Affected and responsible:

A qualitative study of family caregivers in interaction with chronically ill persons and health care professionals

Gunvor Aasbø

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UNIVERSITY OF OSLO
Faculty of Medicine
Institute of Clinical Medicine

and

Health Services Research Unit (HØKH)
Akershus University Hospital

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Summary

The aim of this thesis is to deepen scientific knowledge of the interactions among family caregivers, chronically ill persons and health care professionals, with a particular focus on the work of family caregivers. This knowledge can improve understanding of how to support the caregivers of chronically ill persons. In this study, the interactions among family caregivers, persons with chronic obstructive pulmonary disease (COPD) and health care professionals are analysed in three different contexts: everyday life, acute situations and home visits by pulmonary ambulatory nurses.

The increasing proportion of the elderly in the population and the growing prevalence of chronic diseases, represent future challenges for long-term care services. In recent years, health care policies have emphasised transferring more responsibility for care provision to community health care, and families are expected to take on a greater care responsibility for ill relatives. However, the implications of these shifts in expectations and responsibility for the relation between informal and formal health care provision have received little attention in research and public discourse.

The present study has a qualitative research design. The empirical materials were drawn from qualitative interviews with the spouses of COPD patients and pulmonary ambulatory nurses. The participants were recruited from the patient pool of ambulatory pulmonary services at two hospitals in Oslo. In addition, participant observation was carried out during home visits to COPD patients.

The findings in this study show that family caregivers are both affected by illness and feel responsible for managing it. In this context, the caregivers faced several dilemmas as they made great efforts to maintain continuity and normality in their relationships with the ill
persons and in everyday life. A crucial part of these was the caregivers’ attempts to maintain their shared, continued biographies with their ill partners - their ‘biographical we’. This involved maintaining the routines, practices and arrangements that constituted symbols of their shared life project and maintaining their shared narrative as a couple. However, the caregivers’ sense of affectedness and responsibility resulted in competing considerations in their endeavour to maintain self, reciprocity and the biographies of themselves and the person for whom they cared.

Family caregivers strive to recognise their own needs for support, in a relational process with the ill spouses and formal health care providers. The caregivers expressed needs for respite, a greater sense of safety and sharing of responsibilities. On one hand, they feared letting the ill person feel abandoned by them, but on the other, caregivers made efforts of making health care services fit into their lives. In addition, several caregivers described difficulties having their needs for support recognised within formal health care services.

Health care encounters with pulmonary ambulatory nurses show the importance of the nurses’ ability to grant recognition to both the patients and caregivers to enable discussion of the management of the illness. In these discussions, health care professionals helped both patients and caregivers navigate a complex illness trajectory. This assistance was crucial as management of illness might reflect underlying tensions and support needs that are often unclarified between spouses.

The thesis draws attention to the need to develop a more sensitive approach towards caregivers’ experiences as both affected and responsible. In various ways, this thesis’s findings demonstrate the importance of supporting both patients and caregivers in facing relational dilemmas, such as legitimating and seeking health care within the marital relationship.
This thesis highlights the gap between the ideals in health care policies and the realities in health care provision concerning supporting family caregivers. Caregivers have an ambiguous status in health care policies due to the increased expectations for performance and responsibility without secured rights to support from health care services, or inclusion in health care encounters. As the expectations on family caregivers increase, it is crucial to provide them with accessible and flexible services in both acute care and systematic follow-up throughout the illness trajectory, including a relational focus with explicit attention also to caregivers. In this way, it might be possible for caregivers to maintain a sense of safety while shouldering extensive care responsibilities.
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1 Introduction

Most people experience being a caregiver to an aging and/or severely ill family member at some point in their life course. Often, as I describe in this thesis, the marital relations among the elderly include caregiving relationships. In these relationships, selves, biographies and reciprocity are changing and under negotiation. The experiences of caregivers are significantly similar and significantly different from the experiences of the ill persons. Thus, providing understandings of the considerations caregivers do vis-à-vis their ill spouse and health care professionals, may shed new light on the informal caregiving relationship.

In this qualitative study, I explore from a sociological perspective the dilemmas family caregivers face in relation to both their spouses’ suffering from COPD and to formal health care provision for maintaining their lives and ensuring appropriate care. To generate better understanding of the work of caregivers, I analyse their experiences as embedded in the relationships with the ill persons and linked to wider social structures and cultural contexts.

The point of departure for this study was the introduction of new models of care for many patient groups, including patients with chronic obstructive pulmonary disease (COPD), such as the Hospital at Home models and ambulatory services in which professionals follow up patients in their homes. I was led into this project by my curiosity and interest in analysing the implications of such service provision for caregivers. I expected that such services could be experienced as both invasive and unsafe but also potentially a better context for providing personalised and tailored care.

While working on my masters’ thesis in sociology in 2009, I enjoyed conducting qualitative analysis. I enjoyed the analytical work of making sense of complex processes which involved linking individual choices, or the lack of choices, to structural conditions and the cultural
expectations related to work conditions and construction of gender norms (Aasbø 2009). My motivation for launching this project was my conviction that sociological perspectives and analysis can enhance understanding of the complex processes involving the collaboration (or lack thereof) between informal and formal care providers for persons with COPD. Moreover, analysing the significance of health care polices, health care provision and face-to-face interactions in health care encounters for caregivers’ performance and experience of their role as caregivers triggered my interest throughout this project. In a time when health care policy has emphasised the need for family caregivers to take on greater care responsibilities for ill family members, I found the dilemmas caregivers face while providing care and negotiating their care responsibilities with both the ill person and health care professionals highly relevant issues to study. Simultaneously, better understanding of the challenges and dilemmas caregivers face could provide knowledge of how caregivers can be better supported in and by health care services and can point to how increased expectations for the contribution of family caregivers could intensify the tensions caregivers experience while performing their role.

As I started this project, I was deeply concerned by the possibility that the ‘system’ expects too much of family caregivers and consequently ‘exploits’ them. Early in the study, though, I found that my preconceptions were based on insufficient and too simple understandings of the relations between informal and formal care. Caregivers were interwoven in the experience of illness in a more complex way than I had foreseen. I had expected, as much research describes, that many caregivers shoulder extensive care responsibilities; however, I had not anticipated their ambivalence with regards to performing their caregiver roles in everyday life, in the work of clarifying their needs of external health care support. Generating understandings of this ambivalence prompted the analysis of issues concerning the shared and conflicting considerations caregivers describe in their relations with their ill spouses. Moreover, understanding caregivers’ experiences with formal health care in light of their
ambiguous status and the ambiguities in changing health care provision for chronically ill persons has significance for how caregivers perform and experience their role in relation to both the ill person and health professionals.

The caregivers I interviewed and the people I visited as I collected data for the present study seemed to appreciate describing their work, their everyday life routines, the lives they had lived and how they managed to maintain them despite severe, disabling illnesses. It was also important for them to describe their experiences with health and social care services in which they generally encountered a lack of recognition and understanding of their work and the feeling of being left alone with their responsibility. These crucial aspects of their experiences related to being a caregiver were not only psychological experiences but, rather, experiences of caregiving embedded in the relationships with both the ill person and health care services. My argument is that caregiving is, to a too great extent, understood in research and society almost exclusively in terms of (negative) psychological and bio-medical models which focus on caregivers’ experiences of strain, stress and burden, as well as their needs as exclusively essential.

The point of departure for this thesis is the understanding that caregivers’ experiences and work entail much more than individualised and essentialist concepts can reflect and capture. Moreover, my on-going concern has been to enhance individualist understandings of caregivers’ needs and to see them instead as individuals striving to recognise their own needs for support in a relational process with ill persons and formal health care providers. Therefore, I believe that analysing how caregivers perform their roles in interactions with ill persons and health care services in different contexts makes significant contributions to the research literature and to understandings of family caregiving and the relationships between family caregivers and health care services. Shedding light on caregivers’ various concerns and
considerations may provide a better understanding of the experiences and challenges they face while collaborating with health care services. Moreover, the interactions among caregivers, patients and professionals in health care encounters when the management of illness is discussed might increase knowledge of how caregivers and patients can be supported.

I believe that analysing caregivers’ role and health care provision from the perspective of sociological theory on family relationships, the illness experience and narratives can contribute to an enhanced understanding of the socially constructed experience of family caregivers, their needs of support and how they can be supported in more appropriate ways through formal health care services. I hope that this thesis provides insights and conceptualisations on significant aspects of the caregiving experience which might also serve as a point of departure for new studies addressing these issues.

1.1 Study aim and research questions

The purposes of this study are to develop knowledge that might contribute to improved health care services and support for the family caregivers of chronically ill patients. The aim of this study is to deepen scientific knowledge of the interactions between the family caregivers, the chronically ill persons and health care professionals, with a particular focus on the work of family caregivers. The main research question in this thesis is: How do family caregivers perform their role in relation to both the ill person and health care professionals? How do they experience these roles?

To accomplish the aims of this study, I developed the following research questions:
1. How do the spouses of COPD patients integrate their responsibilities as family caregivers with their role as spouses? What tensions and challenges are involved in this? (Paper 1)

2. How do spouses negotiate their roles as caregivers with patients and health care professionals when chronic illness develops into acute exacerbations for patients with COPD? (Paper 2)

3. How do ambulatory nurses support both COPD patients and their caregivers in management of illness during home visits? (Paper 3)

1.2 Outline of thesis

The thesis is based on empirical data generated in qualitative interviews with spouses who are family caregivers to COPD patients, participant observations on home visits accompanying pulmonary ambulatory nurses and qualitative interviews with these nurses. The design is explorative, inductive and descriptive. The thesis comprises two published scientific papers and one submitted paper, in addition to this introductory section. In the papers, different methodological and analytical approaches are used to provide new understandings of caregivers’ interactions with both patients and health care professionals and their related experiences. In addition, the conditions for improved support of caregivers and patients to live well with the illness are investigated.

In the first paper, I analyse how caregivers work in everyday life to maintain their relationships with their ill partners, particularly investigate the dilemmas they face as both spouses and caregivers. The second paper addresses how caregivers negotiate with both the ill person and health professionals in situations where their partners’ illness or condition
develops into acute exacerbations. The third paper focuses on how ambulatory nurses support both patients and their family caregivers during home visits.

In this introductory section, I present the background for this study in chapter two and outline the theoretical orientations that inform this study in chapter three. In chapter four, I describe the process of generating and analysing the empirical material discussed in this thesis and reflect upon ethical issues. Chapter five summarises the three papers in this study and their findings. In chapter six, I present an integrated discussion of the study results and its overall contributions. In chapter seven, I cover the methodological considerations, particularly the trustworthiness and transferability of this study. In chapter eight, I give a few concluding remarks and suggest potential areas for further research on the issues addressed in this thesis.
2 Background

In this chapter, I present the background of this study. First, I review changes in health care provision to chronically ill persons. Second, I describe the disease characteristics of COPD and current specific recommendations for the care of COPD patients. Third, I provide an account of the understanding of family caregivers in policy, practice and research and more generally address challenges in the collaboration of care from the perspective of caregivers.

2.1 Changing health care provision to the chronically ill

The growing number of the elderly in the national population and higher prevalence of chronic diseases present future challenges for long-term care services. Decreasing hospital days per stay and involving several sectors with support from family and local communities are initiatives necessary to meet these challenges (Ministry of Health and Care Services 2006). Health care policies in western countries explicitly state that complex illness conditions should be treated and managed outside hospitals through various forms of public–private partnerships (Kuhlmann and Annandale 2012, Larkin and Milne 2015). Few studies have examined the implications of the shifting boundary between formal and informal care for family members caring for patients with complex illness trajectories (Allen et al. 2004).

The primary concern in health care service provision is to provide high-quality care within the scope of the sustainability of the health care services. Many COPD patients are hospitalised frequently due to exacerbations; consequently, this patient group is regarded as a great burden on hospitals (Nielsen et al. 2009). National policies increasingly commit municipalities to providing more specialised care to reduce the burden on hospitals. Additionally, specialist
health care is shifting from inpatient care to outpatient care. Integrated care programmes, such as Hospital at Home schemes, at the intersection between hospitals and municipalities are organisational models increasingly used to prevent or reduce hospitalisations and to improve the quality of treatment for patients with chronic disease, such as COPD. A common model is hospital-organised ambulatory services where professionals follow up with patients at home. Studies have indicated that such services to COPD patients are both clinically and economically beneficial (e.g. MacMahon 2001, Hudson 2002, Shepperd et al. 2008, Wong et al. 2008). However, such programmes vary from intensive follow-up during critical illness phases to services with more infrequent follow-up over a long period of time and with a broader focus, including education and counselling aimed at preventing hospitalisations. Moreover, current policies emphasise preventive home visits to a greater population of elderly as a measure to address future health care challenges (Ministry of Health and Care Services 2016).

2.3. Living with chronically obstructive pulmonary disease

COPD is an illness with serious implications for morbidity, disability and mortality. COPD is one of the most common chronic diseases in the world and is expected to be the fifth leading cause of disease burden by 2030 (WHO 2008). As many as 250,000–300,000 people in Norway have COPD (Waatevik et al. 2013), of whom approximately 10 % have very serious health issues (Johannesen et al. 2005).

The diagnoses, causes and prevalence of COPD are highly complex (Wang 2013). Tobacco smoking is generally understood to be the main cause of COPD and can explain 2 of every 3 cases on average (Norwegian Institute of Public Health 2014). However, other factors also
seem to be important in explaining the growing prevalence of COPD (see e.g. Vestbo et al. 2013), such as air pollution, occupational dust and chemicals. The onset of COPD is typically in mid-life, and symptoms of COPD are common among the oldest old, including those with a non-smoking history. In aging populations, the prevalence of COPD is growing. Until recently, COPD was more common among men, but due to increased smoking rates among women (Norwegian Institute of Public Health 2014), the disease now equally affects men and women (Mannino and Buist 2007). It is often under-diagnosed and diagnosed late in the course of COPD (Mannino and Buist 2007).

COPD is characterised by a gradual deterioration in health status and worsening symptoms, including breathlessness, dyspnoea, cough and sputum production. It is a heterogeneous disease. Not only does it vary greatly from person to person in lung pathology, co-morbidity and natural history of disease; it can also coexist with asthma (Mannino and Buist 2007). The illness is marked by unpredictable and sometimes life-threatening, acute episodes of breathlessness. Persons with COPD often have other diseases, are at risk of contracting infections and suffer from anxiety or depression (Gold 2006, Caress et al. 2009). In particular, persons with COPD who suffer from dyspnoea during acute exacerbations often experience anxiety (Becker et al. 1993, Bailey 2004, Fraser et al. 2006, Kvangarsnes et al. 2013). As the illness progresses, the ability of persons with COPD to perform everyday life activities becomes more restricted, reducing their quality of life and increasing their dependence on others (Barnett 2005, Ek and Ternestedt 2008). COPD radically affects the lives of patients and their close family members due to the increasing impairment and isolation throughout the illness trajectory.

Today, there is a strong overrepresentation of people with low education levels among heavy smokers (Lund and Lund 2005). Halding et al. (2010) argue that stigmas of self-infliction and
moral weakness are related to value judgements imposed on people living with COPD. Moreover, persons with COPD experience communication and interactions with health care professionals as challenging or problematic (Becker et al. 1993, Halding et al. 2010). Simultaneously, surveys have also indicated that, in the hierarchical prestige of medical specialities and diagnoses, COPD is of low rank (Album and Westin 2008).

2.2 Service provision to COPD patients

The guidelines for the prevention, diagnostics and treatment of COPD (National Directorate of Health 2012) emphasise the provision of more accessible, coordinated and coherent health care services to COPD patients in both primary and secondary health care services. Patients’ individual needs, wishes, abilities and mode of living should be recognised. The guidelines also point out several challenges: health care services are fragmented and appear overly complex to patients. As well, there is not equal access to rehabilitation programmes in all regions of Norway (National Directorate of Health 2012), even as pulmonary rehabilitation is recommended for COPD patients (Ries et al. 2007). The aim of rehabilitation is to enable patients to orient themselves in and cope with their current life situation. Disease-specific competences, physical exercise, psychological and nutrition counselling, breathing strategies and life-style changes, including smoking cessation, are included in pulmonary rehabilitation.

Self-management education and support in COPD are related to rehabilitation and are aimed at improving patients’ quality of life. Self-management support is characterised by engaging patients in increasing their confidence in their ability to follow a self-care regimen, including strategies to manage exacerbations and delay disease progression (Bourbeau et al. 2004, Newman et al. 2004). The research literature on self-management emphasises a broader focus on family-centred, holistic and relational care in self-management support (Jónsdóttir 2013).
In studies on self-management support interventions, the social context remains under-theorised and empirically under-explored (Ong et al. 2015). In the understanding of behaviour change interventions for self-management, the focus is solely on the individual and on individual attributes that require modification, rather than also on other factors which might facilitate such changes (Ong et al. 2015). Morgen et al. (2016) argue that self-management support can be divided into narrower and broader approaches. In the former approach, people are supported to manage their condition well in terms of disease control, facilitated by persuasive motivation. In the latter approach, people are supported to manage well with their condition, facilitated by a more relational focus, integrating the management of the illness into a more comprehensive understanding of what matters to people and how they can be supported to shape their own lives. Providing new knowledge on the terms for supporting both patients and caregivers and the challenges related to providing such support could contribute significantly to the research literature.

2.3 Understandings of family caregivers: policies, practice and research

Informal caregivers are important providers of care, and the main recipients of this care are elderly persons in the last stages of life. Caregiver refers to a person of any age who provides unpaid support to another person who is unable to manage to live independently or whose health or wellbeing would deteriorate without this help (Carduff et al. 2014). Family caregiver is a broad concept which includes partners and other family members who provide care for a person with severe illness. According to studies in Norway and other western countries, the main caregivers for chronically ill and elderly family members are spouses and children (Allen et al. 2000, Romøren 2001, Gautun 2003). In Norway, it has been estimated
that care carried out by family caregivers is comparable to 100,000 full-time equivalent (FTE) jobs (Rønning et al. 2009). Thus, families provide almost half of the care older people receive (Rønning et al. 2009).

2.3.1 The construction of caregivers in contemporary health policies

Current health care policies in Norway as in other Western countries emphasise that family caregivers should have more explicit roles in health care services in both receiving support and being included in decision making (Ministry of Health and Care Services 2011, p. 10–11, 85–95, Kuhlmann and Annandale 2012). The guidelines for supporting family caregivers under development (National Directorate of Health 2016) emphasise the involvement of caregivers in the treatment and follow up of patients, provision of information to caregivers (with the consent of the patient), establishment of dialogue, recognition of the competence of caregivers and support of caregivers for those with long-term illnesses and disabilities, especially in the last phases of life.

The focus of policies regarding informal care has also been to mobilise such resources. Health care policies appeal to the moral obligations of family caregivers, emphasising ‘responsible citizenry’ and the ‘trust and solidarity between generations’ (Ministry of Health and Care Services 2013, p. 8, 17). Obligations to care can be understood at a normative level and are stronger for close family members than for more distant kin (Finch and Mason 1991). Allen (2000) argues that contemporary welfare ideology reflects a curious blend of left-wing liberalism and right-wing individualism and is based on the assumptions that families should care for their dependent relatives and that the family empowers patients and protects them from feelings of helplessness, which improves compliance and enables early hospital discharge.
Caregivers have an ambiguous status in health care policies, which has consequences for their inclusion in service provision (Glendinning et al. 2015, Larkin and Milne 2015, Seddon and Robinson et al. 2015). Caregivers take on considerable responsibilities but have not secured better rights to support and participation within formal health care in Norway (Kjellevold 2011). For instance, caregivers normally do not have rights to be informed of the diagnosis, treatment and prognosis without the consent of the patient. Paradoxically, children, as next of kin, are guaranteed rights, but adults are not (Norwegian Directorate of Health 2010). Moreover, caregivers’ experiences in the United Kingdom show that enjoying better rights does not necessarily secure recognition of their work and support needs (Glendinning et al. 2015, Milne and Larkin 2015, Seddon and Robinson 2015).

Twigg (1989) describes three ideal types of the relations between formal and informal care provision in health policies: caregivers as ‘resources’, caregivers as ‘co-workers’ and caregivers as ‘co-clients’. Twigg (1989) addresses contradictory aspects of the relationship between informal and formal care provision and difficult questions concerning how health care provision should relate to and support family caregivers, which still has high relevance in contemporary health care provision (Glendinning et al. 2015). The conception of caregivers as co-workers reflects a relation in which formal health care providers work in collaboration with family caregivers, aiming to enable the caregivers to perform their roles, so they are understood to be semi-professionalised or lay experts. Glendinning et al. (2015) argue that the needs of caregivers understood as co-workers are met in order to sustain their care-giving role. Accessible interventions are underpinned by psychological models of empowerment, self-efficacy and coping, and the individual bears the primary responsibility to acquire the relevant knowledge and competences to develop this ‘expertise’ (Taylor and Bury 2007). Caregivers as co-clients reflect a relation in which professionals support informal caregivers, especially those who care for severely ill persons. Legislation, policies and practice give less
emphasis to caregivers as co-clients who have their own support needs (Glendinning et al. 2015). Caregivers as resource is especially evident in Norwegian polices; indeed, the national guidelines for collaboration with family caregivers to mental ill persons are entitled: ‘Caregivers: a resource’ (National Directorate of Health 2008).

The difficulties in including caregivers and allowing their participation reflect the challenge that family involvement poses to the individual focus in public service provision in Western welfare states (Daly 2002, Lewis 2007). Rugkás (2015) argues that to ensure recognition, and more active participation of caregivers in patient care, changes in the existing structures of formal health care provision are needed.

2.3.2 The research literature: family caregiving in COPD

Much of the literature addressing informal caregiving, including in the context of COPD, has focused on burden, strain and stress (Grant et al. 2012). This literature is based on psychological and biomedical models of the caregiver which reflect clinical and public health concerns and is aimed explicitly at preventing ill health and implicitly at minimising caregivers’ use of health care resources (Sadler and McKeivitt 2013).

Although the research on informal caregiving has increased considerably in the past 15 years, the literature on informal caregiving in the context of COPD (Cruz et al. 2015) is far less extensive than the literature on other illnesses, such as cancer. In a review of the impact of caring for a family member with COPD, Cruz et al. (2015) address physical and mental health, social and relational challenges. Caregivers report negative impact on their own physical health, such as fatigue and exhaustion (Spence et al. 2008, Simpson et al. 2010). Many studies also address the psychological impact of family caregiving (Grant et al. 2012). Many caregivers experience anxiety and depression (Grant et al. 2012, Gabriel et al. 2014, Jácome et al. 2014, Lindquist et al. 2014), especially in phases of acute exacerbations (Gysels
and Higginson 2009). The unpredictability of the illness trajectory, patients’ negative attitudes and behaviours and a lack of information from professionals are also challenges caregivers face (Spence et al. 2008, Hasson et al. 2009). Health professionals’ support is perceived as important to overcoming these barriers (Bergs 2002, Spence et al. 2008, Hasson et al. 2009, Lindqvist et al. 2013).

In addition, caregivers experience social isolation and a loss of recreational activities and their expected lifestyle, retirement plans and personal freedom (Seamark et al. 2004, Spence et al. 2008, Simpson et al. 2010, Gautun et al. 2012, Hynes et al. 2012, Lindqvist et al. 2013, Gabriel et al. 2014). Moreover, caregivers describe increasing tensions in their relationship to the ill person (Gabriel et al. 2014), particularly a loss of friendship, intimacy and couplehood identity with their partner (Bergs 2002, Simpson et al. 2010). Together, these make caregivers feel a loss of personal identity and caring motivation (Simpson et al. 2010). However, family caregiving in the context of COPD also has rewarding aspects, such as the ability to meet the needs of the person cared-for (Bergs 2002, Spence et al. 2008) and opportunities for personal growth (Gabriel et al. 2014).

Although this literature gives insights into various implications of caregiving, the understandings, to a great extent, are based on psychological and reductionist models (Sadler and McKevitt 2013). This literature on family caregiving approaches experience and needs as an essentially individual. This literature does not sufficiently take the social structure and cultural contexts into account, but the caregiver’s relationships and interactions with the person for whom they care are also under-analysed. In addition, the literature addressing the cooperation between informal and formal care providers most often focuses on caregivers’ experiences of specific interventions, which does not provide a comprehensive understanding of the interactions between informal and formal health care providers. Thus, the challenges
faced by family caregivers in performing their roles and interacting with health care providers, to a great extent, remain under-researched. It is crucial to gain a better understanding of the terms of supporting caregivers in particular situations and throughout the illness trajectory.

### 2.3.3 Challenges of collaboration in care provision: perspectives of family caregivers

The relations between informal and formal care provision have received increased interest in recent years, particularly in relation to the coordination reform in Norway implemented in 2012 (e.g. Lerum et al. 2016, Røthing 2016). This relation is often idealised in policies, described in terms of partnerships (Rugkåsa 2015, Røthing 2016). Caregivers’ expectations for such partnerships include involvement, clear responsibilities, continuity, high competence, sharing of their knowledge, flexibility in contact, recognition of their efforts and situation and support to take better care of themselves (Røthing 2016).

However, several studies report that caregivers and professionals do not have shared understandings of their roles regarding each other, and health professionals often transgress the reciprocal model or arrangements that caregivers feel should guide their interactions (Rugkåsa 2015, Bove et al. 2016, Røthing 2016). Rugkåsa (2015) argues that many caregivers experience their relationships to professionals as imbalanced and lacking both trust and recognition. Some caregivers report being excluded by professionals from participating in decision making (Ridley et al. 2010), which many caregivers experience as a statement that their contributions are not of constitutive value (Rugkåsa 2015). Moreover, considering the intimate relationship among the caregiver role, family life and personal identity, such experiences must also be understood to indicate a lack of recognition of the aspects of life that are of the highest moral value to the caregivers themselves (Rugkåsa 2015).
Despite the strong emphasis on supporting caregivers and facilitating their participation in decision making in health care encounters, there exists little research on caregivers’ information or support needs or evaluations of interventions implemented to enhance their capacity in the context of COPD (Caress et al. 2010, Cruz et al. 2015). Thus, to better understanding the processes of defining the individual and shared needs of both patients and caregivers and of seeking external care and integrating care into their lives and relationships, it is necessary to shed light on the crucial terms for appropriate service provision to COPD patients and their caregivers.
3 Theoretical perspectives

In this section, I present the theoretical perspectives which I have found fruitful to generate a better understanding of caregivers’ work and experiences of it. I draw on different theoretical approaches to make sense of caregivers’ work, experiences and interactions with both patients and professionals. Theoretical conceptualisations of informal relationships of care, the illness experience, negotiations and narratives have been crucial to develop understandings of the performance of care in everyday life and health care encounters.

3.1 Point of departure


The point of departure in this study is the work carried out in interactions in certain contexts, particularly activities and the organisation of routines and face-to-face interactions. Addressing caregivers’ and professionals’ work can generate understandings of the various dilemmas they face in the complex interactions among patients, caregivers and professionals. The theoretical and methodological approaches of this study are both based on the notion of work. This notion has been developed and applied within the feminist ethnographic tradition (Smith 1987, DeVault 1994, McCoy 2009), which centres the inquiry on the everyday actualities of people’s lives. This notion has also emerged from the interactionist tradition (Corbin and Strauss 1985, 1988), which pays attention to the complex work of managing
chronic illness which involves much more than symptoms management. In both traditions, the notion of work has been used to recognise and understand the practices of accomplishing everyday life through negotiations, decisions, activities and narratives. Thus, this notion can shed light on aspects not normally perceived that nevertheless require a specific embodied, relational effort. To obtain insights into these efforts involves questioning the obvious and taken-for-granted practices.

3.2 Relationships of care

Individualisation theorists argue that late modernity has created intimate relationships which challenge the traditional concepts and theories of family. Intimate relationships are no longer characterised primarily by the obligations of family life but by the quality of personal relationships. Giddens (1992) argues that a transformation of intimacy has produced pure relationships freed from duties and obligations. Beck-Gernshim (1998) describes the erosion of traditional ties and conceptualises the post-familial family. Moreover, theorists of modernity argue that personal identities are more important than social ones (Archer 2003) and that the ethics of self-fulfilment and individual projects are the most powerful in modern society (Beck 1992). However, several sociologists nuance this stance, arguing that family and kinship, along with gender, class and ethnicity, retain importance which must not be underestimated in current understandings of intimate relationships (Roseneil and Budgeon, 2004, Gross 2005, Smart 2007). Pahl and Peavlin (2005) find that, throughout the life course, the importance of kin increases.

I find this debate to be highly interesting as it sets in perspective the individualistic focus in research on family caregivers, as well as the ‘personalisation paradigm’ currently shaping
adult social care practice (Glendinning et al. 2015). Moreover, this critique adds relevance to exploring caregivers’ work and experience as deeply embedded in their relationships with the person for whom they care. Moreover, analysing the implications for these relationships could make visible the dilemmas and challenges of caregivers, along with the ambivalence they express.

Smart (2007) introduced the perspective of ‘personal life’ to capture the various ways in which people are connected and entwined and how deeply people are embedded in the lives of the people with whom they share their lives. These relationships between people constitute the basis for creating meaning in life. Smart (2007) criticises the individualisation thesis and argues that its claims are poorly empirically grounded. Qualitative analysis of intimate relationships generally points to the various ways in which people are entwined in each other’s lives, for instance, when people make individual choices (Smart 2007). The understanding that people need ongoing, formative relationships to develop a sense of personhood or individuality constitutes the basic premise of the concept of relatedness (Smart 2007). However, it must be noted that the emphasis on the significance of relationships does not necessarily mean that the bonds between people are warm or loving (Smart 2007).

Drawing on the views of Smart (2007), I argue that connectedness is a core aspect of family caregiving. The persons I interviewed were connected through shared experiences, reciprocal emotions and intertwined histories. Thus, the caregiver role is intimately linked to a wider set of social roles which may form part of family life. This is a fruitful perspective from which to analyse the complexities involved in personal experiences of caregiving as the subjective, social and cultural dimensions are simultaneously in focus. Caregiving is thus understood as deeply personal and as embedded in intimate relationships, social structures and cultural understandings.
During the 1970s and 1980s, many sociologists criticised the notion of caring from a feminist perspective and argued that the ideology of caring is underpinned by assumptions that it is naturally performed by women, whose labour and status are exploited (Graham 1983, 1993, Wærness 1984). Feminist scholars further contended that the traditional responsibilities of women, including duties for their household, children and neighbourhood, have been understood as natural, instinctual, emotional labours of love and acknowledged neither as work nor as real activities (Graham 1983, Borchgrevink and Holter 1995, Smith 1999, Werner and Malterud 2003).

Among the many definitions of care, Tronto (1995) offers an understanding which places care at the core of personal and social lives. Tronto (1995, p. 142) describes care as ‘a species of activity that includes everything that we do to maintain, continue, and repair our “world” so that we can live in it as well as possible. That world includes our bodies, our selves, and our environments, all of which we seek to interweave in a complex, life-sustaining web’. Thus, care is understood as a process, and judgements made about care arise from the real, lived experiences of people in all their variety. This understanding implies a shift in the perception of human nature from independence to interdependency as people are enmeshed in relationships of care and reciprocal relations form an essential part of the interdependency of care systems (Tronto 1995).

Chattoo and Ahmad (2008, p. 561) argue that care represents ‘an embodied moral practice’ involving the ongoing ‘negotiation of moral boundaries’ to strike a balance between the notions of independence and dependence. Chattoo and Ahmad (2008) argue that the carer and the cared-for often have more intertwined needs than is often assumed, challenging the dichotomous notion of care which locates the patient and the caregiver as separate, unitary, autonomous individuals. The increased focus on individualisation and autonomy is also
criticised by Honneth and Anderson (2005, p. 128), who argue that, ‘while a modern (Western) conception of autonomy builds on the Kantian idea that one’s autonomy must be compatible with that of others, it “sneaks” in an additional component—namely, the idea that individuals realise their autonomy by gaining independence from their consociates’. This understanding that any constraints reduce a person’s autonomy underpins the argument that a fair society is a society in which people are as independent of each other as possible. This argument fails to grasp the neediness, vulnerability and interdependence of individuals (Honneth and Anderson 2005, p.129). Together, these insights shed light on the desire for independence and the fear of dependence described in many studies on aging and relationships (Lewinter 2003, Smart 2007, Chattoo and Ahmad 2008, Breheny and Stephens 2009).


3.3 Between disruptions and continuity

Throughout the work of this thesis, the importance of contextualising caregivers’ work and their interactions with the ill person and professionals in the personal lives of caregivers and
their chronically ill partner, and particularly in their shared biographies, was crucial to make sense of the complex work and experience caregivers described. In the medical sociological literature, the illness experience has been analysed in terms of classical dichotomies, such as change/stability and disruption/continuity (Bury 1982, 1991, Charmaz 1983, 1987, Williams 1984, Corbin and Strauss 1985, 1987). Insights concerning how chronic illness affects self, identity and biography and how and what mediates the experience of chronicity have been generated.

The concept of biographical disruption has been applied and discussed in many studies on the lived experience of chronicity (Bury 1982, Williams 2000, Lawton 2003, Larsson and Grassman 2012). Bury (1982) argues that chronic illness is an experience that disrupts the ill person’s everyday life, the forms of knowledge underpinning it and the normal rules of reciprocity. Chronic illness involves a fundamental re-thinking of the person’s biographical self-concept and demands recognition of the worlds of pain, suffering and possibly death. Thus, the notion of biographical disruption does not refer merely to the bodily experience of chronic illness but also to the social, cultural and structural aspects enmeshed in the illness trajectories which mediate or interplay with this experience. Charmaz (1983) describes the loss of self in similar terms but also emphasises the experiences of discreditation and being a burden on others. Williams (1984) explains the conceptual strategies that people use after experiencing biographical discontinuity to create a sense of coherence, stability and order as narrative reconstruction, involving narrating chronicity within the scope of one’s personal life history.

The concept of biographical disruption has rarely been used without also studying the responses to this experience, in this case, the great efforts of chronically ill people and their intimates to create a sense of continuity, stability and normality after disruptive experience,
which have been conceptualised as biographical continuity or work (e.g. Corbin and Strauss, 1985, 1987, Charmaz 1983, 1987, Becker 1997). Biographical work is characterised by attempts to find identity and meaning, fundamentally rethink or reconstruct life histories, reorganise everyday life and deal with an uncertain future (Corbin and Strauss 1987). The process of defining and redefining the self involves attempts to retain control over the life course, give life meaning again and reorient one’s values (Corbin and Strauss 1987, p. 273, Boeije et al. 2002). Becker (1997) describes the cultural values underpinning the negotiations of disruption and continuity and argues that efforts to create continuity after disruption are a complex cultural process, in which people strive to achieve predictability, normalcy and order in their lives. Becker (1997, p. 199) asserts that ‘the conflict between the desire for normalcy and the acknowledgement of difference is enacted over and over again’.

Although Bury (1982) touches upon the ways in which chronic illness shatters reciprocity, the focus has mainly been on the individual experience (Radcliffe et al. 2013, Hudson et al. 2016). In the process of reintegrating identity into a life with illness and disability, validation and confirmation from others are crucial to developing and sustaining the valued aspects of the self (Corbin and Strauss 1987, Charmaz 1983, 1987). Throughout the illness trajectory, however, the work involved in its management influences couples’ biographies, in terms of transforming their respective and mutual identities (Corbin and Strauss 1985, p. 47).

Caregiving relationships are described as a continuation of previous relationships, but the changes in these relationships are simultaneously seen as highly disruptive (Adamson and Donovan 2005). Biographical disruptions have been explored by both partners within a dyad (Rajaram 1997, Radcliffe et al. 2013, Hudson et al. 2016). Radcliffe et al. (2013) and Hudson et al. (2016) argue that the marital relationship and relational identities mediate the experience of chronic illness and disability and its impact on both individuals’ and couples’ identities.
Keyses et al. (2007), Radcliffe et al. (2013) and Hudson et al. (2016) describe the active biographical work done by couples faced with chronic illness and argue that, in the work of accommodating to illness, the relationship between the chronically ill persons and their spouses are appraised and strengthened, and their lives and expectations revised.

Drawing on these studies, I argue that extending the notion of biographical disruption beyond its current individualistic focus can enhance the understandings of how chronic illness impacts this relationship and how this relationship mediates the experience of chronic illness. I explore the relationality of the experience of biographical disruption and continuity in how the caregivers themselves are embedded in this experience through their shared lives and entangled biographies with the ill partners. I believe that these insights provide better understandings of the dilemmas caregivers face in their relationships with both the patient and health care professionals. In addition, these insights might point to significant aspects regarding how caregivers can be included and supported by health care services in more appropriate ways.

### 3.4 Interactions as negotiations

To develop a better understanding of caregivers’ work in relation to the ill person and professionals, I find analysing the negotiations of care to be a fruitful approach. Negotiations may reflect ambivalence, uncertainty and a lack of clarity, which are themselves important aspects of caregivers’ experiences. Moreover, negotiations might generate an in-depth understanding of how caregivers negotiate the balance of legitimate dependence and personal autonomy in everyday negotiations of care and negotiations of external support with their partner.
According to Strauss et al. (1963), negotiations are the key to understand how order and change fit together. When uncertainty, disagreements and ambiguity exist, negotiations are undertaken as means to achieve understanding or agreement (Strauss 1978, Allen 1997). Negotiations can range from tacit understandings to explicit contracts. In several studies of care, the concept of negotiation has been applied to analyse interactions between family members (Finch and Mason 1993, Thorne 1993), between nursing staff and family caregivers in hospital contexts (Thorne 1993, Allen 2000) and between nurses and doctors in hospital settings (Svensson 1996, Allen 1997). Finch and Mason (1993) argue that, within families, care responsibilities are negotiated explicitly and implicitly. Explicit negotiations involve open discussions in which people develop a common understanding of how to balance the responsibilities of giving and receiving help. Implicit negotiations are characterised by non-decisions, or distributions of responsibilities that simply emerge.

Allen (2000, p. 155) argues that interactions between professionals and ‘expert carers’, or experienced family caregivers with long-standing caring ties who felt a strong moral responsibility, were difficult to integrate into professionals’ routines and work at the hospital. These caregivers challenged the nurses’ claims to expertise and ability to control the caregivers’ work and define appropriate standards of care. Allen (2000) contends that the affective relationship between family caregivers and patients caused difficulties integrating those caregivers into the caring division of labour. Thus, affective bonds and relatedness are also important to understand the interactions between informal and formal caregivers.

3.5 Interactions as narratives

There exists little knowledge and understanding of how professionals relate to the continuous biographical work of the ill persons and their caregivers and the relational dilemmas they face.
throughout the illness trajectory. To shed new light on interactions in home visits by ambulatory nurses, I found the views of Mattingly (1994, 1998) useful to grasp important aspects of the interactions among nurses, patients and caregivers in these health care encounters. Mattingly (1994, 1998) studies interactions in clinical practice as narratives. Activities, imaginaries and interactions in rehabilitation settings are often structured as narratives. In particular, the therapist and patient co-construct clinical plots which give meaning to specific activities in the rehabilitation context. Based on Mattingly’s (1998) analysis of how professionals and patients co-construct such narratives, it can be argued that the construction of narratives in clinical practice is an important tool for professionals to create significant experiences for patients (Tropea 2012). Mattingly (1994, 1998) and Mattingly and Lawlor (2001) describe how, in encounters in rehabilitation contexts, occupational therapists work to develop opportunities to support transformations that enhance the patient’s understandings, wishes, desires, hopes or motivations. The changes might be outward and public (e.g. in activities and performance) or inward (e.g. in thoughts and feelings). Mattingly and Lawlor (2001) describe sequences from consultations, or significant moments which they call a ‘healing drama’. In such healing processes, the therapist and the patient often co-construct imaginatively rich activities that demonstrate that, despite a lost or broken body, the patient still has a self worth making and struggling for.

This perspective offers an understanding of how professionals search for and create moments in which understandings, acceptance and arrangements for managing illness are negotiated. I have found Mattingly (1994, 1998) and Mattingly and Lawlor’s (2001) perspectives stimulating for the analysis of how professionals search for significant moments with transformative potential to support both patients and caregivers in their biographical work.
4 Methods

In this chapter, I describe the methodological procedures carried out in this study and reflect on the choices I made throughout the research process. I give an account of the study’s context, the methodological approach and the data collection and analysis. Finally, I discuss the ethical considerations related to the research process.

4.1 Design and methodological approach

I wished to generate data material that would enable me to study the work of caregivers, their experiences of work and their interactions with both the ill person and professionals. Therefore, I conducted individual qualitative interviews with spouses who are caregivers, participant observations during home visits to COPD patients by ambulatory pulmonary nurses and individual qualitative interviews with these nurses. This research combines two key methods in qualitative research which focus on what participants say and do (Atkinson and Coffey 2003).

The study is placed within the framework of social constructivism, which claims that experience is socially situated and that knowledge is constructed through interaction with others (Hacking 2000). This broad framework allows combining certain theoretical approaches outlined in the previous chapter and the methodological approaches outlined in this chapter. This position has been important to generate new knowledge and understandings of the relationship between formal and informal care provision for COPD patients.

4.2 Study context, recruitment and participants
The data in this study were generated from 10 individual qualitative interviews with family caregivers, 20 participant observations in home visits to COPD patients and four individual qualitative interviews with pulmonary ambulatory nurses. Papers one and two are based on the interviews with family caregivers, and paper three is based on the participant observations and interviews with the nurses.

### 4.2.1 The study context

For several years, pulmonary outpatient clinics at two hospitals in the Oslo region, Norway, have organised nurse-led pulmonary ambulatory services for patients with pulmonary diseases. These services were chosen as the health care context in this study as they represent the provision of health care services recommended for COPD patients, as well as the shift from inpatient care to outpatient care in the specialist health care. Such services stand as interesting examples of public–private partnerships (Kuhlmann and Annandale 2012) which are expected to gain importance in future health care provision.

In this service, pulmonary nurses provide education and monitor the treatment of patients and their relatives in patients’ homes typically once or twice a year. The frequency of the home visits was based on the patients’ recurring needs for counselling and treatment monitoring due to the progression of illness. The nurses had the flexibility to visit more or less often. The patients could contact the nurses when necessary during work hours. The patient pool of the services consisted of mostly patients with severe or very severe COPD. When the study was carried out, 240 patients received the service at hospital A, and 180 patients at hospital B.

The primary aim of the service at hospital A was to monitor patients’ oxygen saturation in home oxygen treatment through a blood gas test to ensure safe, efficient treatment. The service provision from hospital B had broader education and support purposes and often served as an extension of pulmonary rehabilitation and/or self-management courses at the
outpatient clinic. The aim was to educate and support patients and their caregivers in managing COPD in everyday life. However, the content and course of the home visits in the two services did not vary greatly. The nurses monitored oxygen treatment and addressed issues related to the patients’ general physical condition, diet, coping in everyday life, optimisation of medication regimens and management of exacerbations.

In service B, the purpose of the service to monitor oxygen treatment implied that the patients had quit smoking. In service A, this was not a requirement, but at all but one visit, the patient had quit smoking. Smoking cessation counselling, therefore, was not an issue raised in most of the home visits in which I participated.

4.2.2 Recruitment and participants

Participant observations and interviews with ambulatory nurses

I accompanied three pulmonary ambulatory nurses and carried out participant observations in home visits to COPD patients. In addition, I conducted four individual, semi-structured interviews with pulmonary ambulatory nurses. The nurses had all long experience in pulmonary departments and all were women in their fifties or sixties. Two had formal, specialist training as pulmonary nurses.

At hospital A, I interviewed three nurses and participated in seven home visits with two different nurses. The interviews with the nurses were carried out in an office in a hospital ward within two weeks in December 2010.

The fieldwork at hospital B had a longer duration but lower intensity. I accompanied two nurses at this hospital on 13 home visits over a three-month period from February 2011 to May 2011. I interviewed one nurse from this service in a meeting room at the hospital.
The home visits in which I participated lasted from 45 minutes to two hours. Informal conversations with the nurses at the ward before and after the visits were also included. The interviews with the nurses lased 60–100 minutes.

*Interviews with spouses as family caregivers*

The interviews with family caregivers were carried out between January 2011 and June 2011. For these interviews, I used a purposive sampling strategy, as outlined by Patton (2001) and Pope and Mays (2006), including spouses of both genders of different ages and socioeconomic status. All except one was retired. I interviewed six female caregivers and four male caregivers. All of them were spouses or partners of and lived with persons with severe COPD. All were all ethnic Norwegians, except one who was born in another European country. One female caregiver was recently widowed. The symptoms and disabilities of their ill partners varied extensively, from the ability to take short walks to confinement to a wheelchair or even bed bound. Thus, their needs for assistance varied extensively. The illness trajectories of their spouses varied in duration from 5 to 25 years. The individual support and service provision from home care services varied to a great extent. With a couple exceptions, the support from home care services was not extensive.

**Participants**

<table>
<thead>
<tr>
<th>Pseudonyms</th>
<th>Sex</th>
<th>Age</th>
<th>Socioeconomic status</th>
<th>Patients’ function</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hannah</td>
<td>F</td>
<td>70</td>
<td>Teacher</td>
<td>Housebound</td>
</tr>
<tr>
<td>Peter</td>
<td>M</td>
<td>64</td>
<td>Manual worker</td>
<td>Able to take short walks</td>
</tr>
<tr>
<td>Thomas</td>
<td>M</td>
<td>80</td>
<td>Manual worker</td>
<td>Housebound</td>
</tr>
<tr>
<td>Cathrine</td>
<td>F</td>
<td>70</td>
<td>Teacher</td>
<td>Housebound</td>
</tr>
<tr>
<td>Ruth</td>
<td>F</td>
<td>80</td>
<td>Kindergarten assistant</td>
<td>Seldom out of the house</td>
</tr>
<tr>
<td>Name</td>
<td>Gender</td>
<td>Age</td>
<td>Occupation</td>
<td>Status</td>
</tr>
<tr>
<td>----------</td>
<td>--------</td>
<td>-----</td>
<td>--------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>Martin</td>
<td>M</td>
<td>62</td>
<td>Engineer</td>
<td>Able to take walks</td>
</tr>
<tr>
<td>Susan</td>
<td>F</td>
<td>80</td>
<td>Nursing home assistant</td>
<td>Deceased</td>
</tr>
<tr>
<td>Karen</td>
<td>F</td>
<td>60</td>
<td>Trained nurse</td>
<td>Almost housebound</td>
</tr>
<tr>
<td>Hans</td>
<td>M</td>
<td>84</td>
<td>Entrepreneur</td>
<td>Housebound</td>
</tr>
<tr>
<td>Astrid</td>
<td>F</td>
<td>70</td>
<td>Marketing professional</td>
<td>Able to take short walks</td>
</tr>
</tbody>
</table>

The participants were recruited in collaboration with the nurses from the ambulatory pulmonary services. Four caregivers were recruited by the nurses, and six caregivers were recruited during home visits in which I participated. I informed the caregivers about the study and invited them to participate. I informed the nurses that I wished to interview caregivers with different relations to the ill person and varied in terms of gender, socioeconomic background and age.

4.3 Data generation

4.3.1 Participant observation in home visits and interviews with nurses

Participant observation is suitable for studying interactions between people as it allows the researcher to focus on how persons relate to one another in social encounters (Thagaard 2013). In this method, both the researcher and the participants engage actively in constructing meaning. When carrying out participant observation, the researcher observes and describes the activities of the people under study in a social and material context that the researcher has not arranged (Fangen 2010, Hammersley and Atkinson 2007).

I kept my focus very open during the home visits to gain insights into the interactions of the professionals in their work with the patients and caregivers. I was attentive to what was
addressed by whom and how it was discussed among the nurses, patients and caregivers. In
participant observations, the researcher’s role and level of participation are often described as
ranging from purely observational to fully integration into the field (Fangen 2010, p. 72). In
the home visits, my degree of participation was based on how I perceived the needs of the
patient and caregiver for the nurses’ support. During some visits, I found it important to let
the interactions among the nurses, patients and caregivers go on without interruption as the
patients and caregivers actively sought the nurses’ answers, discussions and legitimisation.
Towards the end of these visits, we talked about my research project, and I asked a couple of
questions. In other visits when the patients and caregivers also communicated interest in the
research project and me, I felt that it was more appropriate for me to participate, asking
questions of the patients, caregivers and nurses. In all visits, I made efforts to communicate
recognition and genuine interest in both the patients and caregivers.

An interview guide was developed initially for the interviews with the nurses (Appendix V).
It addresses issues concerning how the nurses worked in home visits and related to both
patients and caregivers and included more general questions about the organisation of services
and accessibility. I found that the interviews with nurses were important to assure them that I
was not evaluating the quality of their nursing practice but, rather, was interested in their
work and how they related to caregivers in health care encounters. The nurses seemed to
enjoy reflecting on their work in the interviews. Interestingly, most nurses under-
communicated the inter-subjective work they did when relating to both the patients and
caregivers when comparing their descriptions of their work with my observations of their
work.

All interviews with the nurses were recorded digitally, and I transcribed the interviews
verbatim. This was very important to keep me in close contact to the recorded speech, which
enabled me to recall important features of the interviews, such as the tone of voice and the flow of speech, and my own participation in the dialogues. This process produced important familiarisation with the data and generated many analytical ideas. In addition, after the interviews, I also wrote down my reflections on them. During most visits, if appropriate, I made short notes and, on the first possible occasion later, described what I had observed in as great depth and detail as possible.

### 4.3.2 Interviews with caregivers

How an interview is carried out and how an interview is experienced are inevitably related to the setting of the interview (Herzog 2012). In this research, the interviews were carried out at sites chosen by the caregivers. Three interviews were conducted in cafés, three in a meeting room at my workplace and four in the caregivers’ homes. The caregivers’ preference in this matter was interesting. One caregiver who invited me to his home stated that he was afraid of leaving his wife home alone, while another caregiver had health issues himself. In other cases, the caregivers took the interview as an opportunity to have legitimate time off from their daily routines as caregivers. In two interviews carried out in the caregivers’ and patients’ homes, the patients were present at times. In one of these interviews, the patient left to rest half way through the interview, while in the other interview, the patient stayed at the other end of the room and spent a lot of the time on the phone. The presence or absence of the ill person contributed to the co-construction of meaning in the interview (Creswell 2013). In both these interviews, the caregivers more directly addressed challenges they experienced as caregivers for their severely ill spouses when their spouses was not present.

The interviews were semi-structured and based on Kvale and Brinkman’s (2009, p. 137) principles for conducting qualitative interviews to obtain descriptions of the participants’ experiences of the meaning of the phenomena in question. The interviews lasted 1–3 hours,
normally approximately 2 hours. The guide developed for the interviews (Appendix IV) was informed both by my experiences of observations in home visits and by the research literature on family caregiving.

In developing the interview guide, I attempted to address issues in ways which were focused enough to obtain detailed descriptions from the caregivers but also open and sensitive enough to explore the concerns raised by the caregivers. The interview guide had three main themes: the everyday life of the caregivers and the ill persons, their experiences with formal health care in general and their experiences with the ambulatory services in particular. To gain understandings of the informal caregiver role, I asked such questions as, ‘Can you describe a normal day? How do you and your spouse organise it?’ I attempted to entice the caregivers describe and reflect on their everyday routines and practices. In most interviews, the caregivers gave vivid descriptions, including tiny details of what was crucial to enable their ill partner to manage independently. However, the implicit and embodied nature of such practices made it challenging for some participants to describe them, as other researchers have also reported (Harris and Guillemin 2011). For instance, a caregiver expressed difficulties describing the everyday life routines of himself and his wife, emphasising that their daily lives were constituted of ‘nothing particular’. However, when describing what his wife could no longer do, the caregiver also described how his role had changed and the challenges he faced, especially due to his own health issues.

With regard to the caregivers’ experiences with formal health care, addressed in the interviews, this issue varied extensively. I had expected that most would have numerous experiences with community health care, particularly home care services; however, this was not the case. Instead, all the caregivers told stories from particular dramatic hospitalisations
and more frequently described hospitalisations as their most important experiences with formal health care.

In all interviews, the caregivers found it difficult to elaborate particularly on the support from ambulatory services. All the caregivers stated that they appreciated the visits and being followed up by the hospital and that they enjoyed the discussions with the nurses. The caregivers did not seem to have particular expectations to the service, likely as the service was not commit to many responsibilities beyond the current visit, and the patients and caregivers had no commitments towards the nurses. The infrequent visits by the nurses probably were also a reason why it was difficult for caregivers to describe their experiences with this service other than in very general terms. I found this result highly interesting as I observed and experienced that many things happened in the home visits, in terms of issues addressed, discussed and agreed on and how the nurses related to both the patients and caregivers. In the analysis of the home visits in paper three, I chose to focus mainly on the participant observations from home visits as they provided in-depth descriptions of the complex interactions among the nurses, patients and caregivers.

While accompanying the nurses on the home visits, I clearly stated before interviewing the caregivers that I was not a health care professional but a social scientist. I informed the caregivers that I was particularly interested in their organisation of everyday life and their experiences or collaboration with formal health care provision.

4.4 Data analysis

In the analysis, I used an interpretive approach, drawing on the principles of qualitative data analysis outlined by Coffey and Atkinson (1997) and Kvale and Brinkman (2009).
Throughout the analysis, literature from medical sociology and anthropology (e.g. Bury 1982, Mattingly 1994) and feminist-oriented sociological perspectives on family (Smart 2007) and work (Smith 1989) were important to generate enhanced understanding of the empirical material. The aim of the analysis was to not (over)simplify, for instance, the work and negotiations of the care rendered by caregivers. Instead, I attempted to make sense of the ambivalent aspects of caregivers’ work and dilemmas they faced in the interactions with patients and professionals. Therefore, I carried out a theoretically informed analysis in which such dilemmas identified in the empirical materials were linked to and understood within broader frames of reference, as outlined by Kvale and Brinkman (2009, p. 214) and Coffey and Atkinson (1996 p. 29).

The data analysis was empirically driven based on the principles of thematic analysis. The analytical frames of reference were Coffey and Atkinson’s (1996, p. 28) perspectives on the coding process and the generation of concepts and the hermeneutical canons of interpretation and inspired by Kvale and Brinkman (2009, p. 216). Coffey and Atkinson (1996, p. 28) describe the process of generating codes and concepts from qualitative data material as a combination of data reduction and data complication. Rather than working with data analysis as a recipe, the principles of data reduction and data complication has guided the thematic analysis in this study.

In data reduction, extracts are separated from the original context and assigned codes. Their meaning is retained, analysed in more depth and seen in connection with other extracts across the material relevant to the same issue (Coffey and Atkinson 1996, Malterud 2001). In this process, I searched for coherence, changes and salient points (Haavind 2000, p. 35) in the participants’ individual descriptions of their experiences as family caregivers or in the descriptions from the home visits. This process enables thinking about the data in new and
different ways and systematising the empirical material (Kvale and Brinkmann 2009, p. 208, Thagaard 2013).

The general analytic approach in data complication is to open up and investigate the data further and to expand the conceptual frameworks. Segmented data is recontextualised, and connections and coherence, as well as conflicts and dilemmas, are explored across the cases to generate new understandings and new analytical questions. In this process, the theoretical frameworks are actualised with the aim to improve understanding of the empirical data within broader frames of reference. In this analysis, I explored the complexity in performing and supporting the caregiver role through the dilemmas, ambivalences and tensions described in interviews and expressed in the interactions between the caregivers and the cared-for during the home visits. These complex experiences and interactions were related to a wide range of issues which differed in content but were related to a coherent set of underlying considerations and issues. For instance, many caregivers faced dilemmas related to performing their caregiver role while simultaneously making great efforts to maintain normality and continuity. In line with Coffey and Atkinson (1996, p. 30), such underlying considerations and issues were further explored in the analysis.

Kvale and Brinkman (2009, p. 216) and Braun and Clarke (2006, p. 86) describe the core of the interpretative process as continuously going back and forth between the parts and the whole. I have switched between doing close readings of the empirical material and seeing the connections in the material as a whole. This technique was an important way to ensure that the understandings I generated were consistent with the context of the excerpts and the informants’ accounts of reality. Brown and Clarke (2006, p. 86) emphasise integrating continuous writing in the analytical procedures. In my analytical work, continuous writing was important to develop understandings of the relationships between the empirical data and
theoretical perspectives and to conceptualise the work and experiences of caregivers in relation to the ill person and health care professionals.

In the analysis presented in paper three, the field notes are the central empirical material to let the complexity of the interactions among the nurses, patients and caregivers form the basis of the findings. In addition to the thematic analytical principles and procedures outlined, I worked in-depth with a few cases which especially well displayed the patterns identified in the thematic analysis. Sandelowski (1995, p. 183) argues that a few complex and rich cases may provide nuanced and in-depth understanding of a phenomenon. Therefore, two cases were selected for presentation in the results in the paper as they provided especially good, vivid illustrations of the patterns found across the material. The cases I selected are good illustrations of the topics addressed and the interactions among patients, caregivers and professionals. Moreover, the cases also accurately show the complexity of nurses’ work in the home visits.

4.5 Ethical considerations

The Regional Committee for Medical and Health Research Ethics in Norway reviewed the study and concluded that it did not fall under the remit of the Health Research Act as the study was not based on patient information (ref 20101966a). The privacy ombudsman at Akershus University Hospital gave approval for the research (ref. 2010/042).

This project’s ethical considerations are primarily concerned with safeguarding the participants (the caregivers, patients and professionals). The study complied with the standards for medical research ethics set by the Helsinki Declaration (World Medical Association 2013). Written, informed consent was obtained from the participants before
interviews and observations were conducted. All the participants received an invitation to take part in the study and an information letter describing the study’s overall objectives, the voluntary nature of participation in it and the participants’ right to withdraw their consent at any time (Appendix I-III). This procedure was unproblematic in the interviews with the caregivers and nurses. The participants were given or sent the information letter in advance, and I also repeated much of its information before starting the interviews. To obtain informed consent from patients and caregivers during the home visits, the collaboration with the nurses was important. During calls to inform the patients about the visits, the nurses informed the patients about the study and asked for permission to be accompanied by a researcher. When possible, the nurses also sent patients and caregivers the information letter in advance. However, in most cases, this was difficult to do, and the patients and caregivers received the information letter in the visit. I repeated the information before the patients and caregivers consented to including my notes from the home visit as data in the study. Various studies have described that, in observational studies of clinical practice, informed consent might be challenging to accomplish in some situations as the patients’ ability to give an informed consent is reduced (Hem et al. 2007). I experienced this difficulty, along with general confusion, at three home visits to terminally ill COPD patients. It was challenging to explain why I needed their consent in a way they could understand. The nurses and sometimes also the caregivers helped to explain these matters on these occasions. The nurses gave time to convey the information about the study and obtaining informal consent during these home visits. In all cases, the caregivers had given consent to participate, and the focus in the observations was on how the nurses interacted with both caregivers and patients, so I judged it acceptable to include data from the visits when I was not sure whether the patients understood to what they consented.
In this study, I worked to ensure the anonymity of the participants in a number of ways. The caregivers and patients were assigned pseudonyms in the transcripts, field notes and in the papers, although their age is given. With regards to anonymisation for the nurses, it is difficult to achieve full anonymisation in qualitative studies which look closely at individuals in contexts where there are close linkages between the researcher, participants and the field studied (Fangen 2010, Ruyter et al. 2014). Since the services studied were provided only by four nurses whom I interviewed, I decided not to personalise them by using pseudonyms. I found it less problematic to generalise in this way as these nurses can be regarded as representatives of their group of professionals.
5 The papers

Summary of paper I


The aim of this paper was to show how the spouses of COPD patients integrate their tasks as informal carers with their role as spouses and the tensions and challenges involved in doing so. The paper draws on 10 qualitative interviews with the spouses of COPD patients. The empirical data were analysed using thematic analysis involving both data reduction and data complication.

The findings show how spouses made great efforts to maintain the routines of ordinary everyday life and a sense of continuity in their relationships despite the progressive illness trajectory of their partners. I propose the ‘biographical we’ as a concept that can highlight the great effort that spouses make to establish a sense of continuity in their lives as couples despite chronic illness. Caregivers facilitated their ill partners’ contribution and participation in everyday life, which reinforced the sense of a shared life project. It was important for the spouses to hold on to previous interests and rituals or values which had always characterised them as couples. The meaning attached to activities, practices, symbols and rituals which confirmed the idea of an ordinary life was emphasised. In addition, protecting a narrative about their independence as a couple contributed to the maintenance of the ‘biographical we’, which was described as a reciprocal endeavour.

Achieving a sense of continuity was a delicate process as the couple faced several dilemmas in this work. They balanced the need to sustain the independence and reciprocity of both
parties with the need to ensure safety and deal with the progression of the illness. The spouses had to find ways in which their ill partner could accept care which did not disrupt the ‘biographical we’. Although the ill persons were highly dependent on their spouses in many respects, maintaining their sense of autonomy was crucial for maintaining the ‘biographical we’. The spouses’ accounts indicated that they actively downplayed their ill partners’ increasing dependence on help. In addition, the spouses highlighted the positive qualities of their ill partners, which redefined what reciprocity could be in their relationship. Expressing appreciation of their partner’s character was a way to recognise their contributions as mutual caring partners and made taking on the work previously performed by the ill person easier for the spouses.

Gradually, the illness became so demanding that it threatened the ‘biographical we’ in the meaning of a fellowship to which both parties contribute to varying degree. In addition, the ill partners’ physical impairment and mental strain due to breathlessness and difficulty in accepting and dealing with the situation threatened the narratives as a couple in various ways.

Summary of paper II


The aim of this paper was to explore how spouses negotiated their role as caregivers with patients and health care professionals during acute exacerbations. Data were obtained from 10 qualitative interviews with the spouses of COPD patients. Data were interpreted using thematic analysis involving both data reduction and data complication.
At the onset of an exacerbation, the caregivers negotiated with their ill spouse how to manage symptoms and determined the right moment to contact emergency services. This demanded nuanced, personalised knowledge of the care needs of the individual patients. According to the caregivers, the patients often did not take their symptoms seriously enough, even when the caregivers saw an increasing need for professional assistance. In negotiations with professionals, the caregivers emphasised the importance of being persuasive, acting proactively and making an effort to present the right symptoms to make professionals understand the severity of the situation.

For the caregivers, it was challenging to find a shared understanding of the situation with both patients and professionals as illness the exacerbated, and the caregivers experienced a need for assistance and relief. The caregivers tried to participate in ways which ensured that the professionals would understand the severity of the patients’ exacerbation and take medical responsibility. However, both being too proactive and not daring to let the professionals know their opinions as caregivers could undermine the possibility of negotiating the need for hospitalisation.

Through acute phases of COPD, it could be challenging for the caregivers to share responsibilities, exchange expertise and agree on standards when negotiating with the patients and professionals. The caregivers’ negotiations with both the patients and professionals showed that their role became unclear as the patients’ care needs intensified. The caregivers experienced that they were expected to take considerable responsibility during phases of critical illness. However, in their encounters with professionals, they were sometimes excluded from participating by providing information or influencing decisions. These interactions reflected ambiguities. The caregivers expected to receive help and relief from emergency services when the situation reached a tipping point, but the caregivers described
the professionals as at least partly unprepared or unwilling to relieve the caregivers of their care responsibility in these situations. The unclear family caregiving role combined with the ambiguity that caregivers experienced in their interactions with professionals could easily be experienced as problematic.

Summary of paper III

Searching for ‘transformative moments’: a qualitative study of nurses’ work in home visits to COPD patients and their caregivers in Norway (submitted for publication)

The objective of this study was to provide knowledge about how professionals support both patients and caregivers in home visits and the challenges professionals face in this work. Data were obtained from participant observations during 20 home visits by pulmonary ambulatory nurses to COPD patients and four individual qualitative interviews with these nurses. In addition to case-centred analysis, thematic analysis which combined data reduction and data complication was undertaken to analyse the data.

In the interviews, the nurses emphasised the potential of the visits to give significant support to patients and caregivers. Meeting patients in their homes made it easier to understand their situations and challenges. The participant observations showed that the nurses made efforts to bring up challenges regarding the management of illness in everyday life in discussions with the ill persons and caregivers.

In the home visits, the nurses sought and promoted ‘transformative moments’ in which they enhanced the patients’ and caregivers’ shared understanding of illness management and encouraged understanding and acceptance between the patients and caregivers. In these discussions, the nurses acknowledged the ambivalence and dilemmas that the patients and
caregivers expressed and showed acceptance and understanding of their conflicts. In this way, the nurses supported both the patients and caregivers in reconciling themselves to the negative consequences of the illness and granted legitimacy and possible room for sustainable arrangements within the scope of their relationships. It was crucial for nurses to attend to the patients and caregivers as individuals but to also understand them within the scope of their relationships.

In transformative moments, the nurses enhanced understanding and acceptance and suggested and legitimised adjustments to activities or arrangements. Support to find orientation in the challenges caused by the illness was an important way to support both patients and caregivers. However, discrepancies and even tensions often existed in the patients’ and caregivers’ understandings and views on the management of illness, and showing understanding of both was important in the work of the nurses. Balancing relating to both patients and caregivers was delicate work. Acknowledging ambivalence, recognising the dilemmas faced by the patients and caregivers and showing acceptance and understanding of the conflicts between them seems an appropriate approach to support both patients and caregivers in home visits. This study provides new insights into the potential role of professional support in developing sustainable management of illness within spouses’ affective and caring relationships. Moreover, a comprehensive approach to self-management support in home visits can improve support of patients’ and caregivers’ management of illness in ways meaningful to patients in their everyday life and work.
6 Discussion of the findings

In this chapter, I present an integrated discussion of the findings of this study and clarify its contributions to new knowledge. The aim of this study is to deepen scientific knowledge of the interactions between the family caregivers, their chronically ill partners and health care professionals serving COPD patients, with a particular focus on the work of family caregivers. This knowledge may improve understanding of how formal health care services can better support caregivers. To achieve this aim, I analyse the work of family caregivers and their interactions with their ill partners and health care professionals in different social contexts (everyday life, critical phases and home visits by ambulatory nurses). In this final discussion, I attempt to provide knowledge of how the dilemmas and challenges that family caregivers face can be addressed in the provision of care for chronically ill persons.

6.1 Co-affected and primarily responsible

The three papers in this thesis show that, from the family caregivers’ perspective, they and the persons for whom they cared were both affected by the illness and responsible for managing it in ways that were significantly similar and significantly different. Being affected by illness and responsible for managing it indicated the embeddedness of caregivers’ experiences, emotions and biographies within the relationship with the ill person in significant ways. I understand the simultaneous experience of being affected and responsible as an embodied and relational experience.

The findings of these three papers all indicate that the caregivers were affected in numerous ways as their lives were deeply embedded in their partners’ lives and illnesses. First, caregivers’ relational experiences of self-concept, autonomy and reciprocity were deeply
affected, and they made great efforts to reconstruct these relational qualities in everyday interactions with their chronically ill partners. Second, the caregivers were affected emotionally by experiencing uncertainty, insecurity and anxiety, particularly from the critical phases of the illness but also from awareness and experience of risks due to progression of the illness and their own support needs throughout the illness trajectory.

In addition, the caregivers felt and took responsibility in a number of ways. First, the caregivers felt responsible for ensuring and maintaining a sense of safety in management of the illness. Second, the caregivers felt responsible for the patients’ treatment adherence and coping with the illness. Third, the caregivers felt responsible for seeking professional support in a timely manner and ensuring that the health care professionals understood the seriousness of their partners’ illness. Moreover, the caregivers felt responsible for integrating this professional support into their lives.

In the sociological literature, experiences of illness have been conceptualised in terms of loss and disruption of self, reciprocity and biography (Charmaz 1983, 1987, Bury 1982, Larsson and Grassman 2012) and biographical work and continuity (Corbin and Strauss 1987, 1988, Boeije 2002, Becker 2007). The existing literature on the relational implications of family caregiving in COPD addresses the losses caregivers experience in their relationships, particularly the loss of friendship, intimacy and couplehood identity with partners (Bergs 2002, Simpson et al. 2010). My work nuances this literature by emphasising caregivers’ active work to maintain the relationship.

The caregivers’ sense of affectedness and responsibility resulted in competing considerations in their endeavour to re-establish continuity and normality in their lives. As shown in paper one, I find that these conflicting considerations created several challenges for the caregivers. As caregivers, the spouses faced dilemmas in their relationships with chronically ill partners
when performing their roles as both spouses and caregivers for their partners. Such dilemmas were manifested in various ways during everyday life, health care encounters and acute phases of illness. The caregivers made significant efforts to preserve everyday life routines and reconstruct their shared narratives to maintain relationships to which both partners could contribute. For instance, in everyday life, the caregivers downplayed and underemphasised their feelings of affectedness and responsibility as a way to confirm the normality and continuity of their marital relationship.

To capture this work in paper one, I propose the concept of the ‘biographical we’, which takes the relational aspects of self and identity (Tronto 1995, Smart 2007), such as affectedness and responsibility, as a premise for understanding the complexity of establishing continuity and normality in these individuals’ lives. Being affected and responsible could disrupt the caregivers’ efforts to maintain their previous lives. However, in certain situations, they had to intervene with the ill person and faced the dilemma of weighing the responsibility they felt and the worry they experienced in regards to their ill partners’ autonomy and self-reliance. The caregivers sometimes perceived different risks in critical situations than their ill partners and consequently found it necessary to defy the wishes of the ill persons in order to avoid risks in situations they saw as unsafe. The caregivers perceived their experiences and expertise as authoritative and saw ensuring safety as a greater consideration than respecting their partners’ autonomy in certain situations. Nevertheless, the caregivers’ interventions disrupted their efforts to maintain both reciprocity and autonomy within their relationships and shattered the balance of legitimate dependence and autonomy (Chattoo and Ahmad 2008).

These relational dilemmas shed light on why the caregivers’ responsibility for management of illness was perceived as ambivalent and represented tensions and conflicts between the
spouses. The integration of increasingly extensive care responsibilities into their relationships and their efforts to establish normality in everyday life were delicate tasks. Through the deteriorating illness trajectories of their ill partners, the caregivers faced and had to consider new risks in everyday life created by the ill persons’ increasing disability and vulnerability. The caregivers negotiated implicit ways to perform their caregiving roles (Finch and Mason 1993) which would not disrupt their sense of self and relationship. This effort recalls Chattoo and Ahmad’s (2008) characterisation of care as an on-going negotiation of moral boundaries.

The combination of affectedness and responsibilities was a potential source of conflict, and it was not always easy for those involved to accept the others’ affectedness by the illness, particularly in attending to the illness and clarifying the responsibilities for self-care and care within the marital relationship. This finding deepens understanding of the tensions in the caregiving relationship described, for instance, by Grant et al. (2012). Moreover, the ‘biographical challenge of caring’ (Chamberlayne and King 1997, p. 601) within the marital relationship has been studied in other contexts (Rajaram 1997, Radcliffe et al. 2013, Hudson et al. 2016) and linked to the broader understanding of biographical disruption (Bury 1982). My work adds to this literature by embracing the relational dilemmas with which caregivers grapple as they are affected by the illness and feel responsible for managing it.

Caregivers’ experiences of being affected and shouldering care responsibilities must be understood in light of the general human need for ongoing, formative relationships to develop a sense of personhood or individuality (Tronto 1995, Honneth and Farrell 1997, Smart 2007, Chattoo and Ahmad 2008). In accordance with Honneth and Anderson (2005) and Chattoo and Ahmad (2008), the insights concerning caregivers’ experiences of being both affected and responsible relate to the view of autonomy and dependence as not mutually exclusive. Moreover, reciprocity emerges as a resource used to manage the tensions in lives linked
together (Breheny and Stephens 2009). Honneth and Anderson (2005) argue that autonomy is not realised by gaining independence from others. Thus, mutual autonomy can be accomplished in relationships through mutual understanding and recognition between the caregiver and ill partner. In addition, health care professionals can play a role in facilitating mutual understanding in health care encounters, which can be important in reconstructing a sense of self, autonomy and reciprocity within the affective and caring relationships.

6.2 Family caregivers’ needs of support

Important to caregivers’ experiences as affected and responsible are the challenges they face related to their needs of support. These experiences create the necessity to recognise, legitimatise and negotiate these needs with the ill person, to seek and obtain support from formal health care services and to ensure that this support fits into their lives. My work shows that caregivers negotiate their support needs and, ultimately, their caregiving role and the limits of responsibilities. Caregivers negotiate implicitly and explicitly with ill partner in everyday life and acute phases of illness and with professionals in health care encounters (Finch and Mason 1993, Allen 2000). Caregivers’ needs shift throughout the trajectory of COPD, often indicating a slow deterioration interrupted by acute and life-threatening exacerbations.

The papers in this thesis show that recognising and negotiating caregivers’ needs of support from health care services is a highly complex process. However, the complexity of the recognition, legitimisation and negotiations of these needs has received little attention and problematisation in the literature beyond the psychological models of essential human needs and the needs for information from health care and social services (Caress et al. 2010, Cruz et
al. 2016). The research literature on the implications of caregiving for persons with COPD, in particular, emphasises caregivers’ physical and emotional strain and burden (e.g. Simpson et al. 2010, Grant et al. 2012, Gabriel et al. 2014). I believe such insights may be further explored in terms of how their needs of support are negotiated in the relationships between the caregivers and the chronically ill partner for whom they care, as well as health care services. In the following, I adopt the perspective of family caregivers as individuals striving to recognise their own needs for support in a relational process with their ill spouses and formal health care providers.

For the caregivers I met, the process of recognising their own needs for support was challenging and ambivalent. My work shows that the caregivers’ needs of support were individual but deeply embedded in their relationship with the ill persons. First, the caregivers described the need to maintain their sense of safety in everyday life and critical phases of the illness. This implied the need to feel safe despite increasing perceptions of the risks of breathlessness and acute exacerbations. Second, the caregivers expressed the need to share care responsibilities with formal health care services. Third, the caregivers explained the need for flexible arrangements for respite to be able to cope in the longstanding caregiving relationship.

Legitimating the caregivers’ needs from the ill person was highly complex. The caregivers’ need for external support was often unclear as it was difficult to discuss and legitimate it within the marital relationship. For instance, the caregivers reported that it was challenging to discuss their need for arrangements for respite and legitimate that need with their chronically ill partners in their relationship. The caregivers feared allowing the ill persons to feel abandoned. However, the caregivers felt increasingly insecure in certain situations, and several also described feelings of anxiety. In paper two, I describe caregivers’ negotiations
with both their ill partners and health care professionals to seek professional support. The ill partners often wished to manage independently and postponed seeking external care. This ambivalence towards health care services made patients and caregivers vulnerable as service provision is based on clearly predefined, explicit needs, not on doubt and ambivalence. These challenges addressing and legitimating own needs made it difficult for the caregivers to obtain adequate support at the right time. Other studies have also pointed out that caregivers play a crucial role in assessing the ill persons’ needs, but assessments and discussions of caregivers’ own needs for support are often underemphasised in health care encounters (Glendinning et al. 2015). My work finds that caregivers faced dilemmas in their attempts to legitimate their support needs in the marital relationship.

The caregivers experienced that their needs were often not appropriately recognised or met by health care services. Paper two shows that several caregivers had difficulties making professionals understand and recognise the severity of acute phases of illness. They experienced access to support and relief to be difficult to obtain at the times that they perceived it to be crucial. I found that several caregivers experienced a lack of belief and recognition of their assessments and contributions by health care professionals. This finding has been confirmed in other studies showing that professionals cannot relate to the affective relationship between family caregivers and patients (Allen 2000, Seddon and Robinson 2015). Several caregivers reported that the support from health care services did not enhance their sense of safety or provide respite and that it was challenging to find appropriate ways to share care responsibilities.

Moreover, for several caregivers, it was not the diagnosis or the disease which created the greatest uncertainty in everyday life and crisis management. Rather, the findings in paper two indicate that the caregivers’ contact with formal health care services and interactions with
professionals were equally taxing as they exacerbated feelings of uncertainty (Jenkins et al. 2005). This situation has also been described from the perspective of COPD patients (Becker et al. 1993). I argue that caregivers experienced feeling dependent and vulnerable without receiving the support they feel that they needed as highly disruptive, which, in this research, triggered dramatic narratives. In my work, many caregivers saw services as inaccessible and inflexible. Caregivers in this and other studies also perceived their care relations with professionals as imbalanced (Rugkåsa 2015, Bone et al. 2016, Røthing 2016). Moreover, caregivers experience that health professionals often transgress the reciprocal arrangements that the caregivers feel should guide their interactions (Rugkåsa 2015, Bone et al. 2016, Røthing 2016). Paper two shows that the caregivers perceived the professionals as lacking understanding of the caregivers’ role. This finding accords with Rugkåsa’s (2015) argument that health care professionals fail to recognise not only caregivers’ expertise but also the aspects of life that have the highest moral value for them and are closely linked to family practice and personal identity. Thus, this thesis indicates that caregivers experienced the lack of recognition from health care services as taxing and a significant negative influence on their experience of being affected and responsible.

The caregivers for persons who regularly received health care services described their efforts to integrate health care services into their lives. They adjusted the amount of health care services they received to find a balance which allowed fitting the service provision into their lives. On one hand, the services provided could be perceived not as invasive but as offering actual relief and respite or as enhancing their sense of safety, which, in turn, made the caregivers feel shared responsibilities with health care professionals. On the other hand, the caregivers weighed their perception of the quality of the services (e.g. continuity, predictability and flexibility) against their own abilities and capacity to perform care. Although the caregivers felt they needed support, it was crucial that it fit into their lives, and
they stretched their own abilities and capacities to care to maintain a sense of normality and autonomy in their lives. Thus, my work provides new insights into the existing research which emphasises that caregivers perceive professionals’ support of COPD patients as important to dealing with the negative implications of caregiving (Bergs 2002, Spence et al. 2008, Hasson et al. 2009, Lindqvist et al. 2013). This thesis demonstrates that caregivers critically adjust support to make it fit into their lives, and this process has significant implications for caregivers’ perceptions of their needs of support.

These experiences and concerns show that, for family caregivers, obtaining appropriate support can become self-contradictory as they experience needs of support but are reluctant to seek such services due to the challenges they face to obtain recognition from health care services and to integrate service provision into their lives. In line with Chattoo and Ahmad (2008), I provided evidence that caregivers’ individual needs are more intertwined with the needs of the persons for whom they care than often assumed. Moreover, my work points to the importance of developing a more sensitive approach to both patients’ and caregivers’ needs and the lives they lead.

6.3 Towards a relational focus in health care provision?

Family caregivers experience needs of support but are reluctant to seek support from the formal health care services due to a lack of sensitivity towards their responsibilities, affectedness and needs of support. This understanding actualises the discussion on how a focus on both patients and caregivers can be translated into practice in health care service provision. A relational focus involves active support and recognition of both caregivers and
patients as affected by illness and responsible for managing it in significantly similar and different ways. In addition, a crucial condition for developing a relational focus in health care services is understanding the dilemmas and conflicts caregivers face in their relationships with their ill partners and how these relationships can be a resource in the management of illness through the maintenance of reciprocity, autonomy and a sense of normality.

My findings also show that caregivers and the persons for whom they care can be supported in accepting the illness and navigating the complex, unpredictable illness trajectory, including managing the dilemmas they face in their relationship. In the third paper in this thesis, I analyse ambulatory service provision to patients with COPD. This service provision provides potential for and examples of the inclusion of a relational focus in service provision. In home visits with both spouses present, the ambulatory nurses made efforts to support both spouses. Recognition of both parties was crucial to promote opportunities to discuss challenging issues, such as the unclear boundaries of responsibilities between the spouses and the support needs of both patients and caregivers. Recognition is crucial to developing a sense of balance in interactions between people (Honneth and Anderson 2007, Rugkåsa 2015), which, in turn, might empower patients and caregivers.

Drawing on the views of Mattingly (1994, 1998) in paper three, I argue that developing opportunities to support transformations that enhance patients’ and caregivers’ understandings, wishes, desires, hopes and motivations was crucial for the professionals. The processes of identifying, clarifying and legitimating these boundaries was addressed by the professionals and viewed by the patients and caregivers as challenging a relational process which often reflected the tensions between the patients and caregivers. Professionals could grant legitimacy to necessary arrangements of relief and increase acceptance of them. Thus, the conversations between professionals, patients and caregivers show how professionals
could initiate and facilitate discussions which helped caregivers and patients understand the illness and accept their mutual affectedness. These discussions could also clarify their respective responsibilities and facilitate integration of external support into everyday life in ways that maintained their selves and relationships. These findings contrast with the findings in paper two that a lack of recognition of the caregivers’ support needs or their nuanced expertise as caregivers reinforced their feelings of insecurity.

Health care professionals might be an important resource in adjustment to the illness trajectory, as Corbin and Strauss (1985) argue. Seddon and Robinson (2015) propose a narrative approach as a tool for assessing patients’ and caregivers’ needs for health care support. A narrative approach is useful for understanding caregivers’ needs, facilitating their reflections on the affective and relational aspects of caring and clarifying their wishes for their caregiver role in the future. This way of supporting both patients and caregivers expands the individual focus based on essentialist psychological understandings of needs. Including the social context was important to orient these parties and establish sustainable arrangements within the scope of their relationship (Ong et al. 2016) or, in other words, to find an arrangement for living well with the illness (Tronto 1995, Morgan et al. 2015).

**6.4 Implications for health care policy and practice**

Family caregivers are expected to take on ever-greater care responsibilities for their ill relatives (Ministry of Health and Care Services 2006). Health care policies emphasise the importance of recognising family caregivers as resources and facilitating their participation in health care services (Ministry of Health and Care Services 2011). Despite this emphasis, application in practice has been relatively modest (Kjellevold 2011, Røthing 2016).
Commitment to health care professionals’ responsibility for supporting caregivers is lacking, and the support services provided to caregivers do not correspond to the extensive responsibilities they shoulder (Kjellevold 2011, Glendinning et al. 2015).

Twigg (1989) addresses difficult questions concerning how health care provision should relate to and support family caregivers. In line with Glendinning et al. (2015), I argue that contemporary formal health care services engage caregivers primarily as ‘co-workers’ (Twigg 1989, Sadler and McKeivitt 2013, Seddon and Robinson 2015). Caregivers are enabled to perform their roles and are understood to be semi-professionalised or lay experts. Accessible interventions are underpinned by psychological models of empowerment, self-efficacy and coping, and individuals bear the responsibility to develop the relevant competences and expertise (Taylor and Bury 2007). Thus, caregivers receive only a small degree of support as ‘co-clients’ (Twigg 1989, Glendinning et al. 2015), as being affected and having support needs in a broader sense beyond a narrow focus on behaviour change interventions (Taylor and Bury 2007). I argue that this model of support reinforces an ambiguous status of caregivers. This thesis contends that regarding caregivers as resources in health care policies but not giving them the necessary preconditions in health care services is highly problematic. My work provides new insights into the persistent gap between the ideals in current health policies and the realities in health care provision concerning provision of support to family caregivers (Milne and Larkin, 2015, Glendinning et al. 2015, Seddon and Robinson 2015). The thesis points to the importance of developing health care services which recognise and in more appropriate ways support caregivers as being both affected by illness and responsible for managing it.

Family involvement challenges the individual focus in health care service provision (Daly 2002, Lewis 2007), while the experiences of caregivers as both affected by illness and
responsible for managing it challenge the idea of the ill person as the exclusive focus of attention. I argue that it is crucial to design, organise and provide health care services with an orientation towards patients and caregivers. Today, patients’ rights come at the expense of caregivers’ rights to be included and supported (Kjellevold 2011). In the UK, patients’ rights co-exist with extensive rights for caregivers, but these appear to sit very uneasily within discourses, and the empowerment of patients has been prioritised in practice (Glendinning et al. 2015). From the perspective of caregivers who shoulder extensive responsibilities, this sole focus on patients in the provision of health care is problematic (Glendinning et al. 2015, Kristvik 2015). Caregivers need accessible services, possibilities for respite and recognition and respect for their competences and assessments. These lacks present crucial future challenges for collaboration between informal and formal care provision.

To take into account the unstable character of illness and to acknowledge that caregivers are often elderly and, in many cases, frail and vulnerable themselves are important, as is highlighted in health care policies (Ministry of Health and Care Service 2015). Accessible, flexible, reliable services must form the basis for supporting caregivers. In line with Rugkåsa (2015), I argue that better ways of including and supporting caregivers in patient care are needed and likely will demand changes to the existing structures of formal health care provision. Systematic follow-up does not replace the importance of accessible service provision in acute situations; instead, through recognition of the work and challenges caregivers do and face, such support might contribute to maintaining their sense of safety and continuity as they undertake extensive care responsibilities. Moreover, there is a need for systematic follow-up services oriented towards both patients and caregivers. Recognising caregivers’ affectedness and responsibilities might allow discussing relational dilemmas in informal care. As well, creating awareness of family caregivers as individuals striving to recognise their own needs for support in a relational process with ill spouses and formal
health care providers is crucial. Doing so can contribute to developing better ways of sharing responsibilities which might make caregivers feel relieved and enhance their sense of safety.

Despite extensive research and political interest in family caregiving over the past decade, knowledge and understanding of the implications of the changing boundaries between informal and formal care from the caregivers’ perspective are limited. This thesis shows that the implementation of new health care services, such as ambulatory services and hospital-at-home programmes, offers new possibilities for collaboration between family caregivers and formal health care services. However, the simultaneous processes rendering in-patient care more exclusive and inaccessible and raising expectations for caregivers to take on greater care responsibilities create challenges in the relationship between informal and formal care provision.
7 Methodological considerations

The arguments I make in this thesis are based on the knowledge and understandings generated about family caregivers’ work and interactions with both patients and professionals. In this section, I discuss some issues concerning the generation of data and the trustworthiness and transferability of the knowledge developed in this study.

7.1 Generation of data

The objective of this study is to improve understandings of the relationships between informal and formal caregiving for chronically ill persons. To generate data about these issues, I interviewed informal and formal caregivers and carried out participant observation in health care encounters. Although I could have also interviewed patients, I believed that talking with caregivers would better serve the purposes of this research to understand these issues.

In the generation of data in both interviews and participant observation, the researcher participates and co-constructs the meaning of the situation (Kvale and Brinkman 2009, Fangen 2010). In interviews, the researcher immediately responds to the participants’ representations of their experience and thus gives them meaning and significance. Narratives are told, and meaning is co-constructed between the researcher and the interviewee (Kvale and Brinkmann 2009, p. 72). In participant observation, interactions unfold, and the researcher perceives certain aspects of them as significant. Participant observation also involves recording the narratives played out in the interactions among the professionals,
patients and, in various degrees, the researcher (Mattingly 1994, 1998, Mattingly and Lawlor 2001). In this study, such narratives were recorded during home visits.

Several methodologists argue that a broad, diverse sample produces rich material with possibilities for describing different aspects of the subject matter (Sandelowski 1995, Patton 2001, Malterud, 2001, 2011, Pope & Mays 2006). In this study, diversity emerges in the various ways spouses as family caregivers interact with both their ill partners and health care professionals. I aimed to interview caregivers who shouldered the primary care responsibility for the chronically ill person. Initially, I did not intend to interview only spouses or partners, but after interviewing half of the caregivers who were all spouses, I found that the relationships between were the spouses highly interesting and worth exploring further and in more depth. I ultimately had a relatively small sample of ten spouses as caregivers. Most interviews were very comprehensive in the details and depth of the descriptions of everyday life and caregivers’ interactions with formal health care services.

Polit and Beck (2004) recommend that the number of participants in a qualitative study be balanced against the richness in the data and quality of the interviews. The sample should be large and varied enough to accomplish the study aim (Malterud 2011). In this case, the interviews had consistency and reached saturation as several caregivers similarly described the themes and concerns. However, individual interviews always reflect individuals’ unique stories and experiences. I experienced, as Kvale and Brinkmann (2009) found, that working with a small sample enabled more thoroughly handling all the interviews in a more flexible manner. Therefore, I was content with a smaller sample. Moreover, Malterud (2001) argues that a large set of material is not a criterion for generalisability in qualitative research and, indeed, might result in superficial analysis as researchers have more difficulty working with counterhypotheses.
To recruit caregivers for the study, I relied heavily on the nurses who decided when and with whom I could accompanies them. The nurses might not have wished for me to accompany them to visit certain patients they felt were especially challenging to support. My awareness of these issues made it important for me to continuously work to establish and maintain a trustful relation with the nurses. In conversations with the nurses, I emphasised that I was interested in participating in a great variety of home visits to develop a broad understanding of the interaction in home visits. Another issue of concern was that the caregivers might have volunteered to be interviewed to avoid disappointing the nurses. However, I do not find these issues problematic as the focus in this study is on the work of caregivers and ambulatory nurses and not exclusively on caregivers’ experiences of ambulatory services.

### 7.2 Trustworthiness and transferability

Different concepts are used to evaluate the scientific quality of qualitative research. Lincoln and Cuba (1985) suggest using the concepts of trustworthiness and transferability to assess the strength and reach of knowledge generated in qualitative research. I find these concepts useful for this purpose but do not claim that the concepts of validity and generalisability are irrelevant in qualitative research.

#### 7.2.1 Trustworthiness, credibility and reflexivity

Validity generally refers to whether a study examines what it is intended to (Malterud 2001, Kvale and Brinkman 2009). The trustworthiness of a study concerns how far the analysis can be trusted, and credibility whether a study produces credible findings and interpretations
I understand the concepts of trustworthiness and credibility to be complementary to the notion of validity in qualitative research.

Many scholars stress the importance of researchers’ reflexivity to increase the trustworthiness of qualitative research (Malterud 2001, Kvale and Brinkman 2009). Qualitative researchers generally respond to the positivistic demand for neutrality with openness and to the demand for objectivity with recognition of the partial and situated nature of knowledge (Haraway 1991). From this perspective, it is possible to be an engaged and participating researcher without failing to fulfil the role of scientific researcher. Personal involvement can be a resource and not a problem. Malterud (2001) argues that this understanding encourages researchers’ commitment to reflexivity and makes their reflections on their own positions central to the generation of knowledge. For example, both in the interviews setting and in the analysis, several caregivers’ dramatic stories about disturbing experiences with health care services engaged me. The caregivers may have used the interviews to legitimise or confirm their experiences and actions related to these events. For me, these stories were also important to generate a nuanced understanding of the caregivers’ complex role in health care services. This also relates to that different researchers might access different representations of the situations studied depending on their positions and perspectives. Although several versions of reality can all be valid, not all versions are equally relevant (Malterud 2001, 2011).

It is crucial to attend systematically to how and under what conditions knowledge is constructed throughout the research process (Malterud 2001). According to Tanggaard and Brinkmann (2015, p. 521), the quality of a qualitative study is generally an everyday affair that involves scholarly discretion and assessment. Trustworthiness then concerns the quality of the craftsmanship in carrying out a qualitative study, particularly the analytical process (Malterud 2001, Kvale and Brinkmann 2009). In qualitative research, trustworthiness arises
from a study’s general consistency, including the research questions, theoretical perspectives, methodological approach, analysis, interpretation and conclusions drawn. Trustworthiness and quality permeate all stages of a research project and are influenced by the choices made throughout the research process to make a study consistent, transparent and valid.

To strengthen the consistency of the study, I attempt to clearly and thoroughly describe throughout this thesis how this study was conducted and reflect on certain critical issues. I present the theoretical framework, account for the choices made throughout the research process, contextualise the study and participants, reflect on the methods used and describe the analytical approach. In addition, I argue that two important principles that guided this study especially increased its credibility: first, integrating theoretical perspectives and reflection throughout the research process, as recommended by Tjora (2012), and second, collaborating with other researchers throughout all the stages of the research process, as recommended by Creswell (2013).

7.2.2 Transferability

In qualitative research, researchers take different stances on the question of generalisation, and many researchers are reluctant to claim that their research findings are generalised even when they generalise from their results (Williams 2000, Payne and Williams 2005, Tjora 2012, Nadim 2015). In quantitative methods, probability sampling is a precondition for generalisation (Williams 2000). Williams (2000) argues that generalisation is possible, inevitable and desirable in qualitative research, but researchers must specify the limits of generalisation, which involves discussing the reach of the conclusions. These limits correspond with the limits of interpretation itself (Williams 2000). Williams (2000) and Payne and Williams (2004) argue that it is problematic that many qualitative researchers avoid the
issue of transferability and generalisation or leave it to the readers to assess whether and how results can be generalised. Payne and Williams (2005) argue that the preconditions for generalisability include careful operationalisations, a logical analytical structure, conclusions that can be contested and discredited and the discussion of findings open to alternative explanations.

The concept of transferability is often raised when discussing generalisation in qualitative research. Transferability refers to whether the findings in qualitative studies are relevant to other groups or individuals and applicable beyond the new insights produced in the specific research context (Lincoln and Cuba 1985, Malterud 2001). I find it likely that the understandings of the associations and patterns that have improved understanding in this study can be generalised to other contexts. Through an in-depth study of the complexity and particularities of certain interactions among family caregivers, chronically ill persons and health care professionals, I have developed new concepts and understandings based on careful operationalisation of the subject matter and a logical analytical structure, which are preconditions for the generalisability of these interpretations (Payne and Williams 2005). I believe that the theoretical concept of the ‘biographical we’ developed in paper one is useful for understanding the dilemmas caregivers face in maintaining their relationships while attending to their ill partners’ illness trajectories beyond the context of COPD. In paper two, the negotiation of care and support needs in interactions among caregivers, patients and health care professionals points to a general human need for recognition which arises in situations when caregivers experience vulnerability. Paper three points to potential to support patients and caregivers in health care encounters at home. This is especially relevant for finding orientation throughout a complex illness trajectory and might contribute to enhanced acceptance of the implications of a menacing illness.
I believe that the complex experiences of caregivers who feel both affected and responsible and recognise, legitimise and negotiate their individual support needs in a relational process have broader relevance for understanding family caregiving beyond the marital relationship and the case of COPD. In addition, previous research (e.g. Rajaram 1997, Chattoo and Ahmad 2008) confirms that autonomy, dependence and interdependence are balanced within caregiving relationships and negotiated and attended to in interactions with health and social care services. Overall, the relationship as a crucial resource for confirmation of self and meaning in life and the difficulty in simultaneously legitimating caregivers’ and ill persons’ support needs in their relationships emerge as crucial tensions in the caregiving relationship. It is important to maintain awareness of dilemmas and conflicts while developing a relational focus in health care service.
8 Conclusions

This thesis contributes new knowledge about the significance of family caregivers’ simultaneous experiences of being affected by illness and responsible for managing it. In addition, family caregivers strive to recognise their own support needs in a relational process with their ill spouses and formal health care providers. The caregivers I met described their needs to increase their sense of safety, share care responsibilities and find respite and relief.

Throughout the deteriorating illness trajectory, the caregivers faced dilemmas in interactions with their ill spouses, for example, with regards to seeking, legitimating and integrating health care services in their everyday lives and relationships. Such dilemmas were related to the caregivers’ work to maintain personal autonomy, reciprocity and normality, both individually and in relationships with the ill spouses. However, considerations regarding seeking and integrating health care services in their lives had to be weighed against maintaining a sense of safety amid their awareness and management of the ill persons’ increasing risks of breathlessness and exacerbations. For several caregivers, these considerations stretched their capacity and ability to maintain their caregiving role.

Caregivers faced challenges to find ways to share responsibilities with formal health care services in ways that offered safety and relief for caregivers. Many caregivers reported that their needs of support were not recognised and that they consequently felt abandoned by health care services. This study indicates that caregivers experienced insufficient collaboration with formal health care services as taxing, adding negatively to their experiences of being affected and responsible. These experiences and concerns illustrate how obtaining appropriate support could become contradictory as family caregivers experiences needs of support but were reluctant to seek related services due to the challenges they faced.
securing recognition from health care services and integrating service provision into their lives.

The policy aims to transfer more care responsibilities to communities and families cannot be realised without developing better services and structures for collaboration between informal and formal care provision. Changes in health care provision also present new possibilities and potentials for providing health care services which more adequately recognise the support needs of family caregivers. It is crucial that community health care services utilise such potentials to develop systematic follow-up and integrate a relational focus into health care provision, supporting the overall aim of developing accessible, flexible, reliable services to improve support for both patients and their caregivers. A relational focus involves increased sensitivity towards and understanding of the complexity of caregivers’ role. However, as the threshold for hospital admissions is raised, conflicts between family caregivers and professional health care providers could intensify unless community health care services develop adequate competence, accessible support and continuity of care, for example thorough outreach services, to follow up patients and caregivers throughout the complex illness trajectory.

8.1 Further research

This research by no means exhausts the relationships between informal and formal care provision to chronically ill persons. Caregivers’ complex experiences of being affected by illness and feeling deeply responsible for managing it serve as a good point of departure for further investigation of the family caregiving role beyond the case of COPD. This study’s insights into the complex process of recognising and legitimising caregivers’ health care
support needs point to a greater awareness in health care services of caregivers’ needs as often implicit and unclarified. Generating sophisticated understandings of the complex process of recognising health care support needs in other caregiver relationships could promote such awareness in health care services. For instance, the considerations involved in the relational process of recognising needs of support might be complex in other ways in other informal caregiving relationships, such as negotiations by parents of children with disabilities regarding their needs for relief and respite vis-à-vis their perceptions of their children’s needs.

How the rhetoric of caregivers as resources can be translated into practice remains a crucial question for improving collaboration among patients, caregivers and health care professionals. Moreover, how to further develop and integrate a relational focus in health care service provision presents fertile ground for empirical inquiries and theoretical understandings. For instance, how to develop better structures in health care services to support caregivers presents a crucial point of departure for such inquiries. Considering the policy aims to raise the threshold for inpatient care, I find it important to develop more knowledge of how to provide better support to caregivers through community health care and social services. Improving knowledge of the potentials and barriers in community services to supporting both patients and caregivers is crucial for designing services that more directly support and attend to caregivers and create accessible contact points for both patients and caregivers. Such inquiries could contribute valuable knowledge for developing services and arrangements which enhance both patients’ and caregivers’ sense of safety in better ways and lead to more adequate sharing of care responsibilities.
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Appendix

Appendix I: Samtykke-skjema pårørende

Kan du tenke deg å bli intervjuet i forbindelse med et forskningsprosjekt om pårørendes omsorg for kronisk syke?

Pårørende sitt omsorgsarbeid for kronisk syke er betydelig, og anerkjennelse av dette arbeidet er viktig. Det betyr at helsetjenestene også må tilpasses behovene til pårørende og at pårørendes erfaringer er sentrale når man skal utvikle ny kunnskap om helsetjenesten.

Hensikten med dette prosjektet er å undersøke hvordan pårørende beskriver sitt omsorgsarbeid, hvordan pårørende og pasient samhandler med helsevesenet og hva oppfølging av KOLS-pasienter i hjemmet betyr for pårørende. Studien har et kvalitativt forskningsdesign, og innebærer intervju med pårørende og helsepersonell, samt deltakende observasjon i forbindelse med helsepersonellets hjemmebesøk hos KOLS-pasienter. Vi vil intervjuje den nærmeste pårørende, enten ektefelle/ samboer, voksen barn eller søsken. Vi ønsker å snakke med folk med ulik bakgrunn med hensyn til kjønn, alder og yrkesbakgrunn.

Studien gjennomføres i regi av Akershus universitetssykehus (AHUS) og er en del av et forskningsprosjekt finansiert av Norges Forskningsråd. Det daglige ansvaret for prosjektet har Gunvor Aasbø som er sosiolog. Prosjektleder og veileder er seniorforsker Anne Werner. Studien er godkjent av Regional etisk forskningskomité (REK) og av personvernombudet på AHUS.

Du er sikret anonymitet

Intervjuene tas opp på lydbånd og skrives ut av Gunvor Aasbø som er den eneste med tilgang til lydbåndopptakene. Lydbåndopptakene slettes senest innen fem år. Utskrift av intervju vil bli behandlet konfidensielt, og dataene vil bli anonymisert slik at ingen opplysninger vil kunne spores tilbake til deg. Vi vil presisere at vi ikke har tilgang til journalopplysninger om pasienten.

Samtykke

Hvis du sier ja til å delta i studien, har du rett til innsyn i data som er registrert om deg, og du har rett til å korrigere eventuelle feil i opplysningene vi har registrert. Du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. I så tilfelle vil den informasjonen du har bidratt med bli slettet.

Målet med studien er å få ny kunnskap om pårørendes rolle. Dine erfaringer er derfor viktige, og vi håper du vil delta i studien.

Hvis du vil delta, ber vi deg sende svarsslippen i vedlagte, ferdigfrankerte konvolutt, så vil vi ta kontakt med deg. Tid og sted for intervju vil bli tilrettelagt slik det passer best for deg.
Hvis det er noe du lurer på, kan du ringe Gunvor Aasbø på tlf 67 96 87 05 (AHUS) eller 48 25 71 36 (mobil).

Med vennlig hilsen,

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

Gunvor Aasbø,      Anne Werner,
doktorgradsstipendiat i studien      seniorforsker og prosjektleder

Jeg bekrefter herved at jeg er villig til å delta i studien.

Jeg har blitt informert om at det er frivillig å delta og at jeg når som helst kan trekke meg fra studien.

Navn..............................................................................................................................................

Adresse..........................................................................................................................................

Telefon...............................................

Appendix II: Samtykkeskjema helsepersonell

Forspørsel om deltakelse i forskningsprosjekt om pårørendes omsorg for kronisk syke.


Forskere på Akershus universitetssykehus (AHUS) er ansvarlig for studien som er finansiert av Norges Forskningsråd. Det daglige ansvaret for prosjektet har Gunvor Aasbø som er sosiolog og som du vil være i kontakt med. Prosjektleder og veileder er seniorforsker Anne Werner. Vi har søkt om godkjennelse av studien fra Regional etisk forskningskomité for Helse Sør-Øst (REK) og fra personvernombudet på AHUS.

Du er sikret anonymitet


Samtykke

Hvis du sier ja til å delta i studien, har du rett til innsyn i data som er registrert om deg, og du har rett til å korrigere eventuelle feil i opplysningene vi har registrert. Du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Informasjonen du har bidratt med vil da bli slettet.

Fordi målet med studien er å få kunnskap om hvordan helsetjenesten kan støtte pårørendes omsorgsarbeid og du har erfaring fra ambulant virksomhet, håper vi du vil delta i studien.
Hvis du vil delta, ber vi deg sende svarslippen i vedlagte ferdig frankerte konvolutt så vil vi kontakte deg. Tid og sted for intervju og hjemmebesøk avtales slik at det passer best for deg.

Hvis du har noen spørsmål om forskningsprosjektet, kan du kontakte Gunvor Aasbø på tlf 67 96 87 05 (AHUS) eller 48 25 71 36 (mobil).

Med vennlig hilsen,

........................................................................................................................................
........................................................................................................................................
Gunvor Aasbø, Anne Werner,
doktorgradsstipendiat i studien seniorforsker og prosjektleder

Jeg bekrerter herved at jeg er villig til å delta i studien.

Jeg godtar å bli intervjuet (sett kryss) □

Jeg godtar å ha med Gunvor Aasbø på hjemmebesøk til pasienter (sett kryss) □

Jeg har blitt informert om at det er frivillig å delta og at jeg når som helst kan trekke meg fra studien.

Navn......................................................................................

Telefon................................................................................
Forespørsel om deltakelse i forskningsprosjekt om pårørendes omsorg for kronisk syke.

Hensikten med denne studien er å undersøke hvordan pårørende beskriver sitt omsorgsarbeid, hvordan pårørende og pasient samhandler med helsevesenet, og hva oppfølging av KOLS-pasienter i hjemmet betyr for pårørende. Studien har et kvalitativt forskningsdesign, og innebærer intervj med pårørende og helsepersonell, samt deltagende observasjon i forbindelse med helsepersonellets hjemmebesøk til KOLS-pasienter. Deltakelse på hjemmebesøk vil gi forskeren en bedre forståelse av hva det vil si for pasient og pårørende å leve med KOLS i hverdagen. Dette er viktig for at helsetjenesten kan støtte pårørende i deres omsorgsarbeid.

Forskere på Akershus universitetssykehus (AHUS) er ansvarlig for studien som er finansiert av Norges Forskningsråd. Det daglige ansvaret for prosjektet har Gunvor Aasbø som er sosiolog. Prosjektleder og veileder er seniorforsker Anne Werner. Studien er godkjent av Regional etisk forskningskomité for Helse Sør-Øst (REK), og av personvernombudet på AHUS.

Vi lurer på om Gunvor Aasbø kan være med helsepersonell på ett ordinært hjemmebesøk til dere. Både helsepersonell, pårørende og pasient må godkjenne dette. Vi vil presisere at forskeren ikke skal forstyrre det daglig arbeidet eller dialogen mellom helsepersonellet og pasienter/pårørende.

**Du er sikret anonymitet**

Etter hjemmebesøket vil Aasbø skrive ned sine observasjoner. Notatene blir behandlet konfidensielt, og dataene blir anonymisert slik at ingen opplysninger vil kunne spores tilbake til dere. Vi har ikke har tilgang til medisinske journalopplysninger om pasienten.

**Samtykke**

Hvis dere sier ja til å delta i studien, har dere rett til innsyn i data som er registrert om dere, og rett til å korrigere eventuelle feil i opplysningene vi har registrert. Dere kan når som helst trekke samtykket dere har gitt uten å oppgi noen grunn. I så tilfelle vil informasjonen dere har bidratt med bli slettet.

Hvis det er orden at Gunvor Aasbø inkluderer dette hjemmebesøket i sin studie, ber vi dere underskrive svarslippen.

Har dere spørsmål om studien kan dere ringe Gunvor Aasbø på tlf 67 96 87 05 (AHUS) eller 48 25 71 36 (mobil).
Vi håper dere vil delta i studien.

Med vennlig hilsen,

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

Gunvor Aasbø, Anne Werner,
doktorgradsstipendiat seniorforsker og prosjektleder

Pasient:

Jeg bekrefter at jeg er villig til å delta i studien.

Jeg har blitt informert om at det er frivillig å delta og at jeg når som helst kan trekke meg fra studien.

Navn..............................................................................................................................................
Adresse..........................................................................................................................................
Telefon..............................................

Pårørende:

Jeg bekrefter at jeg er villig til å delta i studien.

Jeg har blitt informert om at det er frivillig å delta og at jeg når som helst kan trekke meg fra studien.

Navn..............................................................................................................................................
Adresse..........................................................................................................................................
Telefon..............................................
Appendix IV

PÅRØRENDE - INTERVJUGUIDE

Sykehusbehandling i hjemmet for KOLS-pasienter

* 

Temaer til intervjuer med pårørende:

Personalia - bakgrunnskunnskap

Alder, kjønn, relasjon til pasienten, arbeidstilknytning, utdanningsbakgrunn

Pårørendes omsorgsarbeid/-rolle i dagliglivet – og relasjonen til den syke

- Kan du fortelle litt om hvordan er en vanlig dag for deg som pårørende til en KOLS-pasient ser ut? For eksempel i går.
- Hvordan er du med på å håndtere forverrings og forebygging av forverrelse av KOLS? Hjelper du til med å håndtere sykdommen på andre måter, hvordan – i forhold til hva?
- Er det andre i familien som hjelper deg og/eller den syke? Hvordan?

Hjemmebesøk og samarbeid med helsepersonellet

- Kan du beskrive hvordan et vanlig hjemmebesøk foregår? Hva skjer – eller hva gjøres - i slike hjemmebesøk? Hva snakker helsepersonellet om med pasienten og eventuelt med deg?

- I hvilken grad eller hvordan blir du involvert i hjemmebesøket som pårørende? Deltar du i hjemmebesøket? Hvordan eventuelt hvorfor ikke? Hvordan forholder helsepersonellet seg til deg på hjemmebesøkene?
- Hvilke forventninger opplever du at de har til deg som pårørende i slike hjemmebesøk? Og i dagliglivet ellers?
- Hvor ofte kommer de? Kan de kontaktes utenom hjemmebesøke?
Hva får pasienten og du av informasjon og hjelp gjennom hjemmebesøkene og kontakten med sykehuset? Er det noe dere kan bruke i ettertid, synes du? Eller er det ikke noe fra hjemmebesøkene som er relevant for dagliglivet etterpå, synes du?

På hvilken måte kan hjemmebesøkene være til hjelp og avlastning også for deg som pårørende til en kronisk syk?


Hvilke utfordringer eller vanskeligheter opplever du i slike hjemmebesøk hvor du er tilstede?

Hva er et vellykket hjemmebesøk, synes du?

Hjelp fra andre helsetjenester

Har hjemmebesøkene noen som helst betydning for kontakt med sykehuset? Eventuelt hvordan?

Synes du pasienten - eller dere - blir fulgt godt nok opp av helsevesenet? Er det noe dere savner av hjelp?

Hvilken rolle opplever du at du har eller blir gitt av helsepersonell i håndteringen av KOLS-sykdommen?

Hvem er det du eller pasienten henvender dere til når dere har behov for hjelp i forhold til KOLS-sykdommen? Når ringte du lungesykepleier sist eller når kan du ringe lungesykepleier? Når ringer du 113 sist?


Appendix V

INTERVJUGUIDE - helsepersonell

Sykehusbehandling i hjemmet for KOLS-pasienter

* 

TEMAER til intervjuer med helsepersonell:

Personalia – bakgrunnsskunnskap

Arbeidssted, ansettelsessted/hvor lenge har du jobbet her, yrkesprofesjon/fagbakgrunn, alder, kjønn

Hjemmebesøket - pasienttopplæring og samarbeidet med KOLS-pasienten og pårørende

- Kan du beskrive “et typisk” hjemmebesøk - hvor pårørende er tilstede (for eksempel forrige gang du var på hjemmebesøk): Hva gjøres, hvordan - og hvorfor? Hva snakker dere om på slike hjemmebesøk?
- På hvilken måte – eller hvordan - deltar pårørende i slike hjemmebesøk? Eller hvordan forholder du deg til den pårørende når du er på hjemmebesøk?
- Gjør noen forskjell for pasient og pårørende å få hjemmebesøk? Hvordan eller hvilken betydning har hjemmebesøk for pasienten og for pårørende i forhold til å komme på sykehuset?
- Hvem er “den typiske” KOLS-pasienten - og hans eller hennes pårørende? (Eksempel)
- Gjør det noen forskjell om pasienten har pårørende eller ikke? Hvordan/hvorfor?
- Er pårørende til hjelp i hjemmebesøket? Hvordan? (Eksempel)
- Er pårørende på noen som helst måte til hjelp for pasienten i dagliglivet? Hvordan?
- Gjør det noen forskjellen om den pårørende er mann eller kvinne? (Eksempel)
- Gjør det noen forskjell om den KOLS-syke er mann eller kvinne? (Eksempel)

- Hvilke utfordringer eller vanskeligheter kan du møte i slike hjemmebesøk - hvor pårørende er tilstede? Eksempel.
- Det verst tenkelige hjemmebesøket hvordan arter det seg?
- Kan du beskrive et vellykket hjemmebesøk?
Planlegging, prioritering og samarbeid i og utenom hjemmebesøkene

- Hva har betydning for hvordan du legger opp hjemmebesøket? Hvordan planlegger du et slikt hjemmebesøk i forkant?
- Hvor ofte besøker dere KOLS-pasienter som har pårørende? Hvor ofte kommer de på poliklinikken på sykehuset?
- Har dere noen kontakt med KOLS-pasientene og/eller pårørende utenom hjemmebesøkene og på poliklinikken? For eksempel på telefon?
- Hvordan prioriterer du - forhold til tid og hvilke pasienter du særlig følger opp? Hvordan jobber dere mot pasienter som har pårørende som følger mye opp i forhold til KOLS-pasienter som ikke har pårørende eller som har pårørende som i liten grad følger opp?