din pårørende bevege seg fra seng til stol?

- Ja, uten hjelp 1
Trenger noe hjelp 2
Nei, kan ikke 3
Usikker/Vet ikke 4

65. Kan din pårørende spise oppskåret mat?

- Ja, uten hjelp 1
Trenger noe hjelp 2
Nei, kan ikke 3
Usikker/Vet ikke 4

66. Din vurdering av din pårørendes hukommelse

- Normal hukommelse 1
Lett hukommelsestap 2
Stor hukommelsestap 3
Usikker/Vet ikke 4

67. Din vurdering av din pårørendes orienteringsevne

- Orientert for tid, sted, egen person og situasjon 1
Noen vansker med å orientere seg 2
Desorientert 3
Usikker/Vet ikke 4

Appendix 5

Interview guide – follow-up interview

Tematisk intervjuguide til oppfølgingsintervju

Innledningsvis

- Status for prosjektet «Eldre på flyttefot»
- Understreke anonymitet i spørreskjema, interessert i alle historier og fortellinger uavhengig av hva de har fortalt tidligere – ingen kobling før og nå
- Informere om målet med oppfølgingsintervjuene
- Avklare bruk av båndopptaker - samtykke
- Avklare pårørendes tilkynningsforhold til den eldre
- Situasjonen for den eldre nå

Rolle i utskrivningsprosessen og etter utskrivelse

- Kan du fortelle hva som skjedde da din pårørende skulle skrives ut fra sykehuset?
- Hvordan vil du beskrive din deltagelse i utskrivningsprosessen?
- Var det spesifikke hendelser som påvirket din deltagelse?
- Hva var din rolle i utskrivningsprosessen slik du ser det?
- Hvordan gikk det da din pårørende kom hjem fra sykehuset?
- Hvordan vil du beskrive din innflytelse overfor kommunen og kommunens tjenestetilbud?
- Hva var din rolle etter at din pårørende kom hjem slik du ser det?
- Ble du stilt overfor noen dilemma du synes var vanskelige å håndtere i forbindelse med din pårørendes sykehusopphold og tiden etterpå?

Å være pårørende til eldre over 80 år

- Kan du fortelle om hvordan det er for deg å være pårørende?
- Hvordan gikk det etter siste sykehusinnleggelse?
- Hva er din rolle i forhold til de helsefjernetene din pårørende mottar slik du ser det?
- Opplever du å bli stilt overfor noen dilemma du synes er vanskelige å håndtere i forbindelse med å være pårørende i helsevesenet?
- Kan du fortelle om hvilke opplevelser du sitter igjen med i ettertid?

Tillit til helsevesenet

- Hva legger du i det å ha tillit til helsevesenet?
- Kan du fortelle om en hendelse som enten svekket eller styrket din tillit til helsevesenet?
- Hvordan påvirker din (evt. manglende) innflytelse på beslutninger din tillit til helsevesenet?
- Hvilken betydning har din tillit til helsevesenet for hvordan du opptrer som pårørende?

De som sier de har tillit til helsevesenet:

- Hva er det som gjør at du har tillit til helsevesenet?
- Hvilke hendelser har vært viktige for å skape tillit?

Avslutningsvis

- Hadde din pårørendes situasjon sett annerledes ut uten deg?
- Er det noe annet du mener er viktig å få sagt som vi ikke har pratet om?

Demografiske variabler

- Kjønn?
- Fødselsår?
- Swilstand?
- Utdanningsnivå?
- Inntektsgivende arbeid?
 - Hvis pensjonist:
 - Hva jobbet du med før du ble pensjonist?
 - Jobbet du 100%?

