Elderly patients care trajectories from the perspectives of patients, next of kin and health care professionals: A qualitative case study.

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Abbreviations

CTG: Care trajectory game

GP: General practitioner

LE: Life Expectations

NSD: Norwegian Centre for Research Data

PCC: Person-centred care

TA: Thematic analysis

WHO: World Health Organization

Summary

An increasing number of elderly people are living longer with chronic illness and many need healthcare that involves several different health personnel employed at various levels in the health service. While healthcare service has moved in the direction of increased specialisation and fragmentation, many patients and next of kin experience the services as disjointed and fragmented as well as difficult to understand and access. Healthcare professionals, on the other hand, strive to provide coherent and person-centred healthcare. It is also a goal to develop integrated healthcare services for patients with complex health problems. The standardised care pathway has been used as a strategy to achieve integrated health services and to improve the quality of healthcare. Research has shown that standardised care pathways are most effective for a single disease and not as appropriate for patients with complex health problems. Thus, there is a need to gain more in-depth knowledge of the care trajectory of elderly people with complex health needs and to articulate the perspectives of all the actors involved as well as the interactions and management for this patient group.

The overall aim of this dissertation was to explore and describe the care trajectory for elderly patients with complex healthcare needs from their hospitalisation to their return to primary care from the perspectives of the patient, next of kin and involved healthcare professionals. This is illustrated through three substudies. In sub-study I, the aim was to uncover the work that healthcare professionals undertake to achieve coherent and comprehensive healthcare during their journey through the complex healthcare terrain. In sub-study II, the aim was to explore how elderly patients with complex health problems engage in and interact with their care trajectories across different healthcare systems where several health personnel are involved. Furthermore, the purpose of sub-study III was to illuminate the dilemmas and deliberations of patients, next of kin and health professionals during the care trajectory.

The study employed an exploratory and descriptive design with a case approach. A case approach was chosen to gain a more comprehensive understanding of and insight into the care trajectory of the elderly. The study was carried out at a hospital and in nine municipalities within the same healthcare organisation. The data material in sub-study I consisted of interviews with 25 health professionals from the municipality and the specialist health service. In sub-studies II and III, patients were followed during the hospital stay and followed up after discharge in the municipality. A total of 11 patients ranging in age from 65 to 91 were included in the study, as well as seven next of kin. In sub-studies II and III, the data material was obtained from observations, repeated interviews with patients and next of kin and data extracted from the patient record system.

The main findings show that for this patient group, the trajectory was characterised as being long-term with interruptions in the long-term trajectory when admitted to the hospital. Decisions made during the hospital stay and in follow-up breaks with the patients' needed to balance what happened during the illness trajectory with what happened in life in general. All or the parts of health care services were characterised by short time frames and requirements for efficiency. The patient and next of kin's decisions and choices for further follow-up during and after the hospital stay were part of a long-term and continuous process that included conditions about life otherwise. For healthcare personnel, these differences between the patient's long-term needs and organisational requirements led to challenges in providing person-centred healthcare. This tension between different time perspectives led to patients, next of kin and healthcare professionals being in different positions, from being left out on the sidelines to having an active and involved role throughout the patient process. It turned out that in parallel with the health professionals' planning and decision-making processes, the patients and the next of kin had to do extensive work to facilitate healthcare and to ensure coherence throughout the process.

The dissertation reveals that it is a prerequisite that if one is to realise the goal of person-centred services, one must facilitate the needed time and space that reflect and attend to the longer-term perspective in the decision-making processes throughout the care trajectory. This means that the patient's considerations about the choices that must be made need to be seen in the light of their life in general. Healthcare

professionals express the importance of having a broader and more comprehensive picture of the patient's situation beyond the trajectory of the illness to meet the patient's needs. This is difficult to achieve within today's interaction practices. However, developing relational cooperation between healthcare professionals from different service levels seems to strengthen the patient's experience of coherence in healthcare in relation to their preferences. A prerequisite for achieving coherence in healthcare services is to expand the understanding of what is meant by integrated services to encompass and include patient and next of kin work.

Sammendrag

Et økende antall eldre lever lengre med kronisk sykdom og mange trenger helsehjelp som involverer flere ulike helsepersonell ansatt på ulike nivåer i helsetjenesten. I takt med at helsetjenestene har gått i en retning med økt spesialisering og fragmentering, opplever mange pasienter og pårørende tjenestene som oppstykket og vanskelig å orientere seg i. Helsepersonell på sin side strever med å utføre sammenhengende og personsentrert helsehjelp. Det er også et mål å utvikle integrerte helsetjenester for pasienter med sammensatte helseproblem. Standardiserte pasientforløp har vært brukt som en strategi for å oppnå integrerte helsetjenester og å forbedre kvaliteten på tjenestene. Forskning har vist at standardiserte pasientforløp er mest effektive ved et enkelt sykdomsforløp og ikke så hensiktsmessig for pasienter med sammensatt helseproblem. Det er behov for å få mer utdypende kunnskap om pasientforløp til eldre med sammensatt helsebehov og artikulere frem alle impliserte aktørenes samspill og håndtering i pasientforløpet.

Hensikten med denne studien var å utforske og beskrive forløpet til eldre med sammensatte helsebehov fra sykehusinnleggelse til utskrivning til kommunen fra et pasient-, pårørende- og helsepersonellperspektiv. Dette er belyst gjennom tre delstudier. I del studie I var hensikten å avdekke helsepersonell sitt arbeid for å oppnå sammenheng og helhet i helsehjelpen i et terreng av komplekse tjenester, I del studie II var hensikten å utforske hvordan eldre pasienter engasjerer seg og samhandler gjennom pasientforløpet, på tvers av tjenester der flere helsepersonell er involvert. Videre var hensikten i del studie III å belyse dilemmaer og avveielser til pasienter, pårørende og helsepersonell underveis i pasientforløpet.

Denne studien har et utforskende og beskrivende design med casetilnærming. Casetilnærming ble valgt for å få en mere omfattende forståelse og innsikt om pasientforløp til eldre. Studien er gjennomført ved to sykehus og ni kommuner innenfor samme helseforetak. Datamaterialet i del-studie I består av intervju med 25 helsepersonell fra kommune – og spesialisthelsetjenesten. I del studie II og III er pasienter fulgt under sykehusopphold, utskriving og oppfølging etter utskriving i kommunen. 11 pasienter mellom 65- 91 år ble inkludert i studien samt 7 pårørende. I del studie II og III er datamaterialet hentet fra observasjon, gjentatte intervju med pas og pårørende og utskrift fra pasient journal.

Hovedfunn i studien viser at for denne pasientgruppen var forløpet preget av å være langsiktig. For pasienten handlet det om å balansere sykdomsforløpet innenfor det som skjedde i livet generelt. Mens pasient og pårørendes beslutninger for videre oppfølging etter sykehusoppholdet var kjennetegnet av å inngå i en langsiktig og en kontinuerlig prosess som inkluderte faktorer om livet ellers, var helsetjenestene preget av kortere tidsrammer og krav til effektivitet. For helsepersonell medførte disse forskjellene mellom pasientens behov og organisatoriske krav utfordringer i å gi en personsentrert helsehjelp. Denne spenningen mellom ulike tidsperspektiver førte til at pasient, pårørende og helsepersonell beveget seg i ulike posisjoner fra å være satt på siden til å ha en aktiv og involvert posisjon gjennom pasientforløpet. Samtidig med helsepersonells sin planlegging - og beslutningsprosess mobiliserte pasient og pårørende et omfattende arbeid for å tilrettelegge for helsehjelp og å sikre sammenheng gjennom forløpet

Avhandlingen avdekker at det er en forutsetning at man tilrettelegger tid og rom som reflekterer det mere langsiktige perspektivet i beslutningsprosessene gjennom pasientforløpet, hvor pasientens vurderinger i forhold til livet generelt også blir ivaretatt. Helsepersonell vektla betydningen av et bredere og mere omfattende bilde av pasientsituasjonen utover selve sykdomsforløpet for å møte pasientens behov. Relasjonell samhandling mellom helsepersonell synes å styrke pasientens opplevelse av samsvar i helsehjelpen i forhold til sine preferanser. I forutsetningen med å oppnå integrering av helsetjenestene er det nødvendig å utvide forståelsen til å omfatte alt pasient og pårørende arbeid.

List of articles/ original papers

This dissertation is based on the following papers:

I. Kumlin, M., Berg, G. V., Kvigne, K., & Hellesø, R. (2021). Unpacking health care professionals' work to achieve coherence in the health care journey of elderly patients: An interview study. *Journal of Multidisciplinary Health care*, *14*, 567

II. Kumlin, M., Berg, G. V., Kvigne, K., & Hellesø, R. (2020). Elderly patients with complex health problems in the care trajectory: A qualitative case study. *BMC Health Services Research*, *20*(1), 1–10

III. Kumlin, M., Berg, G. V., Kvigne, K., & Hellesø, R. (2022). Dilemmas and deliberations in managing the care trajectory of elderly patients with complex health needs: a single-case study. *BMC Health Services Research*, *22*(1), 1–11.

1 Introduction

The present dissertation contributes knowledge about the comprehensiveness of the care trajectory to elderly patients with complex health care needs by addressing the challenges of achieving coherent and person-centred health care services. For elderly persons with complex healthcare needs, comprehensive work to manage their care trajectory is required. Most commonly, several actors, such as the patient, the next of kin and health professionals across different healthcare systems, are involved during the patient's healthcare trajectory (D. Allen et al., 2004; Doessing & Burau, 2015).

Generally, it has been typical to concentrate on the individual's illness pathway as a single disease, but in the present study, the focus is on elderly person with complex health problems. The concept of care trajectory comprises all the organisational work, not only the management of the illness trajectory (D. Allen et al., 2004). Therefore, the concept of the care trajectory is used in the current dissertation to understand the elderly patient 'journey' through the healthcare system, the patient's interaction with the system and actors involved and the actors' work to manage the care trajectory.

Globally, populations are ageing, which has been linked to shifting demographics, where an increasing number of people are living longer with chronic illnesses. Elderly people with complex healthcare needs are more prone to complications from disease and functional decline. Many patients need healthcare from several health professionals at different levels of healthcare services, which results in several transitions (Chatterji et al., 2015; Doessing & Burau, 2015; McLeod et al., 2011). Today, the pressure on healthcare systems is increasing. The growing demand for healthcare services and focus on cost containment and efficiency have also led to concerns about deteriorating quality of care (Bodenheimer & Fernandez, 2005; Gautun & Syse, 2017; Heijink et al., 2015; Kittelsen et al., 2015).

The care trajectory for elderly persons with complex needs can be characterised by several transfers across specialist and primary care (Aase et al., 2013; Coleman & Boult, 2003). Regarding specialist care, the length of hospital stays has become shorter, and the number of specialist beds has decreased to minimise healthcare costs and optimise patient outcomes. There has been a shift from inpatient to a greater use of outpatient settings, day surgery and treatment and outpatient clinics (Gonçalves-Bradley et al., 2016; Mathew et al.,2015; Melberg & Hagen, 2016). In the process of reducing the length of hospital stays, hospital discharge appears earlier in the trajectory, which has led to increased responsibility being transferred from specialist care to primary care. Therefore, more elderly patients and patients with chronic health care needs are treated at home (Gautun & Syse, 2017; Shepperd & Iliffe, 2005). Decreasing the number of beds in hospitals have also shown to be a readmission risk factor. Readmission increases with age and comorbidities (Mathew et al., 2015; Moen et al., 2017).

Today, there is a political trend that elderly people should live as long as possible at home (Otnes, 2015; Ringard et al., 2013). To meet the needs of elderly with complex health issues, governance has considered it sustainable to transfer health care services from specialist to primary care. Internationally, primary care is organised in various ways, but, generally, its function is to be the first point of contact for a person. Primary healthcare system, help people to live healthier and, when health care is required, to provide the right care at the right time. During one's lifetime, primary healthcare can include health promotion, disease prevention, treatment, rehabilitation and palliative care (World Health Organization, 2016). One principle of primary care is to be a cornerstone of the health system and bring health care close to where people work and live (Valentijn et al., 2013).

The international and national tendency has been moving towards an increased specialisation and fragmentation of healthcare, both in municipal and specialist care (Elliott et al., 2018; Ringard et al., 2013). The WHO (2016) has emphasised that healthcare services for patients with comprehensive health care needs should be integrated and person-centred throughout their trajectory (World Health Organization, 2016). In Norway, the Coordination Reform, which was implemented in 2012, included the intention to develop a seamless pathway across primary and specialist care. Care pathways—which were developed to standardise the health care process—have been used in the strategy of achieving integrated care and improve the quality of treatment through coherent courses, link the best evidence to practice, increase patient safety and improve resource allocation and cost control (Rotter et al., 2010). However, research has shown that care pathways are the most effective with single diseases and when the care trajectory is predictable and that these pathways are not appropriate for patients with multimorbidity and complex health problems (D. Allen et al., 2009; Barnett et al., 2012).

With healthcare services moving in the direction of specialisation and fragmentation, elderly patients and next of kin have found the services fragmented and difficult to orientate themselves in (Doessing & Burau, 2015; Storm et al., 2014). Participation in hospital discharge planning and plans for follow-up care can be limited, and information is often unavailable or insufficient in this process (Bauer et al., 2009; Dyrstad et al., 2015; Gabrielsson-Jarhult & Nilsen, 2016; Neiterman et al., 2015). The health professional's struggle to provide coherent health care to the patient and find collaboration and communication between health professionals at different healthcare levels can be challenging (Bragstad et al., 2014; Doessing & Burau, 2015; Groene et al., 2012; McLeod et al., 2011).

Elderly patients with complex health care problems are more vulnerable to the impact of a fragmented healthcare system and need more coordinated health care and access to providers. Despite the intention and effort to create integrated person-centred care, there are still challenges to achieving coherence within the elderly patient care trajectory (Doessing & Burau, 2015). The elderly patient's perspective as they pass through the entire care trajectory has been insufficiently described (Richardson et al., 2007; Toscan et al., 2013). In addition, the care trajectory for elderly person with complex healthcare needs has often involved several actors, such as the patient, next of kin and health professional. Previous research has tended to emphasise the health care professional's perspective of the care trajectory and addressed factors such as admissions to and discharge from the hospital, information exchange between health care professionals and the coordination of health care between different levels of services (Bauer et al., 2009; Coleman & Boult, 2003; Dyrstad et al., 2015; Hellesø et al., 2016; Storm et al., 2014).

When I first planned the study, little research that included the perspective of the patient, the next of kin and the health professional during the trajectory was identified. However, several actors are involved in the care trajectory. To understand the challenges and issues regarding care trajectory, Toscan et al. (2012) emphasised the perspectives of patients and next of kin and health care professionals to be included. Thus, it was urgent to gain knowledge from all the actor's perspectives to articulate how the actors interact and manage the care trajectory. The present dissertation's ambition is to contribute to novel insights and understandings about the effort to create and achieve coherence in the healthcare services for patient with complex health needs.

1.1 Aim of the study

The overall aim of this dissertation is to explore and describe the care trajectory for elderly patients with complex health care needs from their hospitalisation to their return to primary care from the perspectives of the patient, next of kin and involved health care professional.
The overall aims are reflected in three substudies.

Sub-aims 1: To uncover the work that health care professionals undertake to achieve coherent and comprehensive health care for elderly patients with multiple health problems during their journey through complex health care terrain.

Sub-aims 2: To explore how elderly patients with complex health problems engage in and interact with their care trajectories across different healthcare systems where several health personnel were involved.

Sub-aims 3: To illuminate the dilemmas and deliberations of patients, next of kin and health professionals during the care trajectory of elderly patients with complex health care needs.

The substudies refer to the three scientific articles. Paper I refers to sub-study I, Paper II to sub-study II and Paper III to sub-study III.

1.2 Outline of the dissertation

This dissertation contains six chapters. Following this chapter, Chapter Two provides the background for the dissertation, a description of the concept of care trajectory, the health condition in elderly life, the healthcare services in Norway with some of the historical background, integrated and person-centred care and findings of previous research on the care trajectory of elderly persons. In Chapter 3, a detailed description of the design and methods used in the substudies is provided. In Chapter 4, the results of the substudies are presented, which are discussed in Chapter 5 in addition to methodological considerations. In the final chapter, the conclusions of this dissertation, the implications of the findings for clinical practice and recommendations for further research are presented.

2 Background

The current dissertation's main concept is the care trajectory. The basis of the concept and its relevance in this dissertation will be described in this chapter. Findings from previous research on the care trajectory as it relates to the elderly person are presented at the end of the chapter. To garner an understanding of who the elderly person with complex health care needs is, some characteristics of the elderly persons' health condition and functioning will be described. The settings for the current study are the healthcare system in the municipalities and hospitals in Norway. To obtain a comprehension of today's specialisation and fragmentation of the services, some historical background are illuminated. Coherence in health care services and the person-centred approach are emphasised in different governance policy documents. To achieve these approaches in providing health care, integrated health care has been introduced in recent decades. The framework of integrated health care will be described together with a method for standardisation of the care trajectory.

2.1 The care trajectory

During the planning of the study, I discovered D. Allen et al.'s (2004) concept of care trajectory and found it useful as a conceptual framework for the present dissertation because it opens up for getting a comprehensive understanding of the elderly patient 'journey' through the healthcare system and how the patient's interact with the system and those actors involved. Furthermore, it accounts for the patient, next of kin and health professionals working to manage the care trajectory. The care trajectory has evolved from Corbin and Strauss' (1991) framework of illness trajectory based on social interaction theories. The illness trajectory was developed to understand the complexity of chronic illness, the different stages of illness, the phases of disease management and the impact of the illness on the individual's daily life and activities (Corbin & Strauss, 1991). The illness trajectory management refers to the process by which the illness course is shaped and through all its phases. This management includes 'controlling symptoms and treatment side effects, handling crises, preventing complications, handling disability, and so forth' (Corbin & Strauss, 1991, p. 164). The work required for day-to-day management by patients, family and others were emphasised (Corbin & Strauss, 1991; Nolan & Nolan, 1995).

Although the concept of illness trajectory emphasises the illness course and different stages of the course, the 'care trajectory' also addresses the organising work, which D. Allen (2019) argued is not explicitly articulated in illness trajectory. The total organisation of work is articulated as 'the unfolding of patients' health and social care needs, the total organisation of work associated with meeting those needs and the impact on those involved with that work and its organization (D. Allen et al., 2004, p. 1010). Elderly patients with complex health often need and receive health care from several health professionals at different levels of health care services; the numbers of all the actors, such as the patient themself, the next of kin and all health professionals influence the complexity of the care trajectory (D. Allen, 2019). D. Allen described this as follows: 'Sources of the complexity of care trajectory is not only from the illness and diseases but also from the division of labor, the turbulence of the work environment, and biographic and psycho-social considerations relating to patients, next of kin and staff' (D. Allen 2019, p. 7).

Furthermore, to investigate why complex care trajectories have been shown to be so difficult to manage for patients, their next of kin and health care providers D. Allen et al. (2004) conceptualised the care trajectory game (CTG). The CTG emphasises the relationships between the individual care trajectory and the broader organisation of healthcare services to understand what happens at the micro-organisational level around each individual care trajectory. The CTG arises from an ethnographic case study with a focus on adults undergoing rehabilitation from an acute stroke (D. Allen et al., 2004). In their analysis process, D. Allen et al. used sociological theories by combining Strauss' concept of illness trajectory and Elias game theory to come up with the conceptualisation of the CTG framework; they found that Elias's game theory, which emphasises the need to facilitate exploration of how different components of social wholes are related to each other and ways social networks are changed over time, added value to an extended understanding of interaction where the players influence each other (D. Allen et al., 2004, pp. 1012–1013).

D. Allen et al. (2004) pointed out that health care work is characterised by two features: First, 'Unexpected situations arise not only from the disease process, but from other factors such as organizational and technological, and for that second it is people who are doing the work, who react and affect the work. In the articulation of the complex care trajectories, negotiation, persuasion and discussion are some of the dominant modes' (D. Allen et al., 2004, p. 1011).

D. Allen et al. described the game model as providing a unit of analysis for understanding the series of interactions performed by several 'players' with mutual influence in the complex care trajectories. The intention is to go beyond the events that take the course (care trajectory) in different directions as a way to explore how the different components in the social whole are related to each other. The 'games' are described as an interwoven process with norms and cultural expectations that have meaning for the actors' (players') actions. Individuals and groups, each with their own functions, set constraints on each other. Therefore, changes in the social structure can cause one group to question the other group's power in setting the constraints. For example, if players A and B both experience decreased strength, the resulting less power will give both players an opportunity to employ a certain tactic over the other and change the figuration of the game. The unplanned course of the game repeatedly affects the moves of each player, and the more the game's complexity increases, the more likely it is that unintended consequences will occur (D. Allen et al., 2004, pp. 1012–1013).

Allen et al. argued (2014) that the game model makes it possible to move beyond the negotiation process, focusing on how social actions are intertwined and the network transfers over time; they found that combining the game model with the framework of illness trajectory gave an opportunity to move from a 'mono' casual explanation of a health care system failure to explore the dynamics of the system and those system features that make managing complex care trajectories so difficult (D. Allen et al., 2004).

During the process of the work of the three sub-studies in my dissertation, I discovered that drawing of the CTG framework had relevance according to the findings of these studies. The framework provided an approach for in-depth analysis of the complexity in the care trajectory for the elderly with complex needs. Throughout the present thesis, when referring to elderly patients with complex health problems, I will use the short term ‘the elderly patient’.

2.2 Health condition and functioning in an elderly life

Elderly people are characterised along a continuum from being independent to being vulnerable and having complex health care needs. The typical features of the elderly person’s health condition can range from healthy to chronic illness, multimorbidity and vulnerability or frailty (Almirall & Fortin, 2013). Changes that occur with age are not a linear process; for example, some individuals at the age of 70 will have good physical and mental functions, while others may be frail and need significant support in daily life (World Health Organization, 2015).

Elderly patients are characterised not primarily by their age, but rather by the complexity of their health problem (Wyller, 2015). Defining the patient with complex health problems involves more than comorbidity and complex clinical conditions because psychological, socioeconomic, cultural and environmental circumstances can also contribute to complexity (Ruiz et al., 2015; Safford et al., 2007). Examples of such additional factors can be living situation, access to social network and family, foreign language and cultural background, low income and limited access to services.

Although life expectation (LE) has increased globally, the evidence is less clear about whether the number of years living with chronic conditions has increased, decreased or remained stable (Chatterji et al., 2015). However, studies have shown a tendency for the elderly to cope better with diseases than in the past. This may be related to better medical treatment, physical environment and technology, which facilitates the elderly to manage themselves. Research on years lived with disabilities shows that more people maintain function and independence at an older age (Christensen et al., 2009). In Nordic countries, LE is higher than the global estimate (Storeng et al., 2021). Many elderly people in Norway function well in daily life and are independent at an ever-increasing age. The number of functional life years after the age of 70 has increased by several years over the past two decades (Rogne & Syse, 2017).

Multimorbidity and frailty

With the ageing population, more people are also living with multimorbidity and frailty. Multimorbidity can be defined as ‘the presence of two or more long-term health conditions and can include physical and mental health conditions’ (Almirall & Fortin, 2013, p. 8); however, multimorbidity does not necessarily mean that the patient is vulnerable and frail. Frailty is characterised by a decline in functioning across multiple physiological systems, accompanied by an increased vulnerability to stressors (Hoogendijk et al., 2019). There are multidimensional factors connected to the elderly who are frail, such as fall, fracture, weight loss, inactivity, depression, increased vulnerability with functional decline and infections, risk for unintended events by surgery and medical treatment. Frailty causes an increased likelihood of hospitalisation and admission to long-term care, in addition to the individual burden for a person living with frailty (Almirall & Fortin, 2013; Hoogendijk et al., 2019).

Functioning in daily life

The WHO has emphasised the elderly person’s functional ability and their opportunity to be active and functioning in daily living activities, not only focusing on their disease and multimorbidity. The term ‘intrinsic capacity’ is seen as an indicator of the body’s physiological reserve, along with external adaptation and barriers, which will give the elderly the possibility to be active and functioning in their daily activities (Storeng et al., 2021; World Health Organization, 2015). Elderly people with multimorbidity are at an increased risk of functional decline related to acute illness and hospitalisation and severe functional limitations, which is associated with an increased need for care (Hoogendijk et al., 2019; Moen et al., 2017). Generally, multimorbidity increases substantially with age and increases the burden from chronic illness later in life. This is a global challenge and has implications for healthcare systems (Pearson-Stuttard et al., 2019; Vos et al., 2015). In the present dissertation, the chronological age of 65 years and above has been adopted to define 'elderly', which agrees with the WHO's definition and with the knowledge that recently the number of younger elderly persons with complex health care needs and are receiving care at home has increased (Organization, 2010; Pearson-Stuttard et al., 2019; M. Sogstad et al., 2020).

2.3 Health care services in Norway

The Norwegian healthcare system consists of two organisational structures: municipal and specialist healthcare. The municipality's responsibility for health care comprises health promotion and preventive work, diagnosis and treatment, rehabilitation and emergency care. The municipal healthcare system ensures that all inhabitants of the municipality are provided with necessary health care (Ministry of Health and Care Services, 2011b). Among these services are home care nursing, home care (aid), sheltered housing, nursing homes, physiotherapy, general practitioners (GP) and acute care.

The overall responsibility for specialist health care, including the owners of the public hospitals, falls under the Ministry of Health and Care Services. Specialist healthcare services are organised into four regional areas and consist of inpatient, day-patient, outpatient clinics and centres for rural medicine.

The healthcare system is regulated through several acts and national health policy. The Ministry of Health and Care Services is responsible for the regulation and supervision of the system and ensures that health and social services are provided in accordance with national legislation and regulations (Saunes et al., 2020). The Municipal Health and Care Act (Ministry of Health and Care Services, 2011b) comprises regulations on how the healthcare services in municipalities should be delivered. Specialist care is regulated by the Specialist Care Act (Ministry of Health and Care Services, 1999b) and the Health Trust Act (Ministry of Health and Care Services, 2001). Inserted in the acts is the commitment to enter into a cooperation agreement between the municipality and regional health trust, a requirement for both organisational levels. The aim of the agreement is to facilitate services so that the patient receives comprehensive and coherent health care services.

Traditionally, caring for the elderly and sick was a family matter. At the beginning of the twentieth century, some home care nursing and home nursing were conducted by private charitable organisations in municipalities (Daatland, 1997; Hauge, 2004). In the same period, hospitals in Norway were established as local initiatives and built and run by municipalities and voluntary organisations. The hospitals were ‘mixed’, not specialised or separated into functional divisions. During the 1930s, the development of medical specialties such as surgery, medicine and X-rays resulted in some hospitals being put into functional divisions. In the 1950–60s, several cooperation divisions among hospital were made (Hansen, 2001).

Public health care was introduced during the 1960s and 1970s, driven by, among other things, the Law of Social Care and the Law of Hospital. Home care and home care nursing were implemented in the municipalities, and municipal housing for elderly and people with disabilities was developed. In the 1970s, the Hospital Act gave permission for the national coordination of hospitals. This law made the counties responsible for building and running hospitals, and they were given additional responsibility for the nursing homes. A structure was developed that differentiated hospitals and increased levels of consistency of local, regional and national (i.e., specialist) hospitals. Emphasis was placed on decentralisation, equality and an increase in geographical access to health care services. In the 1980s, the municipalities became responsible for providing and financing primary care, and in 1988, nursing homes were included in the municipalities. During the same period, there was a political agreement to go in for solid primary healthcare based on the so-called LEON principle: the principle of the most effective level of care at the ground level. Here, the greatest benefit from resources is achieved at the ground level of effective health care, that is, in the municipalities where people live and live out their daily lives (Report to the Storting nr.9 1974–75*;* Thornquist & Thornquist, 2009). Governance reinforces a policy that elderly should live in their own home for as long as possible and receive health care there (Otnes, 2015; Ringard et al., 2013). In the 1980–90s, attention to cost containment and efficiency resulted in a reduction in the number of hospital beds (Hansen, 2001; Ringard et al., 2013). Furthermore, today the specialisation of hospitals has increased, and the trend is a higher number of divisions of specialties, shorter hospital stays and a shift towards greater use of outpatient settings (day surgery and treatment, outpatient).

Together with the increased specialisation of hospital services, the municipalities' healthcare services have been transferred to a multitude of new areas. Earlier discharge from hospital and various healthcare reforms, such as a development plan for mental health, drug care reform and expanded health care services for people with physical and mental disabilities, have led to a greater number of younger people with health care needs, in addition to the increased number of elderly patients with comprehensive health care needs (Gautun et al., 2012; Ringard et al., 2013). For patients with long-term conditions and multimorbidity, healthcare services are performed in nursing homes, sheltered houses and by home care services; besides this, a variety of specialised care services and models have emerged at the municipality level. Twenty-four-hour municipal inpatient acute units and home care teams handling specific patient groups. Persons with dementia, palliative care needs and rehabilitation are some examples of these (M. Sogstad et al., 2020).

The various healthcare services in the municipality are usually organised separately. Concerns about different practices within even the same municipality and a commitment to creating a more coordinated service have led several municipalities to apply for services to an allocation office with a purchaser–provider model (Steihaug et al., 2017). Besides these organisational features, GPs are mostly self-employed and have contracts with municipalities. Those GPs who are responsible for delivering primary medical services have a central role regarding hospital admissions and referring patients to more specialist care. Generally, these specialisations and the establishment of new services, together with increased numbers of patients with comprehensive hospital needs, have called for more extensive coordination when compared with before (Melby et al., 2018; Rostad et al., 2020).

In addition, the pressure on healthcare services has caused a shift towards the increased utilisation of family and informal care. Elderly patients' relatives provide considerable assistance in health care work as a follow-up to medical treatment, give practical aid and help organise services (Bragstad et al., 2014; Tønnessen, 2016). Even with health care traditionally being a public responsibility, the future need for health care will be more explicitly met by family and informal caregivers. Governance has highlighted the need to facilitate closer collaboration on common tasks between informal caregivers and health care services (Ministry of Health and Care Services, 2012–2013, 2017–2018).

In line with international trends, Norwegian stakeholders have expressed expectations of the patients and next of kin contributions to provide health care (Ervik & Lindén, 2021). Applying Mattingly et al.'s (2011) concept of homework may provide a deeper understanding of this policy and expectations when the total organisation of the work is transferred to chronically ill patients and their families. The patient and next of kin are, for example, conducting work to follow up medical treatment and tasks they are required to do at home. The treatment work occurs at home during a care trajectory; it is not only a medical matter, but it becomes embedded within a life course and within social and family relationships (Mattingly et al., 2011).

The growing specialisation and fragmentation of healthcare services makes the coordination of services ever more challenging (Rostad et al., 2020; Sogstad & Bergland, 2021). At the same time, the health authorities have an expectation and demand about creating seamless patient pathways that are in coherence with patient needs. The Coordination Reform was implemented in 2012 to improve the synchronisation of primary and specialist care (Ministry of Health and Care Services, 2008–2009). In principle, the reform was based on challenges to meet the patient's needs with coordinated services, limited achievement in preventing disease, an ageing population and more people with illnesses who need help for longer periods of time. Economic, juridical, organisational and professional measures were employed to achieve the goal of a 'proper and seamless patient pathway at the right place and right time' (Grimsmo, et al., 2015; Røsstad et al., 2013). In addition, a central goal was to strengthen prevention work, early intervention and diagnosis, treatment and follow-up. Nevertheless, there is clearly a distinction in ownership and distribution of responsibility between municipality and specialist health care services, which are regulated by their own legislation, management and financing systems (Grimsmo et al., 2015). Furthermore, with the intention of improving the division of labour and developing cost-effective solutions for health care in hospitals and municipalities, financial incentives for the municipalities were initiated. In the regulation for 'municipal daily fees for patients defined as ready for discharge', the municipality has a duty to pay for patients who are registered as ready for discharge and remain in the hospital in anticipation of a municipal offer (Melberg & Hagen, 2016).

In the work to achieve seamless and coherent health care, health professionals have found the exchange of information across care services challenging and deficient (Melby et al., 2014). To improve access to information and improve communication between health care providers across the care services, an electronic messaging (e-messaging) system was developed and implemented in Norway in the period 2005–2015 (Lyngstad et al., 2014). The e-messaging system contains information about the patients' treatment and health care in communications between different health care settings, within municipalities and between specialist and primary care. Today, the e-messaging system plays a central role as a communication tool for health professionals in admission and discharge planning between hospitals and health care services in the municipalities. The system comprises messaging routines for registration when the patient is ready for discharge (Ministry of Health and Care Services, 2011a).

The effort to develop a coherent healthcare system, an overall expectation from all involved actors from the policy level and health professionals is that the patients shall meet a health care system characterised of good quality. This will be elaborated on in the next section.

2.3.1 Quality requirements and patient-centred approach

Quality in healthcare services has received increasing attention, both internationally and nationally. Different health care reforms, models and interventions, with a focus on quality and quality improvement of health care, have been developed (Grepperud, 2009). All patients must meet good quality at all the different meeting points and transitions throughout the patient journey in the healthcare system. Good quality includes coordination and continuity in health care services. Coordination and continuity presuppose that health professionals at different levels cooperate, show flexibility and ascertain needs from the patient's point of view (Health, 2005; Norwegian Directorate of Health, 2005). Patients' (the users') contact with the healthcare services must constitute as coherent and comprehensive as possible. In particular, the importance of coherence for elderly people with complex needs is vulnerable to fragmentation of the services.

The basis for these quality requirements are key areas for improving the quality of care, as developed by the National Academic Institute of Medicine in the USA (National Academies of Sciences & Medicine, 2018). These quality areas have been adapted by the WHO, as well as the Norwegian government, to represent definitions of quality of care and strategy for improvement in quality. These areas for improvement in care cover several conditions (National Academies of Sciences & Medicine, 2018):

- Safe—avoiding injuries to patients from the care that is intended to help them
- Effective—providing services based on scientific knowledge to all who could benefit and refraining from providing services to those who are not likely to benefit.
- Timely—reducing waits and sometimes harmful delays for both those who receive and those who give care.
- Efficient—avoiding waste, including waste of equipment, supplies, ideas and energy.
- Equitable—providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location and socioeconomic status.
- Patient centred—providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions.

In the present dissertation, I will in particular address patient-centred care. This does not mean that the other requirement is not important; however, providing patient-centred care has been an important strategy for improving the quality of health care. In Norway, the emphasis on a patient-centred approach is inserted into various laws, guidelines and policy documents. The healthcare services shall, as far as possible, be designed in collaboration with the patient (or user). The right of the patient or user to participate in the provision of health care is stated in the Patient and User Right Act (Ministry of Health and Care Services, 1999a). Thus, addressing the patient-centred approach in a more in-depth way opens the way for understanding the involvement of patients and actors in the care trajectory in both the planning and development of care services, as well as in the provision of care based on patients' experiences and points of view. This kind of health care can be defined as 'care practice/provision that is consistent with the values, needs and desires of patients and is achieved when clinicians involve patients in health care and discussion and decisions' (Constand et al., 2014, p. 1).

Despite patient-centred care models being developed and implemented in practice, research has shown that such approaches have not always succeeded. For example, medical health care has not been shown to be well facilitated for the individual preferences and needs of elderly patients with chronic illness and functional decline (Kvæl et al., 2022). In long-term care services, patient-centred care is implemented at some levels (Kogan et al., 2016; Røsstad et al., 2013).

Central targets of patient-centred care are to strengthen the shared decision making between the patient and health providers and shift from viewing the patient as a passive receiver of health care to involving the patient as an active part in their health care and decision making (Constand et al., 2014; Håkansson Eklund et al., 2019; Kogan et al., 2016: Mead & Bower, 2000). The relationship between the patient and health professional is characterised by mutual trust and two-way interactive communication where information is conveyed and shared. This develops a relationship where the patient and health professionals take action after finding a common view on the goals and planning for the patient's health care needs. The providers endeavour to understand what problem the patient is most concerned with and how the illness affects their life and subsequently encourages reciprocal problem solving (Constand et al., 2014). Research has shown that health professionals who are trained and educated in a patient-centred approach have stronger skills in performing patient-centred care (Poitras et al., 2018).

Another factor is a care environment in which the delivery of a patient-centred approach is encouraged. These systems are supportive and facilitate shared decisions and make information readily available, an organisational culture where collaboration between health professionals is emphasised and appropriate time and space is made available for it (McCormack et al., 2010).

The terms 'patient-centred' and 'person-centred' care have been used interchangeably (Håkansson Eklund et al., 2019). Despite this, the literature has pointed out that 'person-centred care' encompasses more of a person's needs and preferences in their entirety, going beyond just the clinical or medical and considering the whole of the patient's life (Care et al., 2016; McCormack et al., 2010). In a person-centred approach, the person is put at the centre with their context, their family, individual strengths and weaknesses (Håkansson Eklund et al., 2019). This understanding of a broader perspective of patient-centred care can be considered suitable for the complex health care needs of elderly patients who are living with chronic illness and functional decline in their lives.

As mentioned above, coherence is particularly important to gain quality in person-centred care, which is elaborated on in the next section.

2.4 Ensuring coherence and integration in the care trajectory

The care trajectory for the elderly patients is provided within the Norwegian healthcare services that are characterised by a continuum from general to specialised health and care services. A healthcare system can be understood as a social system consisting of a number of subsystems that are characterised by professional, organisational, institutional and geographic differentiation that constitute increased fragmentation (Vik, 2018). When the healthcare services have moved in a direction to specialisation and fragmentation, it has become obvious that there is a need for integration of the different healthcare services to ensure that the patients and their next of kin experience coherence in line with their preference and needs (Sogstad & Bergland, 2021).

Over the past few decades, as a framework for improving coherence in healthcare services, integrated health care has become a comprehensive concept and widely used. The intention of integrated care is to reduce fragmentation by improving the access, quality and continuity of services that lead to more comprehensive care (Kodner & Spreeuwenberg, 2002). There is no definitive definition of the concept, and over the years, many definitions have been published, including, among other terms, coordinated care, continuity of care, and seamless care (Amelung et al., 2017). In the beginning, when integrated care was introduced, focus was placed on reducing fragmentation between primary and specialist care, but further attention has also been paid to primary care (World Health Organization, 2016).

Valentijn et al. (2013) provided a comprehensive framework of integrated care structured around three levels of integration: macro level (system), meso level (professional and organisational) and micro level (clinical/personal). Accounting for the complexity in integrated care, the framework provides an approach to analyse integration at these levels regarding clinical integration, professional integration, organisational integration, functional integration and normative integration. To connect the dimensions across the three levels, some common values and norms need to be agreed on. One set of values is related to person-centred care and quality of life. Another set of values is having common visions, norms and values that constitute normative integration. These common values can have an effect across healthcare services on the degree to which the services and patient achieve a common vision. The partnership between the healthcare services has a high level of trust between each player, with a clear vision on how best to deliver effective care through collaboration. The dimensions of integration in health care and how they are interrelated to each other are elaborated in Table 1 (Calciolari et al., 2022; Melby et al., 2021; Valentijn et al., 2013).

Table 1: Dimension of integrations in integrated health care

Clinical integration This dimension refers to the patient’s experience of coherence of health care regarding their needs. The health care services are adapted to the needs of the patient by different professionals working together, using common guidelines, protocols and so forth. This coordination is characterised by being person-focused in an overall process across time, place and discipline.
Professional integration Professional integration refers to the existence and promotion of interprofessional partnerships to deliver coherent healthcare services to a defined population/target group. The professional partnership is based on common competence, role clarification and responsibility to provide comprehensive and coordinated care. For example, the importance of interprofessional teams is substantiated by interprofessional training and education.

Organisational integration
Collaborative relationships across organisations, based on a formal agreement, to regulate network organisation and service delivery and so forth. This takes place by, for example, merging organisations or common steering.

Functional integration
Functional integration refers to the possibility of communicating data and information effectively within a health care system, thus enabling the sharing of decision-making between professionals and between professionals and the patient, for example. Functional integration supports and links the clinical, professional and organisational dimensions within a health care system

System integration
Refers to how the system on superior regional/national levels makes an enabling platform that promotes coherent health care. Such as in accordance with acts, regulations, guidelines and financing and incentive arrangements.

Generally, person-centred care is a central value and underlying goal that is reflected in all dimensions of integrated care (Calciolari et al., 2022). During the work with my dissertation, I found it useful to apply the integrated care framework because it acted as an analytical approach to investigate the dimensions of the care trajectory at micro, meso and macro levels.

2.4.1 Standardisation of the care trajectory

For improving the planning, organising and following up on the patient throughout their care trajectory, the use of standardised and specific care pathways has become one strategy in the process of achieving integrated care (Calciolari et al., 2022). One key feature of the care pathway is that healthcare services are based on evidence-based medicine (EBM). The purpose is to improve the quality of treatment, reduce risk in patient outcomes, promote patient safety, increase patient satisfaction and optimise resource allocation to increase health costs (De Bleser et al., 2006; Valentijn et al., 2013; Vanhaecht et al., 2012). Implicit here is the expectation that pathways will ensure person-centred health care services (Schrijvers et al., 2012; Vanhaecht et al., 2010).

In Norway, the patient pathway has been described as ‘the chronological chain of events that make up the patient’s encounters with various parts of the health and care services. Good processes are characterised by these events are put together on a rational and coordinated way to meet the patient’s different need’ (Ministry of Health and Care Services, 2008–2009, p. 15). Over the past two decades, the government has emphasised the development of care pathways to meet the patients’ need for coordination and to achieve good coherent health care services. Standardised patient pathways [*Pakkeforløp*] for cancer treatment are an example of care pathways that have been introduced. These standardised patient pathways have been further developed for other specific diagnoses.

The idea of a care pathway has its roots in the beginning of the 1950s, in the defence and industry-critical path method, where a flow chart with a start point and an endpoint showed all the activities in a process (Schrijvers et al., 2012). In the mid-1980s, clinical pathways were introduced into health care in America with the purpose of improving services and efficiency in meeting health care demand. In England, an important motivation for implementing clinical pathways was to improve the continuity of care across health service levels (De Bleser et al., 2006; Vanhaecht et al., 2012). At the forefront of this process during the 1980–90s were the nurses who developed clinical pathways as tools to manage care (D. Allen et al., 2009; De Bleser et al., 2006).

Internationally and nationally, care pathways have been described in different ways, and many terms have been adopted to refer to them. Table 2 below shows an overview of the concept of ‘care pathway’ with some of the common terms and examples of definitions.

Table 2: Common terms used for the care pathway.

Critical pathway	(Anderson et al., 1994)	Schedules of medical and nursing procedures, including diagnostic test, medications, and consultations designed to effect and efficient, coordinated programme of treatment.
Clinical pathway	(Kinsman et al., 2010)	The intervention is a structured multidisciplinary plan of care; the intervention is used to channel the translation of guidelines or evidence into local structures; the intervention details the steps in a course of treatment or care in a plan, pathway, algorithm, guideline, protocol or other 'inventory of actions'; the intervention has time frames or criteria-based progression; and the intervention aims to standardise care for a specific clinical problem, procedure or episode of health care in a specific population.
Care pathway	European Pathway Association (E-P-A) (Vanhaecht et al., 2010)	A complex intervention for the mutual decision making and organisation of care process for a well-defined group of patients during a well-defined period.
Integrated care pathway	(Degeling et al., 2004)	Describe the diagnostic and therapeutic events that will appreciably affect the quality, outcomes, and cost of care. The use of integrated care pathways for systematising care extends the evidence base, strengthens service integration, and improves clinical effectiveness, quality and technical efficiency, as well as patients' satisfaction and clinicians' work experience.

Regarding the challenge of collaboration between the different health care levels, that is, the primary—hospital continuum, one problem is that the care pathways are not always appropriate for both levels. Health professionals can have differences in their understanding of and approach to the method. In the municipality, where primary care has responsibility for the treatment and maintenance of people from a long-term perspective, health professionals have found care pathways to be less suitable for their needs (Skrove et al., 2016; Van Houdt et al., 2013). In addition, care pathways have been shown, as described above, to be the most effective when the treatment trajectory is predictable.

A significant problem with care pathways is that they are mainly developed for diagnosis-specific purposes and are the most effective for single diseases when the care trajectory is predictable. Furthermore, care pathways are—and have been—traditionally developed for and by hospitals (De Bleser et al., 2006; Kinsman et al., 2010). Diagnosis-specific care pathways have been shown to be not so appropriate for elderly patients with multimorbidity and complex health problems (D. Allen et al., 2009; Barnett et al., 2012) because the care trajectory can be unpredictable and does not always suit into a standardised pathway (Røsstad et al., 2017).

For elderly patients with comorbidity and complex health care needs, the duration of care can be difficult to predict, and research has shown that disease-specific standardised pathways are less effective and perceived as not so appropriate (D. Allen et al., 2009; Doessing & Burau, 2015; A. Grimsmo et al., 2018). Therefore, generic (diagnosis-independent) patient pathways have been developed and introduced in recent years. The purpose is an improvement of the follow-up for the patient's health condition and level of function in the primary health service after discharge (Røsstad et al., 2015; Røsstad et al., 2013; Van Houdt et al., 2013). In a Norwegian context, studies have shown that this generic pathway could be more sustainable and functional in primary care by structuring the provision of home care services and collaboration with GPs (Grimsmo et al., 2016; Røsstad et al., 2015).

For elderly persons, the use of standardised diagnose-specific pathways has been shown to be inappropriate in the care trajectory. Thus, to get a more comprehensive understanding, I found it useful to gain knowledge from the involved actors' perspectives.

2.5 Findings from previous research on care trajectory to elderly

To obtain an overview of the field of research on the care trajectory related to the elderly person, a literature search was conducted in 2017 and updated in August 2021. The search was conducted in the following electronic databases: Medline, Cinahl and Scopus. The keywords used were Older or Elderly and Care Trajectory* (title and abstract). It was limited to studies published from 2001 onwards. The results of the search conducted in 2021: n = 116. Of the 116 articles, 66 were published between 2018 and August 2021. Of the 116 studies, some dealt with the causality and incidence of diseases (Bliton et al., 2019; Brattheim et al., 2012), and some were about the risk factors involved in treatment at hospitals and the risk of readmission (Barnato et al., 2019; de Man et al., 2019; Pedersen et al., 2019; Riall et al., 2010). Recurring themes were palliative and end-of-life care and the evolution and effect of different care models (Bravell et al., 2010; Penning et al., 2017; Xiao et al., 2013). During the reading of the articles, I searched for how the care trajectory for elderly patients was addressed. Furthermore, if the trajectory included different actors' perspectives.

Overall, the literature showed few studies where the focus was on the patient's perspective through the course of the care trajectory or where the patient, next of kin and health professional were included. From this selection process, eight articles were examined. I have chosen to present the studies that are of relevance to the present dissertation, with the aim sorted by the different actors involved: the patient (n=2), the next of kin (n=3), the health professional (n=2) and studies with all the actors included (n=1). Because so few studies were identified, I chose to present them consecutively.

Patient's perspective on their care trajectory

In the study by Van Ee et al. (2018), men above 70 with prostate cancer were interviewed about their experiences with the illness and personalised care trajectory. The burden of illness threat had an impact on their life, so not only the medical condition was of importance. The patient values, possibilities and social circumstances were important factors that the health professional should take into account in the care. The patients also described a setting where many health professionals could be involved during their care trajectory, and they felt the communication, information provision and decision-making was inadequate (Van Ee et al., 2018).

The other study by Kjær and Siren (2020) with the patient perspective was a longitudinal study of ageing where 473 elderly (at baseline) self-reported their use of informal and formal care. The findings showed several transitions and variations in the type of care received. Individual predisposing, capacities and needs factors were important predictors of the variations in care in later life. Old age, functional limitations, medical conditions and living alone predicted the utilisation of both formal and informal care. A key finding was that the trajectories characterised by the sporadic use of informal care were associated with low needs and strong social relations, whereas trajectories characterised by reliance on formal care were associated with high needs and limited contact with children (Kjær & Siren, 2020).

Health professional's perspective.

The study by McLeod et al. (2011) aimed to explore the provider's perspective on the transitions experienced by older hip fracture patients across the care continuum. The factors that influence the transition and information exchanged during transitions were of particular interest. Individual interviews with 17 health professionals were conducted in care settings relevant to the care continuum of older patients with hip fractures. The health professionals expressed that the elderly with complex health problems do not always follow a regular care trajectory. Patient complexity was a major determinant influencing their care trajectory and extended the circle of care, which contributed to less predictable care trajectories, leading to more challenging care. Health professionals often had concerns regarding quick discharge from the hospital, which, together with the patient's complex medical condition, could lead to a decrease in the ability of the patient to recover post discharge. The patient and their family coped with increasing self-care and management after discharge. Information exchange and education were essential to assist self-management (McLeod et al., 2011).

The aim of Kjerholt et al. (2014) was to examine conditions for continuity and integration of the patient perspective in older chronically ill patients' care. The setting was an acute ward and municipalities. The methods used in this exploratory participating action research were observation and interviews. The participants were 29 nurses from acute wards and municipalities. The findings showed that taking a more comprehensive view of the patient's health problems and placing emphasis on continuity and the involvement of the patient were essential for ensuring quality in care transitions and preparing an appropriate health care plan. Despite agreement on the need to take a more comprehensive approach, the nurses struggled with the integration of the patient's wishes and assessment of their needs. Because of time pressure, medical and disease conditions governed the practice. There seemed to be a conflict between the values the nursing ideal of practice and their actual practice (Kjerholt et al., 2014).

Next of kin's perspective

One study shed light on the necessity to understand family care from a life course perspective, the total number of years of care and the number of annual care episodes the relatives provide (Fast et al., 2021). The study was a national survey, where the participants retrospectively reported family care across their life course. The participants were persons aged 65 and older. The findings showed that family care is not a single experience and most of the trajectories involved transitions into and out of multiple care episodes of the life course. It was emphasised that policy makers need to take account and have an awareness of the extent to which they count on family care as an integrated part of health and social care services (Fast et al., 2021).

Lindhardt et al. (2008) investigated collaboration between relatives reporting high versus low satisfaction with the hospital trajectory. The study was cross-sectional using a self-reported questionnaire as a method. The informants were relatives of elderly patients (n = 156) in acute hospital wards. The findings showed that low satisfaction was significantly related to a low level of collaboration. Collaboration between relatives and nurses was associated with relatives' satisfaction. Increased collaboration reduced the relatives experience of powerlessness and guilt. The structured involvement of relatives had a positive influence on the exchange of information and knowledge around the care plan. It was also highlighted a need of a new role for relatives as partners in decision making (Lindhardt et al., 2008).

Another study described by Sivertsen et al. (2018) emphasised the aspects of collaboration with staff during the hospital care trajectory by relatives of older medical patients. The study used a cross-sectional, descriptive and comparative mixed methods design. The participants were relatives of older medical patients. The relatives described the lack of contact with the staff, absence of information, lack of care and not being involved. At the same time, they felt responsible for the patients' well-being and expressed frustration when their need for information was not acknowledged by the health professional (Sivertsen et al., 2018).

Only one study included all the actors. The study aimed to explore the multiple transitions for patients with hip fractures during the care trajectory and included patients, their informal caregivers and a variety of health care providers (Toscan et al., 2012). The participants were interviewed and observed at each care transition. The findings showed that the participants had a common experience of poorly integrated transitional care. The patient and family caregivers experienced they were limitedly informed or involved in the decision-making process around the health care plan. They also described a lack of clarity in the health care provider roles and responsibility, which increased their experience of fragmented care. On the other hand, the health care providers had concerns about incomplete or delayed information with transfer; they expressed that various policies and procedures could hinder the delivery of quality care and that a focus on discharge planning contributed to the pressure to initiate a transition before they felt comfortable doing so. To understand the issues and requirements for integrated transitional care, the study emphasised the importance of including the perspectives of patients and informal caregivers, as well as health care providers (Toscan et al., 2012).

To sum up the perspective from the patient, next of kin and health professionals in the studies above, the care trajectory to elderly patients was described as not being a regular trajectory. The patient’s complexity contributed to less predictability and more challenging health care. Taking a more comprehensive view of the patient’s health problems was essential to secure quality in care transitions (Kjerholt et al., 2014; McLeod et al., 2011). From the patient’s perspective, the burden of illness impacted their life, and their values, possibilities and social circumstances should be taken into account in health care (Van Ee et al., 2018). The patient and next of kin experienced a lack of information and involvement in health care planning and decision making (Fast et al., 2021; Lindhardt et al., 2008; Sivertsen et al., 2018; Van Ee et al. 2018). Informal care was seen as an important part of health care and should be more integrated as a part of health care services (Fast et al., 2021).

Despite the effort throughout the past two decades to ensure coherent and integrated care for elderly patients, there are still limited studies that have addressed the care trajectory from the involved actors, and in particular, we lack an in-depth understanding of the comprehensiveness of the care trajectory to elderly patients.

3 Design and methods

The intention for the present dissertation was to gain a comprehensive understanding and knowledge of the care trajectory for elderly patients with complex health problems. Thus, an explorative and descriptive design with a case approach was used because a case study is regarded as useful for developing new insights and knowledge about a particular case (Tjora, 2017).

There are differences in the underlying paradigm approach to a case study, from a positivistic direction to a more constructivist or critical one: from an approach where protocols are emphasised and followed to a direction where there is necessity of a flexible design (Baskarada, 2014). Case studies can be based on single or multiple cases, include quantitative and qualitative data, go in depth or in the breadth of a phenomenon or do both (Gerring, 2004; Stake, 2013). In the current dissertation, I have aimed for the case study to be close to real situations in their naturalistic context and with a focus on the rich information (Flyvbjerg, 2006; Hyett et al., 2014). My basic assumptions were to investigate social reality and phenomena in some way in their naturalistic life context and that what is being investigated cannot be done, regardless of the context in which it is a part (Hammersley & Atkinson, 2019). Within this understanding, I was a part of the world it researched on, through my preconception and interpretations take part in the construction of data, and it is impossible to separate the researcher from the researched (Mulhall, 2003). There are multiple understandings and, therefore, the need for diversity in perspectives in relation to what is to be studied. The data collection in case study research is typically drawn on multiple sources of information, which give a diversity of perspectives (S. J. Morgan et al., 2017; Patton, 2014).

To explore and describe the case ‘the care trajectory of elderly patient’, I chose to follow the patients throughout their care trajectory with and together with the persons involved in the trajectory: the patient themself, next of kin and involved health professional. More precisely, I followed the patient during the hospital stay, at the discharge and after being discharged to the municipalities. With the intention to follow the care trajectory over a period, it was found appropriate to conduct fieldwork because it gave an opportunity to explore what happens in the real world; as stated by Hammersley and Atkinson (2019), this includes observing what is happening, participating and being present in daily life, listening to what is being said and asking questions. Conducting fieldwork often takes place over a longer period of time, making it possible to use several sources of data. In my study, I used participant observation and interviews as the main methods. In addition, I extracted data from the patients' records because it expanded the information collected from observations and interviews (Fangen, 2010).

Table 3: Overview of aims and method in the three substudies in this dissertation

	Aim	**Method**
Sub-study I	To uncover the work that health care professionals undertake to achieve coherent and comprehensive health care for elderly patients with multiple health problems during their journey through the complex health care terrain	Structured interview with health professional
Sub-study II	To explore how elderly patients with complex health problems engage in and interact with their care trajectories across different health care systems where several health personnel were involved	Multicase, with participant observation and individual interview as method
Sub-study III	To illuminate patients, next of kin and health care professionals' dilemmas and deliberations beyond the decisions to manage the care trajectory in an elderly patient's life	Single case, with participant observation and individual interviews in addition data extracted from the patient's health care record

3.1 Setting

The study was conducted at two hospitals and in nine different municipalities within the hospitals' same health trust region, here representing one rural and one urban hospital. The patients from nine different municipalities were involved, where the populations ranged from 2,000 to 27,000 inhabitants. The distance between the patient home and hospital varied between 5 and 200 kilometres. In the municipality with a larger population size, there was a tendency to provide more specialised and differentiated health care services compared with the smaller ones, where the health care services had a more generalist approach. These differences in the characteristics between smaller and larger municipalities are in line with earlier research (Rostad et al., 2020). In organising the allocation of health and social care services, some of the municipalities had established a purchaser–provider model with the use of an allocation office. In others, allocation of a municipality rehabilitation bed or a short- and long-term stay at a nursing home was conducted by a management team. The diversity of settings gave an opportunity to maximise the setting, which is considered a strength to capture themes with a lot of variation (Flyvbjerg, 2006; Patton, 2014). In the present study, the preliminary intention was not to analyse the health care context in the cases, but the context was implicit in the understanding of the patients' care trajectory. I have chosen not to give a more detailed description of the setting linked to the individual cases to preserve anonymity and confidentiality but instead provide an overview of the setting is illustrated in Figure 1.

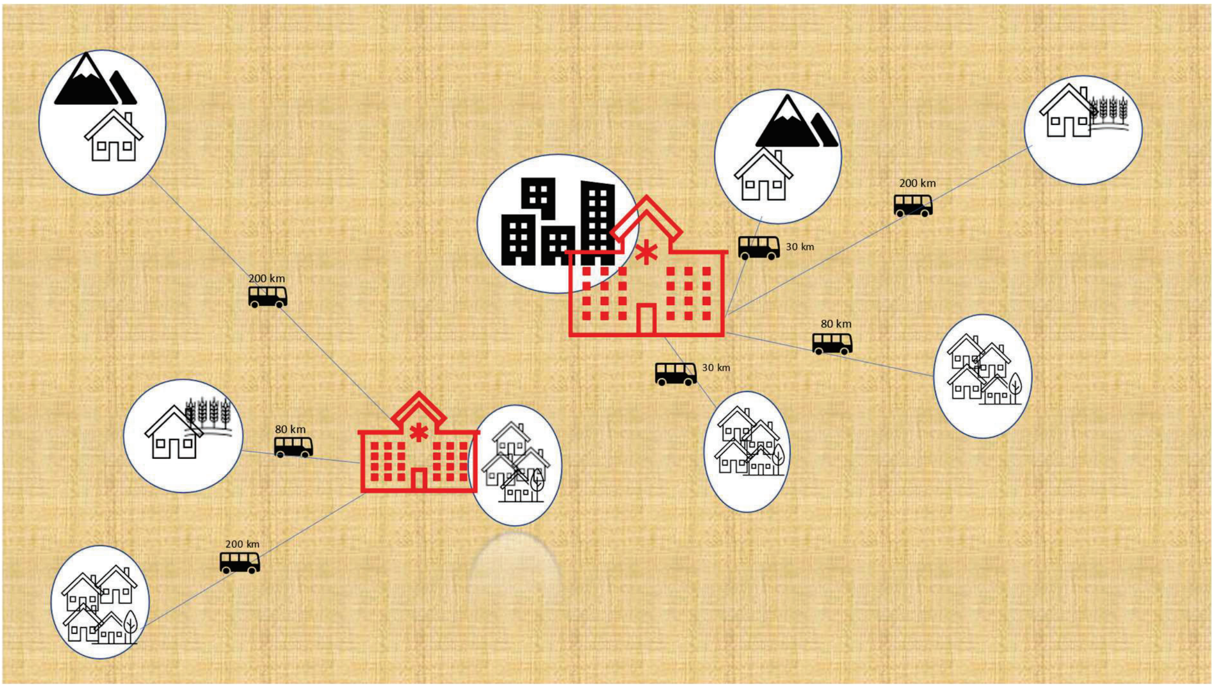

Figure 1. The diversity in the setting of this study: the two hospitals, the different sizes of the nine municipalities (small, medium and city municipalities) and the distance between hospital and patient’s home.

3.2 Recruitments strategy and participants

Based on the aim of the present study, the intention was to choose a purposeful sampling of participants that could give rich information around the elderly patient in a care trajectory. The participants were the patients, their next of kin and health professionals involved in the planning or conduction of care to the patients. Of those 11 patients who participated, they had their settlement in the nine different municipalities, as described above. In seven of the patient’s cases, located in six municipalities, the health personnel were involved in observations or interviews. In the other cases, I met the patient and next of kin without the health personnel present or being interviewed.

Recruitment process/strategy

To obtain a comprehensive understanding of the patients' trajectory, it would have been ideal to follow patients living in their own home, during their hospital stays and trajectories across different health care levels and services. However, it was considered inappropriate and unethical to recruit patient participants prior to possible hospital admissions. Therefore, the recruiting process was conducted at the hospital departments. Patients were selected from two different surgery and internal medicine departments of the hospitals because these departments have eligible patients. Contact and preparations to recruit participants and gain access to the field started at the hospital because the patients were included during their hospital stay.

For permission to conduct the study, verbal and written information was given to the hospital's director and department managers at the internal and surgery departments. In this process, I had support from a person in the hospital staff group who functioned as a gatekeeper to the different person at the different levels. This person had a long experience as employee at the hospital (Fangen, 2010; Hammersley & Atkinson, 2019). When the managers had approved that the study could be conducted in their department, they informed their staff about the project, and written information about the project was available in the personal room.

Establishment and contact with the health care system and personnel in the municipalities had to be done parallel with the patient's trajectory at hospital. Therefore, the time to communicate and give information about the study was shorter than the hospital process in recruitment and gaining access. Contact with the manager of the health care system needed to be established as soon as possible after the patient was included, and formal administrative activities, such as data processor agreement, were needed. Finding the right people to give information about the study with a position to give me access to the actual unit in the municipality was sometimes 'detective work'. Gaining access to the field is described as a demanding process that often requires access negotiations (Hammersley & Atkinson, 2019). It is about developing mutual respect, which promotes good interaction/cooperation between the researcher and field research. Challenges with access to the field may be affected by scepticism, worries about criticism, negative experience with earlier research, use of unknown language and research that is strange/unfamiliar to practice (Hammersley & Atkinson, 2019; Patton, 2014). In the municipality, I had a shorter time than at hospital to establish contact and build trust, and sometimes, I experienced being met with scepticism.

Patient participants

To recruit the participants who had some complexity in their health problem, the inclusion criteria for the patient participants were as follows: older than 65 years, having two or more chronic diseases and living at home before hospital admission. The exclusion criteria were if the patient was not capable of giving consent or in the terminal phase. The fact that the patient was living in their own home before admission was made as a delimitation in the case, with the understanding that living in a nursing home before admission hospital would give a more predictable course after the hospital stay.

Participation was based on informed, voluntary consent. A contact nurse in the hospital departments considered if the patient could give consent, informed the patients verbally and in writing about the study and asked them to participate. Eighteen patients were asked to participate, and 11 patients consented. The main reason for declining was the worsening of their health conditions. Table 4 shows an overview over the patient participants. Inclusion started November 2017 and lasted until June 2018.

Table 4: Patient participants, observation periods, number of interviews and distances between home and hospital (Table from Paper II: Kumlin et al., 2020)

Participants *)	Age ranges**)	Observation period	Number of interviews	Distance between home and hospital
Finn	1	7 weeks	2	175 km
Maria	1	2 weeks	2	5 km
Eva	2	7 weeks	3	30 km
Eric	2	18 weeks	4	40 km
Anna	2	6 weeks	3	5 km
Kai	2	5 weeks	2	80 km
May	3	13 weeks	4	5 km
Martha	3	7 weeks	1	200 km
Albert	3	2 weeks	1	10 km
Henry	3	3 weeks	1	200 km
Hannah	3	10 weeks	1	20 km

*) The participants names are pseudonyms **) The participants are presented in three age range groups. Group 1, between 65 and 70; group 2, between 71 and 80; and group 3, between 81 and 95.

Participants' next of kin

The next of kin were requested to participate after consent from the patient was obtained. In the written consent, the patient had noted which next of kin I could contact. I contacted the relatives by phone and informed them about the study and asked if they would participate. Both verbal and written information were also given at the first meeting. Three patients did not want me to contact their next of kin, with long distance reasons and worrying about disturbing their relatives. Eight next of kin were asked to participate, and seven agreed.

Participants' health professionals

The recruitment process of health professionals to participate in the structured interview was in the two different hospitals and six different municipalities involved in the study. The health care professionals were given verbal and written information about the study, either by the department manager or me. The inclusion criteria were working as a health care professional who cares for elderly patients and having a minimum of a bachelor's degree. Twenty-five health care professionals agreed to participate, and three health care professionals declined to participate because of workflow and time issues. All included health professionals had six months of experience at their workplace, some having several years of experience. Twelve professionals had their workplaces in the municipalities and 13 at the hospitals. There was diversity in profession and gender, as shown in Table 5.

Table 5: Participant interview – Health professionals.
(Table from Paper I: Kumlin et al., 2021)

Participant [a)]	Hospital [b)]	Primary care [b)]
Occupational therapists	1	2
Physicians	5	3
Physiotherapists	2	
Nurses	5	7

[a)] Participants` profession
[b)] Number of participants by workplace.

In addition, depending on the patient's consent, health professionals who were directly involved in the individual case were requested to participate for a short dialogue around the organising of health care in the patient's care trajectory.

3.3 Data collection

Participant observation

When I entered the research area, I was familiar with the professional topic, culture and 'language' based on my professional background as an experienced advanced geriatric nurse. I used some time in the departments to familiarise myself with the field by sitting in the common area, the staff's workspace and staff room to get known of the environment and people working. Taking the time to get known and vice versa has been described as appropriate for gaining access during the observations (Hammersley & Atkinson, 2019; Tjora, 2017).

Before I started with the observations, I had expectations of going out into a field that was difficult to control what happened through the care trajectory. I had prepared to focus on how the patient engages and interacts with the trajectory and persons involved. Relevant literature and central concepts around the topic of study contributed to giving me some point of reference during the observations. In the beginning, I experienced being broad and vague in the observations, and it was difficult to have a precise focus. Later on in the fieldwork, I was more focused around the observations with the intention of following up on specific topics, events or actions. The literature has noted that being a little broad and vague in the beginning of the observation can be appropriate because it is often difficult to say what will be the exact focus before one has been in the field for a while. Switching between showing openness to new topics while maintaining focus can be an appropriate approach (Fangen, 2010).

The intended plan was to follow the care trajectory at the hospital stay, discharge and further trajectory through the health care. Observations could be to sit in the patient room when the patient was informed about discharge and plan for further health care or be present at different interdisciplinary meetings, where the patient's health care needs and discharge were discussed. In some situations, I went together with the patient in their rehabilitation programme—for example, training with the physiotherapist. To be able to grasp the comprehensiveness in the situation, an example was one patient I followed for 10 hours during the discharge day. I was sitting in the patient's room, listening to all the information that was provided from the staff, observing their communication routines and joining the patient in the transfer back home and was present when the patient met the next of kin and health professional. I was also present at different health care services in the municipality, following the health care professional involved in the care trajectory. The setting for these observation points varied, including a doctor's office, short-term unit at the nursing home, work office for home care and interdisciplinary team or the patient's home. The next of kin was sometimes present at observations in addition to the interviews. Observations were based on open participant observation, so my role as observer was known for the observed. During the observations, I experienced moving between being more closed and active with the person observed and the situation, while other times being more passive and at distance from the observed. The literature has described two different roles when the observation is open and visible: observing participating or participating observer (Tjora, 2017). Merging these two—observing participating and participating observer (Tjora, 2017)—can be called *interactive observation*. The meaning that social interaction will always be present between the observer and observed because of the nature in the situations is mutual. Deliberations around how active or passive a role the observer takes are often connected to changing situations one must handle. In open observation, the observer will be in a movement between being more active or passive (Fangen, 2010). Throughout the fieldwork, I tried to be aware of my role and varied according to what I tried to focus on.

Conducting field notes during observations

In addition to the interviews, field notes were significant sources of the data material. There can be different ways to write field notes, and from the beginning of the fieldwork, I decided to sort the observations into descriptive notes, analytical and theoretic notes, method notes and reflection notes (Fangen, 2010; Hammersley & Atkinson, 2019; Tjora, 2017).

During the observations, keywords and shortened sentences were written down to describe observations (what I saw and heard) and short dialogues. Directly after the observations, complementary notes in full sentences were completed. As part of the fieldnote, I made analytical and theoretic notes. Analytical notes could be themes or patterns I would go deeper into or follow up on in further observations. Theory notes referred to the relevant literature that illuminated something from the observations. In addition, I used reflective notes to summarise after two to three days in the field. I wrote down my personal thoughts and reflections around the field work, my role in the research, challenges and necessary choices I had to make, for example, methodical choices. The reflection notes were also a tool for focusing in the observation (redefine scoop), and I experienced going from very broad and details in the observation note to some that were more narrowed.

Table 6: Example from my fieldnotes

Method notes	Where should the interview take place? The patient stays in a room with several patients. It is not very suitable for conversation.
Observation/descriptive notes	He gets up from his chair and starts walking around in the house with the physiotherapist behind him. He is concentrated on the task. His spouse watches constantly and gives encouraging 'cheers'. She walks around and tidies up a bit, arranging flowers.
Analytical/theoretic notes:	'Outliers' is a new word. I am told it means patients who are moved to another unit because of lack of space in the originally associated unit. Maybe it is related to the term 'bed blocking'.
Reflective notes	There was a bit of back and forth on this day in the municipality—I thought this was going to be 'useless' time. At the same time, it is a 'picture' of the services' everyday life—and which I become a part of.

Interview as a part of the observations

Repeated interviews were conducted with the patient and next of kin, consisting of a few open-ended questions. The main theme of the interview was their perspective on the care trajectory, about what has happened in the past and present and thoughts on the further direction (Appendix 1). Another intention with the structured interview was to catch up on what happened in the period between the observations and meeting I had with the participants. Descriptions and stories from the participants can supplement, expand and explain the observations (Hammersley & Atkinson, 2019). The interview with the patient varied in length according to the patient's health status and day-to-day condition. I used an audio recorder for all the interviews, which later were verbatim transcribed. In one of the cases, the patient did not want any visit at home—with the reason it was too soon after discharge to receive someone in the home. The patient consented to do the interview by phone. Additional notification was sent to the Norwegian Centre for Research Data (NSD) before the interview was conducted.

Interviews

All the interviews with the health professionals were conducted at their workplace and varied in length between 20 and 45 min. The interviews were audio-recorded and transcribed verbatim. I used an interview guide that functioned as an overview of the topic I wanted to illuminate. The emphasis in the question were health professional descriptions of the elderly patient with complex problems in a care trajectory, their use of guidelines and standardisation of health care during the care trajectory and perspectives of integrated care (Appendix 2). Through input from the observations, the interviews could change some focus that enriched the observation material. The guide was further developed in relation to questions and interesting findings that arose during the interviews.

Data extracted from the patient record

Notes from the patient record were used with the intention to complement the picture through the care trajectory related to information flow regarding considering's and decisions about health care. These data were useful to obtain an overview of timelines and events in the care trajectory. In addition, data from the e-message system between the hospital and municipality illuminated some of the interactions in the care trajectory. Data were extracted from the patient's recording system after consent by the patient. One patient did not consent to having extract data extracted from the patient record. Data extracted from the patient record system were obtained from the hospital and from home care nursing in the municipality.

3.4 Data analysis

Overall, an iterative, flexible and interpretative approach was used in the analysis process. The iterative process involved a combination of deductive and inductive reasoning, a back-and-forth process between existing theory, the research question and empirical data (Fangen, 2010).

The analysis process began during the data collection and the writing of fieldnotes and extended through the research process until producing the final report in the papers (Braun & Clarke, 2006; Mulhall, 2003). Three data sources were applied in the analysis: fieldnotes from the observations, transcripts from interviews with patients, next of kin and health professionals and additional extraction notes from the patient record system. A total of 52 interviews were transcribed verbatim. The patient interviews ranged from 5–45 minutes and depended on the patient's health status and day-to-day condition. Interviews with next of kin and health professionals ranged from 20–45 minutes.

Table 7: Overview of data sources as the foundation for analysis in the 3 papers

Paper I	Paper II	Paper III
Transcribed data from interview with health professionals	Fieldnote from observations, transcribed data from interview with patient in the case and extracted data from the patient record system	Fieldnotes from observation, transcribed interviews with patient, next of kin and health professional and extracted data from the patient record system

In sub-study I, the transcript data material from interviews with the health professionals were used in the analysis process. In sub-study II, the data material was organised chronologically by each case. The same principle was used in sub-study III for the analysis of an individual case. The purpose was to gather systematic information about each case to search for patterns and underlying themes across the cases. The case study approach to qualitative analysis constitutes a specific way of organising and analysing data; in this sense, it represents an analytical process (Patton, 2014). The specific case stories contributed a significant part of the findings and provided an opportunity to achieve a more complete understanding about each case under study (Morgan et al., 2017). In sub-study II, I chose to describe patterns and underlying themes across the cases, and in sub-study III, I chose to delve deeper into one of the cases to illuminate the identified themes.The thematic analysis approach was used in all three sub-studies according to the six phases of the analysis process described by Braun and Clarke (2006):

Becoming familiar with the data

It began with the writing of fieldnotes and transcribing the interviews. I transcribed all the fieldnotes and interviews by myself, which provided me with extensive insight into the empirical data. The data were re-read several times. In this phase of the analysis, notes about the initial ideas were taken. In sub-studies II and III, the data material was sorted and read chronologically in each case to get a more complete picture of each case.

Generating initial codes

In the next phase, I started a systematic coding of the data, addressing what I considered to be interesting features and collecting data relevant to each code.

Searching for themes

Further, I examined patterns across the dataset, sorted codes into potential themes and gathered all data relevant to each potential theme. This phase was a reflexive iterative process. Table 8 shows an example of the process of sorting codes into subthemes and identified themes.

Reviewing the themes

In this phase, the validity of individual themes was considered by shaping, clarifying and rejecting themes to ensure that they worked well in relation to the coded data, dataset and research question. This was – in line with Braun and Clarke's suggestion – a cooperative process in the research group that occurred from the phase of reviewing the themes until the final part of the analysis.

Defining and naming themes

The last phase was an ongoing analysis to refine the specifics of each theme and the overall story that the analysis told. At the end of this phase, generating a definition and name for each theme was done.

Produce the report (writing forward the themes)

In the final part of the analysis, the themes were reported in Papers I–III, and a selection of quotes from fieldnotes and interviews was presented to make the themes clearer and more understandable.

Table 8. Example of the analysis process of sorting the collected codes into subthemes and identifying themes. (Table from Paper II: Kumlin et al., 2020)

Examples of codes across the cases	From codes to subthemes	Identified themes
It's better to re-housing than move to a nursing home Consider to stay at home or move to relatives The importance of previous contact with and trust in health professionals Despair by not knowing who to contact To get in better shape and see what happens What I can't do anything about is not worth the effort Looking for the best way to react Many unresolved questions and considerations at the same time Organizing and coordinating further treatment and follow-up. Searching for practical solutions that contribute to alternatives Not well-facilitated in the environment for participating	To looking for alternatives and be flexible To have long and - short perspectives To use their strength appropriately	**Continuous consideration of opportunities and alternatives**
	To sought for the most important health personnel To describe my social network To use my long relation with the health personnel	**Consideration for appropriate alliances**
	To deal with unresolved question and unclear responsibilities To consider the access to health care To choose another approach to handle the further direction of the care trajectory	**Circumvention of the health care initiation of planned steps**

In all the phases, the iterative process was evident where there was an interaction between earlier literature, theory and empirical data.

3.5 Ethics

The project was notified by the Norwegian Centre for Research Data (NSD), ID: 54551. The NSD assessed that the processing of personal data was regulated in the Personal Data Regulations [*Forskrift om behandling av. personopplysninger*]. The

NSD considered that the project did not raise any ethical issues that would be in need of ethical approval. The project was also assessed and approved by the data protection officer at the hospital. All participants were informed that participation was voluntary and that they could withdraw their consent to participate anytime. During the observation period, there was special awareness of maintaining voluntary and consent-based participation.

For permission to conduct the study in the hospital wards and in the municipalities the key managers were informed. A data processor agreement was established between the data controller at the hospital and in the municipalities. The agreement described the processing of personal data, how the data should be obtained and storage of the data. Personal information about the participants was removed during analysis. To maintain anonymity and confidentiality, some of the demographic data/information was rewritten in the study’s findings.

4 Results

The overall aim of the present study was to explore and describe the care trajectory to elderly with complex health care needs. Three sub-studies have been developed to answer the purpose of this study.

In this chapter, a summary of the results of the three sub-studies reported in the three papers is presented.

4.1 Paper 1

In this first sub-study, the aim was to uncover the work health care professionals undertake to achieve coherent and comprehensive health care for elderly patients. The health professional stated that planning and facilitating for health care was often a long-term activity and that they could not ignore the patient's life. To achieve a comprehensive description of the patient's situation, it was essential to build coherence in the care trajectory. The health care professionals' work to build coherence in the patient's care trajectory was described in three themes.

Working to manage the illness trajectory during the course of the patient's life

The health professional described the care trajectory for the elderly as lasting for a long time. Changes in the level of health care services or the need for medical treatment were shorter interruptions in the longer care trajectory. The shorter course in the longer care trajectory had an impact on the patient's life and could not be ignored. To plan and facilitate the care trajectory, it was necessary to take the patient's life into account. Knowledge about the patient's life situation and network was essential and included considering the patient's and their relatives' assessments and decisions. The health care professionals expected patients to actively assess their housing situation. In the municipality, the health care professionals experienced it challenging to follow up on the hospitals' decisions on medical treatment and the patients need for health care because it was other prerequisites to provide of health care within the patients home.

Working to achieve a comprehensive overall picture

The health professional in the municipality and hospital emphasised the need for a comprehensive picture of the patient situation for assessing the treatment and developing a health care plan. An interdisciplinary approach and understanding were important to achieve the overall picture. Interdisciplinary work could be time-consuming, and facilitating it was necessary. However, despite the interdisciplinary approach was emphasised the health professionals' descriptions of practice indicated that this was coincidental mode of work.

Considering multiple options in patchwork terrain

The hospital health professionals described how they considered a diversity of possibilities for deciding the best options for the patient after discharge. The doctors in the hospitals often needed to consider whether the patient could receive treatment and be followed up in general practice or in specialist care. These considerations were influenced by the short hospital stays and what the health professionals expressed as the 'emptying beds' policy. In these assessments of where the patient should be followed up on, local knowledge of the municipality's capacity and competence had meaning. On the other hand, the health professional in the municipality had their deliberations about whether the patient met different criteria within the various care models. In their quest to find an appropriate alternative to health care in coherence with the patients' needs, their deliberations were related to insufficient staff resources and the necessary resources for facilitating training and rehabilitation.

4.2 Paper 2

This study had the patient's perspectives on how they engaged and managed through the care trajectory. Patient engagement was not a linear process regarding time, space or situation, and the patient chose different strategies to participate in their management and handling barriers. The care trajectory was characterised by complex and interconnected events and situations. Often, the patient had to deal with numerous contemporary activities. The themes identified according to the patient's engagement are presented below.

Continuous consideration of opportunities and alternatives

Through the care trajectory, the patient continuously considered options and alternatives to handle different challenges and barriers. They considered their strength and capacity and weighed the various possibilities. In situations when the patient needed to prioritise activities and actions, a strategy was considering what was most important and what could wait. When the patient was not ready for decisions regarding house arrangement and health care organising, they chose to prolong the decision-making process. They 'held on' until they felt ready.

Consideration for appropriate alliances

Sometimes, the patient had to interact with many health professionals at different health care levels. A challenge could be getting information about their unanswered question and finding the person who was responsible for ongoing medical treatment. To handle this unclear situation and considerations, the patient searched for a health professional who could support and help them organise their health care needs and obtain access to proper health care services.

Circumventing the health care initiation of planned steps

The hospital's environment and discharge planning did not always functionally allow the patient to participate in the decision-making process around health care planning. It was not well facilitated or appropriate to interact with health personnel, and there was insufficient time to ask questions or give feedback. The patient actively chose another approach to handle the further direction of their care trajectory; they sought a new option for handling their situation and circumvented the hospital personnel's plans and processes for discharge.

4.3 Paper 3

In this study, a single case was chosen to illustrate when the patient entered a standardised care trajectory and did not comply with the standardised condition. The aim was to illuminate patients, next of kin and health care professionals' dilemmas and deliberations to manage the care trajectory in an elderly patient's life. The pursuit of a tailored care trajectory led to dilemmas, considerable deliberations and a comprehensive mobilisation for the patient, next of kin and health professionals.

The pursuit for an appropriate and feasible care trajectory

The patient entered a standardised clinical pathway devised for patients with hip fracture at admission to the hospital. Because of the patients' comprehensive health care needs, the hospital's rehabilitation bed was not available in the postsurgery phase. This situation became a departure for a complex and unforeseen care trajectory. The process of searching for an alternative option ended in multiple dilemmas and deliberations for the health professionals. There was an ongoing negotiation between the hospital and municipality around available beds and resources. To meet the expectation of effective use of bed at hospital, the unit had organised use of 'outliers bed' at another unit. This outside bed was intended for the patient, who was ready for discharge and waiting for an offer in the municipality. In the municipality, the dilemmas were to ensure alterations of the municipality's short-term bed, rehabilitation beds and long-term bed. In the negotiation around the patient's further need for rehabilitation and health care, the demand for an effective bed reflected the dialogue between hospital and municipality health professionals.

The next of kin planning horizons

For the patient, the care trajectory ended in a back-and-forth process between the hospital and municipality. Over the course of this, the next of kin took an active position backstage in the planning work and decisions. They considered continuously different options regarding what they thought should be the best for the patient because of the health care services offered. When next of kin thought the patient was not ready to be discharged from the hospital, they strove to delay the process. By circumventing the original plan and considering an alternative plan, they affected the discharge decisions.

Being the person in the limbo

In the plan and decision process through the care trajectory, the patient seemed almost neglected. The patient was the person standing in the middle of all deliberations and necessary clarifications beyond decisions. It became evident on the discharge day when it was still unclear for the patient if they were ready for discharge, going home or to a nursing home. Necessary clarifications were ongoing and close to the departure time. In addition to being in this unpredictability, several staff members were involved in the discharge process at the hospital, and the patient needed to respond to several health professional teams during the first hour at home.

Reorganising home for the comprehensive health care

The decision to establish the rehabilitation bed in the patient's home led to comprehensive mobilisation and work. The patient, next of kin and several health professionals were committed to this mobilisation. By reorganising the home, moving the bedroom into the living room and installing various aids, the home was modified to provide health care. The home should be a rehabilitation 'bed' for the patient and a working place for the health professional, as well as the home for the patient and spouse. Different activities should be planned, schedules had to go up and work had to be coordinated. In this mobilisation, the next of kin described a 24/7 schedule of being on duty, dividing tasks among themselves and considering who was best to do what.

5 Discussion

In this chapter, I present a discussion of the overarching main findings, which is followed by a discussion of the methodological considerations.

5.1 Discussion of the main findings

The case has been ‘the care trajectory to the elderly with complex health needs’. The overall aim of the present dissertation was to explore and describe the care trajectory from the perspectives of the patient, next of kin and involved health care professionals, which have been illuminated through the three substudies. The main findings across these three studies are the following themes: 1) balancing the illness trajectory within the patient’s life and organisational efficiency, 2) the actors in a continuum from being left out to having an involved position in the care trajectory and 3) expanding the professional integration towards partnership integration. One finding was the challenge in balancing the elderly patient’s life and a need for long-term perspectives in the care trajectories and, on the other hand, the organisational need for efficiency and a short-term perspective. For the patient and next of kin, it was important to include factors concerning life beyond the illness perspective in the trajectory. For the health care professional, these differences between the patient’s needs and organisational requirements made it problematic to provide person-centred care. The tension with different time frames led the actors into different positions, from being left out to having an active and involved position through the care trajectory. In the work to secure coherence in the care trajectory, the health professional described a broader picture of the patient situation as a central factor that depended on interprofessional cooperation. Another finding was how the patient and next of kin conducted comprehensive work to manage and secure coherence in the care trajectory and constitute a part of the health care team. Therefore, at the end of this chapter, I discuss the frame for professional and organisational integration linked to the understanding of partnership within an extended team.

5.1.1 Balancing the illness trajectory within the patient's life and the organisational efficiency

Different time frames

Overall, the care trajectories for the elderly were described as being long, interrupted by the shorter illness trajectory. The long-term care trajectory meant that the patients' decision making was characterised as being a continuous process of considerations from a longer perspective. The considerations were not only influenced by their health condition and illness, but also their life in general. Considerations according to necessary life modification, housing arrangements and the patient's network had an impact on the decisions process (Papers II and III).

For the next of kin, it was a balance between what they thought would be the best for the patient and the patient's life, what the health care system offered and managing their own daily life. They searched for alternative possibilities during the care trajectory, considering the life perspective of the patient (Paper III).

The healthcare services were characterised by a shorter time frame and demand for efficiency, which brought about several negotiations between health professionals regarding the allocation of resources that considered the patient's need for health care. The considerations of available health care and 'bed capacity' could lead to an intensive exchange of information between health professionals, resulting in quick solutions in the decision-making process.

This tension between the patients' needs for long-term perspective and health professionals' demand for efficiency in the delivery of health care services brought about several considerations and deliberations for all the actors (Papers I, II and III). It would seem that to manage and secure coherence in the care trajectory, the patient, next of kin and health professional had different goals and tasks to solve. Therefore, the ideal of putting the patient in focus and securing person-centred health care services was challenged by this time frame. This challenge to achieve a balance between patient needs and preferences and efficiency in the delivery of health care services is in line with previous research. Findings have shown that the requirements for health professionals to be time efficient influence the conditions for delivering health care services, with the time acceleration of the patient's pathway becoming the overall goal (J. Allen et al., 2017; Bendix et al., 2018). Constructing a timely efficient pathway has also led to conflict between the values between the health professional's ideal of practice and actual practice (Kjerholt et al., 2014). In addition, the challenge because of pressure for fast throughput (transitions) and efficiency at the hospital has impacted the understanding and cooperation between health professionals at hospitals and municipalities and impeded attempts to coordinate health care (J. Allen et al., 2017). For patients and next of kin to have the opportunity to create coherence throughout the care trajectory, it is emphasised that arrangements must also be made for this (J. Allen et al., 2014; Kvæl, 2021; Sogstad & Bergland, 2021).

The findings in the present dissertation have shown the patient's need to consider their life during the care trajectory and get the opportunity to have a long-term perspective in the decision-making process. These factors seem to be important to strengthen more appropriate health care services in coherence with the patients' preferences, health conditions and needs. Questions can be asked about how the differences in time frame between the actors in the care trajectory and how these differences may impact the shaping of an appropriate health care service for the elderly patient.

The broader picture of the patient's situation

The health professionals in municipalities and hospitals expressed the importance of gaining a broader picture of the patient's situation. This was explained as a central condition to facilitate health care in coherence with the patient's needs during the care trajectory. Health professionals acknowledged that the patient's life could not be ignored. It was not just about having knowledge about the patient's illness trajectory and health problems, but also about the network, circumstances of life and available resources in the patient's place of living. Interprofessional cooperation was described as an important means to achieve this broader picture (Paper I). The importance of knowledge around the elderly patient's life beyond the illness trajectory and medical matter has been previously described (Olsen et al., 2021; Sinnott et al., 2013) and emphasised to achieve more person-centred health care for elderly (Håkansson Eklund et al., 2019).

The findings in the current dissertation have indicated that how the health care professionals interact regarding knowledge of the patient's life and health care need influences the patient experience of coherence. An example is illustrated in the case Henrik (Paper II), who expressed his confidence and trust in the health care system and talked about a longstanding relationship with the health care professionals. He stated that they knew about his network and life, and he trusted the health professionals in the decision-making process during the care trajectory. The health care professionals in the municipality in the same case talked about long-lasting contact with both the patient and his spouse. In addition, the health care professionals described their interdisciplinary collaboration as consisting of regular contact and good knowledge of each other. Their interaction was characterised by near geographic placement and a low threshold for taking contact with each other, as expressed by the GP: 'We talk together when we needed—the nurse and doctor at the nursing home. It is also regularly interdisciplinary allocation meetings. If the patient shall stay at home, it is important that the next of kin also are safe'. This example of cooperation between the health professionals seemed to not only be about sharing tasks and responsibilities, but it was also characterised by relational contact and dialogue.

In contrast, in Eric's case, the patient experienced several challenges in obtaining access to the health care system. The patient was followed up at two different wards at the hospital and received homecare nursing and physical therapy from the municipal health services. In this case, the patient was unsure where to get information, who could answer his questions and who exactly was responsible for the health care. This led to an experience of unpredictability and less coherence (Paper II).

The first case with Henrik illustrates what Vik (2018) described as relational cooperation. This type of cooperation is characterised by nearness, connection and interaction, where the health professional's different forms of understanding are in contact with each other. Through meeting places, dialogue and negotiations, a basis of knowledge is developed that creates some consensus for the cooperation (Vik, 2018).

In the contrasting example with case Eric, it was more like what Vik (2018) described as a fragmented distribution of responsibilities. This type of cooperation is characterised by distance and differentiation and is often present when interactions happen across different organisational levels. There is no physical meeting place between the health professionals, lack of routines and low reciprocity knowledge. The focus is more on the local context of each health care system. To move to a more coordinated task distribution depends on the connections taking place by the ICT system, guidelines, standard pathways or a coordinator who takes responsibility for the distribution of responsibilities (Vik, 2018).

The health professional's interaction

Based on findings in the present dissertation, it is particularly appropriate to strive for an interaction between health professions characterized by relational cooperation in the care trajectory to the elderly, not just focusing on coordinated task distribution, as standards are often characterised by (Faber et al., 2014). Research has shown the importance of health care personnel having long-term knowledge about the patient and considering the patient's life in general for the patient to experience coherence and understanding of their situation (Ljungholm et al., 2022; Neiterman et al., 2015). At the organisational level, structural factors such as available time, a lack of meeting places and having common goals across subsystems are problematised to achieve coherence with the patient's need. The importance of organising the necessary time and space for collaboration between health care professional has been highlighted (Schot et al., 2020). In prioritising and organising health services for the elderly, the opportunity to have the time and space for collaboration seemed to be a low priority (Hamran & Moe, 2012). From a health care professional perspective, individual conditions have also been shown to influence interactions. There can be different motives, interests and need for collaborations and frustration because collaboration is time-consuming (Schot et al., 2020; Steihaug et al., 2016; Steihaug et al., 2017).

Vik (2018) argued that it is not necessary disagreement and conflicts that challenge the interactions, but rather, it is the absence of such conflicts. In a fragmented distribution of responsibility, the professions do not come into conflict, which leads to a lack of discussion and negotiations about each other's understanding, so the profession performs more with the starting point of its own understanding. Regarding the care trajectory for the elderly with several actors involved the patient, next of kin and health professional, it would be especially suitable to develop systems and arenas that facilitate interactions, including relational cooperation. Therefore, interaction measures that only promote standardisation and efficiency of task distribution without social interaction between the actors can be questioned. Allowing room for conflict and disagreement in the interaction and management of the care trajectory for all the actors can create opportunities to see other options that may be more appropriate in relation to the patient's needs and preferences through the care trajectory (D. Allen et al., 2004).

Care pathway

The findings in the present dissertation have shown how the considerations and decisions in the care trajectory are not only linked to the illness trajectory, but also to what happens within the patient's life.

The care pathway is a method to standardise health care designed to optimise and coordinate the health care process and treatment plan based on best evidence practice (De Bleser et al., 2006). In developing the care pathway, much emphasis has been placed on what happens within health care services and less on what happens within the patient's life (Faber et al., 2014; A. Grimsmo et al., 2018).

For elderly patients with complex health care needs, research has shown that disease-specific standardised pathways are perceived as being less appropriate (D. Allen et al., 2009; Doessing & Burau, 2015; Grimsmo et al., 2018). Efficient organisation and seamless processes do not always suit the needs of individual patients (Faber et al., 2014).

Traditionally, standardised care pathways are built on medical evidence (Kinsman et al., 2010), while complex health problems and social needs are seldom considered (A. Grimsmo et al., 2018; Valentijn et al., 2013). In the discussion around standards and care pathways, it is problematised that the knowledge base is often limited to treatment plans related to evidence-based medicine (Fineide & Ramsdal, 2014). The knowledge base related to health care and welfare services is somewhat less unambiguous. There can be several complex interactions in this system that need a different knowledge base, for example, in patient situations with comprehensive mental or social problems (Fineide & Ramsdal, 2014).

In the light of findings in the current dissertation, which have shown how the care trajectory to elderly patients is linked to the patient’s life, a broader knowledge base in the understanding of evidence practice is considered necessary in developing care pathways. Knowledge to ensure the quality of appropriate processes for the patient in relation to what also happens within their lives is necessary to ensure a person-centred approach. Organising of the work for the patient and next of kin and how to best take into account the patient’s social and living situation could be examples of such evidence.

5.1.2 In a continuum from being left out to having and involved position in the care trajectory

The tension between the time frame of the long-term and short-term perspectives led the various actors into different positions. The patient, next of kin and health care personnel appeared to move on a continuum from being left out to having an active and involved position in the care trajectory.

During the care trajectory, there was not the required time and space for the patient to be involved in the decisions process. It was not always appropriate environment or facilitated their ability to participate (Papers II and III). When the next of kin thought the patient was not ready for discharge from hospital, they tried to influence the discharge by postponing the process (Paper III).

The health professionals described situations where they experienced being left out in the decision-making process about the patients’ health care needs. This example is expressed by the doctor at the hospital linked to the ‘emptying beds’ policy: ‘Many patients need to stay somewhere else [other than in a hospital] because their stay here is so short. So, if you are sick and need treatment and can get it somewhere else, then you should go elsewhere’ (Paper I).

In the continuum from being ‘left out’ or being an ‘active player’ through the care trajectory, the findings indicate that the interaction could appear like games, where the actors play their cards to move to a more appropriate position. To understand some of the complexity and unexpected that happens during the trajectories, I have used the CTG framework (D. Allen et al., 2004).

In the present study, the games could turn out to be someone’s move to circumvent the initial plan in the formal decision process somewhere through the care trajectory and drive the care trajectory further. The patient could delay deciding or considering alternative options to attain health care in coherence with their own preferences and needs (Paper II).

Next of kin often chose to work behind the scenes, making decisions based on what they thought would be the best for the patient and finding practical solutions that could be combined with their own lives and work schedules. For example, in the case with Albert, the initial plan was a rehabilitation stay at a nursing home in a neighbouring municipality. The next of kin considered it too difficult to visit the patient because of the distance. This led to an alternative plan and change in the direction of the care trajectory. From one day to another, the next of kin turned around and made the decisions for the patient to go home (Paper III). These moves set conditions for the other and resulted in comprehensive work and coordination needs and reorganisation for all actors involved. The CTG describes how several players mutually influence the care trajectories. Someone’s moves can affect and set conditions for the other actors’ actions, and these actions shape the care trajectory (D. Allen et al., 2004).

Another factor that influenced the patient and next of kin to either be left out or have an active involved position in the care trajectory was the intensive information exchange between the health professionals. The negotiation around health care resources and available beds made access to information in the decision-making process partly unavailable for the patient and next of kin. For the health care personnel, the challenge was to not have a more comprehensive picture of the patient and knowledge around the patient’s life. It was difficult for all the ‘players’ to keep track of the game’s course (D. Allen et al., 2004). In various ways, this factors led to an more unpredictable course in the care trajectory for all the actors.

According to the CTG, decreased strength for some or all the players will give less opportunity to employ a tactic and change the figuration of the game (D. Allen et al., 2004). In the current dissertation, the limited access to information for the patient and next of kin made it difficult to follow what happened, and to have the possibility to be involved. At the same time, the patient and next of kin could choose to circumvent the initial plan and drive the trajectory in a direction that further created conditions for the other actors. This move affected the balance between the actors and strengthened the position of the patient and next of kin to be involved in the further direction of the care trajectory. With reference to the CTG it is pointed on which way one player (individual or group) have power to set conditions for the others and how it can influence the balance between the players. Although the patient and next of kin in the present study could be left out in the interactions during the care trajectory, they used different moves to set conditions for the other actors (health professionals); thus, they had the possibility to influence the balance.

Using the framework of CTG in the current dissertation has illustrated some of the diversity of explanations for why the course of the care trajectory can take the direction it does. It also shows how the actors made different moves that set constraints for the other and, in that way, influenced the balance between them.

5.1.3 Expanding the professional integration towards partnership integration

The findings in the present dissertation have revealed the actors' comprehensive work and efforts to enhance and secure coherence during the elderly patients' care trajectory. It was not only the professionals that strove to ensure coherence for elderly patients (Papers I and III). The patient and next of kin also had an active role in managing and coordinating the care trajectory and handling several challenges (Papers II and III). For example, they worked to navigate the health care system, including searching for health care professionals who could help with access to proper health care (Paper II). Furthermore, they took responsibility to secure coherence with the patient's needs and preferences and facilitate health care, such as reorganising the home to follow up for rehabilitation and health care in the patient's home (Paper III).

The next of kin described how they strove to organise their lives and jobs around caring for relatives and were on duty 24/7 (Paper III). This work and responsibility conducted by patients and next of kin is in line with previous research, which has shown how they follow up medical treatment, the tasks required to do at home, practical support and organising during the care trajectory (Bragstad et al., 2014; Mattingly et al., 2011; Nyborg et al., 2017; Tønnessen, 2016; Wittenberg et al., 2018). This is in line with Mattingly et al.'s (2011) description of the total organisation of work as 'chronic homework' (Papers II and III). Applying Mattingly et al.'s (2011) concept of homework provided me with a deeper understanding of how policy and expectations play out in real life when the comprehensive organisation of the work is transferred from professionals to chronically ill patients and their family.

Professionals also conduct comprehensive work and the promotion of interprofessional work aims to deliver coherent health care in the care trajectory (Schot et al., 2020). This may be phrased as professional integration, which is seen as a central dimension in the integrated care framework (Valentijn et al., 2013). To extend the understanding of the integrated care framework that has been used to describe and understand how organisational and professional integration are linked to the patient experience of coherence in health care regarding their needs. Since the next of kin and health professional view of the division of tasks and responsibilities may be different. It can be difficult for the next of kin to understand their responsibilities and tasks and what the professionals expect from them. Providing health care in the home is taken for granted and, to a small extent, is discussed between the professionals and next of kin regarding the role and collaboration (Wittenberg et al., 2018).

In the transfer of tasks of health care work to both patients and next of kin, Björnsdóttir (2018) emphasised the significance of the patient and next of kin as becoming a part of what she called the 'care net'. She also highlighted the total organisation work that needed to be done with all the actors and instances involved. Developing a shared understanding among all the 'workers' in the 'care net' requires a health professional team with flexible solutions and the ability to re-evaluate the plan and monitor the health care (Björnsdóttir, 2018). The findings in the present dissertation show that it became obvious that the patients and next of kin felt they had to adapt themselves to the health care system rather than the other way around (Papers II and III).

In the framework of integrated care, professional integration has addressed the partnership between professionals and how the professionals should work together based on shared competencies, roles and responsibilities to provide comprehensive and coordinated care (Calciolari et al., 2022; Valentijn et al., 2013). There was limited emphasis on the comprehensive work and responsibility that the patient and next of kin carried out and actually took on a role as a partner in the health care team (Papers II and II). Clinical integration refers to the extent to which patient care services are coordinated across various professionals and institutions (Valentijn et al., 2013) and depend on the health care work from the patient and next of kin themselves (Mattingly et al., 2011).

Today, there is a growing expectation to involve the patient and next of kin in the approach to the management/governance of health care services, where the patient is intended to be a greater partner in the provision of health care services (Osborne et al., 2013; Vabø et al., 2022). Similarly, the government has highlighted the need to facilitate closer collaboration on common tasks between informal caregivers and health care services (Ministry of Health and Care Services, 2012–2013; Ministry of Health and Care Services, 2017–2018). However, the patient and next of kin as part of the ‘partnership’ and collaboration in the framework of integrated care have been less described.

Collaboration has a greater focus on the professionals and system. It can be appropriate to extend the understanding of partnership, cooperation and work that contribute to integrations of the health care services for the elderly patient to include the work of patient and next of kin. Furthermore, it seems important to also draw attention to what conditions and prerequisites the various actors need to be part of as an extended health care team. The findings in the present dissertation open up for questioning whether the dimensions in the integrated model manage to contribute to user-centred care as intended. Obviously, it seems to not reflect and include the patient and their next of kin’s work properly (Valentijn et al., 2013). It is reasonable to argue that the model needs to be expanded so that the patients and next of kin themselves become partners with the professionals, thus drawing advantages on each other as an extended team. Even if the aim is to be person focused in an overall process across time, place and discipline, it is arguable that the trajectory for the elderly patients will continue to be insufficient. The dimensions at the macro and meso levels are clearly directed at the organisations’ and professions’ work of aiming to enhance coherence and patient-centred care.

5.2 Methodological considerations

There is no absolute consensus on how to judge the quality of qualitative research, but the principles of transparency and reflexivity are regarded as essential throughout the research process (Moen & Middelthon, 2015; Polit & Beck, 2012). Reflexivity involves systematic and continually awareness of what the researcher as an individual brings to the research, including the background, values, professional identity and preunderstanding that can affect the process (Polit & Beck, 2012). In this section, I discuss my role as a researcher—my qualifications and preunderstanding, ethical considerations and the trustworthiness regarding this dissertation. To discuss the trustworthiness of the present dissertation, I use the criteria of credibility, dependability, confirmability and transferability (Lincoln & Guba, 1985).

5.2.1 Reflections of the role as researcher, my qualifications and preunderstanding

When I entered the field in my study, I was rather inexperienced as a researcher; however, during the study, I had to do many reflections and decisions that have provided me with new knowledge. In this section, I discuss my role in the study. My professional background is as a geriatric specialised nurse with decades of experience working in both municipality and specialist health care. During my Ph.D. project, I worked in parallel in a clinical setting in municipal health care services, which means I was in a close position to engage the area and topic I investigated. However, the study was not conducted at my workplace, and the hospitals and health care services in municipalities were unknown to me.

I tried to prepare myself for conducting participant observations and interviews through reading the literature and listening to experienced researchers. In the beginning of the observations at the hospital, I quickly felt the challenge of what it is like to be an observer. It was both exciting and frustrating. Where should I stand or sit, and how active or passive should I be in conversations? Signs of scepticism or uncertainty about my role from other persons also affected me as an observer.

By having a reflexive approach, through notes and in the discussion with my supervisors, I experienced that I developed my skills in my role as a researcher. After a while in the field, I felt less uncomfortable, narrowed the focus and was more reflective in the choice of how active and passive I was in the observations. This reflexivity was also important in illuminating my own preunderstanding and awareness of how I understood what I saw.

Professional experience and knowledge can be beneficial to understand the research field and in giving input to observations and interviews, but it can also be unfavourable if prior understanding and preconceptions make the researcher 'blind' to a new understanding (Hammersley & Atkinson, 2019). Awareness of preconceptions and perspectives and openness to correcting one's understanding during the research can promote seeing new things (Fangen, 2010; Tjora, 2017). In the beginning, I thought that I found little aspects that were new. What I observed was already known for me, and I thought I had seen and experienced this before. It was a process for me to open for new understanding and be aware my preunderstanding during the field research. An example of new understanding was the way the patient used strategies for a more appropriate positions in the interactions. Researchers ought to be aware of the ways their own lens might impact the content and perspectives of their field notes (Peshkin, 2001). Research has shown that to be more than one scholar and entering the field with different lenses can give a broader picture to discuss and interpret the findings (Hellesø, Melby, & Hauge, 2015). Having several observers could have strengthened the methodology of this project. However, due to limited resources, it was only possible for me to do the field observation.

To carry out observations and interviews, I also recognised that conducting research in a good way raises several ethical considerations, which I will elaborate on in the next section.

5.2.2 Ethical considerations

Qualitative research is often done by direct contact with the participants; therefore, as researchers, we become near the person during the observations and interviews. Confidentiality, respect and reciprocity must characterise the contact we have with the participants and the ability to have empathy towards the situation and individuals involved. This requires conscious and critical reflection on oneself, the participants, and the data. In particular, when dealing with vulnerable groups, greater responsibility and caution is required (Ruyter, Førde, & Solbakk, 2014; Tjora, 2017). As a researcher, it is important to develop ethical awareness, insight and judgement to handle ‘situated research ethics’ in the research field (Guillemin & Heggen, 2012). In the current project, where I have followed the elderly patients through the care trajectory, I had to maintain continuous ethical considerations and caution when conducting observations and interviews. The patient participants in this study were particularly exposed to vulnerable situations, and I considered my skills as a nurse to be a strength in handling this in a competent way. In some situations, I chose to wait for the interview if the patient had been through many activities or if I felt that the patient was particularly vulnerable. I was careful to clarify with the patient before all meetings in the home, short-term home or during the hospital stay. On the other hand, following the care trajectory over time provided an opportunity for several shorter interviews, which was appropriate in adapting the information gathering to the patient’s day-to-day health condition (Fangen, 2010). Observations as a method have also been stated as beneficial for research involving vulnerable patients because of including less stress and minor intrusions (S. J. Morgan et al., 2017).

The competence to conduct research in a good way is a research ethical principle. One issue I had to handle was what Hammersley and Atkinson (2019) described as ‘there can be exceptional occasions when a researcher should stop being a researcher and engage in action that is not directed towards the goal of producing knowledge’ (p. 228). The participants in the present study were informed about my background as a nurse, in addition to being a PhD student. I experienced occasions during the data collection where my role as a researcher was challenged regarding be a clinical nurse.(and adhering ethical code considerations). An example was a meeting in the patient’s home where the patient and next of kin experienced a struggle with access to health care services regarding a health problem and asked for advice. I chose to help them gain the necessary contact and in navigating the health care system. I considered it unethical not to take a role as a nurse in this specific situation.

Another aspect is having awareness of the participant's privacy and dignity when conducting interviews and observations (Tjora, 2017). In one example, I considered that the person's privacy could be exposed during an interview with a patient at the patient's home after discharge from the hospital. The person started talking about a story from the past with much character of private content, which I considered was not relevant to the purpose of the study, so I chose to stop the recording. To turn off the recorder was a choice I made with respect to the person's privacy and to maintain trust in the research. I informed the participant that I turned off the recorder and waited to turn it back on until the person had told the story.

Considerations regarding the recruitment of patient participants

The inclusion criteria entailed considerations by those who assisted with inclusion in the selection of possible patient participants. There were considerations about vulnerability to being a participant, but also the importance of getting the older person's voice heard. In the recruitment process of the patient participants, it was an experienced nurse in the hospital department who considered whom to inform about the study and the patient's capacity to consent or not. The patients who were not chosen to be informed about the study and given an opportunity to participate were, therefore, not so obvious. In this, it became a question of whom they chose and whom they did not choose to ask. Furthermore, what influenced that process? These were reflections the group of supervisors and I had during the recruitment process. I found that some patients were shielded from receiving the opportunity to participate in the study. The reason could be that 'the patient has such a low voice, cannot bear to speak, cannot move that much and needs much help'. It could also be the next of kin who influenced the process and expressed that too many people were already involved in follow-up at home, for example, even though the patient consented to this. The challenges to recruitment of elderly to participate in research have been previously described (Cherubini & Gasperini, 2017; Mackin et al., 2009). It is known that recruiting elderly vulnerable patients (e.g., palliative care) by not actually being asked to participate stops at the ‘gatekeeper’ (Ewing et al., 2004). Our experience with the recruitment process showed that both health professionals and next of kin can act as gatekeepers. Health professionals can have a critical role in facilitating, but also preventing, elderly patients from participating in research (Mackin et al., 2009). It is an ethical challenge that the patient does not get the opportunity to illuminate their situation, with a background of and an assessment based on the principle of to do the best for the patient, the other side this assessment can cause an unwanted exclusion from participating.

The ethical considerations and handling of these throughout the research process have influenced the data I gained. At the same time, these were situations that contributed to information about the care trajectory and dilemmas the actors experienced, including the challenges of gaining access to health services.

5.2.3 Trustworthiness

In qualitative research, the term trustworthiness is used to evaluate the degree of confidence in the data. Several quality criteria have been developed in qualitative research; to address trustworthiness, Lincoln and Guba (1985) used the criteria of credibility, dependability, confirmability and transferability.

Credibility is viewed as an overall goal of qualitative research and refers to confidence in the truth of the data and the interpretations of them (Lincoln & Guba, 1985). Triangulation is a recommended strategy to enhance the credibility of a study and involves the use of multiple data sources and/or methods. Method triangulation involves using multiple methods of data collection about the same case/phenomenon (Polit & Beck, 2012). To gain a more comprehensive understanding of the care trajectory of elderly people with complex health problems, I used triangulation methods and combined observation, interviews and extracted data from the patient records. The choice of participant observation together with interviews as a method allowed me to capture the complexity of the trajectories through detailed accounts of real life (Flyvbjerg, 2006; Hyett et al., 2014). In addition, I used person (data) triangulation with the aim of validating data through several perspectives on the case (Polit & Beck, 2012). Using person triangulation proved to be a strength of a study, contributing to illuminating the interactions among the patient, next of kin and health professional. For example, this could be seen in how the work to ensure coherence through the care trajectory was an important contribution from all the actors.

Repeated interviews were conducted with the patient participants during the trajectory. The location for conducting the interviews could be at the hospital, short-term unit or the patient's home (Papers II and III). Research has shown that different interview locations may contribute and evoke insights and knowledge into the issues being studied (Bjørvik et al., 2023). An example of such knowledge was the patient considerations around living arrangements during the trajectory. Finding in my study showed how the patients needed to be ready for decision, and their considering's were different at home than at the hospital.

Generally, the analysis process in a case study has been less described in the literature (Patton, 2014). Arguments against choosing a case study are that it can be challenging to manage comprehensive data material within the framework of a Ph.D. project when being an inexperienced researcher (Yin, 2009). I also experienced it as a challenge to grasp all the data material and prepare it for analysis. To deal with this challenge, I transcribed the interviews consecutively during the data collection. Fieldnotes were written down immediately after observations. In this way, the process of getting to know the material started immediately and helped focus observations while supplementing the input for the interviews. The data material was chronologically sorted in each individual case, which was appropriate to obtain an overview of the material and understanding of each individual case (Yin, 2009).

Throughout the three substudies, thematic analysis was used. Particularly in the analysis in substudies II and III, it was necessary to move from the entire data material in each case to generating thematic mapping. This became a back-and-forth process throughout the analysis to outline the themes. By using observation and interviews, it was central to combine the meaning in the analysis within the context. This was a characteristic of thematic analysis to be flexible and open up to emphasising the context (Morgan et al., 2017; Vaismoradi et al., 2013).

Content analysis is another method of systematic coding and categorising used for exploring large textual information, where the emphasis is on determining trends and patterns of word used, their frequency, their relationship and discourses of communication. However, in content analysis the broader understanding of the particular context in the meaning of the analysis is not so central (Vaismoradi et al., 2013). It has been pointed out that, by content analysis with frequency of codes to find meaning in the text, one can lose the importance of the context (D. L. Morgan, 1993). To understand the care trajectory, the context was of great importance. Thematic analysis was thus used in this dissertation.

Another important factor in establishing credibility is prolonged engagement in the research field, which means investing sufficient time in collecting data to gain an in-depth understanding of the people and study. Prolonged engagement is also essential for building trust with informants, which, in turn, makes it more likely that rich, accurate information will be obtained (Polit & Beck, 2012). The observation periods in the present study varied between 2 weeks and 13 weeks in each case; the total length in the field was 8 months. Following the care trajectory over a long period gave me data that provided me with an in-depth understanding. For example, the patient considerations and decisions throughout the course were often long-term processes related to life in general and the tension between taking care of this long-term perspective of the life course and care trajectory.

I also experienced that conducting fieldwork for a longer period was extensive and time-consuming. It was often a long distance between the hospital and patient’s residence, up to 200 km, which impacted the total time available for observation. On the one hand, it gave me the possibility to prepare for the fieldwork and for reflections. More importantly, it gave me a comprehensive understanding of the 'relationship' between the hospital and municipalities and how their collaboration worked.

Dependability refers to the stability of the data over time and conditions. Dependability can be seen in relation to transferability (external validity), which refers to whether the results of the study are transferable to other settings (Lincoln & Guba, 1985). One way to strengthen the dependability of data is to conduct member checking. In this process, the researcher provides feedback to participants about interpretation and obtains the participants' responses. The argument for doing so is to check if the researcher's interpretation is a good representation of the participants' realties. Member checking can be conducted during data collection or after data have been fully analysed (Polit & Beck, 2012). In the present study, where I conducted repeated interviews throughout the trajectory with the patient participants, I had the possibility to follow up on the participants' meanings in the previous dialogue and interview. In addition, I got information that complemented the observations, field notes and interpretation (Papers II and III). A limitation was regarding the interviews with the health professional (Paper I), where it was not possible to take the analysis and interpretations back for a member check. This is because of the variety of workplaces and distances between them.

Confirmability refers to the degree of objectivity or neutrality in the research. This means that the results of the study are shaped by the participants' contributions, not by the researchers' motivation or interest (Lincoln & Guba, 1985). As described earlier, I aimed to have a reflexive approach to my preunderstanding in all parts of the research process. This also involved reflections on me as a researcher who affected the data collection, analysis and interpretations. Nevertheless, I reflected on and discussed the data with my supervisors throughout all phases of the research process. A challenge I experienced was related to what Sporrong et al. (2022) described as how the researcher may affect and can be affected during the observations. For example, as described in the method section, I experienced that, during the observations, I moved between being close and more active with the person observed and, at other times, being more passive and distant from the observed. During observations in the hospital, I wore hospital clothes with a nameplate that stated, ‘research student’. The literature has pointed out that the research effect can contribute to those being observed behaving differently than they would otherwise. It can be tiring to be an observer, but one’s presence as observer can be tiring and stressful for the person who is being observed (Fangen, 2010; Tjora, 2017). I felt that the health professional was not always comfortable with my presence. In one episode, the health professional explained themselves about their performance in a meeting and explained that what was said was not quite what they had meant. However, in another situation, I could sit in the middle of a group where the group member did not seem to care about my presence. How I, as a researcher, was influenced and how the participants were influenced by me had an impact on the data I received. As a researcher, I accept that I was a coconstructor of the data, through choices in observation, what was written down in field notes and how I again interpreted these (Mulhall, 2003).

Transferability refers to the extent to which findings can be transferred to or have applicability in other settings or groups (Lincoln & Guba, 1985). The patient participants had a good distribution regarding gender and presented a variation in the location of their homes from smaller to larger municipalities and distance between the hospital and home. This was a strength in capturing themes across a great deal of variation in the cases (Papers II and III). In addition, the health care professionals were recruited from both the health municipality and specialist health care services, with a good spread between the two organisational levels. There was no physiotherapist included from the municipality, which was a limitation, including that more elderly people today shall be followed up with rehabilitation at their home

A tick description allows readers to make decisions regarding transferability because the writer describes in detail the participants or setting under study (Polit & Beck, 2012). In Papers II and III, I used the case description to describe themes. In addition, quotes from field notes and interviews were frequently used in Papers I, II and III.

Using the case description and quotes contributed to strengthening the reader's consideration of the decisions regarding the transferability of this work.

6 Conclusion and implications

This dissertation contributes novel insights and knowledge about the comprehensiveness of the care trajectory of the elderly with complex health needs and identifies the challenges of providing coherent and person-centred care.

The care trajectory was characterised of be long term interrupt by the shorter illness trajectory. Thus, it was essential to take into account a broader perspective of the patient's life beyond the illness. For the patients, in respect to their engagement and management of the care trajectory, their considerations of their healthcare needs and the adjustments they needed to make to living arrangements were constant throughout the care trajectory. It could be important for the patient's time for recovery from the illness to consider different possibilities and options before managing necessary modifications in everyday life. The health professional acknowledges the necessity of building an overall picture of the patient situation beyond the illness trajectory to manage the care trajectory. Interdisciplinary work has been highlighted as an expedient for achieving this complete and comprehensive picture.

However, this dissertation shows how the requirements for efficiency in the healthcare services resulted in quick solutions and decisions about the bed capacity both at hospital and in the municipalities and sped up the decision-making process. This made a difference in the relationship between the patient's needs and the organisational requirements, which also influenced the health professionals in providing coherent and person-centred care.

The pursuit of a suitable healthcare service within the care trajectory resulted in several dilemmas, considerable deliberations, and a comprehensive mobilisation of the patient, next of kin and health professional. Overall, the patient and next of kin contributed a comprehensive effort to manage and secure coherence in the care trajectory and thus become an active part of the healthcare team.

During the care trajectory, the actors seemed to move between a continuum from being left out to having a more active and involved position. This dissertation revealed how the patient and next of kin used different strategies, such as to delay decisions until they felt ready for them, circumvent planned steps, and find/chose new directions in the care trajectory.

Implication for practice

One implication for practice is to accept that the patient participating in managing and making decisions during the care trajectory is often in a continuous and long-term process, where the patient's life beyond the illness has to be taken into account. Achieving consistency between the healthcare system and the patient's pace in the decision-making process during the care trajectory may also lead to a more appropriate level of healthcare in line with the patient's preferences.

Another implication for practice is the need to strengthen interaction and to establish a prerequisite for interaction for all actors. Care trajectories to elderly are normally characterised by several persons involved, such as the patient, next of kin and various healthcare professionals. It is necessary to develop healthcare services that make space and time for interactions among all the actors and allow for discussions and disagreement. This can contribute to finding appropriate alternatives and direction for the care trajectory, in coherence with the patient and next of kin's preferences and needs. In addition, there is a need to consider the comprehensive work of the patient and next of kin, their conditions for this work, and cooperation with them as included members of the care team.

Further research

There is still a need to gain additional knowledge of the care trajectories of the elderly to develop trajectories that align with the patient's healthcare needs. Because the care trajectory is characterised by a long-term perspective, studies with a longitudinal design are considered appropriate. In addition, there are few studies that have included the patient, next of kin and a health professional to understand the interactions among these actors, the impact on the care trajectory and the contributions from and work done by all the actors involved. Further research should also emphasise implementations of interventions that strengthen the patient’s participation throughout the care trajectory and where the patient is placed more in the centre of the healthcare services.

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Errata

Page	Section	Original text	Correction type	Correction text
IX (Summery)	2	All and/or the parts of health care services…	Writing error	All or the parts of health care services…
15	2	In the work/efforts to achieve seamless..	Writing error	In the work to achieve seamless…
18	2	(; Constand et al., 2014….	Writing error	(Constand et al., 2014..
39	1	In visible/open observation..	Writing error	In open observation..
46	Headline	Results/Findings	Writing error	Results

Original papers

I. Kumlin, M., Berg, G. V., Kvigne, K., & Hellesø, R. (2021). Unpacking health care professionals' work to achieve coherence in the health care journey of elderly patients: An interview study. *Journal of Multidisciplinary Health care*, *14*, 567

II. Kumlin, M., Berg, G. V., Kvigne, K., & Hellesø, R. (2020). Elderly patients with complex health problems in the care trajectory: A qualitative case study. *BMC Health Services Research*, *20*(1), 1–10

III. Kumlin, M., Berg, G. V., Kvigne, K., & Hellesø, R. (2022). Dilemmas and deliberations in managing the care trajectory of elderly patients with complex health needs: a single-case study. *BMC Health Services Research*, *22*(1), 1–11.

Paper 1

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ORIGINAL RESEARCH

Unpacking Healthcare Professionals' Work to Achieve Coherence in the Healthcare Journey of Elderly Patients: An Interview Study

This article was published in the following Dove Press journal:
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Aim: Today, seamless, person-centered healthcare is emphasized when dealing with elderly patients with comprehensive needs. Studies have uncovered a complex healthcare terrain. Despite a great deal of effort on the part of policy makers and healthcare providers, the work healthcare professionals undertake to develop seamless healthcare is still unclear. Therefore, the aim of this study was to uncover the work that healthcare professionals undertake to achieve coherent and comprehensive healthcare for elderly patients with multiple health problems during their journey through the complex healthcare terrain.

Methods: This study has an explorative design with individual interviews. Twenty-five healthcare professionals from primary and specialist care agreed to participate. A thematic analysis method was employed.

Results: The analyses revealed three central themes in the healthcare professionals' work to build coherence in the patients' care trajectory: Working to manage a patient's illness trajectory during the course of the patient's life, working to achieve a comprehensive overall picture, and considering multiple options in a "patchwork" terrain.

Conclusion: Healthcare professionals have a common understanding that hospital stays are a short part of the elderly person's journey in the healthcare system. In the comprehensive work to obtain the overall picture of the illness trajectory within the patient's life story, healthcare professionals emphasized the importance of working in an interdisciplinary manner. Interprofessional consulting and collaboration should be strengthened to build coherence in the older patient's complex care trajectory.

Keywords: older, care trajectory, complex healthcare, health personnel, interdisciplinary

Background

It has been emphasized that healthcare provided to elderly patients with comprehensive needs should be seamless and person-centered.[1–4] However, the increasing specialization in healthcare has led to a fragmented health system. Indeed, specialization in the provision of care is not only present in specialist care, but also in primary care.[5,6] This has resulted in health systems that are complex and challenging for patients and their next of kin to navigate; many feel that they are on a labyrinthine journey.[7–9] This situation is further complicated by the fact that elderly patients with several health problems often need healthcare services at different organizational levels, in which numerous providers are involved.[10]

Patients with comorbidities are more vulnerable to fragmented healthcare services and can often experience uncertainty about who is responsible for their care.[10]

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One reason for this is that intersectoral collaboration and communication for these patients are challenging and complex.[11] It has been stated that increased specialization places healthcare personnel in professional "silos".[10] Such boundaries must be eliminated to create seamless healthcare collaboration and communication across organizations and disciplines.[2,12] A central aim of integrated care is to enhance the patient's experience during the care trajectory and to move from a fragmented system to one that is person-centered.[12] Person-centered care can be defined as an approach in which the care provider tries to understand the patient's complaints not only in terms of illnesses, but also as expressions of the patient's unique individuality, tensions, conflicts, and problems.[13]

Interprofessional work implies integrated perspectives on patient care among workers in various professions.[10] Professionals from different disciplines have a responsibility to foster the integration of services, especially with the growing burden of disease.[2] In Norway, the government has highlighted the need for a holistic and comprehensive patient care pathway characterized by combining sub healthcare services to coordinate the patient's care. The goal is high quality treatment regardless of who is responsible for each sub healthcare service. Emphasis is thus on interdisciplinary collaboration and prioritization of the patient's needs.[14]

Today, there is a global trend of shorter hospital stays, while the creation of efficient patient pathways has been part of an overall goal to save time in healthcare delivery.[15] On the other hand, studies have shown that increased work efficiency can have an impact on the delivery of healthcare that is consistent with patient needs.[15,16] In recent decades, standardized care pathways have been developed to ensure patient safety, increase patient satisfaction, and optimize the use of resources to enable the best possible care for patients with specific health problems.[12] However, most of the care pathways have been developed for single diseases. For elderly patients with multimorbidities, healthcare personnel can strive to adapt the linear and disease-specific pathway for the organization of care to ensure that it is in line with the patient's preferences.[10,12]

Several studies have revealed that providing coherent healthcare to patients with comprehensive health problems can be difficult and complex.[4,10,17]

In the effort to deliver integrated care, tension as well as a variety of cultures among different healthcare systems and professionals has been described. Healthcare practice is characterized by diverse systems and various work environments.[16,18,19]

Attempts have been made to formalize the work of interconnecting and coordinating healthcare services by means of guidelines. Research on the organization of health services shows that healthcare professionals combine both formalized and non-formalized working methods in practice. However, much of this management and organizational work is not fully "visible" and formalized.[20–22] Defining this "invisible" and non-formalized work is a prerequisite for developing the care organization and collaboration.[23]

Despite a great deal of effort on the part of policy makers and healthcare professionals to ensure seamless experiences for patients throughout their care trajectories, the actual work undertaken to develop seamless care is still unclear.[11,24] Unpacking the work healthcare professionals conduct to achieve seamless and comprehensive healthcare that corresponds with the elderly patients' journeys through the complex healthcare terrain can contribute new insights and understanding of the development of appropriate healthcare.

Therefore, the aim of this study was to uncover the work healthcare professionals undertake to achieve coherent and comprehensive healthcare for elderly patients with multiple health problems during their journey through the complex healthcare terrain.

Methods

This study employed an explorative design with individual interviews. This approach provided a broader insight into the healthcare professionals' perspectives on their efforts and work throughout the elderly patients' journey through the healthcare system. The question under investigation was part of a larger project that studied the care trajectory of elderly patients. In the project we explored how elderly patients engage in and interact with their care trajectory across different healthcare systems.[25] The focus of this paper is how healthcare professionals attempt to achieve coherence in the patients' care trajectory. The data collection was conducted from November 2017 to June 2018. This study complies with the Consolidated Criteria for Reporting Qualitative Research (COREQ) [Supplementary file 1].

Setting and Participants

The Norwegian healthcare system consists of two organizational structures and financial systems. Primary health care is organized and financed by the municipalities, while specialist care is owned by the national health authorities. The local authorities are responsible for planning and providing primary care services, which include the provision of general practitioners (GP) municipal emergency care units, home care services, sheltered housing, nursing homes, preventive services, and intermediate care. The national authorities are responsible for providing specialist care, which encompasses all hospitals and outpatient clinics. National priorities are communicated through policy documents and guidelines for professionals. In recent decades there has been a transfer of rehabilitation and follow up-care tasks from specialist to primary care.[26,27] There is ongoing discussion about the challenges involved in the transfer of these tasks, including the allocation of resources, both financial and in terms of skills and competencies/responsibility.[28,29]

A purposive sampling of healthcare professionals who were involved in the care trajectories of the larger research project[25] was chosen. The participants were recruited from both primary and specialist care. They represented one rural hospital, one urban hospital and six different municipalities. The population of the municipalities ranged from 2000 to 27,000 inhabitants. The healthcare professionals were given verbal and written information about the study by the department manager and the first author. The inclusion criteria were: working as a healthcare professional who cares for elderly patients and has a minimum of a bachelor's degree. Twenty-five healthcare professionals consented to participate in the study (Table 1). Three health healthcare professionals refused to participate because of workflow and time issues. No one dropped out during the study.

Data Collection

All interviews were conducted by the first author at the participants' workplace with only the researcher and participant present. The interviews varied in length from 20–45 min and an interview guide was used. After the first interview some corrections were made to the guide to make the content clearer and broaden the questions. The questions focused on the healthcare professionals' descriptions of elderly patients with complex health problems during the care trajectory, their experiences of the guidelines and standardization of care during the trajectory, and their perspectives on integrated and coordinated healthcare. The participants were encouraged to talk openly by asking open-ended questions, and the interview guide was used to lead into pertinent topics in the research. Reflective field notes were made after each interview and facilitated the discussion about data saturation.[30] No repeat interviews were conducted.

Table 1 Participants Interviewed

Participant[a]	Hospital[b]	Primary Care[b]
Occupational therapists	1	2
Physicians	5	3
Physiotherapists	2	
Nurses	5	7

Notes: [a]Participants' profession. [b]Number of participants by workplace.

Ethical Considerations

The Norwegian Centre for Research Data has been notified about the study (ID: 54,551). Participation was based on informed, voluntary consent.

The informed consent included the use of anonymized responses. The participants were told that they could withdraw from the study at any time without consequences. No participant in this study was in a dependent relationship with the researcher (first author).

Analysis

The interviews were audio recorded and transcribed verbatim by the first author. All data were de-personalized before analysis. Braun and Clarke's[31] thematic analysis approach was applied. Initially, we read the interviews thoroughly to identify essential preliminary characteristics and patterns. Notes were taken to record the descriptive and analytical attributes of the data. Thereafter, the data were read and systematically coded manually, after which the codes were organized into possible subthemes. The back-and-forth process between coding and organizing the data into possible subthemes involved reviewing relevant research and theoretical perspectives to enhance understanding of the data. When disagreement between the members of the research group occurred, we discussed the themes with reference to the aim of study until a common understanding was achieved. This process revealed three main themes. An example of the analysis process can be found in Table 2.

Findings

Overall, the findings show that in the work to build coherence in the patients' journey through the healthcare system, healthcare professionals could not ignore the elderly

Table 2 Example of the Analysis Process

Example of Codes	Example of the Development from Codes to Subthemes	Identified Theme
For the patient it is a lifelong journey.	Organizing the illness trajectory in parallel with the long-term trajectory.	Working to manage the illness trajectory during the course of the patient's life.
"Shorter" illness trajectories impact on the patient's life.	Taking account of the patient's life.	
Worsening of illness or just a change in the need for healthcare.	Considering follow-up in the patient's living environment.	
Patients' involvement in their housing arrangements.		
Early contact with healthcare in the long-term pathway.		
Important to have knowledge of the patient's life situation and network.		
Organising is laborious and must be seen in connection with the patient's life.		
Not thinking too much about the diagnosis but more about the person.		

patient's life. Planning and facilitating the patients' healthcare was described as a long-term activity, often for life. Healthcare professionals worked to achieve a complete and comprehensive picture of the patient's situation in the patchwork terrain of the healthcare service.

The analysis revealed three central themes involved in the healthcare professionals' work to build coherence in the patient's care trajectory: Working to manage the illness trajectory during the course of the patient's life, working to achieve a comprehensive overall picture, and considering multiple options in a "patchwork" terrain.

Working to Manage the Illness Trajectory During the Course of the Patient's Life

The healthcare professionals expressed that when a patient becomes dependent on long-term care, they cannot ignore other aspects of patients' life. There was a common understanding that the care trajectory of the elderly patient lasts for a long time, often until death. The advent of a need for diverse healthcare services was described as a natural part of the patient's lifecycle. Healthcare professionals stated that this long-term care could be interrupted by a shorter ("stop-over") trajectory that results in a change in the level of health services or need for medical treatment. The interruptions during the long-term care trajectory could be related to a worsening of the illness but might also be just a change in the need for health and social services.

> And then, it is really the trajectory of the patient's entire period from being admitted to being . . . until they actually die. Even if one prefers not to use the term 'patient' in order not to make people 'sick' who are really just old.

Hospital stays were not necessarily always involved in these interruptions in the care trajectory, as described by an occupational therapist:

> What I think is that when you become ill or something happens to you, the (GP) may be the first to see you, if there is no emergency. If there is something that needs treatment then maybe you have to go to the hospital, maybe connect to home care in advance via a GP or relatives . . . and sometimes the hospital does not have to be involved either, but most of the time it is, at some point.

Healthcare professionals in municipalities described that this long-term trajectory could begin at an early phase in which the need for healthcare could be low, similar to a "dormant phase". Early contact with the healthcare system could be in the form of support from a volunteer center, preventive home visits, GPs, and/or home care. Healthcare professionals in municipalities see themselves as having longer relationships with the patient. Hospital personnel perceived themselves to have a more temporary role in this long-term trajectory. When their contact with the patient ended, their trajectory with that patient was over and the patient continued on in the system.

> For the patient, it is a lifelong process, for us the process is from admission and what we can do about it at that time and then the patient goes further or home.

Regarding planning and facilitation throughout the care trajectory, it was necessary to take the patient's life into account. A prerequisite was a certain amount of knowledge about the patient's life situation and network.

"Shorter" illness trajectories could make an impact on the patient's life. Healthcare professionals expressed expectations as to patients' levels of involvement, for example, in taking care of their housing arrangements.

> The elderly think too late about changing residence. It goes so far that when they do need help, the threshold for moving will probably be higher than if they had considered it earlier.

Facilitating follow-up in the home changed the care trajectory framework and prerequisites. It was expressed that when patients went home, they wanted to make their own decisions concerning their daily life and to control things themselves. In the home, there could be several actors around the patient, such as a spouse and children, with their own perceptions and opinions. Healthcare professionals had to relate to and communicate with patients and next of kin at the same time as being expected to follow-up on what had been decided at the hospital

> "At the same time it is not just 'running' into the living room" and determining what the healthcare professionals in the hospital expect to be done.

Working to Achieve a Comprehensive Overall Picture

Assessing the treatment and developing a care plan are dependent on having a certain amount of knowledge about the patients. Healthcare professionals in hospitals and municipalities emphasized the importance of gaining a comprehensive picture of the patient. They described that it could take time and a great deal of work to obtain an overview of a patient's situation. It was necessary to see the entirety of a patient's situation during the hospital stay and further follow-up in the municipality, as expressed by a doctor in the hospital:

> You have to pay attention to what happens after the hospital stay. I think that is typical.

A nurse in the municipality described the need in the following way:

> We have to scan every single patient's situation; there is a lot that has to be reasoned around in order to ensure a quality patient trajectory.

Healthcare professionals agreed on the importance of interdisciplinary approaches and collaboration methods. It could be appropriate to become acquainted with the patient over time when many decisions need to be made during the care trajectory.

On the other hand, comprehensive healthcare was also expressed in more medical terms. The patient should experience the treatment as holistic and individually adapted.

> We want the care trajectory to be a smooth treatment line — and adapted to your situation — the best possible overall, integral experience and treatment.

Despite the fact that the importance of an interdisciplinary approach was emphasized, descriptions of practice indicated that this was coincidental mode of work.

> It is a bit casual or random how it is followed up, I must say. Who catches up … and which professional group visits the patient the most? Who asks the questions about how the patient is now? And these interdisciplinary meetings that we have, it is a bit casual I think.

When describing the interdisciplinary mode of work, healthcare professionals were aware of the work of other professions, but at the same time it was not necessarily a practice characterized by interaction, as a GP described:

> It is appropriate to have an interdisciplinary understanding of the patient. We do not always have the same understanding. I do not know everything about the functional level and suchlike. And the decisions taken in the forums where doctors are not involved at all? It will be "twofold".

Considering Multiple Options in a "Patchwork" Terrain

The healthcare professionals in hospitals expressed that they had to consider a diversity of arenas for deciding on the best options for the patients after discharge. Such arenas appeared almost like a patchwork with multiple possibilities. For example, they considered whether a nursing home, sheltered unit, rehabilitation unit, home or other facility would be best for a patient. In hospitals, the doctors often needed to consider if the patient should receive medical treatment and follow-up in general practice or in specialist care. These considerations were a result of what they expressed as the politics of "emptying beds". One hospital doctor described it as follows:

> Many patients need to stay somewhere else [other than in a hospital] because their stay here is so short. And if you are sick and need treatment and can get it somewhere else, then you should go elsewhere.

The healthcare professionals in the municipalities considered whether the patient fulfilled criteria related to one of the care models they provided. Such criteria included whether healthcare could be delivered in the patient's home, in a nursing home, in a short-term specialized unit or in an intermediate unit. They described considerations such as the allocation of staff resources, the patient's needs, and options in the decision-making process.

> What our team does is to … first, we have our case manager on an assessment visit at the short-term ward, the nursing home or at another institution and then we decide if there is rehabilitation potential.

The necessary resources to facilitate professional assessments as well as training and rehabilitation interventions were often lacking.

> One has to be in bad shape to get a rehabilitation bed and we know that it is very difficult to get patients further, which is a dilemma for those who need a rehabilitation place.

However, it was not only the patient's health situation that was considered. Hospital personnel's assessments of where the patient should receive follow-up care and their knowledge of local municipalities also played an important role. One consideration was whether or not municipalities had the capacity and competence. The hospital doctors sometimes expressed concern about "letting the patient go", as they were unsure where the patient would go next and understood that it was not always easy to arrange the best treatment and follow-up at home.

> When treatment is moved out of the hospital, we have to be realistic; we cannot expect very advanced treatment outside of the hospital.

The healthcare professionals in the municipalities also reflected on the patients' situation. Although the hospital doctors expressed concern about where the patient was going next, the GPs described the need for more extensive feedback on the patient's health problems. The GPs considered themselves to have a central role in the follow-up process based on the fact that they had broad knowledge of the patient and her/his network.

> As a GP, I think that getting a comprehensive assessment is what we struggle a lot with. We must try to get help with complex issues.

The other healthcare professionals in the municipalities stated that they had a responsibility to facilitate follow-up and healthcare after a hospital stay. When doing so, they relied on their previous knowledge of the patient and expressed that they were often familiar with patients' lives and networks.

Discussion

The effort to build coherence in the patients' journey through the healthcare system involves comprehensive work for healthcare professionals. Our analysis showed that they had to build an overall picture of the patient's illness trajectory within their life story. They emphasized the importance of working in an interdisciplinary manner to gain such a complete and comprehensive picture of the patient. Their considerations about the best options for the patient after discharge involved multiple negotiations within the unscripted patchwork of the healthcare terrain.

In contrast to our findings, previous studies have revealed tensions between healthcare professionals in hospitals and municipalities regarding the perceptions of patients' readiness for discharge and different perspectives on the need for healthcare after discharge.[16,19] We identified that healthcare professionals seemed to have a common perception and an acceptance of the fact that for older patients, a hospital stay is just a short part of the longer care trajectory. This common understanding influenced their work when they negotiated about the best options for patients after discharge.

According to Schot et al,[11] it is the responsibility of healthcare professionals to negotiate overlaps in the individual care process, patient transfer issues, and discussions of where patients should go. We discovered that healthcare professionals consider multiple options for the follow-up care of patients in a diversity of arenas after discharge. In the municipality, the healthcare professionals considered whether the patient fulfilled criteria related to one of the care models they provided. The challenges of working in this "patchwork" terrain entail a diversity of healthcare overlap, where the following are arenas that require a high level of negotiation.

The short hospital stay entailed deliberations about whether continuing medical treatment was an option at hospital level or in primary care. Furthermore, the healthcare professionals based their considerations on their insight into local capacity, knowledge and competency. In studies, it has been discussed what being ready for discharge means, especially in the context of short hospital stays and complex health problems.[15,16,19] The need for hospital staff to free hospital beds is well known[17,32] and consistent with our findings in which healthcare professionals referred to this phenomenon as the politics of "emptying beds".

The process of negotiating healthcare overlaps is not just about finding practical solutions for releasing beds[17] and considering available resources, but also involves taking each patient's situation into account. Throughout their journey in the healthcare system patients play a role in negotiations regarding their need for healthcare and deliberations about necessary changes in their living arrangements. The negotiation between patients, healthcare professionals and next of kin was often ongoing.[25] The need for knowledge across the organizations is mutual and may require a change in the approach to negotiation and interaction.[11]

In order to manage the patient's journey in the healthcare system, healthcare professionals in hospitals and in the municipalities described the need for broader knowledge about the patient's illness trajectory within her/his daily life. They expressed the importance of achieving a comprehensive picture of the patient. The need for an interprofessional approach and collaboration was emphasized in the work to achieve this comprehensive picture. While healthcare professionals highlighted the need for knowledge of other health professions, they nevertheless described a practice where interprofessional collaboration was coincidental and not intentional.

Challenges concerning the multiple considerations regarding healthcare services were described in our study. The development of specialization and differentiation can contribute to the overall quality of healthcare.[12,18] Therefore, it can be advantageous not to minimize differentiation, but at the same time to focus on integration. A high level of coordination and collaboration will be required to increase integration.[18] Research has shown that the ways in which professionals consult each other can result in the provision of a high level of qualitative care and integrated practice.[11] Our participants emphasized the need for interdisciplinary collaboration for this patient group. However, their perception of what "interprofessional consulting" is was not obvious and seemed to be confined to their own profession, which is supported by other studies.[33] It is a challenge that record systems do not link access to various levels and different professions, which can lead to gaps in the information or to information overlaps.[10,34] In addition, research has identified that healthcare professionals also need to create space for communication and knowledge transfer to ensure the quality of care.[11]

Our study revealed that the elderly patients' journey in the healthcare system is not straightforward and healthcare professionals did not have a clear script to follow. It may be possible that the absence of a "script" has an impact on the gaps in the interdisciplinary work in a changing "patchwork" healthcare terrain, where treatment and follow-up take place in the home to a greater extent. Facilitating follow-up in the home changed the healthcare framework and prerequisites. Other negotiations and collaborative transfers are required for healthcare professionals to provide care in patients' homes, where the patient and next of kin are expected to play a collaborative role.[35]

An example of a type of "script" might be standardized care pathways, described in the literature as possible tools to bridge gaps in collaboration and articulation of knowledge surrounding healthcare. One intention is to strengthen the predictability and quality of treatment.[36] However, to function properly, these care pathways should be relevant to healthcare practice and be able to be maneuvered by those involved.[12] So far, standardized care pathways have been diagnosis specific and do not fit into the picture of the complex patient trajectories and life stories of elderly patients.[10,37] Care trajectories that cannot be pushed into a script may make it more challenging to find common goals and approaches in healthcare practice.

Strengths and Limitations

A strength of this study is the diversity of the participants in terms of profession and workplaces (hospital and primary care). Although whether saturation was achieved is questionable, the data material provided thick and rich information, which contributed new insights into how healthcare professionals work to build coherence in older patients' care trajectory. A limitation is that we were unable to take our analysis and interpretations back for a member check[38] because of the variety of workplaces and distances between them.

The first author is an experienced geriatric nurse, which might have influenced the focus of the interviews. However, her experiences may also open up for questions that otherwise would not have been addressed. Thus, the preunderstanding and assumptions might have influenced the data collection and interpretation of the data. To strengthen the trustworthiness, the entire research group reflected on and discussed the data throughout all phases of the research process and in particular during the analysis phase.

Conclusion

Healthcare professionals have a common understanding that hospital stays are only a short part of elderly patients' journey in the healthcare system and that they must take account of the elderly patient's life. Building an overall picture of the patient beyond the illness trajectory and within her/his life is important for managing the care trajectory. Interdisciplinary work is highlighted as expedient for achieving this complete and comprehensive picture. For this purpose, the findings in our study indicate that interprofessional consulting and collaboration should be strengthened in the work to build coherence within the complex care trajectory of elderly patients.

Data Sharing Statement

The data that support the findings of this study are available from the Innlandet Hospital trust Norway, but restrictions apply to the availability of these data, which were used under license for the study and so are not publicly available.

Ethical Approval and Informed Consent

The Norwegian Centre for Research Data (NSD) was notified about the project, ID: 54,551. The NSD assessed that the processing of personal data was regulated in The Personal Data Regulations 465 [Forskrift om behandling av personopplysninger]. Participation in this research was based on informed voluntary consent and all participants received verbal and written information about the study and were free to withdraw at any time. All participants signed an informed consent form.

Consent for Publication

The written consent form contains information that the publication of the study results will be in anonymous form so that the participants cannot be identified.

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Disclosure

The authors report no conflicts of interest in this work.

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RESEARCH ARTICLE Open Access

Elderly patients with complex health problems in the care trajectory: a qualitative case study

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Abstract

Background: Elderly patients with multiple health problems often experience disease complications and functional failure, resulting in a need for health care across different health care systems during care trajectory. The patients' perspective of the care trajectory has been insufficiently described, and thus there is a need for new insights and understanding. The study aims to explore how elderly patients with complex health problems engage in and interact with their care trajectory across different health care systems where several health care personnel are involved.

Methods: The study had an explorative design with a qualitative multi-case approach. Eleven patients ($n = 11$) aged 65–91 years participated. Patients were recruited from two hospitals in Norway. Observations and repeated interviews were conducted during patients' hospital stays, discharge and after they returned to their homes. A thematic analysis method was undertaken.

Results: Patients engaged and positioned themselves in the care trajectory according to three identified themes: 1) the patients constantly considered opportunities and alternatives for handling the different challenges and situations they faced; 2) patients searched for appropriate alliance partners to support them and 3) patients sometimes circumvented the health care initiation of planned steps and took different directions in their care trajectory.

Conclusions: The patients' considerations of their health care needs and adjustments to living arrangements are constant throughout care trajectories. These considerations are often long term, and the patient engagement in and management of their care trajectory is not associated with particular times or situations. Achieving consistency between the health care system and the patient's pace in the decision-making process may lead to a more appropriate level of health care in line with the patient's preferences and goals.

Keywords: Care trajectory, Complex health problem, Elderly, Care pathway

Background

The World Health Organization [1] highlighted the need to implement an integrated people-centred health service, particularly for people with chronic or complex health conditions in need of care and support. Elderly persons with multiple health problems often experience disease complications and functional failure, resulting in a need for health care across different levels of care and social services. It has been shown that such care trajectories can be complex when many health and social personnel are involved [2, 3].

Several terms have been used to describe patients' needs that span levels of health care system, including care pathways, clinical pathways, critical pathways, care trajectories, standardised patient pathways and care bundles. The term care pathway can be defined as the

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management of care and chronological activities of a health care process for a well-defined group of patients during a well-defined period of time [4]. Standardised care pathways have been suggested as a solution for ensuring patient safety, improving risk-adjusted patient outcomes, increasing patient satisfaction and optimizing the use of resources [5]. Nevertheless, studies have shown that standardised care pathways are more effective in contexts with predictable care trajectories and low uncertainty and complexity [4, 6, 7]. At present, health care authorities have an increased demand for patient treatment standardisation and patient treatment individualisation. Standardised care pathways promote procedures and standardised activities. However, questions have been asked if these pathways are a risk to patient preferences and if individual needs will receive less attention [8, 9].

In this study, we chose the term care trajectory that is commonly used to describe a patient's journey through the health care system. According to Allen et al. [10], the term refers to 'the unfolding of patients health and social care needs, the total organisation of work associated with meeting those needs, plus the impact on those involved with that work and its organisation' [10]. They provide a framework for the understanding of the linkages between individual trajectories of care and broader health and social care systems.

Many elderly patients with multiple health problems perceive health services as complex and challenging to comprehend, and therefore need support from health care professionals to ensure continuity of services. The transition from hospital to home can be an uncertain and challenging experience [11–13]. Information and participation in planning and decision-making during hospital stays and discharge may be inadequate; therefore, elderly patients should be encouraged to participate. Studies have shown that patients' health needs must be considered and the hospital environment should be organised and prepared to encourage patients' participation in their discharge planning [14–17].

International as well as Norway health authorities have deployed standardised care pathways for specific patient groups. However, in Norway, no care pathways have been fully established and understood for elderly patients with multiple health problems [18]. Local tailoring combined with standardisation can be important in developing pathways that enable different purposes and contexts [19–21].

Research has emphasised the need to expand our understanding of complex care trajectories and why integrated health and social service care can be challenging. The importance of investigating how individual activities and decisions take place in an organisational context and how involved persons interact has also been emphasised [22].

The perspectives of elderly patients with complex health problems of care trajectories have been insufficiently described in previous studies [8, 19, 23, 24]. New insights are required to achieve an integrated care pathway. Therefore, this study aims to explore how elderly patients with complex health problems engage in and interact with their care trajectories across different health care systems where several health personnel are involved.

Methods

The study used an explorative design. We adopted a qualitative multi-case approach to obtain an in-depth understanding of patients' perspectives of care trajectories and how patients participate during their hospital stay, discharge and return to home process. This case approach was considered appropriate for examining patients' real care trajectories because it was possible to account for the diversity of context [25]. The multi-case method enabled the exploration of inequalities and similarities across care trajectories, aiming to identify common patterns [26]. We recruited 11 patients representing diversity across contexts for our data collection. For each case, observations and multiple interviews were carried out to elucidate the divergent aspects of care trajectories. The cases provided us with rich and comprehensive information relevant to the aim of this study [25].

Setting and participants

The Norwegian health care system consists of two organisational structures. The local municipalities are responsible for providing primary care services, including general practitioners (GPs), intercommunal emerging primary care centres, home care services, nursing homes and preventive services. The Ministry of Health and Care Services is responsible for specialist care, which involves all hospitals. In 2012, the government implemented the Norwegian Coordination Reform [27] to strengthen the interaction between different levels of health services and to secure coordinated health care. Development of integrated care pathways, especially for patients with long-lasting complex health needs, has increased the focus on developing pathways. This reform, combined with the Patients Right Act, emphasises the importance of patient participation in improving the continuity and quality of care.

To identify patients who met our inclusion criteria, the study's starting point was conducted at two different hospitals located in the same health region: one rural and one urban hospital. We intended to follow patients during their hospital stays and trajectories across different health care levels. We considered it inappropriate to recruit patient participants prior to possible hospital admissions. The recruiting process was, therefore, conducted at the hospital departments.

Patients were selected from the surgery and internal medicine departments of the hospitals. The inclusion criteria for the patient participants were as follows: older than 65 years, having 2 or more chronic diseases and living at home before hospital admission. The exclusion criteria were if the patient was not capable of giving consent or in the terminal phase. A contact nurse in the eligible departments informed the patients verbally and in writing about the study. Eighteen patients were requested for participation. Eleven patients consented to participate whereas seven patients declined due to worsening health conditions. The patients varied in age and the distance between their homes and the hospitals. Patients from nine different municipalities were involved. The population ranged from 2000 to 27.000 inhabitants. Characteristics of the patients who agreed to participate and the observation period for each patient are shown in Table 1. No participants dropped out of the study.

Data collection

We applied an observationally driven approach to this case study [28]. The starting point for the data collection was to meet the patient in the department where he or she was hospitalized. The first author (MK), a PhD candidate and an experienced geriatric nurse, conducted field notes and conversations with the patients and repeated more structured interviews with the patients during the observation period. The professional background of the researcher was known to the participants. Moderate participant observation was used; the researcher was identifiable, interacted with the participants and engaged in activities, but did not participate in the setting [29].

The focus of the observations was to identify situations and activities during the care trajectory in connection with the health services and patient's interactions with the involved persons. Typically, observation points at the hospitals involved sitting with the patient and observing activities and dialogue between the patient and health personnel, observing morning meetings with the staff group, noting pre-visits and doctors' attendance at the patients' rooms and following patients during discharge and their transfer home. In the municipalities, the observations commenced at the professional base of the homecare nursing or the multidisciplinary team and following the staff on their visits to the patients' homes. On some days, when the first author visited patients at their homes or rehabilitation units, the next of kin was also present. The length of the structured interview varied from 5 to 45 min, according to the patient's health status and day-to-day condition. The main theme of the interview was on the patient's past, current, and future perspective on the care trajectory (See additional file 1). Overall, the first author conducted 24 structured interviews and 86 h of observations. The data were collected from November 2017 to June 2018.

Analysis process

The first author transcribed all the recorded interviews verbatim. Field notes were written down as short sentences during the observation. Immediately after the observations, the field notes were expanded into full sentences. All the data was de-personalised before analysis. A thematic analysis approach using Braun and Clarke's [30] was applied. Initially, the first author read the field notes and the interviews thoroughly and chronologically for each case to identify essential characteristics and patterns. Notes were taken to describe the descriptive and analytical attributes of the data. Thereafter, the data were read and coded systematically and the codes were organised into possible sub-themes for the entire cases as illustrated in Table 2. The back-and-forth process between the codes and possible themes involved reviewing relevant

Table 1 Participants, observation periods, number of interviews and distances between home and hospital

Participant [a])	Age ranges[b])	Observation period	Number of interviews	Distance between home and hospital
Finn	1	7 weeks	2	175 km
Maria	1	2 weeks	2	5 km
Eva	2	7 weeks	3	30 km
Eric	2	18 weeks	4	40 km
Anna	2	6 weeks	3	5 km
Kai	2	5 weeks	2	80 km
May	3	13 weeks	4	5 km
Martha	3	7 weeks	1	200 km
Albert	3	2 weeks	1	10 km
Henry	3	3 weeks	1	200 km
Hannah	3	10 weeks	1	20 km

[a])The participants names are pseudonyms

[b]) The participants are presented in three age range groups. Group 1, range between 65 and 70, group 2, range between 71 and 80 and group 3, range between 81 and 95

research and theoretical perspectives to help understand the data. This process revealed three main themes.

Ethical considerations

The study has been notified by the Norwegian Centre for Research Data (ID: 54551) and assessed and approved by the hospital data controller of the two hospitals.

Participation in this research was based on informed, voluntary consent. Ethical issues related to consent were considered during the recruitment process. During the observation period, the first author had a special awareness of maintaining voluntary and consent-based participation. Information about the possibilities to withdraw any time from the study was given both verbally and in writing. The first author had no contact with the patients before they were informed of this study by the nurse. The patients' consent to participate was given both verbally and in writing. To ensure that patient anonymity is protected, some of the demographic data were rewritten. Hospitals and municipalities involved in the studies were anonymised.

Results

The overall findings of this study suggest that patients' engagement in managing their care during the care trajectory is not a linear process regarding time and space or situations and events that need action. They chose a variety of strategies to participate in their care management, driving the care trajectory forward and handling barriers. The patients were engaged and positioned themselves according to three identified themes: continuous consideration of opportunities and alternatives, consideration for appropriate alliances and circumvention of the health care initiation of planned steps.

The analyses revealed that the care trajectory is characterised as a landscape of complex and interconnected events and situations—sometimes planned, chaotic or ad hoc. In some settings during the care trajectory, patients need to deal with many activities simultaneously. The observations revealed that, in some situations, patients had to manage information on the follow-up treatment, medication changes, decisions regarding further health care and readiness to return home or nursing homes, which was given at the same time.

Another simultaneous event that occurred during hospital stays was when health personnel decided to move a patient to another ward or unit at the hospital because of limited space while they were prepared for discharge. Such a situation could be sudden and unexpected to the patient. On the day of discharge from the hospital, several activities, such as ongoing treatment and various controls, were conducted. In the municipality, the patient could receive health care services from several units with different health personnel involved, including homecare nursing and home care assistance, multidisciplinary team, physiotherapists and GPs. Parallel to primary care health services, patients also received outpatient treatment at the hospital.

To provide an in-depth understanding of the themes, cases that are typically for each theme are chosen.

Continuous consideration of options and alternatives

A strategy some patients used was to continuously consider options and possibilities on how they managed

Table 2 Example of the analysis process

Example of codes	Example from codes to sub-themes	Identified themes
It's better to re-housing than move to a nursing home	To looking for alternatives and be flexible	Continuous consideration of opportunities and alternatives
Consider to stay at home or move to relatives	To have long and - short perspectives	
To get in better shape and see what happens	To use their strength appropriately	
	To sought for the most important health personnel	Consideration for appropriate alliances
The importance of previous contact with and trust in health professionals	To describe my social network	
Despair by not knowing who to contact	To use my long relation with the health personnel	
What I can't do anything about, is not worth the effort	To deal with unresolved question and unclear responsibilities	Circumvention of the health care initiation of planned steps
Looking for the best way to react	To consider the access to health care	
Many unresolved questions and considerations at the same time	To choose another approach to handle the further direction of the care trajectory	
Organizing and coordinating further treatment and follow-up		
Searching for practical solutions that contribute to alternatives		
Not well-facilitated in the environment for participating		

different actions and challenges during their care trajectory. The patients expressed their views on their current health situations. Furthermore, they also questioned how they could manage their situations and use their strength and energy appropriately and weighed different possibilities. They consider what was most important, what could wait and what was not possible.

Sometimes patients felt they were not ready to make decisions concerning changes in their housing situation or plan for further health care. They chose to see 'what happens' and prolong the decision. In situations involving several individuals and rapid changes in care environments, patients deliberated about their strength and capacity and assumed a distant or observant position.

Below, we chose to present two typical cases that describe the patients' considerations of their opportunities and alternatives to housing conditions and further health care. The patients needed long-term decision-making beyond the period of hospitalisation and discharge planning. They held off on deciding until they were ready for it.

Case

Anna was admitted to an internal unit at the local hospital due to chronic breathing difficulty that worsened. Anna lived in her apartment in a community near the hospital. A homecare nurse visited her once a day; and during the rest of the day, Anna managed by on her own. In the early phase of her stay at the hospital, she expressed that she was afraid she could no longer manage by herself at home; her health condition was too poor. However, she was still looking for possible options for going home and thinking about what she might need in terms of health care and facilitation, such as night visits by homecare nurses. This option was important for her, as it made her feel safe about being alone at home.

A few days after hospitalization, Anna was discharged to a rehabilitation unit in her home community. During her stay at the hospital and the rehabilitation unit, there was a conversation between her and the health personnel about either being discharged to her apartment or being moved to a nursing home. Anna was reluctant to be active in these decisions. Several times during these weeks, she expressed that she had to be in better shape and wait for further development before making a decision as illustrated in this quote:

> 'When I feel that I can't manage myself at home, there is no point in trying. Then, I just have to get help from someone by applying for a permanent place in a nursing home or a sheltered house. However, I have to say I am not ready for that yet. If I do not get any better, then I will have no choice, but I have to decide on that later. I will take it one day at a time and see what happens.'

After 3 weeks at the rehabilitation unit, Anna expressed that she needed to take it 1 day at a time but could already take a more active position:

> 'I still have problems with my breath, but I am so satisfied and feel I am in better shape. I know my body. Next week, I will go home with help from homecare nurses. Tomorrow, we are going to have a meeting here. Then, we will decide on the number of visits I will need from the homecare nurse. Then, I will know. We are going to have the meeting together with the leader at the unit.'

Anna's case shows how several patients constantly considered their capacity and strength and continuously searched for possibilities and options. Anna chose to wait and hold off on deciding whether she should return home or to a nursing home.

Case

May considered changing the house conditions to achieve the appropriate level of care for herself and her husband. She lived with her husband, who received assistance every day from homecare nurses due to illness and functional decline. They lived in a single house with bedrooms on the second floor. May took care of housekeeping, organised health care, and kept in touch with their GP and homecare nurses, among others. I (first author) met May when she was admitted to a hospital because of vertigo and declining general conditions, and followed her during her hospital stay and some months after her return home. After her discharge, she and her husband started receiving additional homecare nursing assistance, and a personal emergency response system was installed in their home. She worried that she and her husband could fall down their stairs. She mentioned several times that she and her husband were discussing applying for sheltered housing. According to May, the health personnel in community care told them many times that they could move to a sheltered house. She expressed:

> 'We intend to apply for it, but we have not chosen to do so yet. Now, life goes on as before. It's stable, and I've got a personal emergency response system. The neighbour picks up the mail for us. Basically, we do not want to move out of the house as long as we can manage to lock the door!'

The cases show the constant considerations of what options would be the best for them.

Consideration of appropriate alliance partners

One strategy that patients used to handle unclear situations and considerations of health care was to search for health personnel they found trustworthy who could help them organise their health care needs. The patients described the people that supported them in their daily living and the trustworthiness of the health personal. These trusted persons and health personnel were strong alliances for patients during their care trajectories.

The following case describes how a patient actively searched for health care personnel who could help or take responsibility in his situation, which involved persistent health problems.

Case

Eric was a patient with a complicated and persistent illness. After spending several weeks in a hospital for diagnosis and treatment, he was discharged and sent home. He lived with his wife in an apartment. Eric followed-up with two different wards at the hospital and received homecare nursing and physical therapy from the municipal health service. In daily life, he expressed that he and his wife had many unanswered questions about his health problems and symptoms. Eric mentioned several times how challenging it was to find health care personnel at the hospital who could give accurate information and somebody who could be responsible for his ongoing medical treatment. He was told that he needed to contact his GP, but he felt his GP was not particularly involved. Due to his limited interaction with his GP, Eric felt his symptoms were initially not taken seriously, and he lost trust in his GP. At one point, Eric felt he needed advice related to specific symptoms involving his leg and ongoing treatment but felt that he was not likely to receive proper health care. Thus, he approached a homecare nurse he trusted to contact the doctor at the hospital on his behalf about his concern with the leg. He told he did it this way:

> ‘The call becomes a priority when the nurse calls to ask about the symptoms. I talked to the nurse about this physiotherapist too, he needs a case summary and referral from the doctor. Now it’s okay, I got this by the doctor when I was at the hospital for treatment this week.’

This case illustrates how a patient actively searched for alliance partners to obtain access to proper health care in a setting where he needed to interact with many actors at different levels.

Circumventing the health care initiation of planned steps

We also identified cases where patients circumvented the hospitals’ formal planning systems because the situations were not well-facilitated or appropriate for their ability to participate. In some cases, patients design their care trajectory. The following case is an example of how a patient circumvented the hospital’s planning process.

Case

Henry was admitted to a hospital because of heart failure. Some complications in his health situation unexpectedly prolonged his hospital stay. Because Henry suffered from hearing loss and slowed speech, it was challenging for him to understand and follow the information that was given to him at the hospital. During the pre-visit, the nurse and doctor discussed Henry’s return home. The nurse announced that Henry would need to establish some home care services, if nothing else, to help with his medication. During his doctor’s patient rounds, Henry did not have sufficient time to ask questions or give feedback. Henry tries to tell the doctor he has some questions, but it takes time because of his trouble with the speech. After a few seconds, the doctor says he can contact a nurse when he remembers.

After the visit, Henry told me (first author) that he was unsure about what the doctor meant when he told Henry that he should stay for at least one more day, that is, whether it meant that he might return home the next day or not.

Henry lived with his wife in a single house located in a rural area far from the hospital. His next of kin and health personnel from the community could not visit him during his hospital stay. He described his lasting relationship with the leader of the local homecare nursing facility and his GP. He expressed trust in the local health service like this.

> ‘I regularly visit my GP to take blood samples. I think my doctor is very capable. The leader in the homecare facility is a decent person. He knows about everything. He has helped us several times.’

During his hospital stay, Henry spoke of having phone contact with the leader of the homecare nursing facility. Together, they organised his need for health care and the assistance that he would require after discharge. He also contacted a neighbour to take care of snow shovelling at his home. The leader of the homecare nursing facility stated that he had known Henry and his wife for a long time. He added that Henry had been clear about coming home instead of being transferred to a nursing home. According to the leader, phone contact served as a way to stay in contact with the patient during the latter’s hospital stay.

This case is an example of how a patient actively chose another approach to handle the further direction of his care trajectory. The hospital’s environment and discharge planning did not functionally allow Henry to interact with health personnel. The next of kin could not be near the hospital for support. Therefore, he sought a new option for handling his situation and circumvented the hospital personnel’s plans and processes for discharge.

Discussion

How the patients were engaged with and interacted in their care trajectories varied and was influenced by their health conditions and how their situation afterward could be managed. We found that the patients, who are often described as vulnerable, carried out considerable 'homework' to navigate their health condition as well as the system they accounted [31]. The patients constantly considered opportunities and alternatives in interaction, negotiations and relationships between many actors, or 'players' [22] for handling the different challenges and situations that occurred during their care trajectory. To understand why and how they searched for appropriate alliance partners to support them, and in some situations, how they circumvented the planned steps and took different directions in the care trajectory will be discussed against the conceptualisation of care trajectory game (CTG) [22]. The CTG framework merges Strauss et al.'s [32] descriptions on illness trajectories and Elias's [33] game model and provide a framework to understand and address the dynamics and complexity in the system and thus, move away of thinking trajectories in mono-causal explanations which appear to be the characteristics of current policy [3, 8].

The complexity in the patients' care trajectory became visible throughout the patient's multiple considerations about options and multiple alternatives they needed to take into account. They were dealing with balancing their strength and capacity and the complexity of the health care system in how they could be involved in decision-making. Their considerations seemed to be a continuous process. We identified that patient participation in their care trajectory was not linked to specific times or situations. Issues regarding the need for necessary health care and life modifications or changes in living arrangements were deliberated for patients throughout their entire hospital stays and continued after discharge. It was often an ongoing negotiation between patients, health personnel and next of kin. Patients wanted to have options, but time for recovery was often essential in preparing them for participation in decision-making. The patients' also seemed to keep a watchful waiting whereby they try to maintain the status quo to desired preferences for as long as possible. The patients in this study used different strategies in situations with a disagreement between their preferences, health care need and initiation of planned steps. For example, they waited to be ready for decisions, circumvented planned steps and found a new direction in their trajectory. Allen et al. [22] point on that 'disagreement' over plan for further direction in the care trajectory not necessarily needs to be negative for the patient. The negotiations and different input from the involved can bring new opportunities and options, which are more in line with the patients' preferences. It is not appropriate to try to simplify the complex care trajectories, but rather organize the services so that several opportunities and alternatives can be included [22]. Today's health care system is characterised by overall expectations to the health personnel to working quickly and efficiently in bed administration, and hospital period is shortening [34, 35]. With reference to CTG, health professionals can form an alliance to achieve an effective transfer of care. As an example to press for a nursing home placement rather than a home discharge, that can be easier to organize. From a health personnel perspective can this solution simplify the complexity in the organization of the patient care trajectories, but on the other side lock and hinder the patient's ability to see different opportunities and alternatives, which are in preference to the patient's wishes [22].

Our findings describe situations with interactions between patients and many health personnel at different health services levels. These situations increased the patients' perceived considerations regarding which personnel could take responsibility for their treatment and organisation of their care. Existing literature has described patients' and next of kin' experiences of fragmentation regarding obtaining control and access to the health care system during discharge and follow-up care, which are in line with our findings [36–38]. We found that to handle fragmentation and uncertainty about health care, the patients sought alliance partners who could help in their interaction with and access to health care. When complexity increases in the care trajectory, fragmentation increases between the involved actors, leading to a re-grouping of those involved [22]. Unanswered questions about health problems and symptoms were uncertainty patients in our study experience and a lack of available and appropriate information. Kneck et al. [39] have pointed out that the patient is expected to be an active partner, but that the patients at home can have insufficient information to manage their illness. They may be unsure of 'which symptoms might occur and who to contact for different needs' [39]. Mattingly et al. [31] use the term 'chronic homework, about tasks the patients and family caregivers are expected to carry out when moving health care from hospital to home. Their supporting network was essential to handle this 'homework', and to strengthen the patient's possibility to take responsibility for their care. In our study, the patients described how they used their alliance partner strategically as an important support to achieve access to health care and to drive the plan further in the trajectory.

When the patients experienced that they were not involved in decisions concerning themselves, they used their strategies to circumvent the system. Insufficient facilitation of patient participation in the care environment is another barrier described in our study. Time and space for patients to participate in discussions about their health and the need for health care were not always arranged properly. Despite these situations, the patients considered their possibilities and alternatives and circumvented barriers and make their further plans. According to CTG, the resources available can both shape the complexity and cause those involved to make various moves to circumvent barriers.

Findings in our study describe inadequate facilitation of participation and necessary access to health care, norms and the view of the elderly person may contribute to it. Health professionals' views of the elderly and younger are highlighted as a possible challenge in access to treatment and follow-up [40, 41]. Hamran et al. [40] found that only based on a norm understanding that 'they are just old' access to health care could be less, and the time for treatment and improvement was expected to be resolved in the same way as young people who do not have the same complexity. Norms and values are interviewing with the actions and decisions in the care trajectory and increases complexity [22].

Implication for practice

For an elderly patient with complex health problems, there is expedient to develop a care trajectory that is developed to meet the need for flexibility. In practice, it can mean accepting that the patient is about participating in managing and making decisions, often a continuous and long-term process. Facilitating for this in organizing the health system service, and time and space for the patients' considerations to managing necessary modifications in everyday life such as re-housing or move to a nursing home.

Methodological strengths and limitations

Triangulation of data sources, observations and individual interviews were used to investigate the care trajectory from different perspectives and settings, which was appropriate given then intention of the current study to gain a richer and deeper insight of patients' care trajectories.

The first author who conducted the observations and interviews was an experienced geriatric nurse. The researcher's assumption, skills and knowledge will influence the focus in observations and shape the interpretation [42]. Background as a nurse gave the advantage to understand the field. To strengthen the trustworthiness, additional reflection notes were performed describing choices, questions or thoughts that arose during the observations and were for review by the research group.

The first author followed each patient over a long period, which contributed to a broad understanding of each patient's case. We experienced some challenges in recruiting participants due to patients' health conditions and vulnerable situations. Despite that the participants' age, living situation and home setting varied. Since the findings are based on a small sample, they should be considered with caution in the light of generalizability. Nevertheless, we believe these findings provide new insight and understanding of the complexity of elderly patients' care trajectories.

Conclusion

The patients' considerations of their health care needs and adjustments to living arrangements are constant throughout the care trajectory. These considerations are often long term, and the patients engagement in and management of their care trajectory is not associated with particular times or situations. It may be important for elderly patients' time for recovery in order to consider different possibilities and options before managing necessary modifications in everyday life.

Disagreements between preferences, the need for health care and the initiation of planned steps, leads to different strategies from the patients. They wait to be ready for decisions, circumvent planned steps and find a new direction in their trajectory.

Achieving consistency between the health care system and the patient's pace in the decision-making process during the care trajectory, may lead to a more appropriate level of health care in line with the patient's preferences.

Supplementary information

Supplementary information accompanies this paper at https://doi.org/10.1186/s12913-020-05437-6.

Additional file 1. Interview guide. Patient interview schedule

Abbreviations

GP: General practitioner; CTG: Care trajectory game

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Availability of data materials

The data materials generated during the current study are not publicly available due to the sensitive and identifiable nature of the data. Despite names and other identifiers being removed, the in-depth nature of the interviews and field notes themselves may mean that participants can be identified from the full transcripts.

Authors' contributions

MK, KK, GVB, RH contributed to the conception and design the study. MK performed the data collection and the analysis, and developed the manuscript. KK, GVB, RH contributed to the interpretation of analysis. MK and RH critical revised the manuscript. All authors read an approved the final manuscript.

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Ethics approval and consent to participate

The project was notified by the Norwegian Centre for Research Data (NSD), ID: 54551. NSD assessed that the processing of personal data was regulated in The Personal Data Regulations [Forskrift om behandling av. personopplysninger]. NSD considered that the project did not raise any ethical issues, which was in need of ethical approval. The project was also assessed and approved by data protection officer at the hospital. Participation in this research was based on informed and voluntary consent. All patients that filled the inclusion criteria received verbal and written information about the study. A senor nurse in the department assessed and assured the patient's consent competence. No participants included in this study had a cognitive decline. All participants consented to participate on their own behalf and signed an informed consent. They were free to withdraw from the study at any time.

Consent for publication

The written consent form contains information about scientific publication of results of study in anonymous form.

Competing interests

The authors declare that they have no competing interests.

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Dilemmas and deliberations in managing the care trajectory of elderly patients with complex health needs: a single-case study

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Abstract

Background: Today, the ageing population is larger than ever before, and people who are living longer with chronic illnesses and multimorbidity need support from multiple healthcare service levels. Similarly, healthcare systems are becoming increasingly specialised and fragmented. The World Health Organization has highlighted novel policies for developing integrated and person-centred services. However, patients, next of kin and health professionals face several challenges in managing healthcare during the care trajectory. Limited literature has addressed the challenges experienced by these groups. Therefore, this study aimed to identify the dilemmas and deliberations faced by patients, next of kin and health professionals during the care trajectory of elderly patients with complex healthcare needs.

Method: The study had a qualitative single-case design. The case was taken from a multi-case study exploring the care trajectory of elderly patients. The participants were the patient, their next of kin and the health professionals involved in the patient's care trajectory. Data were obtained via observation and individual interviews conducted during the patient's hospital stay and after the patient returned home.

Results: The dilemmas and deliberations in managing the care trajectory were divided into four main themes: the health professionals' pursuit of appropriate and feasible healthcare services, the next of kin's planning horizons, being the person left in limbo and reorganising the home for comprehensive healthcare.

Conclusion: The pursuit of a tailored and suitable healthcare service lead to a comprehensive mobilisation of and work by all actors involved. Having a comprehensive understanding of these conditions are of importance in developing an appropriate care trajectory for the elderly patient with complex need.

Keywords: Elderly, Care trajectory, Complex healthcare needs, Person centred, Coherence

Background

Globally, the mean age of the population is increasing, and within this ageing population, more people are living longer with chronic health conditions and multimorbidity [1, 2]. When these people encounter healthcare systems that are becoming more specialised and fragmented, they must receive healthcare from multiple professionals who work at different levels of the healthcare services [3, 4]. To establish coherence for elderly people with complex healthcare needs, care pathways have been developed with the aims of delivering professional and efficient care, controlling resources and improving patient satisfaction and the predictability of the patient's trajectory [5–7]. A key feature is to achieve a streamlined

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process in a patient's trajectory and to prevent undesirable events.

Research has shown that while care pathways are most effective when patients' care trajectories are foreseeable and when directed towards single diseases [7, 8], care pathways developed for single diseases have limited ability to meet the individual and complex needs of patients with multimorbidity [4, 5, 9–11]. These patients are often in need of care from several health professionals, both from primary and specialist healthcare services [4]. There is a risk of breaches of coherence and continuity of care when patients require services from multiple levels with many actors; hence, patients with multimorbidity are more vulnerable to healthcare service fragmentation, and they experience less continuity of care than patients with a single condition [4, 12].

Inadequate care coordination negatively affects the care experience and patient outcome [13, 14], and it has been shown that elderly people and their next of kin experience insufficient coherence in healthcare services and fragmentation in care delivery [15, 16].

A person-centred approach aligns the healthcare services with the values, needs and desires of the patient and reinforces the importance of involving patients in discussions and decisions [17]. However, patients experience to be inadequately involved in the decision-making about their own healthcare needs [18–20]. It has also been found that patients and their next of kin experience a high workload when they attempt to achieve coherence in their care trajectory [21–23]. Furthermore, patients with chronic conditions and their next of kin are expected to constantly attend to managing and changing their daily routines as part of treatment or healthcare. This work not only includes tasks at home, but also comprehensive planning and coordinating of healthcare [16, 24, 25].

An increasing awareness of the limitations of care pathways for patients with multimorbidity has led to efforts to develop more generic patient care pathways and strategies to enhance care coordination; the focus is on being more flexible and adaptable to the needs of individuals with multimorbidity [9, 26–29]. Despite the many strategies currently available for developing interdisciplinary care pathways, achieving inter-professional collaborations that deliver coherent and seamless healthcare is still far from complete [30].

In Norway, where the current study was conducted, the healthcare system is a two-level model. The national authorities organise and manage specialist care, governing via policy and professional guidelines [31]. The municipalities govern the primary care services, which encompass home healthcare services, nursing homes, rehabilitation, public health and general practitioners (GPs). These are governed by local authorities. In 2012, to improve the deficiencies identified (namely discontinuity and disintegrated care) across these levels of healthcare, the Norwegian government launched a coordination reform to develop coordinated care pathway across primary and specialist healthcare. With this reform, the municipalities gained more responsibility for overall healthcare and rehabilitation needs, with the aim of decreasing the length of hospital stay. The reform also regulated the municipalities' payment arrangement: municipalities began being charged when there were ready-to-discharge patients remaining in the hospital who were waiting for a municipal offer.

Patients' considerations of their own healthcare needs can be an ongoing issue during their entire care trajectories [32]. Moreover, health professionals have specified the challenges associated with offering coherent healthcare for elderly patients [33]. Much research has been conducted to investigate the interactions between and integration of specialised and fragmented healthcare services [16]. Even though there is ongoing research on developing more generic and integrated care pathways for patients needing complex care [10, 16, 34–36], few studies have addressed the involved actors' dilemmas and deliberations during the care trajectory of elderly patients with complex and comprehensive healthcare needs.

Aim

The aim of this study was to illuminate the dilemmas and deliberations of patients, next of kin and health professionals during the care trajectory of elderly patients with complex healthcare needs.

Design and methods

To gaining an in-depth understanding of the underlying mechanisms behind the problems that occur during a patient's care trajectory, we applied a single-case design. The case was taken from a multi-case study exploring the care trajectories of elderly patients and how they participate in and interact within their care trajectory across various healthcare systems [32]. The case was selected because it contains comprehensive data relevant to the topic of the study, namely the complexity of a care trajectory and dilemmas encountered and deliberations made by the involved actors. The individual stories formed a crucial aspect of the findings and provided an opportunity to achieve more complete knowledge and a comprehensive understanding of the case [37].

Utilising multiple data sources is advisable in case studies because it allows diverse perspectives to be captured [38]. The present case included data from participant observation, individual interviews and the patient record system.

Setting and participants

This study was initiated at a hospital in an urban area. Further along the trajectory, the study took place in the patient's home municipality, which has a larger population size. The healthcare services in this municipality were specialised and differentiated, as is the tendency today in municipalities with larger population sizes. In comparison, smaller municipalities often have a more generalist approach [39]. The physical distance between the patient's home and the hospital was less than 20 km.

Participants

The described participants are the actors involved in the selected case (Table 1). The recruitment process started with a contact nurse in the hospital department who delivered verbal and written information about the study to the patient. When the patient consented to participate, the information was repeatedly delivered to the patient by the first author, and the patient signed a consent form. Furthermore, the patient was asked for consent to contact his next of kin and the healthcare personnel involved in his care trajectory. The patient was also asked for permission to extract his data from the patient record system. After receiving these permissions, the first author contacted and provided verbal and written information to the next of kin and health professionals included in the study.

Data collection

The data collection was conducted during the spring of 2018. The first author carried out participant observations for 2 weeks. The observations were initiated on the day the patient was discharged from the hospital and included the patient's journey back home, as well as the reception and meetings with the interdisciplinary team and home care nurses in the patient's home. Additional observations occurred at the patient's home and the health professionals' offices during workdays. During the observation period, interviews with the patient, next of kin, and health professionals were performed. To extend the understanding of what had occurred during the care trajectory, the main themes and topics of the interview covered events before hospitalisation, the current situation and future perspectives on the care trajectory. Data from the interviews and documentation from the patient's records were gathered to investigate and obtain insight into the period from admission to discharge from the hospital. Furthermore, the first author participated in a meeting in which professionals from the hospital and the municipality discussed their collaboration. Field notes were taken to document the observations. During the observations, only short sentences and key words were written down. More extensive notes were recorded immediately after an observation. Short dialogues with the participants were recorded as field notes.

Table 1 Participants included in this case

Participant		Number of participants
Patient	Albert (aged above 80)	1
Next of kin	Spouse	1
	Son	1
Hospital health professional	Nurse	4
	Physiotherapist	1
	Doctor	1
Municipal health professional	Nurse	3
	Physiotherapist	1
	Occupational therapist	1

Analysis

Field notes, transcribed interviews and documents extracted from the patient record were organised chronologically through the trajectory to coherently comprehend the case's story [38]. All the data were assessed as a complete set and read as a whole several times in search of patterns and themes [40]. Initially, descriptive and analytical codes were generated. Subsequently, subthemes and preliminary themes representing the data were generated. Development of the main themes was guided by the research question. The entire analytical process alternated between the various data sources to investigate, justify, supplement or expand the insight and understanding of the data material along with the study's objective [41].

Ethical considerations

The Norwegian Centre for Research Data was notified about the study (ID: 54551) and determined that the study did not raise any ethical issues that needed ethical approval. The Institutional Review Board at the hospital also assessed and approved the study. Participation in the study was voluntary and based on informed consent given both verbally and in writing. During the observation period, special attention was paid to ensure that the patient was participating voluntarily and with informed consent, and information about the study and voluntary participation was repeatedly provided. Information about the possibility of withdrawing any time from the study was given both verbally and in writing. To ensure protection of the participants' anonymity, some of the demographic data were rewritten.

Findings

The main themes derived from the analysis were illuminated through the account of the care trajectory case. The themes were as follows; the healthcare professionals' pursuit for appropriate and feasible health care services, the next of kin's planning horizons, being the person left in limbo and reorganizing the home for comprehensive healthcare. Initially we will present the case Albert.

Albert resided in a house in the countryside with his spouse. He suffered from several chronic diseases and received daily home care for a chronic ulcer and for help with medication administration. One day, he fell in the garden and was admitted to the hospital, where he was diagnosed with a hip fracture. Albert was immediately entered into a care pathway devised for patients with hip fractures, named the fast-track programme. This standardised and quality assured programme provided him with professional assessments during the preoperative phase and decreased the time he had to wait for surgery. The objective of the programme is to initiate the required surgery within 24 hours to prevent unnecessary complications. It includes patient examination in the ambulance, fast diagnosis upon arrival at the emergency department and immediate preoperative care [42, 43]. Albert arrived at the emergency department in the evening, was immediately diagnosed and given preoperative care, and had prosthetic surgery the following morning. Hence, this part of his care trajectory was successful according to the objectives of the fast-track programme [43].

Elective prosthetic surgery patients at the hospital Albert was admitted typically enter a standardised care pathway before surgery. They are invited to participate in a 'prosthetic school' before being admitted to the hospital. The standardised care pathway accelerates the patients' recovery by including immediate training after the surgery and after discharge from the hospital. The patients should receive physiotherapy in their home municipality after discharge from the hospital, followed by a control at the hospital. This care pathway for prosthetic surgery patients is based on a short-term and effective care trajectory.

Emergency patients with a hip fracture, such as Albert, are offered a physiotherapy programme in the hospital through the fast-track programme. No other standardised care pathway applies to these patients. However, the hospital does have 'rehabilitation beds' for patients who are self-reliant in daily activities but need additional rehabilitation support. Albert required further rehabilitation after his surgery; however, he was ineligible for a rehabilitation bed because his healthcare needs were too complicated. A hospital nurse stated:

> *'Some patients "fall between two chairs". Some complications occur; those who have fallen and are frail need a rehabilitation bed.'*

A physiotherapist noted the differences in the follow-up for the prosthetics patients as follows:

> *'The length of hospital stay has decreased dramatically. The hospital does not want us to use the rehabilitation bed because they have to pay for it. For the oldest patients with a hip fracture and prosthetic surgery, there is no control at the hospital. The municipality should do the follow-up. We do not know exactly how it goes with the oldest.'*

When Albert was deemed ineligible for a hospital rehabilitation bed due to his comprehensive care needs post-surgery, the complex and unforeseen part of his care trajectory began.

The health professionals' pursuit of appropriate and feasible healthcare services

When it became obvious that Albert was too sick and vulnerable to continue in the planned care pathway, several dilemmas arose that were associated with finding the best options for meeting his ongoing healthcare needs. While the municipal health professional was assessing suitable rehabilitation options, the hospital health professionals determined that, due to hospital policy, Albert had to be moved to an outside bed in another unit at the hospital during the waiting time. The outside bed was used for patients who could not be discharged according to plan, and for patients assessed as ready for discharge who were waiting for an offer from the municipality. The health professionals had the responsibility of deciding which patients were eligible for relocation to an outside bed.

Albert stayed at the initial unit for 5 days before being transferred to an outside bed. The professionals articulated that they strived to ensure the quality of care by stating that all patients would stay in the initial unit for at least the first 1 or 2 days. The physicians from the initial unit continued to follow-up patients moved to an outside bed. The nurses expressed that relocating the patient usually resulted in inferior follow-up and meant less professional care and less continuity of care. A nurse described how challenging it was to keep patients in the initial unit and to make assessments regarding the most suitable patients to move:

> *'All units must provide an overview of their bed capacity. We try to put the right patient in the right place. For some patients there has been a lot of changes. We make a list of the most eligible patients to be moved from the initial unit.'*

The day after Albert was moved to the outside bed, he was considered ready for discharge. The municipality offered him a rehabilitation bed at the municipality health centre, and he was transferred the same day. However, on the first evening at the municipality health centre, Albert fell again. This is what his son said about Albert's first hour at the centre:

> *'At the health centre, he only stayed for seven or eight hours. My mother and I travelled back home at five pm, and at nine pm in the evening they called me and told me he had fallen again. My father expressed that he wanted to go home.'*

Albert's health condition was assessed as being too complex for further care at the health centre, and he was re-admitted to the same hospital.

The hospital's bed policy influenced the municipal health professionals' deliberations while they were searching for the best healthcare service for Albert. The hospital's policy of emptying beds was highly challenging for the municipal health professionals because they already had issues with the capacity in the municipality. It was considered challenging to ensure sufficient turnover in the municipality's short-term beds, rehabilitation beds and long-term beds. The health professionals expressed that these beds were too often 'blocked' by patients in need of long-term care, making it a continuous challenge to find an empty bed when needed. Here is a description provided by one of the nurses:

> *'Because those [patients] who get a decision on long-term care are blocking short-term beds, so right now … from last week until today, there are some short-term beds available, but now patients who receive homecare and need to get a "boost" for nutritional follow-up and caring are placed in these beds. It's rolling, but it is just a matter of time when it blocks again.'*

The challenges associated with effective bed use were evident during a dialogue between the municipal and hospital health professionals on Albert's planned discharge date. On day eight, Albert was considered ready for discharge from the hospital, and the municipality arranged a rehabilitation bed for him. However, the hospital physicians decided to perform an additional medical evaluation before discharging. The intense exchange of information on the discharge day between the hospital and municipality is reflected in the digital messaging samples shown in Table 2.

When the municipality received the de-registration, the health professional working there decided to offer the rehabilitation bed initially intended for Albert to another waiting patient. This launched a new search for a rehabilitation bed, which ended in Albert eventually being offered a rehabilitation bed in another municipality.

Figures 1 and 2 illustrate Albert's care trajectory. The entire timeline is shown, from his initial admission to the hospital to the time he was discharged and returned to his home.

The next of kin's planning horizons

During his entire hospital stay, Albert's next of kin were in the background, and they played an active role in the planning, which eventually affected the decision about Albert's discharge location. In line with the health professionals' pursuit of a rehabilitation bed during the care trajectory, the next of kin had their own planning horizons. They constantly followed the planning process and

Table 2 Example of electronic message communication between the hospital and municipal health professionals on Albert's discharge day

Message sender	Time	Message
Municipality	10.45	Thanks for the information. Possibly he will get a place at a health centre tomorrow – for a short-term rehabilitation stay. You will finally be informed this morning.
Hospital	10.50	Notification of patient ready for discharge has been sent. I hope he gets a bed at the health centre.
Hospital	10.56	De-registration of a patient ready for discharge is sent. The patient waits for a medical assessment before he is ready to be discharged.
Municipality	11.02	He gets a place/bed at the health centre tomorrow.
Hospital	13.40	Notification of patient ready for discharge sent. The patient has received medical supervision and is assessed ready for discharge.
Municipality	14.36	Because he was de-registered ready to be discharged earlier today, another patient has been allocated. Therefore, we do not have room for him until next week.

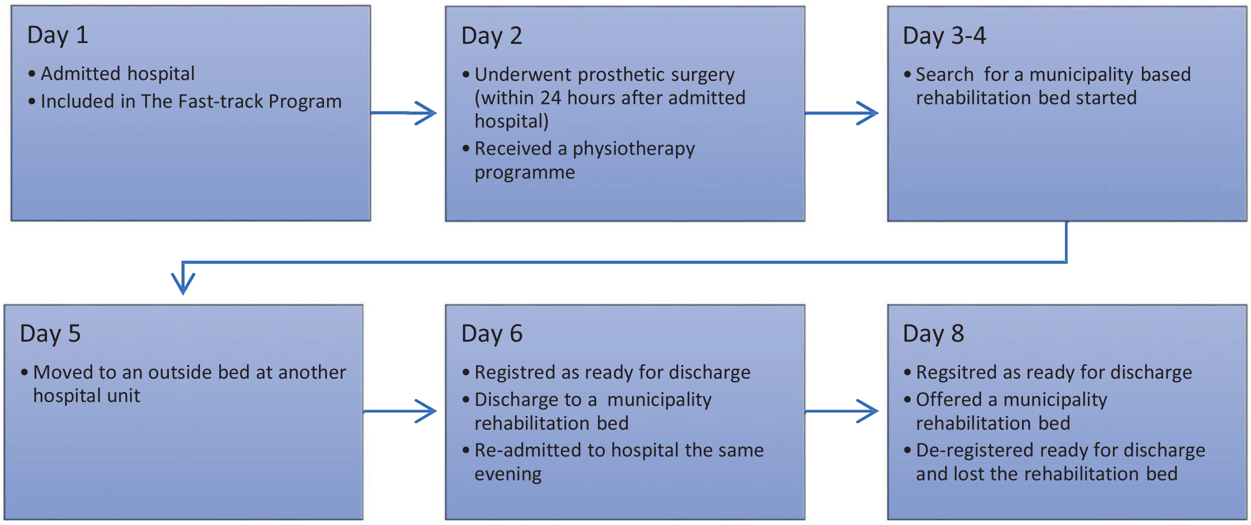

Fig. 1 Timeline of events from admission to the hospital and covering the subsequent 8 days

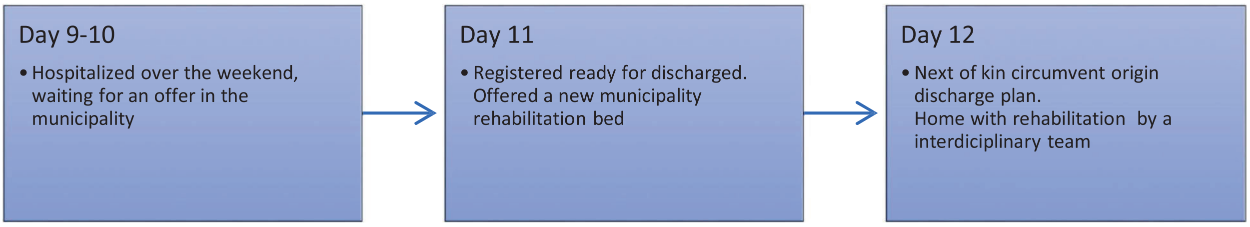

Fig. 2 Timeline of events from day nine at the hospital until day twelve

weighed up the different decisions against what they believed would be best for the patient. With regard to the conversations and negotiations among the hospital and municipal health professionals, the next of kin noted that they had been regularly informed. They were concerned about whether Albert would be sent home and worried about Albert being discharged too soon. They believed that Albert was not ready and strove to postpone the discharge. Albert's son described how they sought to balance what they thought was best for the patient against what the healthcare services had to offer:

> *'I had some phone calls with the staff at the hospital. He [my father] had been ready for discharge for a while ... and they wanted to send him home several times, but we told them that we cannot take him home yet, as my mother is 87 years old, ... but I understand that if a patient is ready for discharge, it costs a lot to stay in the hospital and they want the patient out, but ...'*

After re-admission to the hospital, the next of kin searched for an alternative rehabilitation plan. Albert was offered a rehabilitation bed in a nursing home in the neighbouring city within a few days. The next of kin considered this nursing home to be too far away from his home and shared that it would become difficult to visit Albert, especially for his wife. Thus, they considered possibilities for rehabilitation at home. The day before Albert was discharged from the hospital to a nursing home, the original plan was dismissed, and it was decided that he would return to his home. The next of kin drew up a plan with the municipal health professionals for reorganising the house and securing the necessary aids. This alternative plan involved facilitating Albert's rehabilitation and follow-up care via an interdisciplinary team and home care nurses.

Being the person left in limbo

While the hospital and municipal personnel were devising a possible and feasible rehabilitation alternative, the patient seemed to be left in limbo during this part of the planning. He became the person who was at the centre of all the deliberations, yet not involved in the decisions. This became more evident on the day of discharge.

On the morning of the discharge day, it was unclear whether Albert was ready for discharge or not. Moreover, he was unsure about whether he was going home or to a nursing home. He described his assumptions about what should have happened next as follows:

> *'Yes, today, my children will probably meet at home and then move the inventory from the first floor down to the ground floor. There, we have a bathroom and all, which is simple. The youngest should pick me up today and drive me home.'*

The issues related to discharge were ongoing close to Albert's expected departure time. In line with this process, various activities needed attention, as exemplified in the following field note:

> *'In the morning, a nurse entered the room to weigh Albert. She told him that she should weigh him because he might be going home today—no other explanations. He did not respond to the nurse but placed himself on the chair scales and waited for what would be next. Then, with Albert still sitting on the chair scales, a new nurse entered the room and verified that he could go home today.'*

When the ready-for-discharge decision was finally made, Albert did not have adequate time to make himself ready to leave the hospital. Yet one hour later, he was in a taxi and on his way home. This was recorded in another field note:

> *'Everything seemed to be done quickly; among other things, Albert's personal belongings had to be packed. The nurse had just finished with his documents when the taxi driver arrived. Albert did not say anything but kept attention to what was happening. On the way out of the door, he asked for his box of chocolates and the newspaper. He ensured that he had them.'*

When Albert arrived at his home, his next of kin and two people from a municipal interdisciplinary team were there**.** The house had been fitted with relevant appliances, and Albert's bed had been moved down into the living room. Albert's first hours at home included several activities, and healthcare was the main issue. One of the health professionals called it the 'reception day'. Albert had to respond to questions and instructions from several health professionals from various work teams. The following field note describes some of these activities and what occurred during this afternoon on the discharge day:

> *'Albert managed out of the car and got into the wheelchair with the driver's help. The son and two from the interdisciplinary team were outside the house. His spouse was in the hallway welcoming him. He had a new wheelchair to use inside the house. Before he wheeled into the living room, Albert stopped and made sure that he had paid for the taxi. Someone from the interdisciplinary team enquired if Albert could put weight on the leg in the living room and checked the record. The team soon started testing how he could stand up and walk using a walking frame and show different techniques. The son was worried about all the things his father needed to remember. Albert seemed to manage the instruction. Albert asks for how long he has been away and once tries to get up from the wheelchair with the help of a walker. It goes well, and he looks satisfied. Further, the team informs about the social alarm and how it works. The social alarm has yet to be delivered.'*

Before the day ended, Albert met with two more professional teams. A nurse from the nursing team came to remove an intravenous catheter and evaluate the further need for nursing. Later in the evening, a nurse from the home care service came to help Albert with his mobilisation and to get dressed for the night.

Reorganising the home for comprehensive healthcare

The decision to set up a rehabilitation bed in the patient's home resulted in extensive work for Albert, his next of kin and several health professionals from the interdisciplinary team, the nursing team and the home care services.

Before Albert arrived home, his next of kin had rearranged his bedroom and moved his bed from the first floor to the living room on the ground floor, where various aids could be installed. They expressed that, by reorganising the furniture, they had modified the home to allow for the provision of healthcare services. The reason for reorganising was that the home should be a residence and a suitable place for Albert during his rehabilitation phase, as well as an appropriate working place for the professional teams. However, Albert's spouse shared that she was not so eager about modifying the home. For her, it was a dilemma that she had to sleep in the living room after the beds were moved down from the bedroom. The following is a statement by Albert's spouse:

> *'I don't like modifying our home; I want it to look nice. But, I know it is just temporary.'*

Organising Albert's healthcare included planning various activities, preparing different schedules and assuring work quality. Action lists, report systems and deviations needed coordination. A health professional in the interdisciplinary team said:

> *'We come when the homecare service has finished their work. When the patient has received food and is dressed; we move into exercise, all the daily activities and muscles' strengthening and movement.'*

The extensive scheduling coordinated the activities of not only the various professional teams but also Albert and his next of kin. His next of kin reported how they divided tasks among themselves and decided who was best to do what. They described a 24/7 schedule, where someone was always on duty, both at the hospital and when Albert arrived home. Albert's next of kin described this experience as follows:

> *'All the time, there is something on "my shoulder", anywhere you go, you worry and think about being in another place. If we travel away, the other family members are responsible for looking after them and taking a visit after their job or a call. We do not travel away all at the same time. That will not work—oh no, that will not work.'*

It became obvious that the professionals' schedule was challenging for Albert. He was forced to adapt to various professionals' schedules and working methods. However, in his own way, Albert was able to take some control of the situation. For example, when being helped with getting dressed, he slowed down and performed the activities at his own pace. A nurse from the home care service shared that they are allocated specific time for each patient and noted that the number of patient visits during a work shift could be as high as 30. Still, it was impossible to increase the tempo during her time with Albert. Following Albert's rhythm was essential and this took time, despite the nurse's schedule. The nurse commented on this situation as follows:

> *'Things have clearly changed for Albert; now he needs help with getting dressed. It will now take more time. I cannot follow the listed work time because it is unrealistic.'*

Discussion

The main findings in this study show how the pursuit of a suitable healthcare service within a tailored care trajectory resulted in several dilemmas, considerable deliberations and a comprehensive mobilisation of work for all the involved actors. The search for a suitable healthcare service lasted throughout the entire trajectory, from when the patient went to the hospital until he returned home.

The expectations of efficient healthcare services and the emptying bed policy had a domino effect throughout the patient's care trajectory. Therefore, a dilemma arose for health professionals, who had to negotiate about the use of resources and the coordination of healthcare services, instead of focusing on delivering a person-centred approach [17, 44].

When Albert had occupied a hospital bed, he practically become a 'bed-blocker'. The term 'bed blocking' has been used to describe the situation when a patient is ready for discharge from the hospital but is waiting for admission to a municipal nursing home or for municipal-managed home care [45]. We found that bed blocking is not specific to hospitals but also occurs in the municipality. A municipal health professional described how they strove to ensure that there was a sufficient turn-over of short-term, rehabilitation and long-term beds.

A tension about who held the actual decision-making power became visible during the discourse between the health professionals at the hospital and municipality. The parallel searches for an available bed resulted in several negotiations between the different parties, and both sides had different 'cards' to play. While the hospital health professionals had the authority to decide about the patient's readiness for discharge and register them as ready for discharge, the municipal health professionals had access to bed capacity in the municipality. The need for quick solutions and decisions about the bed capacity in the discharge planning sped up the decision-making process and influenced the communication among the health professionals. It is problematic that structural factors, such as available time, can impact health professionals' work and their interactions to achieve coherence with the patient's needs [30, 46–48].

The patient was left in limbo during the back-and-forth process in the healthcare system. A structured care trajectory designed to ensure that patients receive optimal treatment and avoid complications was followed by an unpredictable course for the patient. Given the complexity of managing the healthcare trajectory, the patient had almost no say in the decisions, causing him to be left in limbo. Therefore, it is appropriate to pose the following legitimate questions: Was the situation too complex for the health professional to include the patient in the plans? Was there a time and place for including the patient in the plans [30, 48]?

Today, it is expected that patients will participate in discussions and decisions about their healthcare, taking an active role, and that healthcare services be considered players in the system [49]. We found that this may create a dilemma for patients; the ideal of participation is weighed down by the attendant facilitation. For Albert, it seems that his involvement in the decisions about his trajectory was limited. The challenges to providing health care services supposed to involve the elderly persons in decisions about their healthcare is in line with previous research [50]. Albert chose to trust his next of kin to support him in the planning and the making of decisions. Research has shown that patients delay their decisions when they feel they are not ready to make them during the care trajectory [32].

The present study's findings also indicated that preparing for and undergoing rehabilitation at home can require a comprehensive mobilisation to reorganise the patient's home. Several health professional teams participated in this mobilisation of rehabilitation care. In this comprehensive mobilisation of care trajectory, the next of kin worked in the background and contemplated the alternatives alongside the health professionals. Next of kin wanted to provide assurance and confidence during the discharge process and after the discharge from the hospital and other transitions in the healthcare system. They also considered what could be best for the patient in their life [22, 51].

The next of kin undertake their various critical tasks under conditions that are different from those experienced by the health professionals. In this case, they had limited influence on the healthcare services decisions and lacked access to information and resources. Thus, they had to adapt to the healthcare system rather than the other way around. They strove to organise their lives and jobs around caring for their relative. Studies on family care for the elderly have stressed the need for flexible hours, schedules and locations to allow carers to manage both jobs and elder care [21]. In the ageing population, family care contributes to filling healthcare gaps [23], and efforts are underway to optimise familial care capacity in many countries. Clearly, there is a need to identify and understand the work and role of the next of kin to examine the actual coherence with policy and expectations.

Methodological strengths and limitations

With her pre-understanding of the topic, the first author (MK), an experienced geriatric nurse, might have affected the observations and interviews. However, her experience and knowledge contributed to the understanding of the research field and to the input during data collection. The study has a limitation in that the observations began on the discharge day at the hospital. Data for the period between hospital admission and discharge were therefore sourced from interviews and documentation from the patient's record. The use of a single case provided a deeper insight into dilemmas and deliberations during the care trajectory of elderly patients and what occurred when the patient's care trajectory deviated from the standardised condition. Thus, this approach increased the value of the present study. A single case can shed light on several larger classes of cases [52].

Conclusion

In this study, where the aim was to illuminate the dilemmas and deliberations of patients, next of kin and health professionals in managing the care trajectory, we found that health professionals strove between negotiation about allocation of resources and being person-centred. The pursuit for tailored healthcare services leads to a comprehensive mobilisation of and work by all the actors across the entire care trajectory. The next of kin sought to balance the patient's needs with the offered healthcare services and the patient's participation in the planning and decisions was limited. Identifying the conditions and work involved is important in developing appropriate care trajectories that align in coherence with complex healthcare needs of elderly patients.

Abbreviation

GP: General practitioner.

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Authors' contributions

MK, KK, GVB and RH contributed to the conception and design of the study. MK performed the data collection and analysis and developed the manuscript. KK, GVB and RH contributed to the interpretation of the analysis. MK and RH critically revised the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets generated during the current study are not publicly available due to the sensitive and identifiable nature of the data but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The Norwegian Centre for Research Data (NSD) was notified about this study (ID: 54551). The NSD assessed that the processing of personal data was regulated in The Personal Data Regulations [Forskrift om behandling av personopplysninger]. The study processed personal data based on consent. The NSD determined that the study did not raise any ethical issues and did not require further ethical approval. In addition, the data protection officer of Innlandet Hospital Trust's Institutional Review Board, where the study was conducted, also approved the study.

All the authors declare that the methods were carried out in accordance with relevant guidelines and regulations.

Participation in this research depended on informed and voluntary consent. All participants received verbal and written information about the study. A senior nurse in the department evaluated and assured the patient's consent competence. The patients' informed consent also included consent to contact their next of kin and the health personnel involved in the trajectory for a request to participate. All participants who consented to participate signed informed consent forms. They were free to withdraw from the study at any time.

Consent for publication

The written consent form contains information about the scientific publication of the results of the study in an anonymous form. All participants in this study, the patient, next of kin and health professionals, consented in written form.

Competing interests

The authors declare that they have no competing interests.

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Appendices

Appendix I

Intervju (dialog) pasient i pasientforløpet.

Pasient

Intervju nr

Setting

Dato

Navn/nr på lydfil

Intervju pasient (dialog om hva som har hendt – her og nå - hva som skal skje)

Kan du fortelle om dagene før du ble lagt inn på sykehus og hva som skjedde da?

- Hva opplevde du av endringer i behov for helsehjelp
- Hvordan opplevde du helsehjelpen
- Kan du fortelle hva som skjer videre fremover nå (hva er kjent for deg)

Kan du fortelle om tiden på sykehus og dagene etter du ble utskrevet fra sykehus?

- Hvis du ser tilbake til tiden før du ble innlagt- hvordan opplever du situasjonen din nå i forhold til den gang?
- Hvordan opplever du helsehjelpen du får?
- Kan du fortelle hva som skjer videre fremover nå**?**

Appendix II

Temaguide intervju helsepersonell

Bakgrunnsdata

Innlede med informasjon om tema for intervjuet. Informasjon om behandling av data/konfidensialitet, muligheten til å trekke seg.

Bakgrunnsopplysninger: Alder, utdanning, antall år arbeidserfaring og på nåværende arbeidssted.

Pasientforløp generelt

- Når du hører ordet pasientforløp hva tenker du da?
- (Andre lignende begreper)

Eldre med sammensatte helseproblemer?

- -Hva mener du kjennetegner et pasientforløp?

Tid og retning i et pasientforløp

- Hva er en tidslinje i forløpet (start og stopp)
- Har du eksempler/kan beskrive eksempler på hendelser og situasjoner som kan føre til endring i pasientforløpet? (retning og tid)

Bruk av retningslinjer og guidelines i pasientforløpet (til pasienter med sammensatte helseproblemer og ulike kontekstuelle forhold)

- Kan du fortelle om dine erfaringer med bruk av retningslinjer/prosedyrer
- Noen nytte/begrensninger?
- Pasienter med sammensatte helseproblem-
- Tilnærming til helsehjelpen

Integrerte helsetjenester (som et av målene i et pasientforløp)

- Hva gjøres for at ulike stadier og overganger i pasientforløpet blir sammenhengende?
- Har du noen eksempel?
- Sentral rolle i dette arbeidet.
- Hva vil du legge i at tjenestene er «koordinerte og helhetlige»
- Hva bidrar til å kunne utøve en til helhetlig og koordinert helsehjelp?

- Hva kan være utfordrende?

Hensiktsmessig til nærming til helsehjelpen

- Hva er hensiktsmessig tilnærming til helsehjelpen til eldre med sammensatte helsebehov i et pasientforløp?
- Hva mener du er av betydning som påvirker forløpet positivt?
- Hva kan være utfordringer
- Hvordan vil du beskrive tilnærming til helsehjelpen - med tanke på medisinske og psyko-sosiale helsebehov
-

Pasienttilfredshet

- Hva er viktig for pasienten?
- Hva opplever du bidrar til økt pasienttilfredshet