Continuity in long-term home health care

Perspectives of managers, patients and their next of kin

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In grateful and loving memory of

Laila Reinate Roth

Ingvard Roth

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FORORD

Denne avhandlingen er resultatet av en langvarig og lærerik prosess. Det er mange som skal takkes for å ha bidratt til at denne forskningsstudien er blitt gjennomført. Til dere som på ulike måter har bidratt, men som ikke nevnes ved navn: Tusen takk! Jeg vil gjerne takke pasienter og pårørende for å ha delt sine erfaringer og meninger med oss og bidratt til ny kunnskap om et viktig fag- og forskningsfelt. Takk til ledere og kontaktpersoner som på en forbilledlig måte bidro til at datasamlingen kunne gjennomføres.

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ABSTRACT

Continuity of care is a core element of health care and is a prerequisite for quality in health care provision. Continuity of care is associated with the number and consistency of health personnel caring for each patient. In around-the-clock home health care where patients receive daily care over time, achieving such continuity of care is a challenge because the number of carers is high in such a context. The aim of this study is to explore continuity in long-term home health care from the perspective of key stakeholders: managers, elderly patients (age > 70 years) and their next of kin.

The study has a cross-sectional design comprising three sub-studies, two quantitative and one qualitative, each reported in original research papers (I-III). A conceptual framework covering the current conceptual understanding of continuity of care in the light of home health care was developed to guide the research process. Continuity of care is broadly understood as having three dimensions: management, interpersonal and informational. The three studies were performed in order to: (I) develop a new method for assessing interpersonal continuity of care by adapting existing measurements methods to high-frequency home health care services and to measure and assess interpersonal continuity of care in that context; (II) to study how managers define continuity of care and what they do to ensure continuity of care in practice and (III) to study the perspective of patients and their next of kin on continuity in home health care and to measure the degree of agreement between them. Data were collected in 16 home health care districts in 12 municipal units. Administrative data concerning 79 patients were used in sub-study I, data from semi-structured interviews with 16 managers were used in sub-study II, and data from structured interviews with 75 matched pairs of patients and next of kin informed sub-study III.

The results show that the degree of interpersonal continuity of care was low, even when taking into account the context, revealing considerable potential for improvement (I). Managers defined continuity of care as a patient having few carers. The managers faced two paradoxes: the continuity ideal versus the practicalities of home health care and caring for patients versus caring for the staff. They made priorities between and within patients and staff, on the expense of interpersonal continuity of care for patients who were assessed to have minor care needs. Low interpersonal continuity of care was accepted as a working compromise (II). Patients and their next of kin reported experiencing continuity of care with regard to how management and informational continuity is understood. Patients reported low

interpersonal continuity of care, but the majority did not consider the large number of carers a problem, which was in strong contrast to the next of kin's views. Predominantly, poor agreement was found between the patient and his or her next of kin. Overall, next of kin made more negative assessments of the care provision than patients (III).

In the realm of long-term home health care, continuity of care is challenging to achieve. The possibility for a patient who receives daily care over time to see the same carer from one care episode to another or from one day to another is small in the context under study. The degree of interpersonal continuity is considerable lower than necessary, revealing a potential for improvement. Incongruence between patients and his or her next of kin revealed different assessments of continuity in home health care. This study has shown that continuity in home health care is complex, and that perceptions of continuity depend on the perspective from which it is seen.

LIST OF ORIGINAL PAPERS

This thesis is based on the following original papers. The papers will be referred to in the thesis by their Roman numerals:

I. Gjevjon, E.L.R, Eika, K.H., Romøren, T.I., Landmark, B.F. Measuring interpersonal continuity of care in high-frequency home healthcare services. 2013; Journal of Advanced Nursing. Published online 22 July 2013, DOI: 10.1111/jan.12214

II. Gjevjon, E.R., Romøren, T.I., Kjøs, B.Ø., Hellesø, R. Continuity of care in home health care practice: two management paradoxes. 2013; Journal of Nursing Management, 21(1): 182-190. Published online 30 March 2012, DOI: 10.1111/j.1365-2834.2012.01366.x

III. Gjevjon, E.L.R., Romøren, T.I., Hellesø, R. Continuity in home health care – patients' and their next of kin's perspectives. (Submitted).

1. INTRODUCTION

This thesis addresses continuity of care for elderly patients who receive daily and long-term home health care in Norway.

Continuity of care is recognized as an important feature of all health care services (Gulliford, 2006; Haggerty et al., 2003) and has been identified as a research priority amongst nurses (Bäck-Pettersson, Hermansson, Sernert, & Björklund, 2008; McIlfatrick, 2003; Ross, 2004). It is a common goal for policymakers and health care providers to avoid discontinuity of care for the sake of patient safety (Cook, Render, & Woods, 2000), patient satisfaction (Saultz, 2004) as well as efficiency and effectiveness of care provision (Wierdsma, Mulder, de Vries, & Sytema, 2009).

Continuity of care is associated with improved health outcomes (Russell, Rosati, Rosenfeld, & Marren, 2011) patient satisfaction (Saultz, 2004), psychosocial wellbeing (D'Errico, 2006), decreased hospitalization and decreased health care costs (Chen & Chen, 2011; Hsiao & Boult, 2008).

Lindberg et al. (2012) define continuity of care as ‘the unbroken and consistent existence or operation of something over a period of time; a state of stability and the absence of disruption’. In the context of health care, an overall aim is to avoid unwarranted breaks and inconsistency in a patient’s trajectory through the health care system (Reed, Cook, Childs, & McCormack, 2005) within or across organizations and health care levels.

Continuity of care is a prerequisite for the quality of care (Sparbel & Anderson, 2000a; van Servellen, Fongwa, & D'Errico, 2006). In Norway, one of the quality goals for all health care provision is that each patient trajectory is integrated and coordinated and that it is perceived as seamless across and within health care levels, so that continuity of care is ensured by the provider and experienced by the recipient (Ministry of health and care services, 2003). Health care provision in the community is based on laws and regulations stating that the municipalities are obliged to provide necessary health care (Ministry of health and care services, 1982, 2012) of good quality (Ministry of health and care services, 2003). According to quality regulations, the municipalities are required to develop and follow procedures to ensure that (own translation):

- ‘The service and the service providers continuously strive to ensure appropriate services according to the individual user’s needs, at the right time, and according to an individual [care] plan when present.’
- ‘An overall, coordinated and flexible service with attention to continuity is provided.’
- ‘Users of care services and when relevant or possible, next of kin, participate in the planning and execution of the service’

(Ministry of health and care services, 2003; §3).

Through a series of White Papers and reports, the Norwegian government has pointed at discontinuity of care as a challenge and as grounds for further development of the services through plans, regulations and health care reforms (Ministry of health and care services, 2005, 2006, 2009, 2011a). Policy reforms aiming at making health care more efficient, modern and cost effective have led to a shift of tasks from specialized health care towards primary health care, giving community health care a central position in the health care services (Kalseth, Midttun, Paulsen, & Nygård, 2004; Ministry of health and care services, 2009; Romøren, Torjesen, & Landmark, 2011; Seim, 2010). The latest reform, ‘The Coordination Reform’, aims at decreasing the demands for hospital services and hence, more and more patients are being treated and cared for in the community (Ministry of health and care services, 2009; Romøren et al., 2011; Seim, 2010). Consequently, home health care services are becoming a cornerstone of health care in Norway. Accordingly, the Government has identified continuity in home health care as a specific theme for research, with reference to the increased pressure on and new tasks for the home-based services that result from this shift towards primary health care (Ministry of health and care services, 2006; p. 69).

Studies addressing continuity of care for home-dwelling patients mainly concern inter-organizational continuity (Haggerty et al., 2003). In Norway, research has been conducted to describe and improve continuity in hospital-to-home transitions (Bragstad, Hofoss, Kirkevold, & Foss, 2012; Gautun, Kjerstad, & Kristiansen, 2001; Hellesø, 2004, 2005; Hellesø & Fagermoen, 2010; Kalseth et al., 2004; Olsen, Hellzèn, & Enmarker, 2013; Paulsen & Grimsmo, 2008; Paulsen, Romøren, & Grimsmo, 2013; Romøren et al., 2011). A similar focus is found in international research (Bauer, 2009; Dossa, Bokhour, & Hoenig, 2012; Efraimsson, 2004; McLeod, McMurray, Walker, Heckman, & Stolee, 2011; Naylor, 2006).

In comparison, few studies concern intra-organizational continuity, that is, continuity of care within the organization providing home health care to individual patients. However, existing studies have identified factors promoting continuity of care for home-dwelling care recipients (here mainly termed patients), such as trusting relationships between carer and patient, care planning and care coordination (Woodward, Abelson, Tedford, & Hutchison, 2004) and the lack of these factors has been found to reduce continuity in home care (Sharman, McLaren, Cohen, & Ostry, 2008). Moreover, consistency of home health personnel (here also termed carers), so that the patient meets as few carers as possible, is in turn associated with psychosocial wellbeing (D'Errico & Lewis, 2010), reduced use of emergency care (Russell et al., 2011) and improved functionality (Russell, Rosati, Peng, Barrón, & Andreopoulos, 2013).

The context of previous studies to investigate continuity of care differs from the context in which home health care is delivered in Norway. In Norway, home health care is provided on a round-the-clock basis and it is common that patients receive daily care over long periods of time, in contrast to the relatively short-term nature and low frequency of US home care services (D'Errico & Lewis, 2010; Russell et al., 2011). The Canadian studies had a broad focus, including domestic care in addition to health care (Sharman et al., 2008; Woodward et al., 2004). In Norway, the differences between home health care and domestic care are considerable. Besides involving different tasks and staff qualifications (Birkeland & Flovik, 2011), domestic care is normally provided every week or every second week (Næss, 2003) and hence it is a low-frequency service.

The substantial home health care services in Norway require three shifts of staff and a number of health personnel to cover the shifts. Legislation on working conditions imposes strict limits on the number of working hours and working days for the staff. The use of part-time positions is extensive in the health care sector (Abrahamsen, 2010) and levels of sickness absence are high (Econ Pöyry, 2009). Consequently, the number of visits and the number of personnel are extensive when patients need daily care, perhaps even many times a day and over time, often for many years (Dale, 2009; Moe, Hellzén, & Enmarker, 2013; Romøren, 2003).

With reference to Lindberg et al.'s definition of continuity (2012), is it possible to avoid 'disruption' and to maintain a 'consistent operation' of home health care in such a context? Three doctoral studies conducted in the Norwegian context suggest that there is a lack of continuity for patients due to the number of carers providing the care (Dale, 2009; Moe, 2013; Tønnessen, 2011). These inferences were made on the basis of information elicited through research questions that did not specifically address continuity of care, but formal and informal compensatory care to elderly people (Dale, 2009), the challenge of providing sound care when prioritization of users is necessary (Tønnessen, 2011) and the significance of receiving care among elderly people (Moe, 2013). Similar findings are reported from studies conducted in Sweden, with close parallels to the context in Norway: (Karlsson, Edberg, Jakobsson, & Hallberg, 2013; Kristensson, Hallberg, & Ekwall, 2010; Olsson & Ingvad, 2001; Öresland, Määttä, Norberg, Jörgensen, & Lützén, 2008).

Continuity in home-based care is defined as 'Care that is experienced as running smoothly, that responds to clients' needs and requires no special effort for clients to maintain' (Woodward et al., 2004; p. 180). This definition implies that continuity of care concerns how the recipient experiences the care given and that how continuity is experienced depends on the quality of the care that is provided (Haggerty et al., 2003; Saultz, 2003). However, few studies explore how the recipient or the people close to them actually experience continuity of care.

It is reasonable to assume that the realm of long-term and high-frequency home health care *per se* represents a challenge to continuity of care. For managers to provide continuity of care for all patients seems difficult. Hence, one might ask whether it is possible for care recipients and their next of kin to experience that continuity of care is achieved.

1.1 Aim and research questions

The aim of this study is to explore continuity in home health care from the perspective of managers, patients and their next of kin. The following main research questions were addressed in three separate research papers:

RQ 1: What is the degree of continuity in the carer-patient encounters for elderly patients who receive daily and long-term home health care?

- Paper I presents continuity in the care encounters between patients and carers through measurement and assessment of interpersonal continuity by means of a new method adapting existing continuity indices to context.

RQ 2: From the perspective of care managers, how can continuity of care for elderly patients who receive daily and long-term home health care be achieved?

- Paper II describes how managers of home health care units understood, assessed and ensured continuity of care.

RQ 3: How is continuity in home health care experienced by patients dependent on daily care over time and their next of kin?

- Paper III describes how patients and their next of kin experienced and assessed continuity in home health care and the degree of agreement between them.

To my knowledge, this is the first study addressing continuity of care in long-term home health care services where elderly patients commonly receive care once or several times per day from multiple carers. This thesis is a contribution to knowledge development in the increasingly important research field of long-term home health care in Norway as well as internationally.

1.2 Outline of the thesis

The study is based on three sub-studies, each presented in original research papers (I-III). Reproductions of these papers are included in this thesis. The thesis comprises nine main chapters. The first three chapters present the background for the study in which the context of home health care is described and where the concept of continuity of care is presented (1, 2, 3), including a conceptual framework for continuity in home health care (3). The literature that informs these chapters was retrieved by literature searches in the main databases concerning health care, nursing and medical literature: CINAHL, MEDLINE and PubMed, in addition to searches in Google Scholar and SweMed+ using the following main search terms: continuity of patient care (MeSH term) and continuity of care (MEsH term), continuity (keyword); home health care (MeSH term) and home care, home nursing care, home nursing (keywords); patients (MesH term), patient (keyword); family, family members, relatives (MeSH terms), next of kin (keyword); nurse managers, nurse administrators (MeSH terms), manager, leader (keywords); nursing, nursing care (MesH terms). All terms were used alone and in combinations. The literature referred to in Chapter 3 was published before or at the time that the study was commenced. The chapter Methods (4) contains a complementary description of the research design and methods, including ethics, validity and reliability. A brief summary of the results from each original paper is found in the Results chapter (5). The Discussion chapter (6) includes a discussion concerning methodological considerations followed by a discussion of the study's main results. Conclusions are summarized in a separate chapter (7) before the thesis ends with reflections on the study's possible implications for practice (8) and finally, recommendations for further research (9).

2. HOME HEALTH CARE

This study was undertaken in a Norwegian home health care setting. In this chapter home health care in Norway is emphasised. However, similar health care challenges are relevant in the international context. Worldwide, living and receiving care at home has increasingly been seen as a favourable alternative for persons with long-term care needs (European Commission, 2008; Genet et al., 2011; Ministry of health and care services, 2006; Tarricone & Tsouros, 2008). The growth in long-term home health care is generally linked to societal changes (Tarricone & Tsouros, 2008) and high health care costs (Seim, 2010). In Western countries, elderly people represent a larger proportion of the total population due to increased life expectancy and decreased birth rates (Tarricone & Tsouros, 2008; United Nations, 2007). Moreover, women are increasingly participating in the labour market and hence the family is less available to provide full-time care, which makes the population more dependent on professional care (Tarricone & Tsouros, 2008). To meet these challenges, a change in the traditional patterns of care has been suggested – from relying heavily on family care towards receiving professional care in the home (ibid.). Consequently, a growing number of elderly persons will meet professional health personnel at home. The home is then not only a private dwelling but to a certain degree also a professional health care facility (Lindahl, Lidén, & Lindblad, 2011).

The municipalities are responsible for all community health care in Norway, such as primary medical care, nursing home care and home health care. The community health care services are regulated by a set of laws and regulations providing a framework for organizing and providing the care. Within these regulations, the municipalities have autonomy to decide the means to realize their responsibilities and consequently, there are some local variations in how the municipalities organize care provision (Vabø, 2012).

2.1 Provision of home health care

From being purely a family matter, caring for the old and sick at home became a part of Norwegian public health care in 1972, but only as a supplement to family care or voluntary care and if found medically acceptable by the family doctor (Birkeland & Flovik, 2011). Since 1984, the law requires municipalities to provide home health care health care service on a par with institutional care (Ministry of health and care services, 1982, 2012). In 2006, the Norwegian Government introduced the 'Care Plan 2015', in which a line was drawn from the commencement of home health care as a public health care service to the challenges we expect to be facing in 2015 (Ministry of health and care services, 2006). The plan pointed out a need to expand and strengthen community health care in general, especially primary medical care and home health care (ibid.). ‘Care Plan 2020’ continues this work with a focus on innovations and future solutions in the health care services (Ministry of health and care services, 2013).

Although home health care is acclaimed as a solution to an array of problems and challenges in health care on a societal, organizational and individual level, it might not be the best setting or the best form of care for some persons (Sørbye, 2009; Thomé, Dykes, & Hellberg, 2003). In Norway, this is reflected in an ongoing debate about the number of nursing home beds and the threshold for admittance to long-term institutional care, which mainly concludes that there is a lack of nursing home beds. Studies show that some professionals argue that the threshold is too high (Landmark & Romøren, 2011), some that it is too low, and others that it is sufficiently high (Gjevjon & Romøren, 2010), but that nursing home beds are nevertheless reserved for those who are most frail and ill (Fjelltun, 2009).

Health care in the patient’s home is mainly provided by professionals, but supplemented by family care where available (Dale, 2009; Hammar, Rissanen, & Persälä, 2008; Hellström, 2004; Karlsson, 2008a). In Norway, care provision is coordinated and organized on two levels within a home health care district. On the lowest level, health personnel – mainly registered nurses (hereafter termed ‘nurses’) or auxiliary nurses – coordinate and organize the delivery of care to their designated patients (Birkeland & Flovik, 2011; Fjørtoft, 2012; Jensen, 2009). The division of labour is based on education, professional and personal competency and sometimes on personal interests, for example if a nurse is especially interested in wound care. Nurses are responsible for the most advanced tasks and have overall responsibility for the quality of care, coordinating the care and supervising other health care personnel and assistants (Birkeland & Flovik, 2011). Individual health personnel are responsible for providing services to the individual patient according to their professional requirements (Genet, Boerma, Kroneman, Hutchinson, & Saltman, 2012; Ministry of health and care services, 1999).

At the highest level in a home health care district, the manager is responsible for organizing and coordinating care provision with regard to laws, regulations, budget and staff resources, and professional standards (Aksøy, 2009). One focus of the current study is the management level of care provision, i.e. the manager’s responsibilities and actions to facilitate continuity of care.

2.1.1 Managers

Managers of home health care in the Nordic countries are mostly nurses (Bondas, 2009; Johansson, Pörn, Theorell, & Gustafsson, 2007) and have the overall responsibility for quality of care, the budget and staff (Aksøy, 2009). A nurse manager’s working role is complex (Coulson & Cregg, 1995). Constant reorganizations as well as staff and financial issues have been reported to make their work difficult (Aksøy, 2009), and to be the main reasons for high turnover in managing positions (Skytt, Ljunggren, & Carlsson, 2007). A Swedish study found that managers thus identify themselves as both nurses and administrators (Johansson et al., 2007). The manager’s status gives him or her the power to organize, manage and monitor the day-to-day work and thus directly and indirectly to influence the quality of care (Kjøs, Botten, & Romøren, 2008; Kjøs, Botten, Gjevjon, & Romøren, 2010).

Although continuity of care is seen as a prerequisite for quality of care and a tenet of professional nursing (Sparbel & Anderson, 2000a), we know little about managers’ work to ensure continuity of care for their patients. How managers understand and assess continuity of care and consequently, how and why they act to ensure continuity of care in a context where this is likely to be challenging is an important contribution to the knowledge base.

2.2 Receiving home health care

Professional home health care takes place in the patient’s own home, in the domain of the patient and his or her family (Sundelöf, 2004; Öresland et al., 2008). This means that receiving long-term home health care becomes an integrated part of the patient’s and in many cases also the next of kin’s everyday life (Romøren, 2003).

2.2.1 Home health care recipients

Elderly people prefer to remain in their own home as long as possible (Borglin, Edberg, & Hallberg, 2005; Moe et al., 2013). More than 136 000 persons, 2.7% of the total population in Norway, received home health care in Norway in 2012 (Mørk, Sundby, Otnes, Wahlgren, & Gabrielsen, 2013). Recipients of home health care are a heterogeneous group spanning patients with minor care needs to patients in need of considerable care, such as frail and sick elderly people, people with dementia, severely ill cancer patients, young persons with acquired and inborn chronic disease and disabilities, persons with psychiatric disorders and persons addicted to heavy drugs. In the Nordic countries, the most typical home care recipients are elderly people, with a predominance of women (Gabrielsen, Otnes, Sundby, Kalcic, & Strand, 2010; Hammar et al., 2008; Mørk et al., 2013; Thomé et al., 2003).

In Norway, the majority of the care recipients (83 000, 60%) are people over the age of 67 and 62% of elderly care recipients are women (Mørk et al., 2013). The number of recipients under the age of 67 has been growing over time (Gabrielsen et al., 2010; Mørk et al., 2013; Romøren, 2007). This rise in the number of younger long-term care recipients has led to an increase in the municipalities' health care costs (McArthur, Tjerbo, & Hagen, 2013), which is attributable to the higher number of hours of care that younger recipients receive (13.6 hours per week) compared to elderly patients (4.6 hours per week) (Mørk et al., 2013).

Elderly recipients of home health care in Norway receive care visits at least once a week (Dale, 2009), and one or more times per day in many cases (Moe et al., 2013). The oldest old (>80 years) face long-term trajectories with varying ending points. Very few of these patients experience long-term improvements in functional level with regard to activities of daily life (ADL). The most frequent reason for ending home health care is admission to a nursing home because of further deterioration in health and low functional level (Romøren, 2003).

From the perspective of elderly home health care recipients in the Nordic countries, criteria for quality of home health care include receiving practical care to compensate for reduced ability to perform daily activities (Dale, Sævareid, Kirkevold, & Söderhamn, 2011), receiving care that takes into account the patient's personal circumstances and preferences (Vaarama, 2009), having a mutual relationship with committed carers, and being able to live his or her life as usual (From, Johansson, & Athlin, 2009; Vaarama, 2009). Moreover, being cared for by competent and skilled carers with sufficient time is seen as a prerequisite for receiving good, safe and secure nursing care (From et al., 2009). Most of these areas that are associated with the quality of nursing care address areas of dissatisfaction that have previously and recently been reported in Nordic and international studies: poor coordination of care (Caris-Verhallen & Kerkstra, 2001) carers' shortage of time (Dale et al., 2011; Moe et al., 2013) lack of competence (Moe et al., 2013), lack of information (Bailey, 2007; Dale et al., 2011) and a high number of carers (Dale et al., 2011; Karlsson, 2008a; Moe et al., 2013; Olsson & Ingvad, 2001). Despite areas requiring improvement, several studies have reported a high level of general satisfaction with received home health care from the elderly patient's point of view (Dale, 2009; Dale et al., 2011; Karlsson, 2008b).

The aspects of care listed above are associated with continuity in home health care (Sharman et al., 2008; Woodward et al., 2004), yet we know little about whether or how patients experience continuity when receiving long-term home health care. This study includes the patient’s perspective in addition to the perspective of next of kin with regard to continuity of care, yielding new knowledge based on key stakeholders’ own experiences of the care received.

2.2.2 Next of kin

Next of kin, often the patient's nearest family member, play an important role and are significant partners for both the patient and the provider (Borglin et al., 2005; Dale et al., 2011; Kirkevold, 2008; Romøren, 2003; Sims-Gould & Martin-Matthews, 2010) and are currently an object of increased focus from the Government (Ministry of health and care services, 2011b, 2013). Next of kin often provide a considerable amount of informal or non-professional care to elderly recipients of home care in Norway, alongside the formal, or professional care from the home care unit (Dale, 2009; Romøren, 2003).

In a longitudinal Norwegian study of people aged 80 years or more, a majority of the next of kin were close family, such as the spouse (9%) daughter (35%), son (19%), daughter-in-law (6%), grandchild (0.5%), sister (8%), and brother (1%). Others were nieces (7%) and nephews (4%) and non-family (4%). One per cent of the 434 elderly persons did not have any next of kin (Romøren, 2003). In Norway, informal care is basically given by next of kin to provide instrumental ADL tasks (IADL) such as housekeeping, shopping, garden work and transport while formal carers, i.e. health professionals provide personal ADL tasks (ADL) such as bathing, personal hygiene, dressing, toileting and mobilization (Dale, 2009).

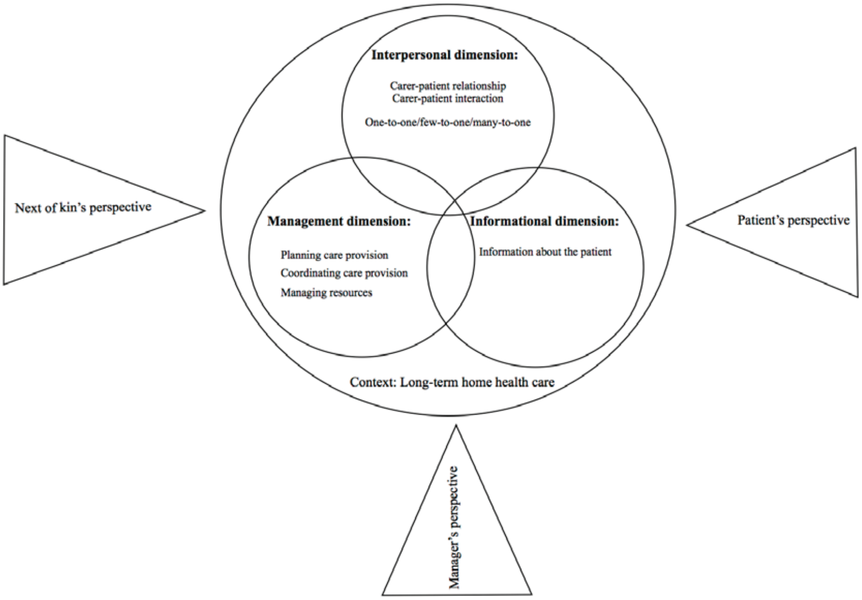
Many studies have focused on the next of kin’s burden of being an informal caregiver. In this regard, there are conclusive findings of heavy burden and high personal costs for the next of kin (Andrén & Elmståhl, 2008; Hansen, Slagsvold, & Ingebretsen, 2012; Munck, Fridlund, & Mårtensson, 2008; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Proot et al., 2003). Others have focused on the next of kin’s role as an informal caregiver (Stajduhar, Funk, & Outcalt, 2013), as a collaborative partner for the patient (Callaghan, 2012) and for the patient and the provider (Sims-Gould & Martin-Matthews, 2010) and as an advocate for the patient (Tønnessen, Førde, & Nortvedt, 2009). Studies indicate that next of kin are more critical to the quality of care, including aspects of continuity of care, than the patient is (Kahanpää, 2006; Næss, 2003; Öresland et al., 2008). Continuity of care is seen as important for quality of care. However, I have not identified any studies studying whether and how next of kin experience continuity of care for the patient. The current study contributes new knowledge concerning next of kin’s perspective on continuity in home health care.

Next of kin are extensively used as a proxy for patients who are unable or unwilling to share their experiences, views and assessments regarding health care issues (Bragstad et al., 2012; Lobchuk, 2002; Norris, 2007). In this study, continuity of care is addressed from the perspective of the next of kin, that is, on behalf of themselves as next of kin and not on behalf of the patient.

3. CONTINUITY IN HOME HEALTH CARE – A CONCEPTUAL FRAMEWORK

To inform and guide the design and the research process for this study, a conceptual framework was drawn. Figure 1 presents the conceptual framework, which will be elaborated on in this chapter. Furthermore, previous research addressing the different dimensions from different perspectives is discussed.

Figure 1. Conceptual framework for the study of continuity in home health care



The triangles outside the large circle illustrate the three perspectives from which continuity of care is addressed in this study. In the context of long-term home health care, represented by the large circle, the three smaller intersecting circles illustrate three dimensions of continuity of care first outlined by Reid, Haggerty & McKendry (2002). The three dimensions form a general framework for continuity of care in health care. Within these dimensions, the key aspects representing the phenomenon of continuity in home health care are categorized. The conceptual framework served as a 'mind map' when the sub-studies were designed, when data collection instruments were developed and when data were analysed and interpreted. The conceptual framework has been a helpful tool to keep the focus within and across the sub-studies as well as during the concluding work on the current thesis. In the following, I will elaborate on the three dimensions of continuity in home health care and its aspects.

Two research programmes addressing continuity of care, one conducted in England (Freeman, Sheppard, Robinson, Ehrich, & Richards, 2001), the other in Canada (Reid, Haggerty, & McKendry, 2002), were undertaken with an aim to advancing the understanding of the concept of continuity of care. Prior to these reviews, the concept of continuity of care was poorly understood (Freeman et al., 2001; Reid et al., 2002; Sparbel & Anderson, 2000a). Continuity of care was defined and measured in a 'myriad of ways' (Reid et al. 2002, p. iv) despite its position as a key feature of health care. Freeman et al. (2001) and Reid et al. (2002) conceptualized continuity of care and suggested six and three dimensions, respectively. The six dimensions in the framework proposed by Freeman et al. (2001) were information; cross-boundary; team; flexible; longitudinal; relational or personal. Reid et al. (2002) proposed a simpler framework with three dimensions – relational; management; informational – which was later adopted by Freeman and colleagues (2007) as a general framework:

- *Relational continuity,* in this study termed *Interpersonal Continuity,* refers to an ongoing therapeutic relationship between a patient and provider(s) that 'bridges past and current care' and 'provides a link to future care'. In the current study, the interpersonal dimension distinguishes between relationships and interaction between patients and carers (see Chapter 3.2).
- *Management continuity* concerns 'the provision of timely and complementary services within a shared management plan'.
- *Informational continuity* connects past, present and future care by using 'information about prior events and circumstances to make current care appropriate for the individual and his or her condition'.

The three dimensions of continuity of care are not mutually exclusive but intertwined, representing processes in practice that link patient care events 'into a coherent whole' (Reid et al., 2002; p. 4).

Owing to this work, literature on continuity of care in health care, mostly medical and nursing care, within and between health care levels largely understands continuity of care in the same way (Aboulghate et al., 2012; Aspinal, Gridley, Bernard, & Parker, 2012; Parker, Corden, & Heaton, 2010, 2011; Sharman et al., 2008; van Servellen et al., 2006; Waibel, Henao, Aller, Vargas, & Vázquez, 2011; Wong, Watson, Young, & Regan, 2008).

Saultz (2003) defined continuity of care as a hierarchy with increasing complexity and relationships between the levels. Informational continuity is placed at the lowest level of the hierarchy, forming the basis for continuity of care; at a minimum, a provider needs information about the patient to perform the care. The next level is longitudinal continuity[1], which represents management continuity in the framework of Reid et al. (2002). Saultz (2003) however suggested that Reid et al. (2002) had addressed care coordination rather than care continuity, but Saultz did not demonstrate the differences between longitudinal and management continuity. ‘Management continuity’ is the term used most frequently in subsequent research literature and hence the one used in the present study. At the top of Saultz’s hierarchy, and the most complex, is interpersonal continuity – an ongoing relationship between a carer and a patient that is characterized by mutual trust, commitment and familiarity. The hierarchy suggests that if there is a lack of interpersonal continuity, arrangements should be made to compensate by ensuring management continuity (Saultz, 2003) in home care through ‘uninterrupted service delivery’ (Woodward et al., 2004). If breakdown in this dimension of continuity of care as well as in interpersonal continuity occurs, a minimum of continuity of care is ensured through informational continuity (Saultz, 2003).

The key aspects within the three dimensions of continuity of care will vary with the context in which continuity of care unfolds or is studied. For the current study, the aspects that are chosen represent the phenomenon of continuity of care in a simplistic way. These aspects are chosen on the basis of previous literature concerning home health care provision and receipt in addition to my own experiences. The conceptual framework (Figure 1) outlines continuity in home health care.

Continuity of care is often associated with related concepts such as coordination of care, integration of care, patient-centred care and case management. Definitions of these concepts vary over time and are connected (Uijen, Schers, Schellevis, & van den Bosch, 2011). However, common to these concepts is that they involve a personal relationship between patient and care provider (carer); communication between carers; and cooperation between carers (ibid.). I will not discuss continuity of care in relation to related concepts in this thesis.

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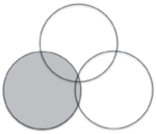
[1] I will continue to use the term ‘management continuity’ when referring to Saultz’ term ‘longitudinal continuity’ because, as I see it, the two terms have the same meaning with regard to the work reported in this thesis.

3.1 The management dimension



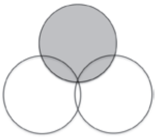
The management dimension is claimed to be the unifying dimension of continuity of care: a precondition for the interpersonal and the informational dimension (van Servellen et al., 2006). The management dimension of continuity in home health care is understood as the planning and coordination of care and resource management (Sharman et al., 2008; Woodward et al., 2004). The management dimension of continuity might be seen as ‘backstage continuity’, that is, measures taken to facilitate continuity of care at the ‘front stage’ (Krogstad, Hofoss, & Hjortdahl, 2002). For example, there must be computers at the workplace so that information can be written down and shared. The right numbers and competence of staff members must be present so that the care tasks are carried out adequately. Shift plans, working plans and care plans are necessary to ensure that the right care is given by the right person with the right competence, knowledge and skills. This is in line with Woodward et al. (2004), who pointed at two dimensions of care that are important to continuity in home-based care: ‘managing care’ (backstage) and ‘direct care provision’ (front stage).

In home health care in Norway, care models are management means typically used with an aim to enhance continuity of care, mostly through variants of primary nursing (Jensen, 2009; Næss, 2005) and team nursing. The primary nursing model assigns the responsibility for the individual patient to a named carer and enables that carer to follow up his or her designated patient (Manthey, 2009; Manthey, Ciske, Robsertson, & Harris, 1970; Procter, 1995). The team model places the responsibility for the follow-up on teams rather than on one named person (Tiedeman & Lookinland, 2004). The team members collaborate and share the responsibility for a group of patients. The use of care models illustrates actions taken within the management dimension to facilitate continuity within the interpersonal dimension and within the informational dimension; one or few named carers have responsibility for the patient, which in turn should ensure that there is adequate information about the patient to connect past, present and future care. However, processes intended to enhance continuity of care, such as organizing care using primary nursing or team nursing, do not guarantee that continuity will be achieved. According to Haggerty et al. (2003), Saultz (2003) and Woodward et al. (2004), continuity of care cannot be achieved until it is experienced as such by the recipient of care, the patient, acknowledging that the patient perspective is important. In reference to the current study, the next of kin's perspective is also regarded as important.

Although less visible to the patient (Woodward et al., 2004) and next of kin, the providers' communication, planning and coordination related to service delivery, i.e. the management dimension, influence their experience of continuity. For example, deteriorating working conditions for the staff, fragmentation of care provision and shorter home visits are found to lead to a lack of continuity in home health care (Abelson, 2004). In a study addressing continuity of care for home health care patients, patients were found to experience lack of continuity of care because of uncoordinated services, lack of skilled personnel and lack of resources, causing breaks in the care schedules, breaks in the information exchange and inconsistency of carers (Sharman et al., 2008). Care recipients, or patients, value consistent timing of care delivery so that it is possible for them to plan their day and to experience predictability (Woodward et al., 2004). Poor information exchange might make it necessary for the patient or the next of kin to inform the carer and re-explain care issues that the carer should have been informed of beforehand (Sharman et al., 2008; Woodward et al., 2004). Being cared for by many and unknown carers might lead to uncertainty for the patient or his or her next of kin and to lack of trust in the service (Olsson & Ingvad, 2001; Öresland et al., 2008).

In the current study, the management dimension covers the managers' general responsibilities, planning and coordination of care and resource management, which are relevant to how patients and their next of kin experience continuity in home health care.

3.2 The interpersonal dimension



The interpersonal dimension of continuity of care concerns the carer-patient encounters where the carer(s) provide care and the patient receives care. The interpersonal dimension of care is a core element of all health care, for example primary medical care (Heaton, Corden, & Parker, 2012), short-term hospital care (Procter, 1995), long-term care in nursing homes (Bergland, 2005) and home health care (Woodward et al., 2004). In the conceptual framework for the present study (Figure 1), I distinguish between a carer-patient relationship and carer-patient interaction.

The interpersonal dimension implies that continuity of care involves interpersonal interaction or relationships between one or more carers and a patient: one-to-one or few-to-one or many-to-one. One-to-one interaction represents a high degree of interpersonal continuity while many-to-one interaction represents a low degree or lack of interpersonal continuity, or discontinuity (D'Errico, 2006). This is in line with the notion that a steady carer-patient relationship is an ideal (Jonsdottir, Litchfield, & Pharris, 2004; Nolan, 2004).

Existing care models are used to enhance continuity of care in terms of a carer-patient relationship, primary nursing (one-to-one) or team nursing (few-to-one). Having a primary carer, cf. primary nursing (Manthey, 2009), might compensate for the possible disadvantages of being cared for by multiple carers. Being cared for by few carers as in team nursing (Tiedeman & Lookinland, 2004), given a stable group of personnel, provides a few-to-one relationship where the patient and the few carers will get to know each other.

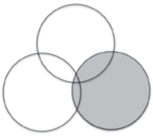
Knowing each other generates commitment from the carers to the patient and generates trust from the patient with respect to the carers (Soodeen, Gregory, & Bond, 2007; Woodward et al., 2004). Knowing the carers builds the trust of the patient and the next of kin in these carers (Saultz, 2003; Woodward et al., 2004; Öresland et al., 2008). Establishing a trusting relationship upholds stability and presumably enhances continuity of care. The carer-patient relationship is seen as ‘the vehicle through which therapeutic nursing can be delivered’ (Luker, Austin, Caress, & Hallett, 2000; p. 775), and it is claimed that ‘Successful home care is grounded in the relationships between workers and clients’ (Sharman et al., 2008; p. 91). The carer-patient relationship is highlighted as a prerequisite for understanding a patient’s needs and his or her overall situation and for being able to customize the services according to this understanding (Eika, 2006; Potter & Peden-McAlpine, 2002; Woodward et al., 2004; Wright, 2002). Such a care relationship is seen as important by both patients and carers (Nolan, 2004; Olsson & Ingvad, 2001; Sharman et al., 2008; Woodward et al., 2004).

Interpersonal continuity through one-to-one or few-to-one interaction allows carer-patient relationships to develop and strengthen, which in turn is presumed to improve outcomes for the recipients of care. D’Errico (2006) studied possible relationships between the degree of interpersonal continuity and the end-result outcomes of functional status, psychological status and use of emergency care for 887 elderly recipients of home health care who were chronically ill. The point of reference was one-to-one interaction between nurses and patients. The degree of interpersonal continuity was high, that is, the same nurse undertook most of the visits to the patient. D'Errico found no statistically significant results indicating a relationship between a limited number of nurses and functional status or use of emergency care. The study however indicated an impact on psychological status, where a higher degree of interpersonal continuity increased the likelihood of psychosocial well-being (D'Errico, 2006). Conclusions from a Norwegian interview study were similar: having few carers to relate to had a positive influence on patients' psychosocial well-being (Birkeland & Natvig, 2008). Olsson & Ingvad (2001) found associations between home health care patients being cared for by many carers and the likelihood of an increased level of conflict and uncertainty. It may be inferred from these studies that the number of carers for each patient should be limited for the sake of the patient's well-being. Others claim that interpersonal continuity is necessary to avoid complications or functional decline (Potter & Peden-McAlpine, 2002).

For a health care provider to be able to deliver around-the-clock home health care to persons in need of daily and long-term care, a high number of personnel is needed. Correspondingly, in such a context elderly people receiving home health care have reported meeting many carers, which has been interpreted in the literature as a lack of continuity of care (Dale, 2009; Karlsson, 2008b). Such findings are confirmed by complaints made by next of kin (Næss, 2003; Öresland et al., 2008). Nevertheless, and in contrast to the next of kin's complaints reported in the study by Öresland et al. (2008), many patients expressed satisfaction with the care they received (Karlsson, 2008b), and many even found the number of carers to be unproblematic and appropriate (Næss, 2003).

The interpersonal aspects of care have traditionally been important and unavoidably of great interest to nurses and nursing scholars (Hartrick, 1997; Peplau, 1997; Travelbee, 1966). It is easy to assume that these aspects are equally important for patients and their next of kin. The present study investigates interpersonal aspects of care provision and receipt from the perspectives of those responsible for planning, coordinating and managing the services, those receiving the services, and those who are closest to the recipient.

3.3 The informational dimension



Sparbel & Anderson (2000a) defined continuity of care as ‘a series of connected patient care events’ (p. 17). Care events are connected in various ways. They are connected when the same carer conducts every care visit, i.e. a one-to-one interaction. This carer will however only be able to follow up the patient care until he or she cannot undertake the next care visit. If the need for care persists over time, it may involve multiple care encounters requiring visits from more than one carer: few-to-one or many-to-one. Follow-up then depends on transfer of relevant social, medical and nursing information to connect the care episodes (Ammenwerth, 2006; Meißner et al., 2007; Moen, Hellesø, & Berge, 2008). Hence, when care tasks and care visits are dispersed among many carers, lack of continuity will occur unless information is transferred to the next carer visiting the patient.

Home health care personnel commonly provide care alone, with no colleagues present, which in turn makes their actions invisible if they are not communicated (Owen, 2005). Information about the recipient’s preferences and resources, their routines and social network is of importance to provide individually adapted care (Attree, 2001; Potter & Peden-McAlpine, 2002; Woodward et al., 2004). Having knowledge about the patient both as a person and as a patient is an essential aspect of nursing (Tanner, Benner, Chesla, & Gordon, 1993), a prerequisite for quality in nursing care (Aronson, 2004) and valued by recipients (Woodward et al., 2004). For patients and their next of kin, informed carers mean that they do not have to re-explain constantly how the patient should be cared for when meeting different carers. Having to inform health personnel who should have been informed beforehand is reported as frustrating and affects the experience of continuity (Woodward et al., 2004).

In home health care, information is exchanged orally through regular report meetings and conversations between personnel, or written through documentation in the patient record. An example of oral reporting is the shift report (Meißner et al., 2007), which in home health care normally takes place in the morning, the afternoon and the evening. The purpose of the shift report is to provide updated information about the patients and relevant organizational issues in the workplace to the next shift, as well as instructions and assignment of tasks. However, to be able to secure valid and relevant information exchange, oral reporting is not enough. The information must be retrievable by relevant personnel when it is relevant to provision of care to the individual patient, preferably through comprehensive written nursing documentation (Moen et al., 2008).

Previous research concerning the informational dimension of continuity has revealed that in general, there is a lack of comprehensive nursing documentation (Ehnfors & Smedby, 1993; Ehrenberg & Ehnfors, 1999, 2001; Stokke & Kalfoss, 1999; Törnvall & Wilhelmsson, 2008; Törnvall, Wilhelmsson, & Wahren, 2004), which is assumed to pose a threat to continuity of care.

The issue of documentation and information exchange remains of great interest within nursing research in general (Blair & Smith, 2012; Wang, Hailey, & Yu, 2011) and for home dwelling patients during inter-organizational transitions (Olsen et al., 2013) and intra-organizational home health care (Gjevjon & Hellesø, 2010). However, the information exchange processes and the quality of the information or documentation are beyond the scope of this study. These issues are thoroughly described and discussed in numerous studies; some examples are provided above. In this study, the informational dimension is addressed with a broad focus; that is, having or lacking information about the patient when providing care.

4. METHODS

4.1 Study design

A cross-sectional design comprising different methods was applied to answer the research questions addressing continuity in home health care, seen from different perspectives. Using a variety of methods is useful for studying complex phenomena and yields a more complete picture of practice (Lund, 2012; Risjord, 2010; Robson, 2002; Teddlie & Tashakkori, 2009). Quantitative and qualitative data were collected simultaneously from different data sources within the same period. A schematic overview of the three sub-studies is presented in Table 1.

Table 1. Overview of the three sub-studies included in the thesis (Paper I-III)

	I	**II**	**III**
Aim(s)	To provide a method for assessing the degree of interpersonal continuity adapted to context; To measure and assess the degree of interpersonal continuity for long-term recipients dependent on daily home health care	To study continuity of care from a manager's perspective	To study continuity of care from the perspective of patients and their next of kin and to assess the degree of agreement between them
Study design	Cross-sectional, descriptive	Descriptive	Cross-sectional, descriptive
Method	Methods development; Quantitative measurements and assessments	Qualitative semi-structured interviews	Quantitative structured interviews
Data sources	From 12 municipal units within 10 municipalities, 16 home health care districts:		
	Administrative data from registers and patient records concerning 79 home health care patients assigned daily and long-term home health care	Data from interviews with 16 managers of home health care districts	Data from interviews with 75 matched pairs of patients and their next of kin.
Data analysis	Quantitative: Descriptive analysis; Calculating benchmarks; Comparing measures with benchmarks	Qualitative: Combining theory-driven and data-driven analysis	Quantitative: Descriptive analysis; Cohen's weighted kappa (K_w)

4.2 Setting and sampling strategy

The study was conducted in 16 home health care districts in Norwegian municipalities. A home health care district covers a geographical area within the municipality (Jensen, 2009).

There might be several districts in one municipality, depending on the municipality's size. In many small municipalities, a single district covers the whole municipality. The health personnel affiliated to the district have the responsibility for providing care to the patients living within the geographical area of the district (ibid.). The number of inhabitants is an essential variable in health services research in Norway due to documented differences between small and large municipalities regarding how health care is organized (Romøren, 2006; Valset & Romøren, 2006) and experienced by recipients and potential recipients of care (Agency for Public Management and eGovernment, 2010). Hence, the municipalities were chosen based on size, measured by the number of inhabitants.

We used staged sampling for this study (Polit & Beck, 2008). First, we chose a purposive sampling strategy to select a maximum variation sample of municipalities (see Table 2). Maximum variation sampling is a widely used method for purposive sampling to identify common patterns and understandings across a range of variations within the sample (Teddlie & Tashakkori, 2009). We approached the research field by means of a formal letter to the head of the health care services in each municipal unit (Appendix 2) and followed up this letter with a telephone call. After consent to participate had been provided, a local administrator facilitated the data collection by assigning a contact person to the project and selecting which home health care district would participate. All contact persons received a document with information about the background for the study, the study design, the data collection plans and procedures, as well as information about the researcher and the researcher team (Appendix 3). We recruited 12 Norwegian municipal units ranging from about 1 400 inhabitants to about 46 000 inhabitants with a mean of about 19 000[2]. We included four urban districts to represent the two largest cities in Norway: one city in Western Norway and the other in Eastern Norway, comprising 260 000 and 600 000 inhabitants, respectively. The other units in the sample covered entire municipalities. In some of the units, the local administrator selected two home health care districts to participate in the study. This was for practical reasons, such as dividing the work between two contact persons and districts to minimize the workload, and enabling smaller municipalities to achieve the requested number of participants. Hence, the total number of participating home health care districts was 16.

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[2] These numbers are rounded to the nearest 100

An overview of the participating municipal units and relevant demographic information is shown in Table 2.

Table 2. Participating municipalities distributed by size, and demographic information retrieved for the year of 2009

Municipality number	*Municipal units*	*Number of home health care districts in the municipal unit (districts participating in the study)*	*Number of inhabitants*[1]
1	**Municipality**		**600000**
1a	Urban district	2 (1)	46000
1b	Urban district	2 (2)	42000
2	**Municipality**		**260000**
2a	Urban district	2 (2)	38000
2b	Urban district	2 (1)	37000
3	Municipality	2 (2)	19500
4	Municipality	2 (1)	19000
5	Municipality	2 (1)	9000
6	Municipality	2 (2)	7000
7	Municipality	1 (1)	6000
8	Municipality	1 (1)	4000
9	Municipality	1 (1)	2500
10	Municipality	1 (1)	1400
10 municipalities, 16 municipal units		*20 districts (16)*	*231400 (4.6 % of the total population in Norway, N=5000 000)*

[1] Population rounded to the nearest 100

Second, the sample of patients for participation was randomly chosen from a list of eligible patients in each home health care district and the sample of next of kin was established after the patients had been approached and informed about the possible participation of their next of kin. Simultaneously, administrative data and health information were collected retrospectively with the patients' consent. The various data sources and the inclusion process are presented and elaborated on in the following.

4.3 Data sources

Managers

The inclusion criteria for the managers were that he or she should be the manager responsible for the delivery of home health care and for managing and organizing the staff who provided care to the patients. He or she should also have at least six months of experience as a manager. The managers were approached by means of a letter containing information about the study and a consent form (Appendix 3). All the managers who were approached gave their written consent to participate, giving a sample of 16. Fourteen of the managers were women and two were men. Their experience as a manager varied from six months to 28 years. All of the participants had a bachelor's degree in nursing and nine had additional management education.

Patients

The inclusion criteria for the patients were age (70 years or older), frequency of care visits (at least once a day), long-term care (>3 months), adequate cognitive function (no obvious impairment according to nurses' clinical judgement), ability to communicate in Norwegian and to give informed consent.

The contact persons identified 218 patients who met the inclusion criteria. From the list of eligible patients, 15 from each district[3] were randomly chosen to receive written and oral information about the study (Appendix 3) and were given the opportunity to consent or decline to participate. In total, 177 patients were approached. Our aim was to include 10-15 patients from each municipal unit because we regarded a number of 120-180 patients as manageable for conducting face-to-face interviews. If the number of patients giving consent was below 10, new patients were approached, where possible, until 10 patients had given their consent. The final sample consisted of 125 patients from 16 districts in 12 municipal units, approximately 10 patients per unit (a range of 9 to 12), 71% of the patients who were approached.

All 125 patients, 46 men and 79 women, received daily and long-term home health care (1-7 times a day, mean 2.1, median 2) and had received care, from commencement, for a period ranging from three months up to 32 years at the time of the interview (mean 4 years, median 3 years). Mean age was 85.5 years with a median of 86 years and a range of 68-97 years. We accepted the inclusion of one patient aged below 70 to reach an acceptable number of patients in one small municipality.

Seventy-seven per cent of the patients lived alone and 56% lived in a home adapted for living with disabilities. The majority (72 %) of the patients had one or more functional limitations. Here, functional limitation is defined as needing personal assistance. Even a frail patient

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[3] In one small municipality, only 12 patients met the inclusion criteria, and the total number of patients who consented to participate was below 10.

might be regarded as independent if the patient could use technical aids to perform a function adequately without personal assistance (Romøren & Blekeseaune, 2003).

Next of kin

Inclusion criteria were that the person was listed in the patient record as next of kin to the patient, had adequate cognitive function (no known impairment), was able to communicate in Norwegian and was able to give informed consent.

After the 177 selected patients had been informed about the study, their next of kin were approached by means of a letter containing information about the study, including the inclusion of patients, and a consent form (Appendix 3). The patients were informed that the next of kin would be asked to participate as well. The final sample of next of kin was 92, 52% of the next of kin approached.

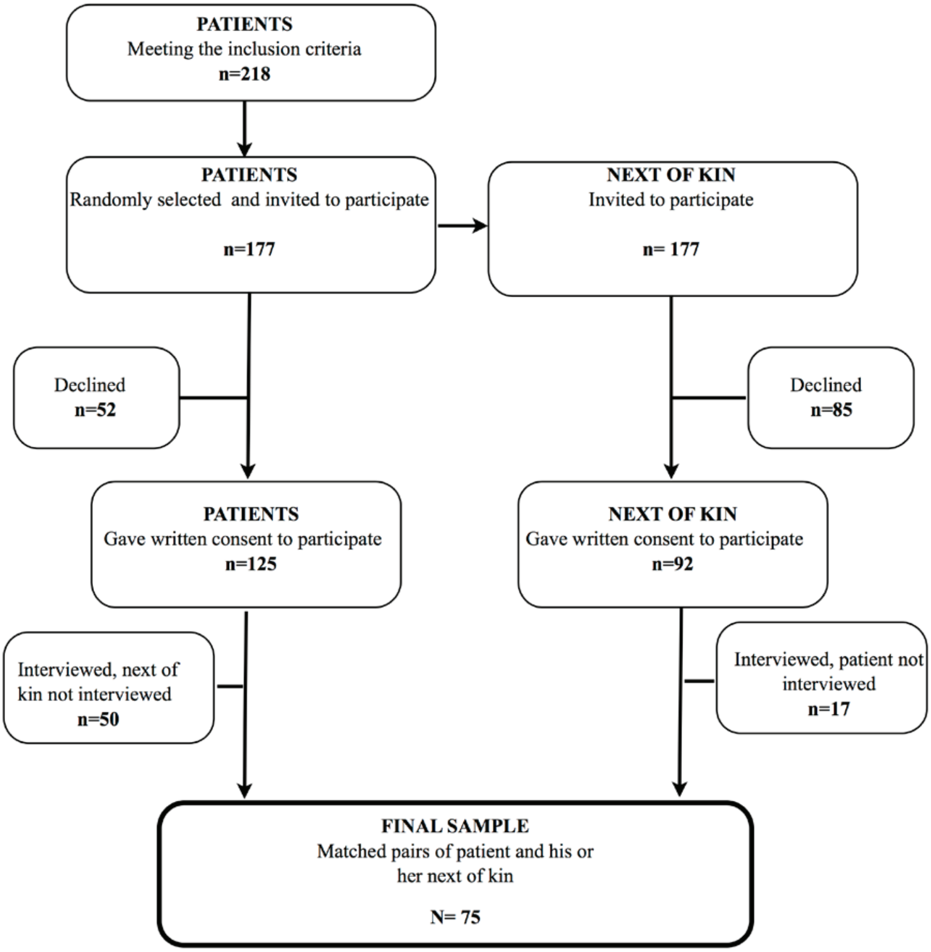
The sample of next of kin consisted of 34 men and 58 women, in the age range 36-89, mean 59.7 (median 59). Most of the next of kin were daughters (34%) or sons (26%); 20% were spouses, 18% other family and 2% were non-family. Twenty-eight per cent of the next of kin lived with the patient.

Matched pairs

Figure 2 illustrates the inclusion process of patients and next of kin, in total 217 participants. Due to decisions on sub-study design (III), we excluded data from 50 patients and 17 next of kin. We chose to focus on similarities and differences in how patients and next of kin experienced continuity in home health care and hence, the sample of 75 matched pairs, instead of the whole sample of 125 patients and 92 next of kin, was used. The rationale behind this decision was that we found it especially interesting to compare how the patient and his or her next of kin experienced continuity of care in the care provision, that is, when reporting from the same care trajectory. Based on cross-table analysis with regard to gender and age between the samples of patients and next of kin respectively, no statistically significant differences were found between those who were included and those excluded in the sub-study.

Using the whole sample of 125 patients and 92 next of kin would have provided a larger sample, which would have strengthened the external validity. However, by doing so we would only have been able to explore general differences in how patients and their next of kin experienced continuity of care. By assessing the degree of agreement between matched pairs of participants, we were able to identify specific differences in their views and assessments about their experience of continuity in home health care.

Figure 2. Flow chart of the sampling process for sub-study III: 'Continuity in home health care – patients' and their next of kin's perspectives*

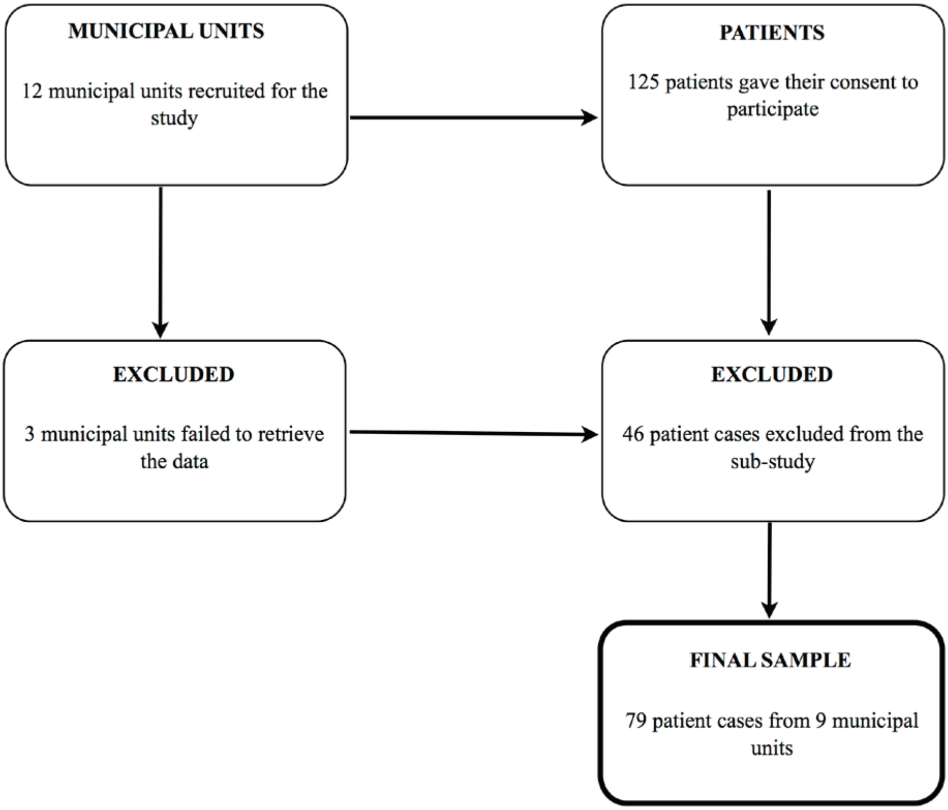


*From Gjevjon, Romøren & Hellesø (submitted), p. 3.

Administrative data

Administrative data were collected from administrative plans and work schedules so that information about the number of visits, the sequence of visits, the number of carers and the different carers could be obtained. Although 125 patients gave their consent to participate, we were only able to collect administrative data from 79 patient cases, representing 63% of the consenting patients. Only four units could retrieve the information needed by means of automated reports. The rest of the units used a form developed by the research team for this purpose, or printed out a large amount of non-structured data. One small and one medium-sized unit did not keep any information after assigning the carers for care provision despite being informed about the study process, and retrospective data collection was thus not possible. One large unit did use its electronic record system for planning and organizing care assignments, but declined to retrieve the data due to resource issues. Figure 3 illustrates the sampling process for the sub-study (I).

Figure 3. Flow chart of the sampling process for sub-study I: 'Measuring interpersonal continuity in high-frequency home healthcare services'



Patients' health information

In this study, health information consisted of data about the patients' functional status measured in terms of Activities of Daily Living (ADL) (Kempen, 1990). The patient's ADL level was routinely assessed beforehand by health personnel using the ADL variables in

IPLOS[4]. All applicants for and recipients of home health care are registered in and assessed in accordance with IPLOS, which is a national obligatory register containing relevant and standardized information about all persons who request or receive municipal health care and social care (The Norwegian Directorate of Health, 2013). The provider is responsible for reassessing the patient at least twice a year, or every time there is a change in the patient's care needs (ibid.). One part of the IPLOS register contains an assessment instrument, which comprises 17 items categorized by a work group at the Directorate of Health in terms of Social Functioning; Mastering Health Condition; Household; Self-care; and Cognition (Strand, 2010). We collected the self-care variables *washing, eating, dressing, toileting* and *indoor mobility* to indicate the patients' functional level.

4.4 Data collection

The data collection took place in each municipal unit, at the workplace in the care district (I, II), in the patients' home (III), or at a distance by telephone (III). Data collection started in January 2009, and was completed in May 2010. This chapter describes the data collection instruments and data collection procedures.

4.4.1 Data collection instruments

Continuity indices

We developed a method for adapting two established continuity indices to context so that the degree of interpersonal continuity could be assessed. The indices used in this study were Continuity of Care Index (COC) (Bice & Boxerman, 1977) and Sequential Continuity Index (SECON) (Steinwachs, 1979). These indices are presented and explained in Table 3.

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[4] IPLOS is an acronym for *Individbasert pleie- og omsorgsstatistikk* [National statistics linked to individual needs for care].

Table 3. Measures of interpersonal continuity*

Measure:	*Purpose:*	*Properties:*
Continuity of Care Index $\mathrm{COC} = \frac{\sum_{j=1}^{s} \mathrm{n}_{\mathrm{j}}^{2} - \mathrm{n}}{\mathrm{n}(\mathrm{n}-1)}$	An index for the dispersion of the carers: the total number of carers, the number of interactions between patient and individual carers and the total number of interactions.	n is the total number of visits from the carers, n_j is the number of visits by the individual carer j, and s is the total number of carers visiting the patient within the four weeks of investigation. Score 1= all the visits are made by the same person/ 0 = none of the carers are the same
Sequential Continuity SECON= $\frac{\sum_{i=1}^{n-1} s_i}{n-1}$	An index for the sequence of visits: the order of which the carers visit the patient.	n is the total number of visits from the carers, which generate $n-1$ sequential pairs of visits. Values assigned to si; $s = 1$ if i and $i + 1$ are to the same carer and $s = 0$ otherwise. We disregard additional visits by the same carer within the same shift. Visits by the same carer from one day to another were counted as a sequence.

*From Gjevjon, Eika, Romøren & Landmark (2013), p 4.

A full-time shift plan

To be able to adapt the continuity indices to context, a common six-week roster (shift plan) for a full-time employee was used to calculate the benchmark representing highest feasible continuity scores in practice. The roster complied with Norwegian labour laws and regulations.

The roster was retrieved from a development centre for home care in a municipal unit not included in the study sample. The process of adapting the measures to context is described in detail in Paper I.

Semi-structured interview guides

A semi-structured approach with a written interview guide was used to collect data from the perspective of managers. The questions in the interview guide were ordered in a logical sequence to ensure that the topics of interest were covered (Polit & Beck, 2008). First, an open question was asked to get a picture of the managers' role and responsibility, followed by questions that concerned home health care more specifically. These questions emphasized continuity of care corresponding to the three dimensions of continuity of care described in the literature (see Chapter 3). The interview guide was presented to and discussed with one manager in a municipal unit that was not included in the final sample as well as with researcher colleagues and co-authors before it was used for data collection. The interview guide is shown in Appendix 5.

Structured interview guides

A structured approach by means of a structured interview guide was used to collect data from the perspective of patients and next of kin (III). The interview guides consisted of questions on background factors, on general issues regarding perceptions of care received, and on specified issues regarding continuity of care. The interview guides were developed through phases inspired by Haraldsen's (1999) recommendations for questionnaire development, as listed in Table 4.

Table 4. Phases of the development of structured interview guides

Phases	
1	Literature review and operationalization
2	First version reviewed and assessed by persons with domain knowledge
3	Pilot test
4	Final version

Phase 1: Literature review and operationalization

The operationalization of continuity in home health care from the perspectives of patients and next of kin was based on relevant conceptual and empirical literature addressing continuity of care (Chapter 3) and empirical literature concerning home health care (Chapters 2 and 3). In addition, questions from previous Norwegian survey studies of care recipients' welfare, living conditions and assessment of health and care services were reused:

- A survey exploring patient experiences in Norwegian nursing homes, home care and home health care (6 questions) (Næss, 2003).
- A survey exploring patient experiences in Norwegian hospitals (2 questions) (Guldvog, Hofoss, Pettersen, Ebbesen, & Rønning, 1998).
- A survey of home health care users' care satisfaction in the municipality of Oslo (2 questions) (Theisen, Falck-Monsen, & Karterud, 2008).

Initially, I formulated questions that had high face validity, that is, questions that appeared to measure what they were expected to measure. Therefore, the first draft was more extensive than the final draft, with the intention that the drafts should be narrowed during the process, resulting in well-formulated and focused questions.

Phase 2: First version reviewed and assessed by persons with domain knowledge

A group of persons with domain knowledge, consisting of one nurse manager and two nurse consultants (nurses) from a home health care district in a municipal unit that was not included in the final sample, two colleagues and two of my supervisors, assessed the first draft of the interview guides. The nurse consultants and the nurse manager were informed about the study, the study aim and the goal for the interviews before they made their assessments. As a guide to the assessment, they were asked to evaluate the interview guides and specify their answers.

The interview guides were revised according to the assessments and comments made in Phase 2. A second version was then developed.

Phase 3: Pilot test

A pilot test was undertaken to test the questions on persons representing the participants: nine patients and five next of kin, all meeting the inclusion criteria for the study. These participants were connected to a home health care district in a municipal unit not included in the final sample. The test persons were informed about the study beforehand, as the participants in the actual study were to be. The interviews were conducted in the same manner as the interviews in the actual study were planned to be. I conducted all of these interviews myself. After the interview, I asked the participants to provide feedback about how they experienced the interview, whether the questions were clear and logical, difficult or easy to answer; and whether they understood the questions as relevant and descriptive for their experience of their encounters with the home health care service as care recipients and next of kin, respectively.

Phase 4: Final version

The final versions were based on the procedures described above. The interview guide used in interviews with patients was reduced by 10 questions and one question was added to the interview guide used to interview the next of kin. The questions mainly addressed continuity in home health care, as described earlier. Patients were also asked questions relevant for collecting background information such as duration of and extent of receiving care services, self-rated life situation and self-rated health situation, age, marital status, previous occupation and living conditions. Next of kin were in turn asked questions about their collaboration with the home health care provider and contact with the patient. Other questions concerned their cooperation with the provider in addition to background information: their connection with the patient, visits to the patient, age, gender, marital status and occupation.

The closed-ended questions (main questions and sub-questions) had graded response alternatives. For the sub-study, questions were posed to both the patients and next of kin; in addition, some questions were specific to each participant group (see Paper III for details). The interview guides are included in Appendices 6 and 7. Within the framework of this study, we did not give priority to using data from the open-ended questions, nor did we analyse data from all of the questions, but chose to focus on the questions that were similar regarding the participants' experiences of continuity of care. The surplus data material will be used in future work.

4.4.2 Data collection procedures

Administrative data

The contact person in each municipal unit retrieved administrative data retrospectively from plans and working lists in electronic records or manual plans and working lists in accordance with procedures defined beforehand by me. The procedures, one for municipal units using electronic records for administrative registration and one for manual extraction of data, were provided in writing (Appendix 4).

Health information

Health information, in this study data on the patients' functional level, was retrieved retrospectively from the IPLOS registration in the patient record. The data were extracted by the contact person or by other health personnel with legal access to the patient records. All municipal units used electronic patient records.

Semi-structured interviews

Data on continuity in home health care from the managers' perspective were collected by means of semi-structured interviews. The interviews were conducted by me and took place in each manager's office, except for one conducted by telephone for practical reasons. The interviews started with an open question in which the managers were asked to identify and describe their main tasks as a manager. I then proceeded with questions in the interview guide, and when necessary asked follow-up questions to ensure that the themes were covered, relevant aspects of continuity in home health care were addressed, and answers were clarified.

During the interviews, the term ‘continuity of care’ was used directly and indirectly to determine the managers’ own understanding of continuity of care through what they said and through what they reported doing in practice, to look for consistencies and inconsistencies. The last question in all interviews was ‘Are there any questions you think I should have asked you, that I haven’t asked?’ This gave them the opportunity to give any information they themselves found relevant or important, and thus provided a basis for reflection after the interviews and for identifying potential new issues that had not been foreseen.

The taped interviews were transcribed by using HyperTRANSCRIBE (RESEARCHWARE, 2013) and the transcribed text was transferred to Microsoft Word files before the analysis was performed.

Structured interviews

Data on continuity in home health care from the perspective of patients and next of kin were collected by means of structured interviews. The patient interviews were undertaken in the patient’s own home by one interviewer from a group of eight. The interviewer called the patient to make an appointment for the interview. The interviewers followed the structured interview guide from beginning to end, but they were encouraged to try to make the interview as informal as possible by creating a natural situation of conversation. Most of the interviews were tape-recorded (n=102). Twenty-three patients declined tape recording.

Data that were collected through structured interviews were immediately entered into IBM SPSS and then scrutinized to check for errors or irregularities. The entries were verified in this process. Before the analyses were performed, the data files were re-checked and prepared. During the four-year research period, the statistics software SPSS, versions 16, 17, 18, 19 and 20 for Macintosh were used (IBM, 2013).

4.5 Data analysis

4.5.1 Analysing administrative data

The administrative data containing information about the number of carers, the number and sequence of visits made by these carers was analysed in three steps to make it possible to measure and assess interpersonal continuity, as shown in Table 5.

Table 5. Steps in data analysis to measure and assess the degree of interpersonal continuity	
Step	*Procedure*
1	We applied the COC and SECON indices to our sample and calculated continuity scores on each of the patient cases in a period of four weeks.
2	We simulated a four-week work situation using the shift plan by counting work presence by health personnel, i.e. when the carer could in principle be assigned to the same patient(s) on each of the days that the carer was at work.
3	We used each of the two measures to assess the degree of interpersonal continuity, by comparing the actual continuity scores calculated in the first step with the benchmark. The actual continuity score was measured as a percentage of the appropriate benchmark in each case.

We measured and assessed interpersonal continuity in context by simulating a four-week work situation counting work presence by health personnel according to a full-time shift plan. By doing so, we could estimate benchmarks indicating the highest feasible degree of continuity of care by the dispersion of carers (COC) and by the day-by-day sequence of carers (SECON). This gave us the opportunity to analyse the data against a benchmark that was realistic in practice. Both COC and SECON are based on a benchmark of 1, that the same carer visits the patient in every care visit (COC) or every day (SECON). The analysis was undertaken by comparing each case's actual continuity score on COC and SECON with the benchmark found using simulation (see Table 5). The actual continuity scores' percentage of the benchmark gave the degree of interpersonal continuity and revealed the potential for improvement in practice.

We used Microsoft Excel to sum and calculate continuity of care scores from individual table records and IBM SPSS Statistics 19 to perform descriptive analyses to describe frequency distributions, central tendencies and variability of the scores.

4.5.2 Analysing qualitative data from semi-structured interviews

The preliminary phase of the analysing process started during the data collection (Huberman & Miles, 2002). Personal notes were taken during the interviews and immediately afterwards. The notes taken during the interviews were keywords and leads that came to mind, and reflections based on my own experience as a manager in home health care. The reflections were actively used to clarify my preconceptions and pre-understanding about continuity of care, home health care and management to reduce bias when interpreting the findings (Jootun, McGhee, & Marland, 2009).

I used the three continuity dimensions (Figure 1) as an *a priori* template (Polit & Beck, 2008) and applied a theory-driven (deductive) and data-driven (inductive) coding scheme (Fereday & Muir-Cochrane, 2006). The analysis strategy is described in Table 6.

Table 6. Strategy for the analysis of semi-structured interviews with managers

Approach to data analysis	
Theory-driven coding	**Data-driven coding**
Deductive coding to organize data material according to manager's perspective on: 1. Interpersonal continuity 2. Informational continuity 3. Management continuity	Inductive coding to organize the data material according to the research questions: 1. How do managers understand the concept of continuity of care? 2. How do managers assess continuity of care? 3. How do managers work to ensure continuity?

Procedure	**Description of the data analysis procedure**
Reading the transcripts	Each transcription was read several times to provide an impression about the essence of each interview. A brief summary of each interview was written by hand.
Coding	Theory-driven and data-driven coding of the transcribed text was conducted. The coded text was extracted from the text and applied to a matrix with headings corresponding to the dimensions of continuity of care and the research questions, respectively.
Identification of themes	Identification of themes through comparison of the codes across and within the transcribed interviews (text). Validation with co-authors of Paper II.
Interpretation	Connection of text, codes and themes by describing the meaning of each theme in writing during the writing of the paper. Themes were further clustered, resulting in two overarching themes reflecting the study's final findings. Validation with co-authors of Paper II.

The analysis process was not as linear as it may appear in Table 6. The process was rather iterative and reflective, where the original transcribed text and summaries were re-read in the light of the codes, and the codes served as building blocks for the final development of themes. This process involved collective data examination and discussions with two of the co-authors of Paper II until there was consensus that the final themes reflected the main findings of the study.

4.5.3 Analysing quantitative data from structured interviews

Descriptive statistics were applied to display frequency distributions, central tendencies and variability of demographic and individual characteristics of the participants in addition to frequency distributions of responses from patients and their next of kin regarding their perspectives on continuity of care.

Cohen's weighted kappa (K_w) was used to calculate the level of agreement in each matched pair between the patient and the next of kin regarding the experience and assessment of continuity in home health care when they reported from the same patient care episode. The kappa statistic is widely used to measure agreement between two persons observing the same situation or phenomenon. Cohen's kappa (K) measures whether there is agreement or not between the observations made by the two persons, beyond what is expected by chance (Altman, 1991; Cohen, 1960). However, K treats all observations equally and does not take into account the degree of disagreement. The weighted kappa (K_w) takes into account the degree of disagreement by giving different weights to the disagreements relative to the proportions of inconsistency between the observers and hence strengthens the validity of the results (Altman, 1991).

4.6 Validity and reliability

Assessments of validity and reliability are essential in empirical research as they refer to the quality of the data and the trustworthiness of the inferences made on the basis of these data (Lund, 2005; Polit & Beck, 2012; Tashakkori & Teddlie, 2010). The study uses different methods; three sub-studies with different sub-study designs, two quantitative and one qualitative. Therefore, validity and reliability are discussed separately for each sub-study (I-III). In addition, validity and reliability concerning the overall study, i.e. across the three sub-studies, are discussed at the end of this chapter.

4.6.1 Sub-study I

The two indices, COC and SECON, are well known and widely used measures for continuity in medical care but seldom (COC) or never (SECON) used to measure continuity in nursing care. The measures are nevertheless considered valid across all health care settings (Jee & Cabana, 2006) due to the core elements of continuity of care; care for the individual patient and care over time (Haggerty et al., 2003). The original indices were however developed with a one-to-one interaction as the benchmark. Because one-to-one interactions over time are unfeasible in the context under study for this thesis, we found it necessary to adapt the measures to context to be able to retrieve valid results from the current study. The method that is developed in this study is general and applicable to all health care settings.

The reliability of the data can be compromised by measurement errors made by the researcher(s). The data collected were extensive, comprising data on care encounters between 79 individual patients and all of the carers visiting them during four weeks of a patient trajectory. These care encounters were registered and analysed. To prevent or correct errors, the data entries were made by two researchers in sequence. First, I structured the data and entered the care encounters into an IBM SPSS data file. Then a colleague, the fourth author of Paper I, entered the results from the descriptive analysis performed in IBM SPSS, the number of carers and the dispersion and sequence of visits, into a Microsoft Excel file. In this file, the equations for the indices (see Table 5) were entered as formulas for calculating the values representing interpersonal continuity with regard to dispersion (COC) and sequence (SECON). Finally, the concluding analyses to assess the latter values against the benchmark were made by using IBM SPSS version 19. Both of us checked and re-checked the data entries before applying the indices to the data.

4.6.2 Sub-study II

With regard to the interviews, a threat to the reliability of the data was that the data could be biased due to the interaction between the participants and the interviewer (Kvale & Brinkmann, 2009). When one conducts interviews, there is no assurance that the informants are telling the truth rather than trying to enhance the truth. Informants might be inclined to give answers they believe the researcher anticipates or wants, or to give the 'correct' answer (Tjora, 2012). In this regard, it was in some respects an advantage that I had domain knowledge and experience as a manager in home health care as I 'spoke their language'. My experience has given me a unique insight that enables me to identify patterns and complexities less visible for an outsider during the analysis (Jootun et al., 2009; Patton, 2002). Yet such domain knowledge may lead to biased conclusions because of personal views and preconceptions of the phenomenon under study (Polit & Beck, 2012). It is a possibility that being familiar with the field and the jargon causes the interviewer to take the interviewee's answers for granted, failing to pursue unexpected leads.

4.6.3 Sub-study III

The structured interview guides were pilot-tested. Persons with domain knowledge, that is, patients, next of kin, managers, nurses and researchers tested and evaluated the content of the interview guides. They reported that most of the questions were relevant and easy to answer.

Altogether, eight interviewers performed the 217 structured interviews: 125 with patients and 92 with next of kin. Using many interviewers might be a threat to the reliability of the data because the interviewers might have understood the answers from the participants differently (Haraldsen, 1999). Although most of the response alternatives were fixed, the setting itself, along with the instructions given to the interviewers, invited conversation between the parties and following the interview guide rigidly could thus be challenging. A course specifically designed for this study was obligatory for interviewers so that they could clarify questions in a uniform way and assist the respondents if they found it difficult to grade the answers (Appendix 8).

With the patients' consent, most of the interviews were audiotaped (102 of 125), so that, because of the number of different interviewers, I could assure the quality of the data entries by retrieving information if details were unclear or missing.

4.6.4 Validity and reliability across the sub-studies

Content validity

Content validity refers to how precisely relevant concepts are operationalized (Polit & Beck, 2012), in this study that the interview guides addressed what they were supposed to address: continuity of care. There is a broad consensus in the research literature on the basic understanding of the dimensions of continuity of care (see Chapter 3). A framework based on conceptual and empirical literature in addition to domain knowledge was drawn. This framework contributed to operationalizing continuity in home health care (Figure 1) and formed the basis of the study's interview guides. Studying a complex phenomenon, such as continuity of care, requires a multifaceted research approach (Robson, 2002). Sparbel & Anderson (2000b) concluded in a review of methodologies used to address continuity of care in nursing that the development and use of a conceptual framework would 'enhance understanding of this fundamental tenet of practice, anchor the research and strengthen the interpretation of findings' (Sparbel & Anderson, 2000b; p. 134). The latter authors further encourage studies combining different methods with a focus on different perspectives using a conceptual framework. The design of this study is consistent with their advice.

External validity

External validity refers to the degree to which inferences made on the basis of the results are generalizable to other settings or other patient groups, or conceptually beyond the empirical data generated from the study (Lund, 2005). I cannot claim that the results from this study are generalizable to all municipalities, patients, next of kin or managers in Norway, but we intended to enhance generalizability to similar contexts through the sampling scheme. We used staged sampling combining a non-probability sampling of municipalities and a probability sampling of patients and next of kin (Polit & Beck, 2012).

We selected a purposive sample of municipal units from municipalities mainly situated in the area of Eastern Norway. Within the scope of this research project, it would not be possible to attain a representative sample of Norwegian municipal units, geographically and by size. Therefore, we chose to select a maximum variation sample representing large contrasts in the population size of the municipal unit and hence, variations in how the home health care services are organized and provided (Agency for Public Management and eGovernment, 2010; Romøren, 2006; Valset & Romøren, 2006). An important advantage of such maximum variation sampling is that common patterns and understandings emerge across the diversity of the sample (Patton, 2002; Polit & Beck, 2012). See Table 2 for details about the sample of municipal units in the current study.

Due to the study's design, in which the participants' experiences and views were requested, the most frail and vulnerable patients were excluded from the study. This may have resulted in a response bias, as the participating patients were the least frail patients within the group of elderly patients receiving daily and long-term care in the municipalities. Frailer patients and their next of kin may have different experiences and make different assessments of continuity of care than those who participated in the study. We were not able to retrieve information about either the excluded persons or the persons rejecting participation and hence no comparisons between participating and non-participating patients were possible. Therefore, we do not know how representative the final sample was relative to the population of eligible patients in the municipal units. The patients in our sample are however representative of the population under study in terms of age and gender (Gabrielsen et al., 2010; Mørk et al., 2013; Sørbye, 2009). In Norway, the largest group (69%) of older (>67) home-based care recipients is over 80 years of age (Mørk et al., 2013). In our study 79% of the total sample of patients (N=125) were aged 80 or older and the mean age was 85.5 years. In Norway, the majority of the recipients are women (62%) (ibid.); in our sample, 63% were women. In the total sample of next of kin (N=92), the majority of the next of kin were the participants' children (61%), more daughters (32%) than sons (29%), followed by spouses (16%), other family members (19%) and non-family (4%). Similar findings are reported in a longitudinal Norwegian study, which is referred to in detail on page 10 in the present thesis (Romøren, 2003). A majority of the patients lived alone, in line with those participating in previous studies (Dale et al., 2011; Sørbye, 2009).

Before presenting the results from the three sub-studies, I will describe the approvals obtained and ethical issues considered prior to the commencement of the study.

4.7 Approvals and ethical considerations

The study was approved by the National Committees for Research Ethics in Norway (S-08673a 2008/18005), and the Norwegian Social Science Data Services gave consent for collection and filing of data material (Project number: 2000. Kontinuitet i hjemmetjenesten).

The research team provided oral and written information to the potential participants. Informed written consent was obtained from all participants. All participants were telephoned beforehand to confirm their consent and to make an appointment for the interview.

We provided written and oral assurance before the interview that if they gave their consent to participate they could still withdraw from the study at any time. Withdrawal or participation would not cause any consequences for them, their family, current or future services, or working conditions. We guaranteed confidentiality and took steps to ensure that the published results did not enable personal identification. All personal details about the patient that were needed by the interviewers, such as name, telephone number and address, were destroyed after the interview was completed.

Most of the interviews with patients were audiotaped with the patient's consent; 23 patients declined. When the SPSS file was complete and the data entries verified, the audio files were securely stored. These files cannot be connected to personal patient information. During the research process, only the main researcher and the contact persons were able to identify the participants. Identifying information was removed from the data by the contact person and replaced with a case ID number. A list connecting the ID number and personal patient information was securely stored within the research institution and destroyed after completion of the study.

Thorough instructions concerning preparations and completion of interviews were handed out in writing to the interviewers in addition to the five-hour course especially developed and held for this study (Appendix 8).

Elderly, frail recipients of home health care are in a vulnerable situation. Our participants were dependent on daily and long-term care due to functional limitations or chronic health problems. The interviews were undertaken in the participant's personal sphere, which required that the interviewers showed respect and sensitivity. The contact persons assessed the participants' ability to go through with an interview beforehand. In addition, the interviewers made ongoing assessments during the interview and were instructed to stop or postpone the interview if the participants showed signs of discomfort or tiredness. It was emphasized that the next of kin were not to answer any questions on behalf of the patient, but that they should answer the questions on behalf of themselves.

5. RESULTS

The results from the three sub-studies are summarized in this chapter. Table 7 provides an overview of the research questions, aims, knowledge contribution and papers.

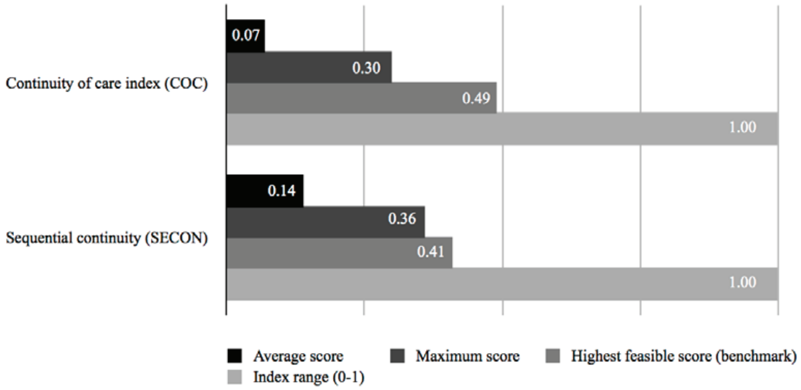
Table 7. Overview of research questions, aims, knowledge contribution and original papers

Sub-study	*Main research question*	*Aims*	*Knowledge contribution*	*Original paper*
I	What is the degree of continuity in the carer-patient encounters for elderly patients who receive daily and long-term home health care?	To provide a method for assessing the degree of interpersonal continuity adapted to context; To measure and assess the degree of interpersonal continuity for long-term recipients dependent on daily home health care	A new, general method for assessing the degree of interpersonal continuity; A degree of interpersonal continuity in practice; Identification of potential for improvement in continuity	I: 'Measuring interpersonal continuity of care in high-frequency home health care services'
II	From the perspective of care managers, how can continuity of care for elderly patients who receive daily and long-term home health care be achieved?	To study continuity of care from a manager's perspective	Managers' definition of continuity; Managers' possibilities and actions to ensure continuity in home health care	II: 'Continuity of care in home health care practice: two management paradoxes'
III	How is continuity in home health care experienced by patients dependent on daily care and their next of kin?	To study continuity of care from the perspective of patients and their next of kin and to assess the degree of agreement between them	How patients and their next of kin experience continuity in home health care; The degree of agreement between these perceptions	III: 'Continuity in home health care – patients' and their next of kin's perspectives'

Paper I: Measuring interpersonal continuity of care in high-frequency home health care services

We developed a method for assessing the degree of interpersonal continuity by adapting two existing continuity measures to context – the Continuity of Care Index and the Sequential Continuity Index – and by using a full-time shift plan. First, the indices were applied on administrative data retrieved from records concerning each patient. Then, the indices were applied to a full-time shift plan and a benchmark was established to represent the highest feasible degree of continuity of care, according to the specific shift plan. The percentage of continuity of care determined by comparing the actual continuity scores to the benchmarks represented the degree of interpersonal continuity in practice. Figure 4 shows a comparison between the average scores, the maximum scores, the highest feasible scores (benchmark) and the original index scales.

Figure 4. Average, maximum achieved and the highest feasible scores on continuity indices, aligned with index range[*]



[*] From Gjevjon, Eika, Romøren & Landmark (2013), p. 6.

The results demonstrated that the patients met many carers when receiving frequent care. During a period of one month, a mean of 17 carers visited the patients for care provision. Relative to the benchmark the scores were low, reflecting low interpersonal continuity. The patients seldom met the same carer – on average only three times per month. According to the shift plan, the patients could have met the same carer up to 16 times. The patient saw the same carer from one care episode to another about 15% of the times that would have been possible in practice according to an assessment of the dispersion of different carers (Continuity of Care Index), and 35% according to an assessment of the next-day sequence of carers (Sequential Continuity Index). In other words, it is in principle possible for a carer to visit the same patient every day that the carer is present at work. Our results imply that this seldom happens.

The study concludes that interpersonal continuity is low in the context of high frequency and long-term home health care. There is considerable potential for improvement. The context-specific method for measuring the degree of interpersonal continuity of care is general and applicable to all health care settings if a shift plan or work schedule is available.

Paper II: Continuity of care in home health care practice: two management paradoxes

For the managers, continuity of care was understood as patients being cared for by few carers. Ideally, the number of carers for each patient should be limited in practice. However, ensuring continuity of care for all patients was seen as challenging and even unfeasible. The managers stated that they faced challenges with regard to budget constraints, efficiency demands, staff shortages, heavy workloads for the staff and high rates of sickness absence.

The managers had a dual focus. Their responsibility as a manager was to prioritize patients' needs and preferences on one hand and to prioritize needs and preferences of the staff on the other. Hence, they expressed that they were forced to prioritize between and within patients and staff. Managers said that they gave some patients priority over others, such as patients with dementia or terminal cancer. Accordingly, patients with so-called minor care needs had to relate to more carers than the high-priority patients did. For clinical reasons, limiting the number of carers for patients with minor care needs was not seen as a necessity, as opposed to the situation of patients with major care needs. Consideration for the staff was seen as equally important. The managers reported that they sometimes prioritized well-being of the staff at the expense of interpersonal continuity for the patients. An important goal was to minimize the risk of sickness absence and burnout among the staff. Therefore, they said, flexible schedules for the staff were given preference over interpersonal continuity for the patient so that the staff could avoid heavy workloads. In addition, deliberate interpersonal discontinuity was seen as improving quality because the managers feared that seeing the same patient too often could blind the carer to new signs and symptoms.

The study concludes that the managers' work to ensure continuity of care led to paradoxical situations. They said they were forced to set priorities in conflict with ideals or professional standards on one hand and in conflict with the patient's wellbeing or the wellbeing of the staff on the other. According to the managers, it was impossible to achieve continuity of care for all patients.

Paper III: Continuity in home health care – patients' and their next of kin's perspectives

In general, both patients and their next of kin reported experiencing continuity of care with regard to how management and informational continuity is understood: A large majority said that the patient received necessary care. About half of them trusted the carers to be on time, and the carers were mainly seen as having knowledge and skills. A majority of patients and their next of kin reported that the carers were informed about the patient's situation and less than half of them experienced having to inform the carers themselves. At face value, patients and their next of kin seemed to have concurrent experiences with regard to management continuity and informational continuity but had different views on interpersonal continuity. Almost all of the patients reported that they met many carers in their home. Although about half of the patients regarded having few carers as important, only a minority – less than one third of the patients – said that they had too many carers. In contrast, almost two thirds of the next of kin assessed the number of carers as too high and more than two thirds considered it important for the patient to have few carers. Comparison of the variable scores showed that the level of agreement between the patients and their next of kin was predominantly poor for all three dimensions of continuity of care. Table 8 shows the degree of agreement on all variables distributed by the three dimensions of continuity of care.

Table 8. Continuity in home health care: Degree of agreement between the patient and his or her next of kin[*]

Interpersonal continuity in home health care	*Degree of agreement (K_w)*
Assessment of the number of carers	0.15
Importance of being cared for by few carers	0.13
Management continuity in home health care	*Degree of agreement (K_w)*
Patients get care as needed	0.35
Trusting carers to be on time	0.15
Experiencing that carers have competence and skills	0.06
Informational continuity in home health care	*Degree of agreement (K_w)*
Trusting carers to be informed	0.16
Experiencing that carers are informed about patient's situation	0.15

Cohen's weighted kappa (K_w) (Altman, 1991): < 0.20 = poor; 0.21-0.40 = fair; 0.41-0.60 = moderate; 0.61-0.80 = good; 0.81-1.00 = very good

[*] From Gjevjon, Romøren & Hellesø (submitted), p. 8.

The poor level of agreement shows that there was an overall incongruence between how patients and next of kin viewed and assessed continuity of care. Hence using the next of kin as a proxy, that is, representing the patient if he or she is unable or unwilling to communicate, should be done with caution.

6. DISCUSSION

This thesis addresses continuity of care for elderly patients who receive daily and long-term home health care. A variety of methods and perspectives has been used to study continuity in home health care. The study's design has strengths and limitations. Methodological choices that were made have influenced the results. Other approaches might have provided different insights (Polit & Beck, 2012; Robson, 2002). Therefore, methodological considerations are discussed prior to the discussion of the main results.

6.1 Methodological considerations

In this section, three methodological issues are given extra attention: 1) my own preconceptions and pre-understanding, 2) the structured interview guides, 3) data collection and response rate. These issues are discussed in particular because they represent important limitations to the study as well as strengths. It is therefore important to discuss these issues and to account for the choices that were made during the research process.

6.1.1 Preconceptions and pre-understanding

Conducting research in one's own professional field gives rise to some methodological challenges. Knowing the field well influences all parts of the research process, from the design of the study to the questions asked and results interpreted. 'Insider problems' such as the researcher's preconceptions and pre-understanding may lead to biased conclusions; the researcher may be blind to alternative explanations (Robson, 2002). Being an 'insider' may also be an advantage (ibid.). Pre-existing knowledge and experience of the service and the people involved are likely to facilitate the development of data collection instruments for asking nuanced and comprehensive questions to the data sources. It is however necessary for the researcher to be conscious of his or her pre-understanding and preconceptions about the phenomenon under study (Jootun et al., 2009). In the case of the present study, a threat to the reliability of the data and the validity of the results was my background as a manager and a nurse as well as my extensive and broad experience from working in home health care practice. My pre-understanding and preconceptions have affected the selection and formulation of the questions, the analysis of the data and the interpretation of the results. I tried to deal with this possible threat by keeping a research diary, which in addition to helping me keep track of the process (Robson, 2002) was valuable as a place to write my own reflections with regard to my preconceptions and pre-understanding. Such reflections are especially important to ensure reliability of the data that are collected (Jootun et al., 2009).

My domain knowledge was useful in the development of the data collection instruments. How the study's data collection instruments were developed is shown in Chapter 4.4.1.

6.1.2 Researcher-developed structured interview guides

Researcher-developed interview guides were used for data collection in sub-study III because we could not identify any interview guides or questionnaires covering the aspects of interest when commencing the study. Uijen et al. (2011) developed a questionnaire to measure continuity of care from the patient's perspective that could have been useful as a basis for the development of the current study's structured interview guides. 'The Nijmegen Continuity Questionnaire' was not published until after the completion of the data collection for the present study.

There are basic similarities between 'The Nijmegen Continuity Questionnaire' and the structured interview guides developed for the current study. They are all based on interpersonal aspects, informational aspects and management aspects of continuity of care. However, aspects specific to health care contexts where a high number of health care personnel within an organization interact with the patient on a long-term basis are not covered in 'The Nijmegen Continuity Questionnaire'. This questionnaire focuses on how the patient experiences his or her relationship with the most important care provider (doctor) and how he or she perceives the collaboration between health personnel, within and across inpatient and outpatient medical care settings (Uijen, Schellevis, et al., 2011). The structured interview guides developed and used for the present study focuses on how patients and next of kin experience interpersonal, informational and management continuity of care when a patient receives daily and long-term care from multiple carers in his or her own home.

6.1.3 Data collection and response rate

The structured interview guides used for interviews with patients and next of kin were similar to some extent. The patients were interviewed face-to-face while next of kin were interviewed by telephone. The choice of interview mode may have affected the response rate (Sapsford, 2007). Of 177 approached, 125 (71%) of the patients gave their consent to participate, and there were no dropouts during data collection. Collecting data through personal face-to-face interviews is regarded as the best method because of the quality of information provided (Polit & Beck, 2008, 2012). It is a costly data collection method, but compared with, for example, self-administered questionnaires the response rate tends to be higher (Sapsford, 2007). Moreover, for collecting subjective data from sick, old and frail people, face-to-face interviews might be the only suitable mode because filling out a self-administered questionnaire might be too demanding for this group of participants. Face-to-face interviews may provide some ethical challenges. The person being interviewed might find it more difficult to abort a face-to-face interview than to end a telephone call or stop answering a postal survey. Interviewees may feel that they cannot refuse to answer because the feeling of obligation is likely to be stronger when they are physically close to the person interviewing – in contrast to a distant telephone call.

Fewer next of kin participated than patients, 92 of 177 (52%). Next of kin, especially family members, are to a large degree dedicated to the welfare of their elders and they are often critical of the care that is provided (Kahanpää, 2006; Larsson, 2004; Öresland et al., 2008). One might therefore assume that next of kin would be eager to answer questions and share their experiences and views on the health care service provided to the patient. In addition, discussions and reports in the media create the impression that continuity of care is a topic of great interest to them (see footnote on page 50). The lower participation rate for next of kin may however not be caused by lower interest alone. Next of kin were interviewed by telephone. The response rate tends to be lower for telephone interviews (Sapsford, 2007). Interviewing 92 more persons face-to-face was not possible within the time frame and funding available for the research project. We gave priority to the interviews with patients in this regard. The use of telephone interviews is a less costly method than personal face-to-face interviews. Moreover, interviewing by telephone saves time, and a large number of respondents can be interviewed during a short period of time. Many perceive telephone interviews as intrusive or ‘pushy’, as most of us have experienced through telemarketing or market research calls. Procedures were developed to avoid potential participants experiencing our approach as ‘pushy’. After receiving their written consent to participate, the interviewers called the respondents beforehand and made appointments for the interview. Thus, the respondents were prepared when the interviewer called them to conduct the interview. There were no drop-outs after consent was given and the interviews were carried out as planned.

6.2 Discussion of the main results

This study provides new knowledge about continuity in home health care from the perspective of managers, patients and next of kin. The results show that their views and experiences are not the same, which confirms that continuity of care cannot be understood or defined in only one way. For managers and next of kin, the number of carers seemed to be the most important aspect of continuity of care. For the patient, the number of carers seemed subordinate to other aspects of care continuity. About half of the patients (49%), most of the next of kin (81%) and the managers regarded it as important that the patient had few carers to relate to, implying that a limited number of carers is generally preferred.

Through mathematical calculations, this study revealed that interpersonal continuity was low, and lower than necessary according to planned carer presence in terms of a typical shift plan. The patients met many carers during the four-week period of investigation. The managers described a situation where limiting the number of carers to each patient was difficult or even unfeasible because of clinical and resource priorities. Most of the patients (88%) confirmed that they received many carers in their home and the majority of their next of kin (60%) regarded the number of carers as too high.

The managers said that they gave more attention to and higher priority to those whom they assessed as needing interpersonal continuity the most, such as terminally ill patients or persons with dementia. This means that lower priority was given to the ‘typical’ elderly patient, like the ones comprising the sample in the present study, although many of them had chronic conditions and all of them needed daily and long-term care. In addition, the well-being of the staff in terms of avoiding burnout and sickness absence sometimes came before interpersonal continuity of care for the patients, especially for those with minor care needs – again, ‘the typical patient’. The latter practice is open to criticism. According to how they described their deliberations the managers gave the impression that they saw the well-being of patients and staff as well as managing the resources as equally important management goals. According to Johansson et al. (2007) managers define themselves as both nurses and managers; yet, being a nurse prioritizing the ‘nurse goal’ was seen as the most important activity before ‘the administrator goal’ and ‘the leadership goal’ (p. 153). According to findings from the present study managers expressed that they wanted to limit the number of carers to each patient. In practice they said, they were not always able to prioritize according to their nursing ideals because they also had to prioritize the well-being of the staff or organizational issues. These are examples of ‘contradictory rationales’ that may reduce continuity of care in a patient’s care trajectory (Kjerholt, Wagner, Delmar, Clemensen, & Lindhardt, 2013; p. 9). The managers accepted low interpersonal continuity for patients as a working compromise.

The main goal of any health care provision is quality of care for each patient, which includes having attention to continuity of care and to the patient’s needs (Ministry of health and care services, 2003). A manager's main responsibility is therefore to assure that each patient receives the care that he or she needs, when he or she needs it, by skilled personnel. Obviously, professional health care is about caring for the sick and frail, not for professionals, and therefore the patient should always be given priority over the staff (Nordhaug & Nortvedt, 2011). Prioritizing otherwise may pose a threat to the quality of care (Tønnessen, Nortvedt, & Førde, 2011). Health personnel typically assume that patients want to see the same carer as often as possible and over time and correspondingly, that low interpersonal continuity of care is a result of failure in the organization (Heaton et al., 2012). Researchers have associated system flaws or low quality of care with low interpersonal continuity of care (Byrne, Frazee, Sims-Gould, & Martin-Matthews, 2012; Moe et al., 2013; Sharman et al., 2008; Tønnessen et al., 2011; Öresland et al., 2008). Previous doctoral studies addressing home health care in Norway interpreted the high number of carers per patient as a lack of continuity of care (Dale, 2009), as a lack of individualized care and hence, unsatisfactory and against the principles of good nursing (Moe, 2013; Tønnessen, 2011). Therefore, the results from the current study might be seen as alarming from a professional perspective; the patients had to relate to 17 different carers on average during a month, and they saw the same carer only three times on average when, according to the shift plan, they could have seen him or her 16 times. Moreover, almost none of the patients reported having a primary carer and according to the managers only a few, the most frail and ill patients, were given priority in terms of limiting the number of carers.

Given the focus on interpersonal continuity as an ideal in home health care (Byrne et al., 2012; Dale et al., 2011; Karlsson et al., 2013; Moe et al., 2013; Olsson & Ingvad, 2001; Sharman et al., 2008; Öresland et al., 2008) and in the media[5], it is rather surprising that the majority of patients (77%) did not regard the high number of carers as excessive, but unproblematic. However, similar results were found in an earlier Norwegian study (Næss, 2003). In contrast to studies suggesting that patients dependent on care prefer a close,

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[5] Some examples of how continuity of care is described in Norwegian media:

Stavanger Aftenblad: *For mange ulike pleiere på besøk.[Too many carers visiting] URL (10.12.2008): http://www.aftenbladet.no/nyheter/lokalt/stavanger/ndash-For-mange-ulike-pleiere-p-besk-2807053.html#.UatI8ZW_3Qk*
Bergen Arbeideravis: *Gyda (68) gruer seg til hjemmesykepleieren kommer. [Gyda dreads the visit from the home health carer]* URL (21.02.2011): http://www.ba.no/nyheter/article5938079.ece
NRK: *Hjelpetrengende må forholde seg til opptil 25 pleiere.[Care dependents have to relate to up to 25 carers]* URL (15.07.2011): http://www.nrk.no/ostafjells/telemark/helsetilsynet-refser-hjemmetjeneste-1.7714341
NRK: *Skal slippe ukjente ansikter. [No more unfamiliar faces]* URL (17.01.2012): http://www.nrk.no/sorlandet/skal-slippe-ukjente-ansikter-1.7957419

personal and mutual relationship with one or few carers (Moe, 2013; Tønnessen, 2011) having such relationships is perhaps not important for or not even preferred by all patients.

It is not unlikely that some patients enjoy having many visitors, for example if they cannot be socially active outside the home. Over time, carers may then become a part of the social network for homebound patients with a reduced network. Having a social network or not may have an impact on a person's health. Social isolation and loneliness are risk factors for physical, mental and psychosocial problems (Cornwell & Waite, 2009; Luanaigh & Lawlor, 2008). Receiving long-term care at home becomes a significant part of everyday life for patients and their next of kin, so that *knowing the carers* might be especially important. Correspondingly, knowing the patient and his or her next of kin is equally important for the carers (Stajduhar, 2011). Having established a relationship with a carer who knows him or her promotes trust and predictability for both patients and next of kin (Byrne et al., 2012; Parker et al., 2011; Waibel et al., 2011; Woodward et al., 2004), thus being visited by a stranger may be a negative experience for them (Öresland, Määttä, Norberg, & Lützén, 2009). Moreover, having a trusting relationship with a health professional strengthens the patient's control of his or her situation (Kristensson et al., 2010) and self-determination (Breitholtz, Snellman, & Fagerberg, 2012). However, because of time-pressured working conditions and conflict situations between the patient's needs and organizational issues, interpersonal contact between a health professional and a patient is found to be less prioritized (Breitholtz, 2013), in line with findings from the present study.

With an increasing number of carers, it is easy to assume that the ability to establish a trusting relationship with carers will decrease. However, a majority of the patients in the present study reported knowing the carers who visited them (69%), and most of them (75%) had met all or almost all of the previous week's carers before. In contrast, only 41% of the next of kin reported knowing the carers. These findings may therefore imply that for the patients, knowing the carers could compensate for possible disadvantages of having to relate to many carers. For the next of kin, not knowing the carers might partly explain why they are more critical of the service than the patients are.

In the present study patients may actually have expressed a genuine satisfaction with the care they have received, although this is inconsistent with the views of their next of kin and professional ideals promoted by the managers. Patients might accept, appreciate and even choose discontinuity of care when wanting a second opinion, wanting staff with better skills or wanting a distance from the service (Parker et al. 2011). Freeman and colleagues (2007) related patients' acceptance of low interpersonal continuity to a trade-off with service access, meaning that for patients, having access to health care was more important than seeing the same person. In the context under study, the whole group of carers designated to a care district, or in some districts a smaller team, catered for the care provision to each patient. Bergland's term 'generalized caregiver', which refers to the group of carers rather than individual carers (2005; p. 370), is a suitable term in this regard. In Bergland's study, some nursing home residents found it more important to receive competent care than to receive care from specific persons, while others preferred a closer relationship with one or few carers (Bergland, 2005). In the context of long-term home health care, one might assume that many patients who receive care from multiple carers see the many carers as the 'generalized caregiver' and hence, might experience continuity of care in terms of 'uninterrupted service delivery' from competent carers (Woodward et al., 2004; p. 182). A patient then emphasizes getting the care he or she needs; the fact that different carers perform the task might be subordinate in this regard. The majority of both patients and next of kin in the present study reported that the patient received necessary care. They regarded the carers as having knowledge and skills, and they perceived the carers as informed about the patient's situation. Many trusted the carers to be on time. These are aspects reported to be important for continuity in home care, by patients, next of kin and personnel (Woodward et al., 2004).

According to Eika (2009) care dependents often refrain from making complaints about the service on which they depend. Therefore, it is important to have in mind that their assumed acceptance might instead be a result of having no choice but to accept the current situation (Eika, 2009; Fex, 2010). Recent studies imply that older patients receiving home health care are generally satisfied with the care they receive despite being cared for by many carers (Dale et al., 2011; Karlsson et al., 2013). In general, elderly patients are found to be more satisfied with care provision than younger patients. According to Hansen & Slagsvold (2012) elderly persons to a larger extent than younger ones adapt to the current situation by adjusting their goals and expectations. An important consequence of this adaptation might be that they refrain from sanctioning low quality of care, which in turn can lead to a vicious circle, as patients who do not sanction are in danger of receiving low quality care (Eika, 2009). In such a situation the patient's next of kin plays an important role. In Paper III, we concluded that using next of kin as proxy should be done with caution because of the low degree of agreement between them. Nevertheless, the next of kin is an important partner for both the patient and the provider (Dale, 2009; Sims-Gould & Martin-Matthews, 2010). In many circumstances it is an advantage, sometimes paramount, for the patient that his or her next of kin expect and demand higher quality of the care than the patient does, especially when the patient is unable to express his or her complaints (Eika, 2009). The discrepancy between how the majority of the patients assessed the number of carers (no problem) and how their next of kin did (too many carers) raises the question of whether these patients may have accepted an unfortunate situation.

According to Freeman (2012), over time there has been a shift in how continuity of care is understood, from an emphasis on the professional perspective towards an emphasis on the patient's perspective, meaning that the power of definition is transferred from health personnel to the patient. The present study's results imply that for older recipients of daily and long-term care, who are not terminally ill or suffering from dementia, meeting only few carers may not be the most important aspect of the care provision. However, that is not to say that interpersonal continuity of care is without importance. Interpersonal continuity of care improves the patient's psychosocial well-being (Birkeland & Natvig, 2008; D'Errico & Lewis, 2010) facilitates carers' early recognition of symptoms (Dick & Frazier, 2006), reduces the patient's need for emergency care (Russell *et al*. 2011) and improves the patient's ADL functionality (Russell et al., 2013). Whether interpersonal continuity is necessary for all patients has been questioned (D'Errico & Lewis, 2010; Freeman et al., 2001). Hence, giving some patients priority over others in this regard might be acceptable, in line with the practice reported by the managers and indications based on patients' answers in the current study. However, from a professional point of view such priorities may pose threats to the quality of care. For the next of kin, experiencing that a parent or a family member is being cared for by many and perhaps for them unknown carers is likely to increase their worries.

The study's results underline the complexity of continuity of care and therefore it is difficult to conclude whether continuity of care in the context under study can be achieved because, how continuity of care is experienced or assessed depends on from which perspective it is seen. However, Heaton et al. (2012) suggest that there has been a paradigm shift towards a new understanding of continuity of care as co-constructed between the provider (here the manager), the patient and the next of kin. According to this 'partnership paradigm', continuity is not delivered 'to' the patient, but rather achieved through collaborative interaction (p. 6). It is not obvious which patient needs interpersonal continuity the most.

Is it the patient with minor care needs who prefers being cared for by few carers because then he or she feels safe and secure? Or is it the patient who has a serious condition and extensive clinical needs, for whom the number of carers should be limited according to professional assessments, but who is nevertheless content to have many carers? Or perhaps it is the patient whose next of kin are worried and claim that the carers visiting the patient fail to detect deterioration because the same carer seldom or never arrives on two consecutive days. In all cases, professionals, including managers, must assess whether close follow-up from a nurse is necessary for the sake of the patient's treatment or care. Clinical assessments should however not be seen in isolation. For homebound care recipients, other factors may play an important role, such as living conditions, social networks, family relations or lifestyle challenges. Professional and management deliberations need to be complemented with descriptions and assessments of the patient's situation from the patient and the next of kin to achieve continuity of care.

7. CONCLUSIONS

This study has confirmed the initial assumption that achieving continuity of care in the realm of long-term home health care is difficult. The premise for this assumption is a general and common understanding of continuity of care as being dependent on the number of health professionals visiting the patient. The number of health professionals was found to be high and the degree of interpersonal continuity of care was low.

For most of the patients, the high number of carers did not seem to be a problem. This was in strong contrast to how their next of kin assessed the number of carers and in contrast to the continuity ideal promoted by the managers. Patients and their next of kin experienced continuity of care to some extent, according to how management and informational continuity is understood. Yet overall, the degree of agreement was predominantly poor. The patients made more positive assessments of continuity aspects than their next of kin did.

The managers regarded a limited number of carers for each patient as a prerequisite for continuity of care, but the managers were not able to provide such interpersonal continuity for all patients. They set priorities because of contextual constraints and competing management tasks and foci.

The possibility for a patient who receives daily care over time to see the same carer from one care episode to another or from one day to another is small in the context under study. Although interpersonal continuity is difficult to achieve in this context, the degree of interpersonal continuity was lower than necessary. According to the benchmark for the highest feasible degree of interpersonal continuity based on planned carer presence in a shift plan, the potential for improvement was considerable.

This study has shown that continuity in home health care is complex, and that perceptions of continuity depend on the perspective from which it is seen. Although the majority of the patients made positive assessments of interpersonal continuity despite being cared for by many carers the patient’s individual situation, their needs and preferences must be taken into consideration so that those in need of close follow-up from few carers are prioritized.

8. IMPLICATIONS FOR HOME HEALTH CARE PRACTICE

Having few carers to relate to is not necessarily important for all patients receiving frequent and long-term care. However, reducing the number of carers may still benefit patients. Although many patients regard visits by multiple carers as unproblematic, it is of clinical relevance that nurses visit the same patient on a regular basis. The frequency and sequence of visits by the same nurse or other health professional must be assessed in each case, in accordance with the patient's clinical and personal needs. In addition, the manager, the nurse and other health personnel should cooperate with patient's next of kin to ensure that the patient's interests are taken care of.

Various factors inhibit or complicate the achievement of interpersonal continuity, yet there is potential for improvement. Increased awareness of this potential might lead to actual improvement of interpersonal continuity by avoiding ad hoc planning of carer assignments, and instead scheduling visits by one carer to the same patient as often as possible. The method developed in this study enables the provider to estimate the degree of interpersonal continuity for the patient beforehand, to survey the degree of interpersonal continuity during the trajectory and to assess the quality of care.

This study has revealed that ensuring that each patient has only few carers to relate is unfeasible in this context. That does not necessarily mean that overall continuity in home health care is equally unfeasible. Ways to compensate for interpersonal discontinuity should be provided to ensure overall continuity of care in the individual patient trajectory. When interpersonal continuity is low, informational continuity is required in terms of written, comprehensive documentation in the patient record. Good planning and coordination of the care provision is imperative to be able to provide care that takes into account the patient's individual needs when resources are scarce.

9. RECOMMENDATIONS FOR FURTHER RESEARCH

This study contributes new knowledge in the increasingly important research field of long-term home health care. This is the first study addressing continuity of care in a context where the realm of long-term home health care *per se* presents challenges to achieving continuity of care for the patients receiving daily and long-term care. The study has provided knowledge about the degree of interpersonal continuity of care and the potential for improvement (I). It has identified how managers define continuity of care and what they do to ensure continuity for their patients (II), and describes how patients and their next of kin experience continuity of care and the degree of agreement between them (III). However, future studies are needed to fully understand and describe continuity in home health care practice. The current study has provided the first pieces of this picture.

We have provided a new method to measure and assess continuity of care, which we claim to be applicable to all health care settings (I). It would be useful to test its applicability in home health care practice; as a tool for planning and coordinating care as and a tool for surveying the service as a part of routine quality assessments. In this regard, an important question is whether such planning and coordination improve the degree of interpersonal continuity and the quality of care.

We have grounds for assuming that health personnel make deliberations and priorities that have an impact on continuity of care for patients (I, II), but we do not know if they see continuity of care as important, which dimension they emphasize in their work, or the rationales behind their priorities. Nor do we know the consequences that priorities made by managers and staff might have for patients.

We have suggested that, for long-term patients who receive daily care, being cared for by few carers might not be of great importance. According to the findings, they see a large number of carers as unproblematic and appropriate. We do not know the reasons for their answers, but the study has provided some assumptions that would be interesting to pursue. For example, do they reluctantly accept an unfortunate situation or are they genuinely satisfied? Why do they accept the situation, or why are they satisfied?

More studies are needed to explore the situation for the next of kin when a family member or a close friend receives daily and long-term care. For example, how do they experience being next of kin in such a situation; how is their relationship and collaboration with the services; what is the next of kin's role in the care provision?

It is necessary to study continuity of care for other patient groups receiving home health care, such as younger patients, terminally ill patients or cognitively impaired patients, to understand fully how continuity in home health care unfolds, and how managers and health professionals arrive at their priorities. For example, what is the degree of interpersonal continuity for younger patients? Are younger patients given priority over older patients in this regard? How do younger patients and their next of kin experience and assess continuity of care?

In this study, we did not use the term ‘continuity of care’ directly when interviewing patients and next of kin, but interpreted the results in accordance with the conceptual framework, which has been defined through reviews of existing research studies. There is a need for a conceptual understanding derived from those who receive and experience the care provision and therefore, studies discussing the term ‘continuity of care’ directly with patients and their next of kin are required.

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ERRATA

Page xii:
I. Gjevjon, E.L.R, Eika, K.H., Romøren, T.I., Landmark, B.F. Measuring interpersonal continuity of care in high-frequency home healthcare services. 2013; Journal of Advanced Nursing. Published online 22 July 2013, DOI: 10.1111/jan.12214

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Appendix 1

Approval from the National Committees for Research Ethics in Norway (REK)

UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

Tor Inge Romøren
Senter for omsorgsforskning
Høgskolen i Gjøvik
Pb. 191
2802 Gjøvik

Regional komité for medisinsk og helsefaglig forskningsetikk Sør-Øst A (REK Sør-Øst A)
Postboks 1130 Blindern
NO-0318 Oslo

Telefon: 22 84 46 66
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Nettadresse: www.etikkom.no

Dato: 17.11.08
Deres ref.:
Vår ref.: S-08673a 2008/18005

S-08673a Kontinuitet i hjemmetjenesten [6.2008.2018]

Vi viser til brev datert 12.11.08 med svar på komiteens merknader vedlagt reviderte informasjonsskriv, kopi av brev fra NSD samt kopi av svar til NSD.

Komiteen tar svar på merknader til etterretning.

Komiteen har ingen merknader til revidert informasjonsskriv med samtykkeerklæring.

Komiteen godkjenner at prosjektet gjennomføres.

Med vennlig hilsen

Kristian Hagestad
Fylkeslege cand.med., spes. i samf.med
Leder

Jørgen Hardang
Komitésekretær

Kopi: Edith Roth Gjevjon, edith.gjevjon@hig.no

Appendix 2

Template for letter to the municipalities

Senter for
omsorgsforskning
ØSTLANDET

Stipendiat Edith Roth Gjevjon,
Senter for omsorgsforskning, Høgskolen i Gjøvik,
Postboks 191,
2802 GJØVIK

[Navn]
[Kommune]
[Adresse]
[Postnummer,
poststed] [Dato]

Forespørsel om gjennomføring av forskningsprosjekt i [Navn] Kommune

Norsk Pensjonistforbund har initiert og finansiert et forskningsprosjekt rettet mot kontinuitet i hjemmetjenesten. Høgskolen i Gjøvik ved Senter for omsorgsforskning har fått i oppdrag å gjennomføre prosjektet, som er undertegnedes doktorgradsprosjekt. Hovedmålet med denne studien er å utvikle kunnskap om kontinuitet i hjemmetjenesten, hvilken betydning kontinuitet har for pasienter, for pårørende og for helsepersonell. Mer konkret vil studien bidra med ny kunnskap som kan danne grunnlag for å kunne finne frem til tiltak som gjør at pasienter i hjemmesykepleien får best mulig hjelp, både faglig sett og i forhold til egne ønsker. På administrativt nivå kan studien bidra til å styrke kunnskapsgrunnlaget for planlegging, utvikling og forbedring av tjenestene.

Prosjektet vil bli gjennomført på følgende måte:

Undersøkelsen vil bli gjennomført i hjemmesykepleietjenesten. Vi vil innhente data gjennom personlige intervjuer med hjelpetrengende eldre pasienter, deres nærmeste pårørende og avdelingsledere. I tillegg vil spørreskjema benyttes for innhenting av data fra ansatte i tjenesten. Data fra elektronisk pasientjournal vil gi viktige tilleggsopplysninger. Hovedtema for intervjuene er dagens situasjon for pasienter, pårørende, ansatte og ledere i et kontinuitetsperspektiv, både på individuelt og på organisatorisk nivå. Antall pasienter og pårørende som vil bli intervjuet i kommunen er 10-15, og vi vil intervjue nærmeste leder. Når det gjelder spørreskjemaet, vil vi inkludere alle ansatte i hjemmesykepleietjenesten. Journaldata vil bli samlet av avdelingens leder eller andre med rettmessig tilgang til slike data, oppnevnt av leder. Kun relevante data vil bli samlet inn etter at pasienten har gitt sitt samtykke til dette.

Undertegnede eller andre tilknyttet prosjektet skal ikke ha tilgang til journaler. Forskningen vil bli gjennomført i henhold til de etiske retningslinjene i Helsinkideklarasjonen og er tilrådet av Regionale komité for medisinsk og helsefaglig forskningsetikk (REK Sør-Øst) og Norsk Samfunnsvitenskapelige datatjeneste (NSD). All data vil bli oppbevart på et sikkert sted uten tilgang for andre enn undertegnede og prosjektets leder. Se vedlagt prosjektbeskrivelse for nærmere beskrivelse av studien.

Samfunnsvitenskapelige datatjeneste (NSD). All data vil bli oppbevart på et sikkert sted uten tilgang for andre enn undertegnede og prosjektets leder. Se vedlagt prosjektbeskrivelse for nærmere beskrivelse av studien.

For å kunne gjennomføre datasamlingen etter intensjonen har vi behov for noe bistand fra avdelingens leder eller en utnevnt kontaktperson. Lederen eller kontaktpersonen vil være

For å kunne gjennomføre datasamlingen etter intensjonen har vi behov for noe bistand fra avdelingens leder eller en utnevnt kontaktperson. Lederen eller kontaktpersonen vil være sentral i arbeidet med å velge ut aktuelle intervjupersoner, dvs. eldre tjenestemottakere som fyller inklusjonskriteriene, og deres nærmeste pårørende og å ta ut tilleggsopplysninger fra intervjupersonenes journaler. Datasamlingsprosedyrene er testet gjennom en pilotundersøkelse på forhånd. Dette gjør at gjennomføringen er godt forberedt og avdelingslederens ressursbruk for prosjektet ikke vil være større enn nødvendig.

[Kommunen] vil gjennom deltakelse i forskningsprosjektet medvirke til prosjektets mål om å bidra med et kunnskapsgrunnlag for utvikling og forbedring av hjemmebaserte tjenester til de skrøpeligste mottakerne og for planlegging, utvikling og forbedring av tjenestene.

Vi ønsker å kunne starte studien relativt raskt og ser for oss at første del (intervjuer) vil kunne bli gjennomført i tidsrommet [måned-måned] 2009 og andre del (spørreskjemaundersøkelse blant ansatte) høsten 2010. Prosjektet avsluttes i 2012. Professor Tor Inge Romøren ved Senter for omsorgsforskning, Høgskolen i Gjøvik er hovedveileder og prosjektansvarlig. Han kan kontaktes på telefon: [tlf.nr.] eller e-post: [e-postadresse]

Med vennlig hilsen

(Sign.)

Edith Roth Gjevjon,
Stipendiat ved Senter for omsorgsforskning, Høgskolen i Gjøvik,
Doktorgradsstudent ved Universitetet i Oslo
Telefon: [tlf.nr]
E-post: [e-postadresse]

Vedlegg:
Forkortet prosjektbeskrivelse av prosjektet "Kontinuitet i hjemmesykepleien"

Appendix 3

Information folder

Senter for
omsorgsforskning

Gjennomføring av forskningsprosjektet

Kontinuitet i hjemmesykepleien

Senter for omsorgsforskning, høgskolen i Gjøvik

Edith Roth Gjevjon©

2008/2009

Innhold

Senter for omsorgsforskning

Avtale om prosedyre for rekruttering og datasamling for forskningsprosjektet ”Kontinuitet i hjemmesykepleien”.

Denne avtalen fastsetter kriteriene for innhenting av data for ovennevnte prosjekt.

Datakilder og metoder:

Det skal samles inn data fra følgende kilder og med følgende metoder:

Kilder	**Metoder**
Eldre pasienter i hjemmesykepleien	Personlig intervju
Pårørende	Telefonintervju
Registerdata/sykepleiedokumentasjon	Utskrift
Nærmeste leder	Personlig intervju
Ansatte	Spørreskjema

Retningslinjer og prosedyrer

Det er utarbeidet detaljerte prosedyrer og retningslinjer for hvordan rekruttering av intervjupersoner og innsamling av data skal foregå. Kommunen/bydelen ved kontaktperson har fått disse utdelt og vil bistå prosjektet i henhold til disse.

Sted

For kommune/bydel
For prosjektet

Edith Roth Gjevjon

Kontinuitet i hjemmesykepleien

Kortfattet beskrivelse av forskningsprosjektet som gjennomføres av stipendiat Edith Roth Gjevjon ved Senter for omsorgsforskning, Høgskolen i Gjøvik.

Dette prosjektet er initiert og finansiert av Norsk Pensjonistforbund og skal gjennomføres som et doktorgradsprosjekt ved Institutt for sykepleievitenskap og helsefag ved Universitetet i Oslo. Hovedveileder for forskningsprosjektet er professor Tor Inge Romøren og medveiledere er postdoktorstipendiatene Ragnhild Hellesø og Kari H Eika.

De seneste års utvikling innebærer økt spesialisering og differensiering av helsetjenester. Dette medfører blant annet at gamle, syke pasienter har kortere liggetid i sykehus og i større grad mottar behandling, pleie og omsorg i egen kommune. Samtidig er det et uttalt politisk mål at flere hjelpetrengende mennesker, også eldre, skal kunne bo i eget hjem så lenge som mulig. Antall institusjonsplasser reduseres og hjemmetjenesten er blitt et satsningsområde, blant annet med ”flere hender” til tjenesten. Helhetlige tjenester og helhetlige pasientforløp er viktige mål, både faglig og politisk til tross for at utviklingstrekkene kan tyde på at dette er vanskelig å oppnå.

Mål
Forskningsprosjektets overordnede mål er å utvikle kunnskap om kontinuitet i hjemmesykepleien med fokus på pasienten – sett fra ulike perspektiver.

Gjennomføring av forskningsprosjektet
Datainnsamling vil skje fortløpende etter at aktuelle intervjupersoner er rekruttert og har samtykket til å delta. Vi vil samle data fra totalt 12 kommuner i Norge; fire store (bydeler i store byer), fire middels store og fire små. Datasamlingen starter i desember 2008 og vi tar sikte på å være ferdig med denne innen påsken 2010.

Hvem som spørres	**Metode**	**Kriterier for å kunne delta**
Pasienter	Personlig intervju	Pasienten må være over 70 år; ha hjemmesykepleie daglig; ha hatt hjemmesykepleie i mer enn tre måneder; ha ett eller flere ADL-tap; være i stand til å bli intervjuet
Pårørende	Telefonintervju	Nærmeste tilgjengelige pårørende; være i stand til å bli intervjuet
Ledere	Personlig intervju	Nærmeste leder; ha minst 6 mnd erfaring som leder i hjemmesykepleien
Ansatte	Spørreskjema	Er ansatt i hjemmesykepleien. Fast eller vikar.

Kontinuitet i hjemmesykepleien

Utdrag fra prosjektbeskrivelse

Introduksjon

Omtrent 170 000 mennesker mottar for tiden hjemmebaserte tjenester i Norge. Av disse er 123 000 er pasienter i hjemmesykepleien (SSB 2006). Det har vært en betydelig økning i andelen mottakere av hjemmesykepleie de siste 10-15 år. Flertallet består av mennesker over 80 år, men den sterkeste veksten har vært i aldersgruppene under 67 (Romøren 2006). I hovedsak er det politiske reformer for å effektivisere og modernisere helsetjenestene som har ført til at hjemmebaserte tjenester nå utgjør et tyngdepunkt i norsk helsevesen (Hofseth and Norvoll 2003; Kalseth, Midttun et al. 2004). Med de siste års utvikling innen helse- og omsorgssektoren har kommunene fått et betydelig ansvar for behandling, pleie og omsorg for mennesker med behov for omfattende tjenester. Sykehusene blir mer og mer rene behandlingsinstitusjoner, mens pleie- og omsorg under sykdomsforløpet utføres av kommunale tjenester (Kalseth, Midttun et al. 2004; Romøren 2007). Parallelt har det pågått en avinstitusjonalisering med det formål at flest mulig hjelpetrengende skal kunne bo i eget hjem ved hjelp av hjemmebaserte tjenester (Regjeringen 2005). Presset på de kommunale pleie- og omsorgstjenestene har følgelig økt (Hofseth and Norvoll 2003; Kalseth, Midttun et al. 2004).

En viktig konsekvens av disse utviklingstrekkene, som bl.a. innebærer spesialisering og differensiering av tjenester, er et oppstykket tjenestetilbud (Philipsen and Stevens 1997). Det er grunn til å tro at helhetlige pasientforløp er vanskelig å oppnå til tross for at dette er et uttalt politisk og faglig mål (Regjeringen 2005; NOU 2005:3). Med pasientforløp menes her pasienters møte med, og forhold til helsetjenesten fra første kontakt for én eller flere sykdommer til tjenesten er avsluttet. Det kan være motsetninger mellom ønsket om å utvikle effektive, virksomme og spesialiserte tjenester på den ene siden, og å gi helhetlig, individuell pleie og omsorg til pasienter med behov for langvarige og sammensatte tjenester på den andre (Philipsen & Stevens 1997).

Denne doktorgradsstudien tar utgangspunkt i spørsmål som opptar nåværende og potensielle mottakere av kommunale pleie- og omsorgstjenester og deres pårørende. Studien er initiert og finansiert av Norsk Pensjonistforbund (NPF), en politisk uavhengig organisasjon med 170 000 medlemmer, som har gitt Senter for Omsorgsforskning ved Høgskolen i Gjøvik i oppdrag å gjennomføre forskning om kontinuitet i hjemmetjenesten. Kontinuitet er en nøkkelfaktor i behandling og pleie av mennesker med langvarige og sammensatte behov for helsetjenester. Det synes å være en allmenn oppfatning at kontinuiteten er mangelfull i hjemmetjenesten, noe som også ligger til grunn for Norsk Pensjonistforbunds initiativ til dette prosjektet. Det er behov for å kartlegge, beskrive og forstå dette fenomenet i praksis da forskningen på kontinuitet innen dette feltet synes begrenset.

Gjennomføring av forskningsprosjektet

Respondenter/informanter	**Metode**	**Kriterier for å kunne delta**	**Tidsbruk**
Pasienter	Personlig intervju; - strukturert intervjuskjema - lydopptak av intervju	Pasienten må • være over 70 år • ha hjemmesykepleie daglig • ha hatt hjemmesykepleie i mer enn tre mnd • ha ett eller flere ADL-tap • være kognitivt i stand til å bli intervjuet • kunne kommunisere adekvat	30-60 minutter
Pårørende	Telefonintervju; - strukturert intervjuskjema	• nærmeste tilgjengelige pårørende; • være i stand til å bli intervjuet	20-30 minutter
Ledere	Personlig intervju; - semistrukturert intervju - lydopptak av intervju	• nærmeste leder; • ha minst 6 mnd erfaring som leder i hjemmesykepleien	Ca. 60 minutter
Ansatte	Spørreskjema - elektronisk eller - papirbasert	• er ansatt i hjemmesykepleien • fast eller vikar.	20 minutter

Etiske overveielser

Tillatelse til gjennomføring av studien i den enkelte kommune vil bli innhentet skriftlig. For gjennomføring av personlig intervju vil skriftlig, informert samtykke innhentes på forhånd. Prosjektet vil bli lagt frem for og godkjent av regionale komiteer for medisinsk og helsefaglig forskningsetikk (REK) (http://www.etikkom.no/REK) og Norsk samfunnsvitenskapelige datatjeneste (NSD) (http://www.nsd.uib.no/). All data vil bli oppbevart på et sikkert sted hvor kun stipendiat og prosjektleder vil ha tilgang. Videre vil resultater fra studien søkes presentert ved aktuelle konferanser og arrangementer og gjennom skriftlige arbeider i vitenskapelige tidsskrifter

Organisering og samarbeid

Studien gjennomføres på oppdrag fra Pensjonistforbundet, som også bidrar til finansieringen. Stipendiaten er ansatt ved Høgskolen i Gjøvik 2008-2012. Senter for omsorgsforskning ved professor Tor Inge Romøren er prosjektansvarlig og vil være hovedveileder for doktorgradsstudien. En ressursgruppe vil bli opprettet og består foreløpig av følgende personer:

- Professor Tor Inge Romøren, Senter for omsorgsforskning ved Høgskolen i Gjøvik (hovedveileder)
- Postdoktorstipendiat Ragnhild Hellesø, Institutt for sykepleievitenskap og helsefag ved Universitetet i Oslo (medveileder)
- Professor emeritus Peter F. Hjorth, Universitetet i Oslo
- Forbundsleder, Norsk Pensjonistforbund
- Seniorrådgiver Steinar Barstad, Helse- og omsorgsdepartementet
- Spesialrådgiver Anne Marie Flovik, Fagpolitisk avdeling, Norsk Sykepleierforbund

Ressurser

Prosjektet har midler til forskningsbistand. Vi vil rekruttere intervjuere som, i tillegg til stipendiaten, vil gjennomføre intervjuer med henholdsvis pasienter og pårørende. Intervjuerne vil ha helsefaglig bakgrunn, er enten under utdanning til eller har oppnådd mastergrad eller hovedfag innen sykepleievitenskap. Intervjuerne vil få opplæring tilpasset dette prosjektet som gjør dem i stand til å gjennomføre intervjuer av god kvalitet.

Offentliggjøring og spredning av resultater

Det er utarbeidet en rapport til oppdragsgiver basert på første analyse av materialet, sommeren 2009. Deretter vil vitenskapelige artikler bli produserte fortløpende og på bakgrunn av videre analyser. Artiklene vil bli søkt publisert i vitenskapelige, internasjonale tidsskrifter i henhold til krav for godkjenning av vitenskapelig arbeid for graden phd. Videre vil resultater fra studien søkes presentert ved aktuelle konferanser og arrangementer.

Intervju av pasienter – prosedyre for praktisk gjennomføring

Pasienter i hjemmesykepleien vil få en forespørsel om de ønsker å la seg intervjue om deres erfaringer knyttet til kontinuitet i hjemmesykepleien. Arbeidet med gjennomføringen av datasamling fra pasienter deles av kontaktperson i bydelen/kommunen, stipendiaten og intervjuere. I det følgende beskrives prosedyrer og retningslinjer for denne gjennomføringen:

Kriterier for utvelgelse av pasienter:

- Pasienten må være over 70 år
- Pasienten må ha hjemmesykepleie daglig
- Pasienten må ha hatt hjemmesykepleie i minst tre måneder
- Pasienten må ha ett eller flere ADL-tap; dvs. skårer 3-5 på minst ett av følgende IPLOS-variabler:
    - (16) Bevege seg innendørs
      ”Har behov for bistand/assistanse til å gå, bevege seg eller forflytte seg på ett plan innendørs; på flatt gulv, over terskler, ut og inn av seng, opp og ned av stol”
    - (18) Vaske seg
      ”Har behov/assistanse til å vaske og stelle hele kroppen inkludert pusse tenner/munnhygiene”
    - (19) Kle av og på seg
      ”Har behov for assistanse til å ta på og av seg klær og fottøy, finne fram og velge i overensstemmelse med årstid, vær og temperatur”
    - (21) Spise
      ”Har behov for bistand/assistanse til å innta servert mat og å drikke”
    - (22) Gå på toalett
      ”Har behov for bistand/assistanse til å utføre toalettbesøk/funksjoner”
- Pasienten skal ikke velges dersom han/hun skårer 3-5 på følgende IPLOS-variabler (IPLOS):
    - (26) Hukommelse
      ”Har behov for bistand/assistanse til å huske nylig inntrufne hendelser. Finne fram i kjente omgivelser. Være orientert for tid og sted, gjenkjenne kjente personer, huske avtaler og viktige hendelser den siste uken”
    - (27) Kommunikasjon
      ”Har behov for bistand/assistanse til å kommunisere med andre personer. Med kommunikasjon menes å forstå og uttrykke seg verbalt/nonverbalt, evt. ved bruk av kommunikasjonsutstyr, tolk og teknikker”

    - (28) Styre adferd
      ”Har behov for bistand/assistanse til å styre egen adferd. Med dette mener å ha kontroll over impulser, verbal og fysisk aggresjon overfor seg selv og andre”

Bakgrunnsopplysninger

Hvis pasienten samtykker til deltakelse i forskningsprosjektet, samtykker vedkommende samtidig til at noe informasjon fra pasientjournal kan tas ut. Følgende data skal hentes ut:

- IPLOS-skåre for alle funksjonsvariabler
- Har pasienten primær/sekundærkontakt? (eget skjema)
- Har pasienten individuell plan? (eget skjema)
- Registerdata/sykepleiedokumentasjon:
    - Om bydelen/kommunen har Gerica skal følgende tas ut:
        - Utskrift av området ”sykepleiejournal” siste fire uker:
            - Gir oversikt over tidsbruk, besøksfrekvens, besøksårsak, hvem som har gitt hjemmesykepleie og dennes kompetanse
            - Det er ikke behov for fritekst (hak av for ”ikke fritekst” når journal tas ut)
    - Om bydelen/kommunen ikke har Gerica, skal samme data tas ut, men på den måten bydelen/kommunen finner hensiktsmessig
        - Følgende data skal tas ut/registreres
            - Besøksfrekvens: hvor mange besøk har pasienten hatt i løpet av de siste fire uker:
                - Daglig; morgen, middag, kveld, natt (hverdag og helg)
            - Tidsbruk: Hvor lang tid ble brukt ved det enkelte besøk?
            - Besøksårsak: Hvilke tiltak ble gjennomført ved det enkelte besøk?
            - Hvem utførte tiltakene ved det enkelte besøk:
                - Hvem som utførte det enkelte tiltak
                - Denne personens kompetanse (sykepleie, hjelpepleier/omsorgsarbeider, ufaglært)

Praktisk gjennomføring

1. Lage en liste over alle pasienter i den/de aktuelle avdelingen(e) som fyller kriteriene (se senere i dokumentet). Ansvar: kontaktperson
2. Gi stipendiaten en oversikt over hvor mange pasienter som fyller kriteriene. Om for eksempel 50 personer fyller kriteriene har vi en liste fra 1-50. Ansvar: kontaktperson
3. Stipendiaten trekker ut et tilfeldig utvalg fra listen ved loddtrekning. Ansvar: Edith
4. Velge ut aktuelle pasienter ut fra numrene som ble valgt tilfeldig av stipendiaten. Føre opp pasientens navn og id-nummer og telefonnummer som oppbevares hos kontaktpersonen. Ansvar: kontaktperson
5. Informere den enkelte ansatte som skal besøke den enkelte, aktuelle pasient og gi ansatte informasjons- og samtykkeskriv, sammen med svarkonvolutt. Dette skrivet gis til pasienten samtidig som den ansatte leser opp innholdet og spør pasienten om han/hun vil delta. Ansvar: kontaktperson
6. Om pasienten samtykker med en gang, og skriver under samtykkeskjema, kan ansatte være behjelpelig med å postlegge svarkonvolutten. Om pasienten trenger å tenke seg om, er det fint om ansatte kan spørre pasienten om dette etter noen dager og være behjelpelig med å postlegge svarkonvolutten om aktuelt. Ansvar: kontaktperson
7. Kontakte pasienten per telefon for avtale om intervju når informert samtykke er mottatt. Ansvar: Edith/ intervjuere
8. Ta ut ovennevnte data fra dokumentasjonssystem/pasientjournal. Ansvar: kontaktperson
9. Lage en liste over alle ansatte som utøver hjemmesykepleie på avdelingen, med kompetanseoversikt. Denne listen skal anonymiseres (se prosedyre og liste senere i dokumentet).

Retningslinjer for informasjon til aktuelle pasienter om deltakelse i forskningsprosjektet "Kontinuitet i hjemmesykepleien".

Pasientene som er valgt ut til å forespørres om deltakelse i forskningsprosjektet må få god informasjon, både muntlig og skriftlig. Informasjon om prosjektet skal foregå på følgende måte:

- Prosjektets kontaktperson i bydelen/kommunen deler ut informasjons- og samtykkeskriv til en utvalgt ansatt som er gitt i oppdrag å besøke den aktuelle pasienten.
- Den ansatte informerer pasienten om forskningsprosjektet, gjerne ved å lese informasjonsskrivet for pasienten, eller si noen korte setninger som foreslås nedenfor.
- Pasienten mottar informasjons- og samtykkeskrivet.
- Den ansatte tilbyr seg å bistå; ved f.eks å lese skrivet for pasienten, rive ut samtykkeskjema og poste samtykkeskjema for pasienten om aktuelt (ferdig frankert konvolutt er vedlagt).

Informasjon til pasienten:

Dette er et forskningsprosjekt som Norsk Pensjonistforbund har tatt initiativ til. Forskeren er sykepleier og ansatt ved Høgskolen i Gjøvik. Hun ønsker å sette fokus på hjemmesykepleien og vil derfor snakke med pasienter i hjemmesykepleien om deres erfaringer med å være pasient i hjemmesykepleien. Tema for prosjektet er kontinuitet; dvs. om pasientene for det meste har kjente pleiere å forholde seg til, eller om det stadig kommer nye folk. Hun vil belyse flere sider av temaet, både fra din side, din nærmeste pårørende, ansatte og ledere i hjemmesykepleien.

Dine synspunkter og erfaringer er veldig viktige. Du vil bidra til at vi kan utvikle ny kunnskap som igjen kan gi bedre tjenester for pasientene i hjemmesykepleien. Hensikten er å finne frem til tiltak som gjør at pasienter i hjemmesykepleien får best mulig hjelp.

Alle opplysninger om deg og alt du forteller oss vil bli behandlet konfidensielt. Det er kun forskerne og de som intervjuer deg som vil ha tilgang på opplysninger om deg og hva du har svart.

Du bestemmer selv om du vil delta og du kan trekke deg når som helst uten å oppgi grunn. Ønsker du å delta skriver du under på samtykkeskjema som du har fått utdelt her og sender dette i konvolutten som ligger vedlagt. Den som skal intervjue deg vil ringe deg for å avtale tid for intervju. Intervjuet vil vare i ca. 30 minutter.

Forespørsel til om deltakelse i forskningsprosjektet

"Kontinuitet i hjemmesykepleien"

Dette er et spørsmål til deg om å delta i et forskningsprosjekt. Du er valgt ut av ansatte i hjemmesykepleien som kjenner deg. De mener at du kan bidra til forskningen gjennom dine erfaringer med å være pasient i hjemmesykepleien. Norsk Pensjonistforbund har tatt initiativ til dette prosjektet, og Høgskolen i Gjøvik ved Senter for omsorgsforskning vil gjennomføre det.

Mål og hensikt med prosjektet

Målet med dette forskningsprosjektet er å belyse temaet kontinuitet i hjemmesykepleien, dvs. om pasientene for det meste har kjente pleiere å forholde seg til, eller om det stadig kommer nye folk. Vi vil belyse flere sider av temaet, både fra din side, din nærmeste pårørende, ansatte og ledere i hjemmesykepleien. Dette er et tema det finnes lite kunnskap om, og som Norsk Pensjonistforbund er særlig opptatt av. Vi trenger kunnskap om dine opplevelser, erfaringer, tanker og meninger knyttet til dette temaet. Vi vil gjerne også vite hvilke områder du mener er viktige for å kunne få god kontinuitet i tjenesten. Hensikten er å finne frem til tiltak som gjør at pasienter i hjemmesykepleien får best mulig hjelp.

Gjennomføring av forskningsprosjektet

Dersom du ønsker å delta, ber vi deg skrive under på samtykkeerklæringen til slutt i dette brevet. Så vil du bli kontaktet for avtale om intervju. Intervjuene vil foregå ved at en forsker kommer hjem til deg, eller møter deg et annet sted om du ønsker dette. Intervjuene vil bli tatt opp på lydbånd og skrevet ned på papir. Hvert intervju vil vare mellom 30-60 minutter. Alle opplysninger behandles konfidensielt, og lydbåndet og det som skrives vil merkes med nummer som igjen viser til en atskilt navneliste som kun forskerne vil ha tilgang til. Når resultatene skal presenteres, vil det ikke være mulig å tilbakeføre noen opplysninger deg personlig eller noen av de andre deltakerne i prosjektet. Det som kommer fram vil for det meste være tall i tabeller.

I tillegg til informasjon fra deg gjennom et intervju vil vi også spørre deg om vi kan bruke informasjon fra din pasientjournal. Vi kan gjennom pasientjournalen få en konkret oversikt over hvor mange besøk av hjemmesykepleien du har hatt og hvor ofte du har fått besøk. Vi vil også kunne få vite hvilke yrkesgrupper de som har besøkt deg tilhører, og hvor ofte nye pleiere er kommet hjem til deg. Pasientjournalen din vil i tillegg kunne gi oss opplysninger som kan hjelpe oss å finne ut om det er sammenheng mellom kontinuitet i tjenesten og din helsesituasjon. Vi vil bare bruke de opplysninger som er relevant for prosjektet. Om du samtykker til innsyn i din pasientjournal ved å skrive under på samtykkeerklæringen, vil ansatte i tjenesten som kjenner deg og som har rettmessig tilgang til din journal ta ut relevant informasjon. Forskerne skal ikke se journalen. Ditt navn og personnummer fjernes helt fra de opplysningene vi mottar.

Vi gjør også oppmerksom på at din nærmeste tilgjengelige pårørende vil bli spurt om å delta i prosjektet og bli intervjuet per telefon da vi ønsker pårørendes synspunkter, vurderinger og erfaringer omkring prosjektets tema.

Prosjektet avsluttes i juli 2012 og alle innsamlede opplysninger skal da gjøres anonyme ved at personopplysninger slettes.

Du bestemmer selv om du vil delta

Det er frivillig å delta i prosjektet. Du kan trekke deg når som helst, uten å oppgi noen grunn. Deltakelse i prosjektet ikke vil medføre noen fordeler/endringer i forhold til mottak av hjemmetjenester. Det å trekke seg underveis vil ikke få noen negative konsekvenser for ditt forhold til hjemmesykepleien eller helsevesenet for øvrig. Det medfører ingen kostnader å delta i studien, og du vil ikke få betaling for å delta.

Om du ønsker å delta i prosjektet ber vi deg skrive under på samtykkeerklæringen som ligger sist i dette brevet. Etter du har signert samtykkeerklæringen river du ut siden og legger den i den ferdig frankerte og adresserte konvolutten som ligger ved. Konvolutten er adressert til oss. Du vil bli kontaktet for avtale om intervju kort tid etter vi har mottatt samtykkeerklæringen.

Resultatene fra forskningsprosjektet vil bli presentert i en rapport og i artikler i både internasjonale og norske fagtidsskrifter. Vi sender gjerne kopier om du ønsker dette.

Dette prosjektet er altså et oppdrag fra Norsk Pensjonistforbund som gjennomføres av Høgskolen i Gjøvik ved Senter for omsorgsforskning. Ansvarlig for prosjektet er professor Tor Inge Romøren og stipendiat Edith Roth Gjevjon er ansatt til å gjennomføre arbeidet. Med hilsen

Edith Roth Gjevjon

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Teknologiveien 22,

2802 Gjøvik

Telefon 473 76 809

Tor Inge Romøren

Professor

Samtykkeerklæring

Jeg har mottatt skriftlig informasjon om forskningsprosjektet ”Kontinuitet i hjemmesykepleien” og ønsker å delta.

Sted/ dato

Underskrift

Intervju av pårørende – prosedyre for praktisk gjennomføring

Pårørende til pasienter i hjemmesykepleien vil få en forespørsel om de ønsker å la seg intervjue om deres erfaringer knyttet til kontinuitet i hjemmesykepleien. Arbeidet med gjennomføringen av datasamling fra pasienter deles av kontaktperson i bydelen/kommunen, stipendiaten og intervjuere. I det følgende beskrives prosedyrer og retningslinjer for denne gjennomføringen:

Kriterier for utvelgelse av pårørende:

- Er pasientens nærmeste tilgjengelige pårørende
- Pårørende må være intervjubare. Kognitiv svikt eller andre begrensninger etter vurderinger av kontaktperson vil ekskludere personen fra studien. I slike tilfeller vil den nærmeste *intervjubare* pårørende bli forespurt om å delta.

Praktisk gjennomføring

1. De aktuelle pårørende føres opp på skjemaet hvor de aktuelle pasientenes navn står oppført. Dette skjemaet oppbevares av kontaktperson. Ansvar: kontaktperson.
2. Forespørsel om deltakelse via informasjons- og samtykkeskriv sendes per post, sammen med frankerte svarkonvolutter adressert til stipendiaten. Ansvar: kontaktperson.
3. Kontakte pårørende per telefon for avtale om intervju når informert samtykke er mottatt. Ansvar: Edith/ intervjuere

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Forespørsel om deltakelse i forskningsprosjektet

”Kontinuitet i hjemmesykepleien”

Dette er et spørsmål til deg om å delta i et forskningsprosjekt. Du er valgt ut av ansatte i hjemmesykepleien som mener at du kan bidra til forskningen gjennom dine erfaringer med å være pårørende til en pasient i hjemmesykepleien. Norsk Pensjonistforbund har tatt initiativ til dette prosjektet, og Høgskolen i Gjøvik ved Senter for omsorgsforskning vil gjennomføre det.

Mål og hensikt med prosjektet

Målet er å belyse temaet kontinuitet i hjemmesykepleien, dvs. om pasienter og pårørende for det meste har kjente pleiere å forholde seg til, eller om det stadig kommer nye folk. Vi vil belyse temaet både fra din side, pasientens side og fra, ansatte og lederes side. Dette er et tema det finnes lite kunnskap om, og som Norsk Pensjonistforbund er veldig opptatt av. Vi trenger kunnskap om dine opplevelser, erfaringer, tanker og meninger om det. Vi vil også gjerne høre om hva du som pårørende mener er viktig for at pasienter skal kunne oppleve god kontinuitet i tjenesten. Hensikten med studien er å bidra med kunnskap og finne frem til tiltak som gjør at pasienter i hjemmesykepleien får best mulig hjelp.

Gjennomføring av forskningsprosjektet

En av dine nærmeste pårørende, som er pasient i hjemmesykepleien, er forespurt om å delta i prosjektet. Da vi ønsker nærmeste tilgjengelige pårørendes synspunkter, vurderinger og erfaringer knyttet til prosjektets tema, ønsker vi også å snakke med deg. Dersom du ønsker å delta og skriver under på samtykkeerklæringen til slutt i dette brevet, vil du bli kontaktet for avtale om intervju. Intervjuene vil foregå ved at en forskeren ringer deg etter avtale og gjennomfører intervjuene på telefon. Forskeren vi stille deg noen spørsmål som er utformet på forhånd i et skjema, og ta notater underveis Alle opplysninger behandles konfidensielt, og det som skrives vil merkes med nummer som igjen viser til en atskilt navneliste som kun forskerne vil ha tilgang til. Hvert intervju vil vare mellom 30-60 minutter. Når resultatene skal presenteres, vil det ikke være mulig å identifisere deg eller noen av de andre deltakerne i prosjektet. Prosjektet avsluttes i juli 2012 og alle innsamlede opplysninger skal da gjøres anonyme ved at personopplysninger slettes.

Du bestemmer selv om du vil delta

Det er frivillig å delta i prosjektet. Du kan trekke deg når som helst, og uten å oppgi noen grunn. Deltakelse i prosjektet ikke vil medføre noen fordeler/endringer i forhold til mottak av hjemmetjenester. Det å trekke seg underveis vil ikke få noen negative konsekvenser for ditt forhold til hjemmesykepleien eller helsevesenet for øvrig. Det medfører ingen kostnader å delta i studien, og du vil ikke få betaling for å delta.

Om du ønsker å delta i prosjektet, ber vi deg skrive under på samtykkeerklæringen som ligger sist i dette brevet. Etter du har signert samtykkeerklæringen river du ut siden og legger den i den ferdig frankerte og adresserte konvolutten som ligger ved. Konvolutten sender du til oss. Du vil bli kontaktet for avtale om intervju kort tid etter vi har mottatt samtykkeerklæringen.

Resultatene fra forskningsprosjektet vil bli presentert i en rapport og i artikler i både internasjonale og norske fagtidsskrifter. Vi sender gjerne kopier.

Dette prosjektet er altså et oppdrag fra Norsk Pensjonistforbund som gjennomføres av Høgskolen i Gjøvik ved Senter for omsorgsforskning. Ansvarlig for prosjektet er professor Tor Inge Romøren og stipendiat Edith Roth Gjevjon er ansatt til å gjennomføre arbeidet.

Med hilsen

Edith Roth Gjevjon

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2802 Gjøvik

Telefon 47376809

Tor Inge Romøren

Professor

Samtykkeerklæring

Jeg har mottatt skriftlig informasjon om forskningsprosjektet ”Kontinuitet i hjemmesykepleien” og ønsker å delta.

Sted/ dato

Underskrift

Intervju av leder – prosedyre for praktisk gjennomføring

Vi ønsker å intervjue avdelingens leder om temaer knyttet til kontinuitet. Eksempelvis om mulige årsaker til kontinuitet/ mangel på kontinuitet, hva lederne gjør for å redusere kontinuitetsproblemer, og hvilke tiltak som ser ut til å virke best.

Kriterier for utvelgelse av leder:

- Er leder for en hjemmesykepleie-avdeling
- Har minst seks måneders ledererfaring fra hjemmesykepleien

Praktisk gjennomføring

1. Kontaktpersonen velger ut en leder på bakgrunn av kriteriene, om kontaktpersonen ikke selv er den aktuelle leder
2. Lederen får informasjons- og samtykkeskriv
3. Stipendiaten avtaler intervju etter mottatt skriftlig samtykke
4. Stipendiaten gjennomfører intervjuet

Forespørsel om deltakelse i forskningsprosjektet

”Kontinuitet i hjemmesykepleien”

Dette er et spørsmål til deg om å delta i et forskningsprosjekt. Du er valgt ut på bakgrunn av at du er nærmeste leder for ansatte i hjemmesykepleien. Norsk Pensjonistforbund har tatt initiativ til studien, og Høgskolen i Gjøvik ved Senter for omsorgsforskning gjennomfører den.

Mål og hensikt med prosjektet

Målet med dette forskningsprosjektet er å belyse temaet kontinuitet i hjemmesykepleien gjennom kunnskap om den oppfølgingen eldre pasienter får når de mottar hjemmesykepleie. Vi vil belyse flere sider at temaet, både fra din side, ansattes side, nærmeste pårørende og pasienter. Dette er et tema det finnes begrenset kunnskap om, og som Norsk Pensjonistforbund er særlig opptatt av. Vi trenger kunnskap om dine erfaringer som leder, og hvilke områder du mener er viktige for å kunne få god kontinuitet i tjenesten. Hensikten med studien er å bidra med kunnskap og finne frem til tiltak som gjør at pasienter i hjemmesykepleien får best mulig hjelp, både faglig sett og i forhold til egne ønsker, og til å styrke kunnskapsgrunnlaget for planlegging, utvikling og forbedring av tjenestene.

Gjennomføring av forskningsprosjektet

Dersom du ønsker å delta og skriver under på samtykkeerklæringen til slutt i dette brevet, vil du bli kontaktet for avtale om intervju. Forskeren vil intervjue deg med bakgrunn i noen tema som er utformet på forhånd og som er styrende for intervjuet. Intervjuet vil bli tatt opp på lydbånd. Alle opplysninger behandles konfidensielt, og lydbåndet og det som skrives vil merkes med nummer som igjen viser til en atskilt navneliste som kun forskerne vil ha tilgang til. Hvert intervju antas å vare mellom 30-60 minutter. Når resultatene skal presenteres, vil det ikke være mulig å identifisere deg eller noen av de andre deltakerne i prosjektet. Prosjektet avsluttes i juli 2012 og alle innsamlede opplysninger skal da gjøres anonyme ved at personopplysninger slettes.

Du bestemmer selv om du vil delta

Det er frivillig å delta i prosjektet. Du kan trekke deg når som helst, og uten å oppgi noen grunn. Om du ønsker å trekke deg, vil det ikke få noen konsekvenser. Det medfører ingen kostnader å delta i studien, og du vil ikke få betaling for å delta. Om du ønsker å delta i prosjektet ber vi deg skrive under på samtykkeerklæringen som ligger sist i dette brevet. Etter du har signert samtykkeerklæringen river du ut siden og legger den i den ferdig frankerte og adresserte konvolutten som ligger ved og sender den til oss. Du vil deretter bli kontaktet innen kort tid etter vi har mottatt samtykkeerklæringen for avtale om intervju.

Resultatene fra forskningsprosjektet vil bli presentert i en rapport og i artikler i både internasjonale og norske fagtidsskrifter. Vi sender gjerne kopier av publisert materiale om du ønsker dette.

Dette prosjektet er altså et oppdrag fra Pensjonistforbundet som gjennomføres av Høgskolen i Gjøvik ved Senter for omsorgsforskning. Ansvarlig for prosjektet er professor Tor Inge Romøren og stipendiat Edith Roth Gjevjon er ansatt til å gjennomføre arbeidet.

Med hilsen

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Professor

Samtykkeerklæring

Jeg har mottatt skriftlig informasjon om forskningsprosjektet ”Kontinuitet i hjemmesykepleien” og ønsker å delta.

Sted/ dato

Underskrift

Spørreskjemaundersøkelse blant ansatte – prosedyre for praktisk gjennomføring

Vi vil spørre en andel ansatte i bydelens/kommunens hjemmesykepleie om å delta i en spørreundersøkelse. Vi vil belyse kontinuitet fra flere sider, også de ansattes. De ansatte vil få skriftlig informasjon om prosjektet og undersøkelsen. Om de velger å svare på undersøkelsen og returnerer spørreskjemaet er det å anse som informert samtykke.

Vi vil velge ut ansatte på bakgrunn av kriterier. De ansatte plasseres så i grupper. Antallet ansatte i hver gruppe fastsettes før utvelgelse starter. Dette regnes ut statistisk på forhånd.

Kriterier for utvelgelse av ansatte til spørreskjemaundersøkelse:

- Er ansatt i hjemmesykepleien i bydelen/kommunen
- Fast eller vikar

Praktisk gjennomføring:

1. Kontaktpersonen lager en liste over alle ansatte i hjemmesykepleien i følgende grupper:
    a. Sykepleiere
    b. Hjelpepleiere/omsorgsarbeidere
    c. Ufaglærte (har ikke helsefaglig utdanning, men utfører hjemmesykepleie hos pasientene)
2. Disse nummereres fra 1 i hver gruppe. F.eks om det er 20 sykepleiere nummereres disse fra 1-20, likeledes når det gjelder hjelpepleiere og ufaglærte.
3. Stipendiaten får en liste med antallene og trekker ut et gitt antall ansatte fra hver gruppe som skal få tilgang til spørreskjema, basert på statistiske utregninger.
4. De aktuelle ansatte får et informasjonsskriv med prosedyre for utfylling sv spørreskjema.
5. Ved elektronisk spørreskjema mottar den ansatte et brev med en internettadresse hvor spørreskjemaet befinner seg, brukernavn og passord. I disse tilfellene fylles spørreskjema ut elektronisk og sendes inn automatisk når en er ferdig med utfyllingen.
6. Ved bruk av papirbaserte spørreskjema får den ansatte utdelt spørreskjema av kontaktpersonen. Den ansatte fyller ut skjema om han/hun ønsker å delta og sender dette per post i vedlagt svarkonvolutt.

Vil du delta i en spørreundersøkelse om kontinuitet i hjemmesykepleien?

Spørreundersøkelsen er en del av et forskningsprosjekt som skal belyse temaet kontinuitet i hjemmesykepleien. Kontinuitet er en nøkkelfaktor i behandling og pleie av mennesker med langvarige og sammensatte behov for helsetjenester, og vi har behov for mer kunnskap for å kunne finne frem til tiltak som gjør at pasienter i hjemmesykepleien får best mulig pleie- og omsorg. Prosjektet vil bidra til å styrke kunnskapsgrunnlaget for planlegging, utvikling og forbedring av tjenestene.

Ved å svare på dette spørreskjemaet vil du - ved å gi uttrykk for dine synspunkter, vurderinger og erfaringer - gi et viktig bidrag til økt kunnskap om prosjektets tema. Spørreskjemaet sendes til ansatte i hjemmesykepleietjenesten i din bydel/kommune.

Norsk Pensjonistforbund har tatt initiativ til og finansiert dette forskningsprosjektet. Undertegnede, som er sykepleier og doktorgradsstipendiat ved Senter for omsorgsforskning, Høgskolen i Gjøvik, skal gjennomføre prosjektet. Veileder og prosjektansvarlig er Tor Inge Romøren som er professor samme sted.

Det er frivillig å delta. Alle opplysninger du gir vil bli konfidensielt. Det at du svarer på spørsmålene fungerer som informert samtykke. Du kan trekke deg når som helst uten å oppgi grunn. Legg derfor merke til, og noter respondentnummeret ditt som er oppgitt på spørreskjemaet.

Elektronisk spørreskjema: Du vil motta et brev med en internettadresse hvor du kan finne spørreskjemaet. Du vil få et brukernavn og et passord. Når du logger deg inn, finner du spørreskjemaet og kan fylle ut. Når du er ferdig med å fylle dette ut, sendes det automatisk.

Papirbasert spørreskjema: Jeg ber om at du legger det ferdig utfylte spørreskjemaet i vedlagt svarkonvolutt, som er frankert, og legger det i nærmeste postkasse. Konvolutten er adressert til undertegnede.

Det vil ta ca. 20 minutter å fylle ut skjemaet.

Prosjektet avsluttes i 2012 og alle identifiserende opplysninger vil da bli slettet.

Ønsker du mer informasjon eller har kommentarer kan du kontakte undertegnede på telefon 472 76 809 eller e-post edith.gjevjon@hig.no

Med vennlig hilsen

Edith Roth Gjevjon,

Senter for omsorgsforskning, Høgskolen i Gjøvik,

Postboks 191 Teknologivn. 22, 2802 Gjøvik

Appendix 4

Procedure for extraction of administrative data

UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

Journaldatasamling

Registrering av journaldata:

1. Pasient nr. henviser til liste som kobler navn og nummer. Denne skal være sendt/gitt til kontaktperson.
2. Enkle registreringer først i skjema. Viktig at dette registreres.
3. Faste tiltak: lag en oversikt over faste tiltak slik at dere slipper å skrive dette gjentatte ganger i skjema på side 3 og utover. Kodene henviser til det enkelte tiltak. Før opp kodene i rubrikken for tiltak der dette passer.
4. Fra side 3: Velg ut de siste fire ukene forut for at pasienten ble intervjuet (se egen liste for intervjudato). Disse nummereres 1-4, som nedtegnet i skjemaet under.
5. Det er laget rom for å registrere inntil seks besøk per dag. Har pasienten flere besøk, lag flere mellomrom ut fra den elektroniske versjonen av dette skjema.
6. Tidspunkt for hjelp betyr at dere registrerer når tiltaket starter og når det slutter, ut fra arbeidsplanen/arbeidslisten).
7. Tiltak: før opp de tiltak som står i arbeidsplan/arbeidsliste.
8. Ansatt: før opp initialer med bakgrunn i liste over ansatte som også skal følge med denne registreringen. Med alle ansatte menes både fast ansatte, vikarer og ekstravakter som har arbeidet i perioden.
9. Kompetanse: se koding for den enkelte faggruppe i skjema. Før inn koden.
10. HUSK: ta ut IPLOS-historikk for pasienten (kun funksjonsvariablene)

Ferdig utfylte skjema sendes til:

Edith Roth Gjevjon,
Gartnerveien 12,
1450 Nesoddtangen

Ta gjerne kontakt om det er behov for oppklaringer, eller ved spørsmål:
edith.gjevjon@hig.no
Tlf. 47376809

Appendix 5

Semi-structured interview guide

INTERVJUGUIDE LEDERE – KONTINUITET I HJEMMESYKEPLEIEN

Hovedtema (ikke nødvendigvis i rekkefølge):

1. Hvordan definerer lederne kontinuitet?

2. Hva, i følge lederne, betinger kontinuitet?

3. Hva gjør de for å sikre kontinuitet?

Intervjuspørsmål:

Kan du først beskrive hvilke oppgaver du har som leder?

Hva mener du er viktig å vektlegge når man gir hjemmesykepleie?

Kan du fortelle om et typisk pasientforløp for pasienter over 70 år – fra en pasient søker hjemmesykepleie for første gang, til tjenesten avsluttes?

Hva legger du i begrepet kontinuitet?

Hva er kontinuitet i et pasientforløp i hjemmesykepleien, slik du ser det?

- hvordan vurderer du kontinuiteten i din avdeling?
    - hvorfor

Gjør du noe aktivt som leder for å bedre og/eller sikre kontinuitet i din avdeling?

- Har du erfaringer med at dette har lykkes? Kan du fortelle om en slik erfaring (gi et eksempel)
- Har du erfaring med at dette ikke har lykkes? Kan du fortelle om en slik erfaring?

Er pasienter og pårørende en del av dette arbeidet? (Blir deres syn tatt med?)

Hva, etter ditt syn, skal til for å sikre god kontinuitet?

Hva mener du kan være årsakene til mangel på kontinuitet?

Er det til slutt noe du vil si før vi avslutter?

Bakgrunn:

1. **Kjønn**

Kvinne ☐ 1

Mann ☐ 2

2. **Hvilken grunnutdanning har du?**...

3. **Har du lederutdanning?**

Ja ☐ 1

Nei ☐ 2

Hva slags?.................

4. **Hvor lenge har du vært i den stillingen du er i nå?**

…………..måneder/ år

5. **a) Totalt sett, hvor mange fast ansatte har du ansvaret for?**

……… ansatte

b) Hvor mange av disse har:

Treårig høgskoleutdanning	antall……	vet ikke	☐
Videregående utdanning	antall……	vet ikke	☐
Ingen utdanning	antall……	vet ikke	☐

6. **Totalt sett, hvor mange ekstravakter/ vikarer har du ansvaret for?**

……… ansatte

b) Hvor mange av disse har:

Treårig utdanning	antall…..	vet ikke	☐
Videregående utdanning	antall…..	vet ikke	☐
Ingen utdanning	antall…..	vet ikke	☐

Appendix 6

Structured interview guide for patients

UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

Prosjektet ”Kontinuitet i hjemmesykepleien”

INTERVJUSKJEMA- PASIENTER

Leses inn før intervjuet starter:

Kommunens navn:…………………………………………

Respondentnummer:…………………..

Intervjuers navn:………………………………………………..

Dato:………………………..

Tid brukt:…………………..

Lydopptak?

Ja ☐

Nei ☐ **Årsak:………………………………………………**

Opptaker (merke og modell):…………………………………………….

Mappe/file nr. :…………….

Dette intervjuet består av 21 hovedspørsmål om dine erfaringer, opplevelser, meninger og vurderinger knyttet til det å motta hjelp fra hjemmesykepleien. I tillegg vil jeg be om noen opplysninger om deg. Jeg vil underveis lese spørsmål og svaralternativer for deg og vil gjerne at du sier i fra om noe er uklart eller vanskelig å forstå. Da vil jeg forsøke å gjøre det klarere. Du kan når som helst ta en pause om du ønsker det, og du kan når som helst trekke deg fra intervjuet. Det vil ikke få noen konsekvenser for deg.

[Tekst i kursiv er presiseringer og opplysninger til intervjuer]

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1. **Hvor lenge har du fått hjemmesykepleie?**

   ----

2. **Kan du si noe om hvorfor du får hjemmesykepleie?**

   ----

3. **Hvor mange ganger i døgnet får du hjelp fra hjemmesykepleien? Jeg ønsker at du gir ett svar for hverdager og ett svar for helg/helligdager.**

<u>Hverdager:</u>		<u>Helg/helligdager:</u>	
Én gang per døgn	☐ 1	Én gang per døgn	☐ 5
To ganger per døgn	☐ 2	To ganger per døgn	☐ 6
Tre ganger per døgn	☐ 3	Tre ganger per døgn	☐ 7
Mer enn tre ganger per døgn:	☐ 4	Mer enn tre ganger per døgn:	☐ 8
Spesifiser:…………………….		Spesifiser:…………………….	

4. Er det en fast pleier som har hovedansvar for deg *[primærkontakt, kontaktsykepleier]*?

Ja ☐ 1

Nei ☐ 2

Vet ikke ☐ 3

a) *[Hvis ja:]* **Er dette en:**

Sykepleier? ☐ 1

Hjelpepleier/omsorgsarbeider? ☐ 2

Ufaglært? ☐ 3

Annet? ☐ 4 Spesifiser:………………………..

Vet ikke ☐ 5

b) *[Hvis ja:]* **Har du mer kontakt med denne pleieren** *[kontaktsykepleier/primærkontakt/o.l]* **enn de andre pleierne som hjelper deg?**

Ja ☐ 1

Nei ☐ 2

c) *[Hvis ja:]* **Hvor ofte har du kontakt med ham/henne?**

Daglig ☐ 1

Flere ganger i uken ☐ 2 Spesifiser………………

En gang i uken ☐ 3

Sjeldnere enn en gang i uken ☐ 4 Spesifiser………………

d) Kan du komme på en hendelse hvor dette *[fast pleier eller ikke]* har hatt betydning for hjelpen du har fått *[konsekvenser]*?

----

5. Har du mange eller få pleiere som hjelper deg?

Hverdager:		Helg/helligdager:	
Få	☐ 1	Få	☐ 3
Mange	☐ 2	Mange	☐ 4

a) Hvilken yrkesgruppe tilhører de fleste av disse? Er det for det meste:

Sykepleiere? ☐ 1

Hjelpepleiere/omsorgsarbeidere? ☐ 2

Ufaglærte? ☐ 3

Annet? ☐ 4 Spesifiser:……………………

6. Hva synes du om det antall pleiere som hjelper deg? Er det:

Hverdager:		Helg/helligdager:	
Altfor mange?	☐ 1	Altfor mange?	☐ 6
Litt for mange?	☐ 2	Litt for mange?	☐ 7
Passe/ikke noe problem?	☐ 3	Passe/ikke noe problem?	☐ 8
Litt for få?	☐ 4	Litt for få?	☐ 9
Altfor få?	☐ 5	Altfor få?	☐ 10

a) **Kan du komme på en hendelse hvor dette** *[å ha for mange eller for få pleiere]* **har hatt betydning for hjelpen du har fått** *[konsekvenser]***?**

----

7. Hvor mange av pleierne som har kommet hjem til deg den siste uken har vært hjemme hos deg tidligere?

Hverdager:		Helg/helligdager:	
Alle	☐ 1	Alle	☐ 6
De fleste	☐ 2	De fleste	☐ 7
Noen	☐ 3	Noen	☐ 8
De færreste	☐ 4	De færreste	☐ 9
Ingen	☐ 5	Ingen	☐ 10

8. Vil du si at du kjenner pleierne som kommer hjem til deg?

Hverdager:		Helg/helligdager:	
Ja, alle	☐ 1	Ja, alle	☐ 6
De fleste	☐ 2	De fleste	☐ 7
Noen	☐ 3	Noen	☐ 8
De færreste	☐ 4	De færreste	☐ 9
Nei, ingen	☐ 5	Nei, ingen	☐ 10

9. Kommer pleierne for å hjelpe deg til faste tider?

Hverdager:		Helg/helligdager:	
Ja, alltid	☐ 1	Ja, alltid	☐ 6
Som oftest	☐ 2	Som oftest	☐ 7
Av og til	☐ 3	Av og til	☐ 8
Sjelden	☐ 4	Sjelden	☐ 9
Nei, aldri	☐ 5	Nei, aldri	☐ 10

10. *[Hvis ja på spørsmål 10:]* **Har du fått være med på å bestemme dette** *[tidspunktene for hjelp]***?**

Hverdager:		Helg/helligdager:	
Ja, alltid	☐ 1	Ja, alltid	☐ 6
Som oftest	☐ 2	Som oftest	☐ 7
Av og til	☐ 3	Av og til	☐ 8
Sjelden	☐ 4	Sjelden	☐ 9
Nei, aldri	☐ 5	Nei, aldri	☐ 10

a) **Kan du komme på en hendelse hvor dette** *[faste tider eller ikke]* **har hatt betydning for hjelpen du har fått** *[konsekvenser]***?**

----

11. Hender det at du må vente lenge før det kommer noen fra hjemmesykepleien for å hjelpe deg?

<u>Hverdager:</u>		<u>Helg/helligdager:</u>	
Ja, alltid	☐ 1	Ja, alltid	☐ 6
Som oftest	☐ 2	Som oftest	☐ 7
Av og til	☐ 3	Av og til	☐ 8
Sjelden	☐ 4	Sjelden	☐ 9
Nei, aldri	☐ 5	Nei, aldri	☐ 10

a) *[Hvis svart alternativene 1-4 og/eller 6-9]* **Hvor lenge har du ventet på det meste?**

Hverdager:………………………

Helg/helligdager: ……………….

b) Kan du komme på en hendelse hvor dette *[å måtte vente lenge på å få hjelp]* **har hatt betydning for hjelpen du har fått** *[konsekvenser]***?**

----

12. Vet du på forhånd hvem *[av pleierne]* **som skal komme og hjelpe deg?**

<u>Hverdager:</u>		<u>Helg/helligdager:</u>	
Ja, alltid	☐ 1	Ja, alltid	☐ 6
Som oftest	☐ 2	Som oftest	☐ 7
Av og til	☐ 3	Av og til	☐ 8
Sjelden	☐ 4	Sjelden	☐ 9
Nei, aldri	☐ 5	Nei, aldri	☐ 10

a) Kan du komme på en hendelse hvor dette *[å vite hvem som kommer eller ikke]* **har hatt betydning for hjelpen du har fått** *[konsekvenser]***?**

----

13. Må du informere pleierne om ting de burde vite før de kommer til deg?

<u>Hverdager:</u>		<u>Helg/helligdager:</u>	
Ja, alltid	☐ 1	Ja, alltid	☐ 6
Som oftest	☐ 2	Som oftest	☐ 7
Av og til	☐ 3	Av og til	☐ 8
Sjelden	☐ 4	Sjelden	☐ 9
Nei, aldri	☐ 5	Nei, aldri	☐ 10

a) **Kan du komme på en hendelse hvor dette** *[å måtte gi informasjon de burde vite eller at pleierne er godt informert]* **har hatt betydning for hjelpen du har fått** *[konsekvenser]***?**

----

14. I hvilken grad opplever du at pleierne som hjelper deg kjenner til din situasjon?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

15. I hvilken grad opplever du at du får den hjelpen du trenger fra hjemmesykepleien?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

16. I hvilken grad kan du være med å bestemme:

a) Hvem *[hvilken pleier]* som skal komme hjem til deg og hjelpe deg?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

c) Når de skal komme fra hjemmesykepleien for å hjelpe deg *[tidspunkt]*?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

d) Hva du skal ha hjelp til *[innholdet i hjelpen]*?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

17. I hvilken grad kan du stole på at:

a) Pleierne kommer til rett tid?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

b) Du får beskjed dersom det er forsinkelser?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

c) Pleierne holder det de lover *[gjør det de har sagt de skal gjøre]*?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

d) Pleierne er godt nok informert om din situasjon før de hjelper deg *[kjenner din situasjon]*?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

e) Pleierne har nok kunnskap til å utføre god og forsvarlig pleie- og omsorg for deg *[er flinke]*?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

18. I hvilken grad opplever du at pleierne har nok tid til deg?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

19. I hvilken grad opplever du at pleierne har omsorg for deg?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

20. Hvor det viktig er det for deg:

a) Å ha få pleiere å forholde deg til?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

b) At du kjenner pleierne som kommer?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

c) At pleierne har nok kunnskaper og ferdigheter til å utføre god og forsvarlig pleie- og omsorg for deg *[er flinke]*?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

d) At pleierne som hjelper deg er sykepleiere?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

e) At pleierne som hjelper deg er hjelpleiere/omsorgsarbeidere?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

f) At pleierne som hjelper deg har annen helsefaglig utdanning enn sykepleier eller hjelpepleier/omsorgsarbeider? I så fall hvilken:………………………………….

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

g) At du vet på forhånd når pleierne kommer for å hjelpe deg?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

h) At du vet på forhånd hvem *[hvilken pleier]* som skal komme for å hjelpe deg?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

i) At du får den hjelpen du selv mener du har behov for?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

j) At pleierne er presise og holder tiden?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

21. Opplever du at pleierne har nok kunnskaper og ferdigheter til å utføre god og forsvarlig pleie- og omsorg for deg *[er flinke]***?**

Ja, alle ☐ 1

Ja, de fleste ☐ 2

Det er både og ☐ 3

Nei, de færreste ☐ 4

Nei, ingen ☐ 5

a. **Kan du komme på en hendelse hvor dette** *[pleiernes kunnskaper og ferdigheter/om de er flinke]* **har hatt betydning for hjelpen du har fått** *[konsekvenser]***?**

----

22. a) **Hva er det som gjør at du opplever noen pleiere som flinke?** *[Hva kjennetegner disse]*

----

c) **Hva er det som gjør at du opplever noen pleiere som mindre flinke?** *[Hva kjennetegner disse]*

----

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

Helt til slutt – noen opplysninger om deg

24. Hvordan synes du din livssituasjon er nå?

Best tenkelig ☐
God ☐
Noenlunde ☐
Verst tenkelig ☐

25. Hvordan synes du din helse er nå?
Best tenkelig ☐
God ☐
Noenlunde ☐
Verst tenkelig ☐

26. Hvilket år er du født?

☐☐☐☐ å/å/å/å

27. Bor du alene eller sammen med noen?

Jeg bor alene ☐

Jeg bor sammen med:

Ektefelle ☐

Samboer ☐

Sønn ☐

Datter ☐

Søster ☐

Bror ☐

Andre ☐ Spesifiser:………………………………

28. Hva er din sivilstand?

Gift	☐	1
Ugift	☐	2
Enke/ enkemann	☐	3
Samboer	☐	4
Skilt	☐	5

29. Hvilken type arbeid *[yrke]* **har du hatt** *[hvis flere yrker – hvilket har han/hun hatt lengst]***?**

Lønnet arbeid ☐ 1 Spesifiser:……………………………………….

Ulønnet arbeid ☐ 2 Spesifiser:………………………………………..
[f.eks hjemmeværende]

a. [*Hvis ulønnet arbeid og hvis gift/enke/enkemann]*: **Hvilket yrke har/hadde din ektefelle?**:…………………………..

30. Hvordan bor du?

Enebolig ☐

Leilighet m/ heis ☐ Etasje:……….

Leilighet u/heis ☐ Etasje:……….

Annet ☐ Spesifiser:………………………….

b) Er boligen din tilrettelagt/ tilpasset din situasjon?

Ja ☐

Nei ☐

Vet ikke ☐

TUSEN TAKK FOR AT JEG FIKK LOV TIL Å INTERVJUE DEG!

INTERVJUERS NOTATER ETTER AVSLUTTET INTERVJU:

Appendix 7

Structured interview guide for next of kin

UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

Prosjektet ”Kontinuitet i hjemmesykepleien”

INTERVJUSKJEMA- PÅRØRENDE

Leses inn på lydopptaker før intervjuet starter:

Kommunens navn:………………………………………

Respondentnummer:…………………...

Intervjuers navn:……………………………………………………

Dato:………………….

Tid brukt:…………….

Lydopptak?

Ja ☐

Nei ☐ **Årsak:……………………………………………….**

Opptaker (merke og modell):………………………………………………..

Mappe/file nr. :…………………

Dette intervjuet består av 21 hovedspørsmål om dine erfaringer, opplevelser, meninger og vurderinger knyttet til det å være pårørende til en pasient i hjemmesykepleien. I tillegg vil jeg be om noen opplysninger om deg. Jeg vil underveis lese spørsmål og svaralternativer for deg og vil gjerne at du sier i fra om noe er uklart eller vanskelig å forstå. Da vil jeg forsøke å gjøre det klarere. Du kan når som helst ta en pause om du ønsker det, og du kan når som helst trekke deg fra intervjuet. Det vil ikke få noen konsekvenser for deg eller din pårørende.

[Tekst i kursiv er presiseringer og opplysninger til intervjuer]

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1. **Hvilket tilknytningsforhold har du til den eldre? [***Pårørende er:]*

Ektefelle	☐	1	
Barn	☐	2	
Søsken	☐	3	
Annet	☐	4	Spesifiser………………..

2. **Bor du sammen med han/henne** *[inkluderer det å bo i samme hus/leilighet, på samme gårdstun, f.eks kårbolig]***?**

   Ja ☐ 1 **a) Har dere felles hushold** *[spiser måltider sammen]***?** Ja ☐1 Nei ☐ 2

   Nei ☐2

   a. *[Hvis nei på spørsmål]*: **Hvor ofte besøker du din pårørende?**..................................

   b. *[Hvis nei på spørsmål]*: **Hvor lang tid bruker du på å reise mellom ditt hjem og din pårørendes hjem? Oppgi reisetid fra arbeidssted dersom dette er nærmere:**

   ……………………………………

3. a) I hvilken grad opplever du at din pårørende får den hjelpen han/ hun har behov for?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

4. I hvilken grad får din pårørende, etter <u>ditt</u> syn, nok hjelp av hjemmesykepleien?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

5. Har din pårørende en fast pleier som har særlig ansvar for ham/henne?

Ja [_] 1

Nei [_] 2

Vet ikke [_] 3

a. Kan du komme på en hendelse hvor dette *[fast pleier eller ikke]* **har hatt betydning for hjelpen din pårørende har fått** *[konsekvenser]***?**

----

6. *[Hvis ja på spørsmål 5]:* **Har du som pårørende egen kontakt med den faste pleieren?**

Ja, ofte [_]1 Spesifiser hvor ofte:………………………………..

Av og til [_]2 Spesifiser hvor ofte:………………………………..

Sjelden [_]3 Spesifiser hvor ofte:………………………………..

Aldri [_]4

a. Kan du komme på en hendelse hvor dette *[egen kontakt med kontaktperson eller ikke]* **har hatt betydning for hjelpen din pårørende har fått** *[konsekvenser]***?**

----

7. Hva synes du om det antall pleiere din pårørende må forholde seg til? Er det:

Altfor mange? [_] 1

Litt for mange? [_] 2

Passe/ikke noe problem? [_] 3

Litt for få? [_] 4

Altfor få? [_] 5

a. Kan du komme på en hendelse hvor dette *[mange eller få pleiere]* **har hatt betydning for hjelpen din pårørende har fått** *[konsekvenser]***?**

----

8. Kjenner du pleierne som kommer hjem til din pårørende? *[ikke personlig, men at pleierne er kjent for pårørende]*

Ja, alle ☐ 1
Ja, de fleste ☐ 2
Ja, noen ☐ 3
Ja, én ☐ 4
Nei, ingen ☐ 5

9. I hvilken grad opplever du at pleierne kjenner din pårørendes situasjon?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

10. I hvilken grad opplever du å måtte informere pleierne om ting de burde vite om din pårørende?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

a. **Kan du komme på en hendelse hvor dette** *[å måtte gi informasjon de burde vite eller at pleierne er godt informert]* **har hatt betydning for hjelpen du har fått** *[konsekvenser]***?**

----

11. I hvilken grad kan du stole på at:

a) Pleierne kommer til rett tid?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

b) Din pårørende får beskjed dersom det er forsinkelser?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

c) Når det er aktuelt - at <u>du</u> får beskjed dersom det er forsinkelser?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

d) Pleierne holder det de lover *[gjør det de har sagt de skal gjøre]*?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

e) Pleierne er godt nok informert om din pårørendes situasjon før de hjelper han/henne?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

f) Pleierne har nok kunnskaper og ferdigheter til å utføre god og forsvarlig pleie- og omsorg for din pårørende *[er flinke]*?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

12. I hvilken grad opplever du at pleierne har nok tid til din pårørende?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

13. I hvilken grad opplever du at pleierne har tid til deg dersom du har behov for det?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad	6-ikke aktuelt

14. I hvilken grad opplever du at pleierne har omsorg for din pårørende?

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

15. I hvilken grad opplever du at pleierne har omsorg for deg som pårørende *[spør de for eksempel hvordan du har det]***?**

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I ganske stor grad	5-I stor grad

16. Opplever du at pleierne har nok kunnskaper og ferdigheter til å utføre god og forsvarlig pleie- og omsorg for din pårørende *[er flinke]***?**

Ja, alle er flinke ☐

Ja, de fleste ☐

Det er både og ☐

Nei, de færreste ☐

Nei, ingen ☐

a. Kan du komme på en hendelse hvor dette *[pleiernes kunnskaper og ferdigheter/om de er flinke]* **har hatt betydning for hjelpen din pårørende har fått** *[konsekvenser]***?**

----

17. a) Hva er det som gjør at du opplever noen pleiere som flinke? *[Hva kjennetegner disse]*

----

b) Hva er det som gjør at du opplever noen pleiere som mindre flinke? *[Hva kjennetegner disse]*

----

21. Hvor viktig synes du det er at din pårørende kan være med å bestemme:

a) Hvem *[hvilken pleier]* som skal komme hjem til ham/henne og hjelpe ham/henne?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

c) Når de skal komme fra hjemmesykepleien for å hjelpe ham/henne *[tidspunkt]*?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

d) Hva han/hun skal ha hjelp til *[innholdet i hjelpen]*?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

22. Hvor viktig er det for deg å kunne være med på å bestemme:

a) Hvem *[hvilken pleier]* som skal komme hjem til han/henne og hjelpe ham/henne?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

c) Når de skal komme fra hjemmesykepleien for å hjelpe ham/henne *[tidspunkt]*?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

d) Hva han/hun skal ha hjelp til *[innholdet i hjelpen]*?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

23. Har du noen du kan henvende deg til om din pårørende hvis du har behov for det?

Ja ☐ Spesifiser *[Hvem]* :………………………………….

Nei ☐

24. Hvordan snakker du og hjemmesykepleien sammen?

Veldig godt? ☐ 1

Godt? ☐ 2

Verken/eller? ☐ 3

Dårlig? ☐ 4

Veldig dårlig? ☐ 5

25. Hvordan opplever du som pårørende samarbeidet med hjemmesykepleien?

1-Svært godt	2-Nokså godt	3-Verken/eller	4-Nokså dårlig	5-Svært dårlig

26. Har samarbeidet mellom deg og tjenesten betydning for kvaliteten på pleien til din pårørende?

Ja, i stor grad ☐ 1

Ja, i noen grad ☐ 2

I liten grad ☐ 3

Nei, ikke i det hele tatt ☐ 4

a. **Kan du komme på en hendelse hvor dette** *[godt eller dårlig samarbeid]* **har hatt betydning for hjelpen din pårørende har fått** *[konsekvenser]***?**

Her er noen påstander jeg vil du skal angi viktigheten av, slik <u>du</u> ser det.

27. Det er meget viktig at:

a) Min pårørende har få pleiere å forholde deg til

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

b) At han/hun kjenner pleierne som kommer

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

c) At jeg som pårørende kjenner pleierne som kommer

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

d) At pleierne har nok kunnskap og ferdigheter til å utføre god og forsvarlig pleie- og omsorg for min pårørende *[er flinke]*

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

e) At pleierne som hjelper ham/henne er sykepleiere?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

f) At pleierne som hjelper ham/henne er hjelpleiere/omsorgsarbeidere?

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

g) At pleierne som hjelper ham/henne har annen helsefaglig utdanning enn sykepleier eller hjelpepleier/omsorgsarbeider? I så fall hvilken:…………………………………..

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

h) At han/hun vet på forhånd når pleierne kommer for å hjelpe ham/henne

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

i) At jeg som pårørende vet på forhånd når pleierne kommer for å hjelpe ham/henne

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

j) At han/hun vet på forhånd hvem som skal komme for å hjelpe ham/henne

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

k) At jeg som pårørende vet på forhånd hvem som skal komme for å hjelpe ham/henne

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

l) At den som kommer kjenner godt til hans/hennes situasjon

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

m) At han/hun får den hjelpen han/hun selv mener han/hun har behov for

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

n) At pleierne er presise og holder tiden

1-Ikke i det hele tatt	2-Litt viktig	3-Ganske viktig	4-Veldig viktig

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

Til slutt noen opplysninger om deg:

29. Når er du født?

Fødselsår:………………………….

30. Kjønn

Kvinne ☐ 1

Mann ☐ 2

31. Hva er din sivilstand?

Gift ☐ 1

Enke/ enkemann ☐ 2

Skilt/separert ☐ 3

Samboer ☐ 4

Ugift ☐ 5

32. Hvilken type arbeid har du/har du hatt *[hvis flere yrker – hvilket har han/hun hatt lengst]***?**

Lønnet arbeid [_] 1 Spesifiser:……………………………………….

Ulønnet arbeid [_] 2 Spesifiser:………………………………………..
[f.eks hjemmeværende]

a. [*Hvis ulønnet arbeid og hvis gift/enke/enkemann]*: **Hvilket yrke har/hadde din ektefelle?**:…………………………..

TUSEN TAKK FOR AT JEG FIKK LOV TIL Å INTERVJUE DEG!

INTERVJUERS NOTATER ETTER AVSLUTTET INTERVJU

Appendix 8

Course plan and instructions for interviewers

Program for opplæring av intervjuere til ”Kontinuitet i hjemmesykepleien”

Tid: 23.11.08 klokken 10-15

Sted: Nedre Ullevål 9 (Stjerneblokka), rom 201

10.00-10.15 Presentasjon av personer og prosjektet, ved Edith

10.15-10.30 Organisering av studien, ved Edith

10.30-10.50 Å intervjue i praksis – noen erfaringer og refleksjoner, ved Anders Kvale Havig

10.50-11.10 Telefonintervju i praksis – noen erfaringer og refleksjoner, ved Bente Ødegård Kjøs

11.10-11.15 PAUSE

11.15-12.00 Intervjuteknikk, ved Bente og Edith

Hvordan bruke intervjuskjemaene:
Kategorisering og åpne felt
Følge tekst og svarkategorier eller improvisere?

Den menneskelige faktor -

12-12.45 LUNSJ

12.45-14.15 Øvelser

14.15-14.20 PAUSE

14.20-15.00 Spørsmål og diskusjon

Intervjuveileder for studien ”Kontinuitet i hjemmesykepleien”

Et forskningsprosjekt initiert og finansiert av Norsk Pensjonistforbund. Gjennomføres av Senter for omsorgsforskning ved Høgskolen i Gjøvik

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Et forskningsprosjekt initiert og finansiert av Norsk Pensjonistforbund. Gjennomføres av Senter for omsorgsforskning ved Høgskolen i Gjøvik

Stipendiat: Edith Roth Gjevjon

Prosjektansvarlig og hovedveileder: Professor Tor Inge Romøren

Medveileder: Postdoktorstipendiat Ragnhild Hellesø

Kort presentasjon for respondenten:

Du har samtykket til å være med i et forskningsprosjekt som handler om kontinuitet i hjemmesykepleien. Målet med prosjektet er å få kunnskap om et tema vi vet lite om. Derfor ønsker vi å spørre deg som mottaker av/pårørende til en pasient i hjemmesykepleien. Ditt svar vil bidra til økt kunnskap som kan hjelpe oss å finne frem til tiltak som gjør at pasienter i hjemmesykepleien får best mulig hjelp. Alle opplysninger behandles konfidensielt. Hjemmesykepleien eller andre som kjenner deg vil ikke få vite hva du har svart. Det som skrives vil kun merkes med et nummer og ikke ditt navn. En liste som kobler navn og nummer vil holdes innelåst og vil kun være tilgjengelig for de prosjektansvarlige. Når resultatene skal presenteres vil det ikke være mulig å identifisere deg eller andre deltakere i prosjektet. Det er helt frivillig å delta. Du kan når som helst trekke deg uten å oppgi grunn. Det vil ikke få noen konsekvenser for deg.

Informasjon om studien

Utvalg:

Vårt utvalg består av følgende:

- Vi har valgt et utvalg av kommuner i Norge som representerer viktige kontraster: tre små kommuner (under 6000 innbyggere), middels store kommuner (10-20 000 innbyggere) og store kommuner (over 30 000). Vi lar to bydeler i Oslo og én bydel i Bergen representere store kommuner. Dette for å skape størst mulig kontrast.
- Mottakere av hjemmesykepleie (pasienter) over 70 år, som har hatt hjemmesykepleie i minimum tre måneder, har hjemmesykepleie daglig. I tillegg har de to eller flere ADL-tap (funksjonsnedsettelse som medfører behov for hjelp) og være kognitivt intakt.
- Pasientens nærmeste tilgjengelige pårørende
- I tillegg vil vi intervjue nærmeste leder og sende ut spørreskjema til ansatte.

Vi ønsker data fra til sammen rundt 100 pasienter og like mange pårørende. Antall kommuner som totalt vil bli inkludert i studien er ikke fastsatt ennå da vi må gjøre noen beregninger av antall mulige respondenter i små kommuner. Vi rekrutterer respondenter på følgende måte:

- En kontaktperson for hver kommune/bydel finner potensielle respondenter på bakgrunn av inklusjonskriteriene. Informasjon omstudien gis muntlig og skriftlig til pasienten. Om pasienten ønsker å være med skriver han/hun under på et samtykkeskjema i to eksemplarer. Det ene eksemplaret skal pasienten beholde. Samtykkeskjema sendes per post til stipendiaten.
- Pårørende rekrutteres ved at informasjonsskriv og samtykkeskjema sendes per post til vedkommende. Underskrevet samtykkeskjema sendes per post til stipendiaten. Frankert returkonvolutt ligger vedlagt.
- Stipendiaten tar kontakt med intervjuerne og oppgir navn og telefonnummer til pasient og/eller pårørende.

returkonvolutt ligger vedlagt.

- Stipendiaten tar kontakt med intervjuerne og oppgir navn og telefonnummer til pasient og/eller pårørende.

Intervjuernes oppgaver:

1. Ta kontakt med pasient per telefon for å avtale intervju snarest mulig etter mottatt kontaktinformasjon.
2. Intervjue pasienten i hans/hennes hjem eller annet sted om pasienten ønsker dette.
3. Kontakte pårørende per telefon for å avtale intervju.
4. Gjennomføre telefonintervju med pårørende. Det kan være personlig intervju om pasient og pårørende bor sammen eller om pårørende insisterer på dette.
5. Vurdere fortløpende om det er nødvendig å avslutte et intervju underveis på grunn av respondentens tilstand eller andre situasjoner. Skriv ned hva som forårsaket dette og hvorfor du valgte å avslutte.
6. Om respondenten trekker seg må du varsle stipendiaten og gi beskjed om dette slik at en ny respondent kan rekrutteres.

Intervjuene

Pasientintervjuet skal gjennomføres som et personlig intervju og **pårørendeintervjuet** som telefonintervju. Intervjuet er et såkalt ”survey”-intervju hvor vi benytter et intervjuskjema som likner et spørreskjema. En survey er en standardisert utspørring av et stort utvalg personer. Det må ikke forveksles med det kvalitative intervju. Denne typen intervju er sterkt strukturert og intervjueren gis lite frihet til improvisasjon. Det er selvsagt rom for å kunne oppklare misforståelser og utdype spørsmålene. Utdyping av spørsmålene må være avtalt, og forstått likt av alle intervjuerne. Et personlig intervju er et samspill mellom to mennesker. Dette kan gi muligheter for feilkilder. Det er derfor viktig å være godt forberedt og å følge intervjuprotokollen.

Før intervjuet:

- Bli godt kjent med intervjuskjemaet på forhånd.
- Ved personlig intervju: Presenter deg selv og ha med legitimasjon med bilde. Bruk gjerne studentkort om dere har dette. Ved telefonintervju: Presenter deg og fortell hvorfor du ringer (de har samtykket til et intervju om kontinuitet i hjemmesykepleien), at intervjuet vil ta omtrent 20 minutter.
- Pasienter og pårørende har fått skriftlig og muntlig informasjon om studien tidligere – men – forklar kort hva studien går ut på, hensikten med studien, og om konfidensialitet (se forsiden).
- Gjør pasienten oppmerksom på at du bruker båndopptaker og spør om det er greit å slå den på. Om pasienten ikke ønsker at det blir gjort opptak, selv om hun/han har samtykket til dette skriftlig, respekter dette. Da er det viktig å gjøre gode notater.
- Snakk inn følgende etter at opptaker er slått på og før intervjuet starter:
    - Kommune nummer
    - Respondent nummer
    - Dato
    - Navnet ditt

Under intervjuet:

- Snakk tydelig og still spørsmålene slik de står. Der det er naturlig å bruke andre uttrykk, som for eksempel der hvor det står ”din pårørende”, si ”din far” der du vet relasjonen slik at det blir mest mulig naturlig språk.

- Snakk tydelig og still spørsmålene slik de står. Der det er naturlig å bruke andre uttrykk, som for eksempel der hvor det står ”din pårørende”, si ”din far” der du vet relasjonen slik at det blir mest mulig naturlig språk.

- Ofte vil respondenten svare på spørsmål som kommer lengre ut i spørreskjemaet. Kjenner du skjemaet godt, noterer du deg dette og setter kryss ved dette svaret. Da slipper du å spørre dem om noe de allerede har svart på.
- Spør ikke om ting du vet, som for eksempel når du vet at han/hun bor alene. Ikke spør om det, sett kryss.
- Gi respondentene god tid til å svare. Noe av det vi spør om har det kanskje ikke tenkt på før, og da trenger de tid til å finne svar. Gi ikke inntrykk av å ha dårlig tid.
- Mange gamle mennesker har nedsatt hørsel. Vær oppmerksom på dette og ta hensyn ved å snakke tydelig.
- Oppklar misforståelser og uklarheter underveis. Om de ikke forstår spørsmålet, forklar dette med et forståelig språk, men gjør det ikke om til et ledende spørsmål. Spørsmålene skal være standardiserte. Det er lite rom for improvisasjon. Må du improvisere, skriv opp hva du gjorde/sa og hvorfor i notatene bakerst i skjemaet.
- Det er fint å gjøre intervjuet så avslappet og naturlig som mulig. Unngå likevel å gi for mye tilbakemelding på svarene respondenten gir. Dette kan påvirke respondenten til å gi svar han/hun tror *du* vil høre.
- Hvis respondenten ikke klarer å svare på et spørsmål, eller sier *vet ikke*, *både-og*, o.l, der de nevnte kategoriene ikke finnes i skjemaet, forsøk å stille det igjen. Omformuler gjerne, men unngå å avvike fra det opprinnelige spørsmålet så mye at det endrer mening. Her er det også en fare for å stille ledende spørsmål. Vær oppmerksom på dette og unngå det.
- Mange mennesker liker å snakke mye og kan noen ganger snakke om andre ting enn det spørres om. Her kan du høflig avbryte ved å stille spørsmålet på nytt eller gå videre til neste spørsmål om du har fått svar på det forrige. Handler historien om det du spør om, ikke avbryt, men lytt til respondenten. Om ikke båndopptakeren er på er det fint å notere hva som blir sagt. Slike historier kan gi viktige opplysninger som skjemaet kanskje ikke fanger opp, og de kan gi gode illustrasjoner i publikasjoner tilknyttet studien.
- De aller fleste spørsmålene har kategoriserte svaralternativer knyttet til seg. Noen av kategoriene er enkle og trenger kanskje ikke å bli forklart på forhånd da det antas at respondenten naturlig vil svare på en slik måte at det passer med kategoriene. Et eksempel:

  ”Hvor viktig er det for deg å vite på forhånd når pleierne skal komme?”

  Her er det naturlig for respondenten å svare direkte på hvor viktig dette er. Dette passer med svarkategoriene som er: ”Veldig viktig; Ganske viktig; Ikke så viktig; Ikke viktig i det hele tatt.” Du kan be om presisering hvis respondenten for eksempel sier at det er viktig. Da spør du ”hvor viktig – er det ganske viktig eller veldig viktig?”.

- Andre kategorier bør opplyses om på forhånd. Eksempel:

1-Ikke i det hele tatt	2-I liten grad	3-I noen grad	4-I stor grad

  Forklar gradene på forhånd og vis gjerne respondenten spørsmålet og skalaen. det kan bli lettere å svare når han/hun ser dette samtidig som spørsmålet stilles. Det er ikke like lett å skille mellom gradene som ved mer konkrete alternativer som i eksempelet i forrige punkt. Her vil ikke et svar som ”både og” være klart nok for å kunne krysse av ved et alternativ.

- Åpne spørsmål. I de tilfellene hvor respondenten (pasientene) ikke ønsker at intervjuet tas opp på bånd, må gode notater tas. Det er da viktig at disse notatene blir så utfyllende som mulig. Skriv gjerne ned stikkord i de åpne feltene under intervjuene, men renskriv og gjør utfyllende notater så snart som mulig etter intervjuet. Når intervjuet tas opp på bånd er det likevel ønskelig at du noterer ned i stikkordsform hva pasienten svarer på de åpne spørsmålene.

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Etter avsluttet intervju:

- Gå igjennom intervjuskjema for å sjekke om alle spørsmålene er besvart.
- Oppklar eventuelle uklarheter med respondenten.
- Husk å takke for at han/hun tok seg tid til dette og at det har vært veldig nyttig.

Notater etter endt intervju:

Til sist i intervjuskjema skal du skrive en logg etter gjennomført intervju. Her ønsker vi refleksjoner rundt intervjusituasjonen. Var det noe i situasjonen som er viktig å få frem, oppsto det mange misforståelser. Gjorde du noen vurderinger underveis som endret intervjusituasjonen? Vurderte du at respondenten ikke kunne la seg intervjue av ulike årsaker som f.eks at han/hun så ut til å være utilpass, ikke ønsket å fortsette, virket kognitivt svekket til tross for å være vurdert til å oppfylle inklusjonskriteriene, etc.

Ved uklarheter eller spørsmål, nøl ikke med å ta kontakt med Edith for oppklaringer.