

Interdisciplinary Cooperation in the Norwegian Primary Care Sector

Identifying Functional and Normative Enablers of Integration

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Abstract

Integrated health systems improve access to health care, quality of services, and continuity of care. This is especially important for people living with complex health challenges, such as dementia, requiring multidimensional interventions from various care providers.

Organizational and financial fragmentation in the Norwegian healthcare system challenges coordination of services for this patient group in and between sectors. At the same time, the aging population will result in the number of people living with dementia in Norway doubling in the next 30-40 years. The Norwegian Ministry of Health and Care Services (2015) recognizes this as one of the greatest challenges they face at present, and state that current municipal health and care services are not adequately tailored to meet the needs of people living with dementia or their families. To address this issue, Dementia Plan 2020 was created with the intent to develop “good, flexible and tailored municipal health and care services with a focus on prevention, timely diagnosis and post-diagnostic follow-up” (Norwegian Ministry of Health and Care Services, 2015, p. 8). Dementia Plan 2020 emphasises that good, quality follow-up care requires close cooperation between municipal care providers and the patient’s general practitioner, and that in the current system, communication and cooperation between these entities is not optimal. With this as a basis, this thesis has investigated how Norwegian municipal health and care services cooperate with primary care physicians to ensure continuity of care across disciplines for home-dwelling dementia patients in a healthcare system that on the surface appears to lack integrative mechanisms. Valentijn and associates’ (2015c) conceptual framework – the Rainbow Model of Integrated Care – has been applied to this study to identify functional and normative enablers for integrated care that are currently being used to facilitate clinical, professional and system level integration. The functional enablers that have been identified appear to be top-down and state driven (centralized), whereas normative enablers appear to be bottom-up and individualistic in nature (decentralized). Although the functional enablers may signal a transition in the provision system (toward a more centralized mandate), there remains a need for improved conditions to facilitate better cooperation between municipal care providers.

Keywords: *integrated primary care; interdisciplinary cooperation; healthcare delivery*

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Living and studying in three culturally diverse European cities has been a learning experience in itself – something I will always treasure. The invaluable friendships I have made will surely last a lifetime! I hope that the extensive knowledge I have gained from my studies is reflected in this thesis work and that the value of an international education is evident.

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1. Introduction

Dementia is a neurodegenerative condition characterized by a progressive loss of cognitive, psychological, and physical functioning, resulting in impaired memory, a decreased ability to perform activities of daily living, as well as changes in one's social-emotional characteristics and personality traits (Alzheimer's Association, 2019; Norwegian Ministry of Health and Care Services, 2015; Robinson, Tang & Taylor, 2015; Sancesario & Bernardini, 2018; Wyller, 2018, p. 285). The incidence of dementia increases significantly with age and the prevalence is highest among the "oldest of the old" (Nies, Minkman & van Maar, 2017; Wyller, 2018, p. 288). The complex health challenges faced by people living with dementia are often further exacerbated by multimorbidity and frailty, which results in a multidimensional condition requiring multidimensional interventions (Nies et al., 2017; Norwegian Ministry of Health and Care Services, 2015). Integrated health systems work to achieve improved access, quality and continuity of care; this is specifically important for people living with complex health challenges, such as dementia (Fares, Chung, Passey, Longman & Valentijn, 2018; Leijten et al., 2018; Nies et al., 2017; Valentijn, Schepman, Opheij & Bruijnzeels, 2013). Due to the ageing population, it is estimated that by 2030 there will be approximately 135.5 million people worldwide living with dementia (OECD, 2015). This will put extensive demands on society for both human and financial resources (OECD, 2015; Robinson et al., 2015). Although there is currently no cure available for dementia, there are various steps that can be taken to manage the disease and improve quality of life for patients and their families (Harrison-Dening, 2013). This requires a timely diagnosis, appropriate post-diagnostic follow-up care and good coordination of services throughout the disease trajectory (Norwegian Ministry of Health and Care Services, 2015).

The number of people living with dementia in Norway is expected to double in the next 30-40 years (Norwegian Ministry of Health and Care Services, 2015). The Norwegian Ministry of Health and Care Services (2015) recognizes this as one of the greatest challenges they face at present, and state that current municipal health and care services are not adequately tailored to meet the needs of people living with dementia or their families. To address this issue, Dementia Plan 2020 was created with the intent to develop "good, flexible and tailored municipal health and care services with a focus on prevention, timely diagnosis and post-diagnostic follow-up" (Norwegian Ministry of Health and Care Services, 2015, p. 8).

Dementia Plan 2020 emphasises that good, quality follow-up care requires close cooperation between municipal care providers and the patient's general practitioner (GP), and that in the current system, communication and cooperation between these stakeholders is not optimal (Norwegian Ministry of Health and Care Services, 2015).

Challenges with communication and cooperation can perhaps be explained by the organization of the Norwegian healthcare system. In this semi-decentralized (fragmented) system, municipalities (or boroughs in the case of Oslo) decide how primary care services are organized and prioritized (Nylenna, 2014; Ringard, Sagan, Saunes & Lindahl, 2013). This can lead to discrepancies in availability of services depending on the resources available within the municipality and the priorities that are set. Geographic location within the country can therefore have an impact on accessibility as well as other health related outcomes (Ringard, et al., 2013). In this regard, follow-up care for dementia patients, and the way in which it is organized, varies in and between municipalities. Furthermore, most primary care physicians in Norway are "contract doctors" and not municipal employees, which further complicates the coordination of services for this patient group (Godager, Iversen & Lurås, 2009).

With this as a basis, this thesis will investigate how Norwegian municipal health and care services cooperate with primary care physicians to ensure continuity of care across disciplines for home-dwelling dementia patients in a healthcare system that is challenged by fragmentation.

1.1 The Norwegian healthcare system: financing and organization

The Norwegian healthcare system is modeled after a National Health Service (NHS) system, which works to provide universal and automatic healthcare coverage to all residents, under the national insurance scheme (Nylenna, 2014; Ringard, et al., 2013; The Commonwealth Fund, 2017). This system *should* ensure that all residents have equal access to healthcare services regardless of socioeconomic status or geographic location (The Commonwealth Fund, 2017). This system is publicly owned and mainly publicly financed (Westin, 2011). There are, however, some exemptions from the typical NHS framework: The healthcare system is (semi) decentralized in that primary care is the responsibility of the municipalities and secondary care is the responsibility of the regional health authorities, which are owned

and operated by the central state, that is to say that primary and secondary care are only loosely integrated (Hagen & Kaarbøe, 2006; Helse- og- omsorgsdepartement, 2014; Ringard, et al., 2013). Additionally, many GPs are not public employees, but rather private enterprise owners (Godager et al., 2009; Ringard, et al., 2013; The Commonwealth Fund, 2017). This results in fragmentation in the primary care sector and impacts vertical coordination of services.

The role of the government in this system is very significant as they decide which services are included in the basic benefit package, the cost of co-payments and ceiling caps, which services are included in the co-payment ceiling caps, and how services are organized and financed (Nylenna, 2014; Ringard, et al., 2013; The Commonwealth Fund, 2017). In other words, the state funds, controls, and delivers healthcare.

1.1.1 The financing system

The national healthcare insurance scheme is very comprehensive, and the basic benefit package covers most healthcare services, including access to primary and secondary care services, acute care, preventative care, and rehabilitation (Nylenna, 2014; Ringard, et al., 2013; The Commonwealth Fund, 2017). This low-threshold system requires a moderate co-payment for many outpatient/ambulatory services. In-patient and emergency services do not require a co-payment. The national insurance scheme also covers the expenses for medications, nutritional supplements, and medical equipment that are on the “blue prescription list,” that is, medications or medical equipment used for treatment of chronic conditions requiring at least 3 months of treatment (Nylenna, 2014; Ringard, et al., 2013; The Commonwealth Fund, 2017). This may be beneficial for patients newly diagnosed with dementia, wishing to adapt welfare technology into their homes.

Healthcare services in Norway are primarily publicly financed by means of general taxation, a typical feature of an NHS (Hagen & Kaarbøe, 2004; The Commonwealth Fund, 2017). Over 85% of all healthcare expenditures are paid by the national government via the national insurance scheme (Ringard, et al., 2013; The Commonwealth Fund, 2017). The remaining 15% of healthcare expenditure is financed through out-of-pocket (OOP) payments by means of co-payments (14%) and private insurance (1%) (Nylenna, 2014; Ringard, et al., 2013). Purchasing medications on an outpatient bases, dental care, and co-payments at point-of-service account for the majority of OOP spending.

Approximately 9% of the population in Norway also have some form of voluntary private health insurance, where premiums are often community-rated and are paid for through employers (Ringard, et al., 2013; The Commonwealth Fund, 2017). Private insurance plays a supplementary role and can provide people with quicker access to secondary (or specialized) care, shorter waiting times for planned operations, and provide them with a greater choice in providers. Private insurance cannot be used for acute care services. Due to its minimal role, there is no governmental incentive provided for purchasing voluntary insurance.

Each year the minister of health, who is responsible for health and care services, presents the annual national budget which includes an overview of the allocation of funds for the year, the pre-determined provider fees, the out-of-pocket co-payment amounts, and the set ceiling caps for co-payments (Nylenna, 2014; Ringard, et al., 2013). Ceiling caps specify how much one is to pay towards select health services per calendar year in co-payments (Ringard, et al., 2013; The Commonwealth Fund, 2017). When this amount is reached, the resident receives a “free-card” which means that they are not required to pay any further co-payments for the remainder of the calendar year within that category of services (Helfo, 2019b; Nylenna, 2014). There are also various exceptions for co-payment requirements. Seniors, for example, are exempt from co-payments for any medication or equipment that is found on the blue prescription list.

Figure 1 illustrates the financing flows and the differences in the financing mechanisms used in primary and secondary care in the bi-sectoral Norwegian healthcare system (Nylenna, 2014; Ringard, et al., 2013; The Commonwealth Fund, 2017). Public financing of healthcare services happens in three ways: through direct allocation of funds to the four regional health authorities who have responsibility for secondary care; through direct allocation of funds to the municipalities who have responsibility for primary care; through the public reimbursement commissioner (called Helseøkonomiforvaltningen or HELFO) who has the responsibility for managing the financial reimbursement for health services that fall outside of the direct responsibility of the regional health authorities or municipalities, GPs for example (Nylenna, 2014; Ringard, et al., 2013).

Main financial flows in the Norwegian health-care system

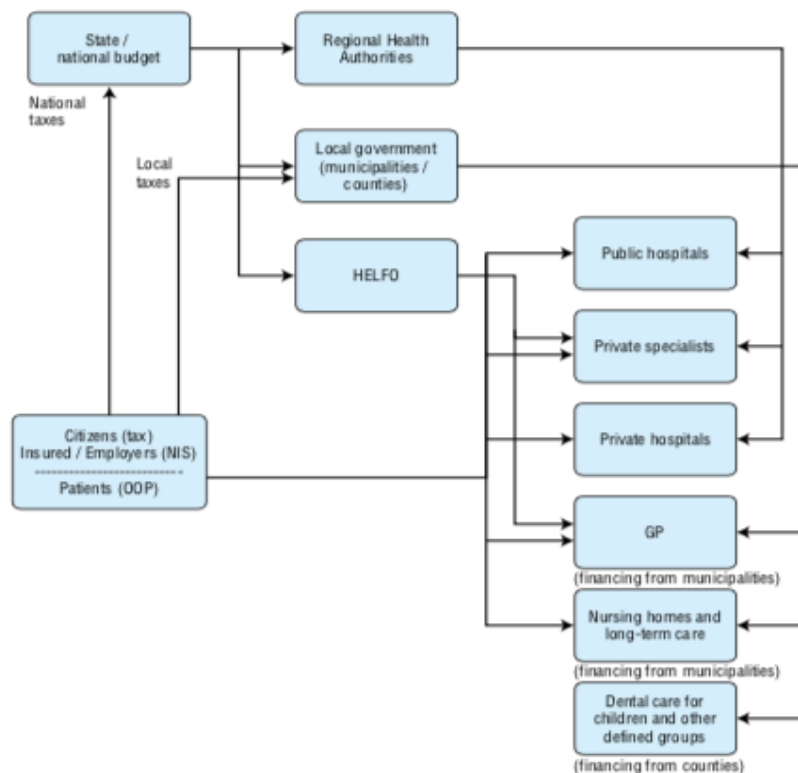


Figure 1. Financing flows in the Norwegian health care system (Ringard et al., 2013)

There are different mechanisms in place for the financing of hospitals depending on the services provided. Somatic hospitals are funded 50% on risk-adjusted capitation (the number of patients they are expected to treat) and 50% on activity-based financing through a diagnostic related group (DRG) system, which specifies a certain amount of money that the hospital will be reimbursed for different patient groups/services (Helse- og omsorgsdepartement, 2014; Ringard, et al., 2013; The Commonwealth Fund, 2017).

Psychiatric hospitals are financed solely through risk-adjusted capitation, which is based on population age, health indicators, social indicators and climate.

Long-term care (LTC) is partially subsidized under the basic package; however, there is quite a substantial co-payment requirement (Ringard, et al., 2013; The Commonwealth Fund, 2017). The co-payment amount is calculated using the patient's income as they are required to pay a set percentage of their income towards the cost of living at the facility (Oslo Kommune, 2019). There is also a sort of ceiling cap for long-term care in that the residents should have at least 25% on their income for their own personal use.

1.1.1.1 Physician payment methods

Most GPs in Norway are self-employed and are paid through a combination of capitation, fee-for-service (FFS), and by OOP co-payments from patients (Ringard, et al., 2013; The Commonwealth Fund, 2017). GPs can have between 500-2500 patients on their patient list, depending on what other responsibilities they have. Most have responsibility for 1200-1500 patients. The GP receives a certain amount of money for each patient on their list (capitation), which accounts for 35% of their total salary. They are also compensated for the actual procedures/ consultations they perform, in which 35% of their salary comes from reimbursements from HELFO based on an FFS scheme, and 30% is paid directly from the patient in the form of a co-payment. In small rural communities, physicians are paid by salary because they would not generate enough income using the capitation/FFS payment method (Nylenna, 2014). There are also GP's who are employed by the municipalities to run after-hours emergency clinics, who are paid by a combination of salary, FFS and OOP co-payments (Ringard, et al., 2013; The Commonwealth Fund, 2017). Reimbursement amounts for FFS payments are negotiated between the state and the Norwegian Medical Association; Regional health authorities determine how much a patient may be charged for a co-payment (Nylenna, 2014; The Commonwealth Fund, 2017). Outpatient specialists may be self-employed or be employed by the hospital. Self-employed specialists are paid in a number of lump-sums, and wages are divided in the same way as a GP (35% capitation, 35% FFS, 30% OOP co-payment). Specialists and physicians employed by hospitals are salaried.

1.1.2 The provision system

In the provision of healthcare services, there is maximal insurer-provider integration as the state acts as both the insurer and the provider. There is, however, a segmentation between the provision of primary and secondary care in that the regional health authorities have responsibility for the provision of secondary care, and the municipalities are responsible for the provision of primary care (Nylenna, 2014; Ringard, et al., 2013; The Commonwealth Fund, 2017). In other words, primary and secondary are only loosely integrated, which challenges coordination between these sectors.

All residents in Norway have the right to a GP and can change their GP up to two times per calendar year (Helfo, 2017; Ringard, et al., 2013; The Commonwealth Fund, 2017). GPs act as gatekeepers and patients are required to have a referral from their GP to access most

specialist/secondary care (acute psychological/somatic care are excluded) (Helse- og omsorgsdepartement, 2014; Nylenna, 2014). GPs also play an important role in referring patients to some municipal care services, such as to municipal memory/dementia teams (Kirkeland, 2020).

Patients also have the right to decide where they want to receive elective services (where they want to be referred to) and can access online information regarding quality indicators and waiting times in order to facilitate informed decisions (Helsedirektoratet, 2017; Helse- og omsorgsdepartement, 2014; Nylenna, 2014; The Commonwealth Fund, 2017). A patient can only choose to receive treatment from the pre-determined appropriate level of care, which was assessed by their physician. Patients cannot choose where they receive acute/ emergency care.

Provision of secondary care (hospital care) is organized by the regional health authorities, who own and operate the hospital trusts (Nylenna, 2014; Ringard, et al., 2013; The Commonwealth Fund, 2017). Each health authority has responsibility for many hospitals, and the organization of the hospitals varies between the health authorities according to the needs of the local population. The state owns all public hospitals (Helse- og omsorgsdepartement, 2014). There are also a number of privately-owned not-for-profit local hospitals who work through contracts with, and are funded through, the regional health authorities. There are a few private for-profit hospitals in Norway, but their role is highly regulated and limited by the government (Nylenna, 2014; Ringard, et al., 2013; The Commonwealth Fund, 2017). Although they provide a variety of inpatient and out-patient services (primarily elective treatments), they are not permitted to provide acute/ emergency care services. If you choose to receive treatment from a private treatment center that does not have a contract with the public authorities, you must pay for the services out-of-pocket, or by means of a supplementary private insurance (Ringard, et al., 2013).

In the Norwegian system medical specialists are employees of the hospital and outpatient services are often provided through hospitals in what is called “polyclinics”. (Nylenna, 2014; The Commonwealth Fund, 2017). There are also a number of specialized treatment centers, which work on a national basis to provide highly specialized treatment for target groups. The idea behind the centralization of specific treatments/ patient groups is that higher patient volumes result in higher quality care and better patient outcomes, while contributing to medical research. Memory clinics are an example of a centralized initiative for dementia

patients. These clinics play an important role in supporting GPs in the diagnostic process, as well as referring patients to appropriate municipal services.

1.1.3 Recent reforms

The current organization and financing of the Norwegian healthcare system is a result of various health system reforms, which were influenced by political and managerial climates over time. Two of the most significant recent health reforms in Norway were the Hospital Reform (2002) and the Coordination Reform (2012).

The Hospital Reform (2002) focused on shifting the responsibility of the provision of secondary care services (hospital care) to the regional health authorities from the municipalities, which in turn shifted the then decentralized model to a semi-centralized model (Hagen & Kaarbøe, 2004; Ringard, et al., 2013). The goal was to implement a more business-oriented approach in order to improve cost control, improve access (by decreasing waiting times for specialized services), and achieve better coordination and management of specialized care by decreasing bureaucratic processes and improving transparency (Byrkjeflot, 2005; Hagen & Kaarbøe, 2004; Ringard, et al., 2013).

Through this plan, the state became exclusively responsible for the provision of secondary care (Hagen & Kaarbøe, 2004). Hospitals and the regional health authorities (RHAs) were re-organized and treated as enterprises. This meant that the RHAs were not directly integrated with the central state but remained publicly owned. There was also a major restructuring of the RHAs in response to a key element of the hospital reform and in 2007, two of the five health authorities merged to create the current composition of four RHAs. All RHAs contained a university hospital, but they were also given responsibility for managing the smaller, “local” hospitals. This new managerial regime eventually led to hospital mergers and resulted in larger, cross-local, organizations (Byrkjeflot, 2005; Ringard, et al., 2013). This has provoked many political reactions which resulted in the RHAs cautiously proceeding with their specialization-based, managed-care merger strategy (Rohde, Torvatn, Magnussen, & Kalseth, 2015).

The key political initiatives within this reform were to give patients the freedom of hospital choice and to reduce waiting times (Hagen & Kaarbøe, 2004). The proposal came from the Social Democrat prime minister and was passed in parliament without much resistance, one

year later (Byrkjeflot, 2005; Hagen & Kaarbøe, 2004). “From a New Public Management perspective, one would perhaps suggest that the reform came as a consequence of a shift in Norwegian politics towards a neo-liberal agenda for the government,” (Byrkjeflot, 2005, p.13). The reform did not include changes to the financing of secondary care, but there were separate reforms suggested to parliament in the following years addressing, among other things, the financing aspect (Byrkjeflot, 2005). In 2004 parliament passed a proposal to use a combination of block-grants and DRG-based financing for secondary care (Hagen & Kaarbøe, 2004).

After the implementation of the hospital reform, the primary care sector also began adapting pro-competitive mechanisms. Primary care physicians, psychologists, and physical therapists became contract employees with the municipalities, and homecare services and long-term care introduced competitive elements (Godager et al., 2009). This reform was effective in clearly defining the responsibilities of the state and the municipalities in the provision of care, which increased accountability, transparency, and aided in cost containment (Hagen & Kaarbøe, 2004). Coordination, however, remained a challenge.

The Coordination Reform (2012) was intended to resolve three main challenges in the provision/ coordination of health services: absence of coordination of services was affecting patients transitions between healthcare institutions, there was lack of focus on preventative measures, the system continued to be challenged by cost containment and efficiency (Nylenna, 2014; Ringard, et al., 2013). The reform was first introduced to parliament in 2008 due to the need for better, safer, more efficient coordination between hospitals and municipalities and was passed and implemented in 2012 (Ringard, et al., 2013; The Commonwealth Fund, 2017). Improving coordination in health services was an important political issue at the time. The legislation had wide support from parliament, with a few exceptions from opposition parties who argued that the changes would burden small municipalities with administrative and financial responsibilities.

Through this reform, municipalities were given responsibility for 20% of the hospitals costs associated with inpatient rehabilitation through the DRG system (co-financing of secondary care) (Monkerud & Tjerbo, 2016; Ringard, et al., 2013). This gave municipalities and the health authorities joint responsibility, clinically and economically, for patients whose care pathways led to access of services in both primary and secondary care (Meld. St. Nr 47

(2008-2009), 2013). The intent was to improve integration and thereby improve quality of care and cost containment. This reform also allowed for municipalities to be fined for not having appropriate capacity to receive patients into their care when they were discharged from the hospital (and required municipal care services), making municipalities economically responsible for these patients. The fine is substantial, 4000kr (400 euros) per day, for each day the patient remains in the hospital after they are deemed ready for discharge (Ringard, et al., 2013; The Commonwealth Fund, 2017). Finally, this reform led to the implementation of municipal acute bed units (MAUs), which are intermediate care units designed to reduce admissions to hospitals for patients living with chronic conditions, especially geriatric patients.

The implementation of the coordination reform gave the municipalities greater responsibility for coordination of care, including discharge care, development of individual plans, and management of patients living with chronic conditions (The Commonwealth Fund, 2017). As a result of this increased responsibility, the government moved NOK 4.7 billion from the secondary care budget to the municipal block grants (Meld. St. Nr 47 (2008-2009), 2013). This transfer of responsibility was a means to incentivize a smoother and quicker transition between institutions and to ensure timely follow-up care for patients. Furthermore, hospitals and municipalities were obliged to collaborate on treatment plans for complex patients.

There were two key legislative acts associated with this reform. *The Municipal Health Care Act of 2011* gave the municipalities freedom to organize the provision of care within their district and gave GPs the possibility to be hired as public or private employees (Ringard, et al., 2013). This was also the means for giving municipalities responsibility for discharged patients and the introduction of co-financing for secondary care. *The Public Health Act of 2011* focused on developing health policies and societal development at the local level, which improved public health coordination across various sectors. In 2015 the part of this reform that gave municipalities responsibility for partially financing hospital costs (those associated with DRG groups) was abolished as it did not have the intended effect of decreasing admission rates (The Commonwealth Fund, 2017).

Both the hospital reform and the coordination reform have had a significant impact on the present-day organization of the Norwegian healthcare system. However, better integration and coordination of services continues to be a political focus, signalling that the intended affect of improved coordination remains unresolved. People living with complex health

challenges, such as dementia, rely on appropriate coordination of services throughout the disease trajectory in order to maintain quality of life (Nies et al., 2017; Norwegian Ministry of Health and Care Services, 2015; Harrison-Dening, 2013). Effective state-driven and local initiatives to improve coordination can therefore have a significant impact for this patient group.

1.2 Dementia

Dementia is a neurodegenerative condition that results from neuron (nerve cell) damage or cell death in the brain (Alzheimer's Association, 2019; Medical Research Council, 2020). These cells typically do not reproduce or replace themselves when cell death or injury occurs, so the body is unable to replace them as they die, resulting in a progressive condition which gets worse over time. As cell death occurs people experience symptoms such as memory loss, cognitive and physical dysfunction, and changes in their social and emotional states (Alzheimer's Association, 2019; Norwegian Ministry of Health and Care Services, 2015; Robinson et al., 2015; Sancesario & Bernardini, 2018; Wyller, 2018, p. 285). Dementia is an umbrella term used to describe a collection of symptoms (a syndrome) associated with *abnormal* memory loss (Harrison-Dening, 2013; Nies et al., 2017, p. 370; Wyller, 2018, p. 285). There are many different underlying diseases that can cause dementia which are categorized into three main classifications for dementia diseases: degenerative brain disease, vascular dementia, and secondary dementia. Under these three categories there are many subtypes of dementia, Alzheimer's disease being the most common (responsible for 60-70% of all cases) (Nies et al., 2017; Robinson et al., 2015; Wyller, 2018, p. 285). A dementia diagnosis is therefore a two-step process: the first step is to identify if the patient has dementia, and the second step is to determine what underlying disease(s) are the cause of the dementia. The World Health Organization's *International Classification of Diseases (ICD-10)* outlines diagnostic criteria for the first step of this process. If a patient meets these diagnostic criteria, they require further investigation to attempt to determine which underlying disease(s) are present, that is, to determine the subtype (Harrison-Dening, 2013; Wyller, 2018, p. 285). This diagnostic process is complex and often requires cooperation between primary and secondary care (in Norway this cooperation often takes place in centralized memory clinic). Additionally, many Norwegian municipalities have dementia or memory teams that may assist the GP in assessing patients for dementia (although setting the diagnosis remains the GPs responsibility). Proper diagnosis of the subtype of dementia will

help care providers to establish an appropriate plan for management of the disease and to prepare patients and families for the expected disease trajectory (Robinson et al., 2015).

Improved living conditions and access to better healthcare has significantly extended life expectancy, this increases one's risk of developing multiple chronic conditions, including dementia (Nies et al., 2017). Age is the greatest risk factor associated with dementia and most people who receive a diagnosis are over the age of 75 (Alzheimer's Association, 2019, p. 12; Robinson et al., 2015). The prevalence of dementia in people aged 65-69 is 2%, whereas people 90 years or older have approximately a 40% chance of developing the condition (OECD, 2015). Other important risk factors for dementia include genetic susceptibility, having a high vascular risk, Parkinson's disease, or learning disabilities (Robinson et al., 2015; Strydom, Chan, King, Hassiotis & Livingston, 2013; Norwegian Ministry of Health and Care Services, 2015). Furthermore, many modifiable risk factors associated with other non-communicable diseases have been linked to dementia and therefore provide an opportunity for primary prevention by means of adopting healthier lifestyles and improving living conditions (Alzheimer's Association, 2019, p. 13; Baumgart et al., 2015; Prince, Albanese, Guerchet & Prina, 2014, p. 10). Primary prevention measures should include engaging in mentally or socially stimulating activities, achieving a higher education, regular physical activity, and maintaining a healthy body weight, blood pressure, cholesterol and blood glucose levels. Secondary prevention (after a diagnosis is made) can be effective in avoiding the development of additional, unnecessary symptoms and can help patients to maintain their functional abilities (Norwegian Ministry of Health and Care Services, 2015, p. 23). Secondary prevention should focus on maintaining physical function through strength and balance training, maintaining social and cognitive function by participating in meaningful activities and using supportive aids if needed, preventing undernourishment and ensuring proper medication use. These measures can be used as the basis for non-pharmacologic treatment/ follow-up after a dementia diagnosis (Aguirre, Woods, Spector & Orrell, 2013; Farina, Rusted & Tabet, 2014; Groot et al., 2016).

Although dementia and its underlying cause will affect people differently (depending on the area of the brain that is affected, the presence of co-morbidity and the patients age, among others) the signs and symptoms can generally be categorized into three stages (Harrison-Dening, 2013; World Health Organization, 2019). Early stage dementia has a gradual onset and can therefore be easily overlooked. Common symptoms in this stage include

forgetfulness, difficulty finding words, losing track of time and getting lost in familiar places. This can affect one's ability to cope in daily life (Wyller, 2018, p. 286). Signs and symptoms become clearer and more restrictive in middle stage dementia, and often patients cannot cope without help from others (World Health Organization, 2019; Wyller, 2018, p. 286). Symptoms include forgetting recent events or names, becoming lost at home, difficulty with communication, requiring help with ADLs and behavioral changes such as wandering and repeating questions. In the final stage, or late stage dementia, patients become totally dependent on others. Memory problems become serious and physical symptoms become more pronounced. Symptoms include becoming disoriented to time and place, not recognizing family and friends, difficulty with physical mobility and behaviour changes that may result in aggression (Alzheimer's Association, 2019, p. 5; World Health Organization, 2019).

The *Behavioral and Psychological Symptoms of Dementia (BPSD)* are often the most difficult for patients and family members (Wyller, 2018, p. 287). These symptoms involve a number of behavioral or personality changes that can develop in different ways. Some of the most common BPSD symptoms include depression and withdrawal, anxiety and lack of emotional control, changes in eating behavior, delusions, illusions and hallucinations, apathy and loss of interest, restlessness, irritability and aggressiveness, repetitive actions and changes in circadian rhythm. These symptoms, if left untreated, can reduce quality of life and accelerate functional decline, and are the leading cause of admission to long-term care facilities, mainly due to care-giver burn out (Alzheimer's Association, 2013). Teaching informal caregivers behavioral management techniques to reduce difficult behaviors can be an effective intervention to delaying initialization and reducing caregiver stress/depression (Harrison-Dening, 2013; Yaffe, et al., 2002). Non-pharmacological therapies such as memory training, music therapy and using special lighting to improve sleep can help to alleviate some of these BPSD symptoms (Prince et al., 2014, p. 11).

There are various approaches to understanding dementia (The Dementia Services Development Centre, p. 6, 2009). A *biomedical approach* applies biological factors to understand the medical condition; there is a focus on diagnostics and pharmacological treatment. Using this approach, the patient is often seen as the illness or disease and psychological or societal factors that influence the disease are often neglected. This approach is important for ensuring a proper medical diagnosis and pharmacological treatment for the

underlying pathologies. A *psychological approach* assumes a more holistic view of dementia. It focuses on how an individual's life history and personality will influence their experiences of living with the disease. This approach views dementia as more than a medical condition and implies that one's psychosocial environment can either positively or negatively affect one's cognitive or social abilities. Using this approach, care providers would reflect on how their attitudes impact the patient's symptoms, behaviours or experiences with the disease. A *gerontological approach* encompasses a wider perspective of how the lives of people living with dementia are influenced by societal and structural factors. Gerontology focuses on older people's views and experiences with the ageing process. Society's perspectives of older people impacts the way they are treated and understood, often negatively, and can therefore influence the range and quality of care they receive. Finally, there are several *societal approaches* that focus on how dementia is understood in terms of society and culture. Some of these societal points-of-view include "dementia as a disability" "role of physical environment" "labelling the disease" "cultural differences and ethnicity" and "person centered approach". Harrison-Dening (2013) states that both a medical and social approach are needed to ensure good quality dementia care and that person-centeredness should be adopted regardless of the model that is used, that is, to see the person and not the disease. Person-centeredness "takes into account the person's individual needs and preferences and seeks to respect their independence, autonomy and right to make their own choices. It views each person with dementia as a unique individual, with a unique set of needs and requirements and with a rich past or life story" (Harrison-Dening, 2013, p. 132). Person-centeredness is considered a crucial characteristic of successful integrated initiatives (Fares et al., 2018; Nies et al., 2017).

Active management of dementia improves quality of life for individuals living with the condition and for their family members (Alzheimer's Association, 2019; Grossberg et al., 2010; Robinson et al., 2015; Vickrey et al., 2006). Active management includes:

Appropriate use of available treatment options, effective management of coexisting conditions, coordination of care among physicians, other health care professionals and lay caregivers, participation in activities that are meaningful and bring purpose to one's life, having opportunities to connect with others living with dementia, ... becoming educated about the disease, planning for the future (Alzheimer's Association, 2019, p. 11).

These actions require both horizontal and vertical cooperation and should be started early in the disease trajectory. In the primary care sector, close cooperation between municipal care providers and the patient's GP is required to deliver quality follow-up care for home-dwelling dementia patients (Norwegian Ministry of Health and Care Services, 2015).

1.2.1 Dementia Plan 2020

The Norwegian Ministry of Health and Care Services developed a plan for quality assurance and expertise in the health and care services sector, namely, Care Plan 2020, based on recommendations brought forward in the white papers Future Care (Meld. St. 29 (2012-2013)) and Primary Health and Care Services of Tomorrow (Meld. St. 26 (2014-2015)) that received widespread political support in 2013 (Norwegian Ministry of Health and Care Services, 2015a, p. 5). The goal of this document was to identify priority areas in the care services sector, to ensure high quality services through competency and capacity measures, and to improve systematic cooperation and coordination among different services and between municipalities.

In Care Plan 2020, dementia was identified as a priority area and therefore Dementia Plan 2020 was developed with more specific measures and targets for this specific population (Norwegian Ministry of Health and Care Services, 2015, page 8). The goal of Dementia Plan 2020 was to create a more dementia-friendly society and to deliver tailored services, which are influenced by patients and their family members, with a focus on prevention, timely diagnosis and post-diagnostic follow-up. In collaboration with patients and family members, Dementia Plan 2020 identifies six strategies/ measures for the period 2016-2020: self-determination, involvement and participation; prevention; timely diagnosis and post-diagnostic follow-up; activity, coping and respite care; a patient care pathway with systematic follow-up and tailored services; research knowledge and competence. Although these focus areas are largely interconnected, this thesis focus' primarily on systematic post-diagnostic follow-up, which is dependent on good routines for communication and cooperation between the different actors in the care delivery sector.

Good follow-up of people with a dementia diagnosis requires close cooperation between the home care services and the person's GP. Many personnel find that there is too little communication between the different services. At the dialogue meetings it

was pointed out that lack of cooperation between GPs and home care services impeded good post-diagnostic follow-up. Thus there is a need for better coordination of the medical services and cooperation between them and the home care services to ensure adequate follow-up throughout the course of the disease. (Norwegian Ministry of Health and Care Services, 2015, p. 29).

1.2.2 Early intervention

Early intervention is a broad term used to describe the management of the core needs of patients and their family members in the early stages of dementia and is an essential part of post-diagnostic follow-up care (The Dementia Services Development Centre, 2009). These needs often include information regarding therapeutic interventions (pharmacological and non-pharmacological) and availability of services, emotional support and help to plan for the future (Norwegian Ministry of Health and Care Services, 2015; Robinson et al., 2015). A timely and proper diagnosis is essential first step for ensuring that patients are offered appropriate treatment and follow-up care (Alzheimer's Association, 2019). Coordination and cooperation between different stakeholders is needed for both establishing the diagnosis and managing the patient's needs appropriately after a diagnosis is in place (Norwegian Ministry of Health and Care Services, 2015).

Therapeutic interventions for dementia include pharmacological and non-pharmacological treatments. Currently, there are no medications that can cure or slow the progression of dementia, but there are medications that can improve the symptoms of dementia by either increasing the amount of certain neurotransmitters available in the brain or by blocking certain receptors in the brain from excessive stimulation (Alzheimer's Association, 2019; Robinson et al., 2015). These medications differ in their effectiveness and duration among patients. Non-pharmacological treatment, or psychosocial intervention, also cannot stop the damage to brain cells that occurs due to dementia but *may* be able to slow the progression of the disease, and can help patients to maintain cognitive and functional abilities, improve quality of life, and alleviate BSPD symptoms (Aguirre et al., 2013; Alzheimer's Association, 2019, p. 11; Farina et al., 2014; Fukushima et al., 2016; Harrison-Dening, 2013; Robinson et al., 2015). These interventions include cognitive stimulation therapy, life-story work, reminiscence therapy, music therapy, physical training, and use of assistive technology

(which can keep people at home longer and decrease carer anxiety), among others. Use of good and effective communication techniques are essential when providing therapeutic interventions to this patient group as language is profoundly affected by dementia, especially in the later stages (Harrison-Dening, 2013). Prince et al. (2011) state that “early therapeutic interventions can be effective in improving cognitive function, treating depression, improving caregiver mood, and delaying institutionalization” and that interventions are more effective if started early. Pharmacological and non-pharmacological treatment require tight cooperation between GPs and municipal healthcare workers in order to monitor and assess the effectiveness of the interventions being offered and to identify when new interventions should be implemented (Harrison-Dening, 2013; Norwegian Ministry of Health and Care Services, 2015).

Information regarding availability of services, emotional support and help to plan for the future should be provided for both patients and their family members, as dementia is a condition that affects the entire family (Harrison-Dening, 2013; Norwegian Ministry of Health and Care Services, 2015). Family members often have responsibility for providing care and supporting their loved ones throughout the course of the disease and should be considered partners in care provision. Family carers are at risk for developing mental and physical illness as a result of care-giver burnout/fatigue and therefore should be provided with continuous support and guidance (Harrison-Dening, 2013; Robinson et al., 2015). In Norway, “during the last month prior to admission to a nursing home, family members spend around 160 hours caring for the person, while over the same period only about 16 hours on average are spent by home care nurses” (Norwegian Ministry of Health and Care Services, 2015, p. 19). Supporting family carers and assisting them in maintaining their own health and wellbeing is a crucial role for GPs and municipal health workers (Robinson et al., 2015). Adopting a family-centered approach (where the family is seen as the patient) can be beneficial for helping the family to resolve conflicts, clarify differences and improve family relationships that may have been affected in the time leading up to the diagnosis (Harrison-Dening, 2013). Ongoing emotional and practical support after a diagnosis improves quality of life for the entire family (Norwegian Ministry of Health and Care Services, 2015, p. 30). Day activity services and other forms of respite care, that are tailored to the family’s need and wishes, work to relieve family carers and help patients to live a meaningful life. These services should be integrated in the standard care package.

Decisions regarding preferences for end-of life care should take place while the patient maintains capacity to make such decisions, early in the disease trajectory (Harrison-Dening, 2013; Robinson et al., 2015). *Advanced care planning* can help to reduce unnecessary hospitalization at end of life, can alleviate family members from needing to make difficult decisions, and can ensure that patient preferences are maintained even when their mental capacity is diminished. Advanced care planning may include a statement of wishes and preferences, an advanced directive, a proxy decision maker or power of attorney. “Nurses are key in ensuring that one-to-one discussions with people with dementia are facilitated as early as possible to explore their preferences and wishes and support planning for future care in the short, medium and long term” (Harrison-Dening, 2013, p. 133).

Dementia Plan 2020 states that many patients newly diagnosed with dementia and their family members express the need/desire to have a contact person or coordinator at the municipal level who can help them to understand their *treatment* options and provide support/guidance, even if they do not require any immediate care (Norwegian Ministry of Health and Care Services, 2015, p. 29). Lack of appropriate follow-up care can leave patients and family members without the support they need to deal with feelings of grief and anger, without help make future plans or to make appropriate adaptations to home and social environments. Close coordination and cooperation between municipal care services and the patients GP is required for good follow-up care (Kirkeland, 2020, p. 9; Norwegian Ministry of Health and Care Services, 2015, p. 29).

1.3 Research question

In response to the shifting governmental focus toward better integration of care services, as seen through e.g. Dementia Plan 2020, I hypothesize that GPs and municipal care providers have developed routines and procedures to facilitate better cooperation. This thesis will therefore investigate how Norwegian municipal health and care services cooperate with primary care physicians to provide holistic and continuous care for home-dwelling dementia patients. I will apply a conceptual framework embedded in integrated care, the *Rainbow Model of Integrated Care* (RMIC) (Valentijn et al., 2015a), to identify how integration is currently being achieved in the Norwegian healthcare system for this specific patient group.

My primary research question is:

How do Norwegian municipal health and care services cooperate with primary care physicians to ensure continuity of care across disciplines in the primary care sector for home-dwelling dementia patients?

I will identify how and when in the patient pathway cooperation begins, how the needs for cooperation change over time, which routines are currently in place, how communication happens, and what municipal healthcare workers believe is important for achieving even better cooperation. This study focuses on the point-of-view from municipal care service providers and does not incorporate reflections from the GPs side.

2. Theoretical Framework

2.1 Integrated care and inter-professional cooperation

Integrated health systems achieve better equity by improving access, quality and continuity of care (Fares et al., 2018; Valentijn et al., 2013). This is specifically important for people living with complex health needs characterized by frailty, multi-morbidity and dementia (Leijten et al., 2018; Nies et al., 2017). Integration of services is often challenged by organizational and financial fragmentation; this is also true in Norway. Goodwin, Stein & Amelung (2017) use the “Alzheimer Web of Care” to depict the complexity of service delivery that can result from fragmentation (See figure 2). They state that these fragmentations can lead to a number of problems, including a lack of ownership/ responsibility for holistic patient follow-up, a lack of patient/carer involvement, poor communication and information sharing among professionals due to silo-based working and cultural norms, duplication of services and gaps in care, poor user experiences and outcomes, and poor system outcomes.

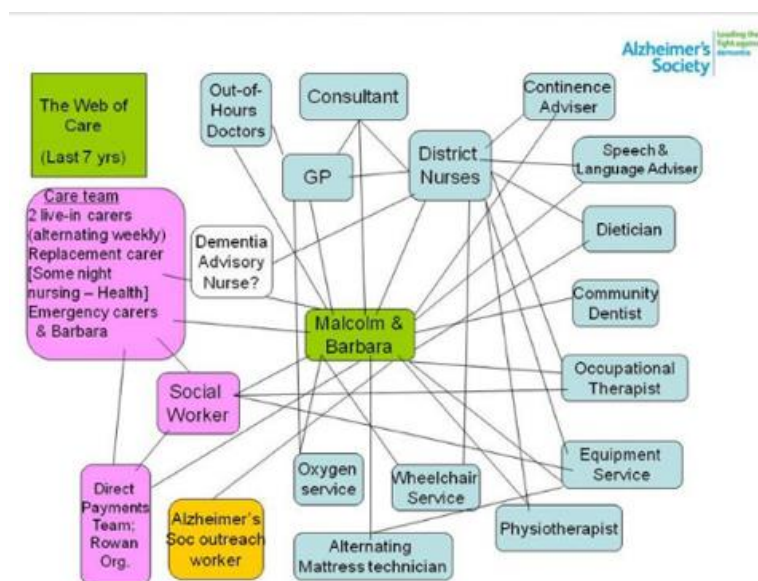


Figure 2. The Alzheimer Web of care (National Voices, 2011)

But what does the term “integrated care” actually mean, and how can this be achieved?

Goodwin et al. (2017) state that using a simple definition to explain this complex term will facilitate a better overall understanding: *Integration* generally means “combining parts so that they can work together or form a whole”, while *care* refers to “providing attentive assistance or treatment to people in need” (p. 17). Integrated care, therefore, results when integration (bringing together separate entities) leads to better care for patients. It is important to

understand that this does not necessarily indicate the bringing together of formal structures or organizations, and that even within a single practice integration can be challenged by poor internal communication and “silo-based” working. It is rather the *coordination* of care that is the most important (Curry & Ham, 2012). Leijten et al. (2018) define integrated care as “structured efforts to provide coordinated, pro-active, person-centred, multidisciplinary care by two or more well-communicating and collaborating care providers either within or across sectors” (p.13). Fares, et al. (2018) also point to the coordinating mechanisms of integrated care, and state that coordinating activities among health professionals (especially) for patients living with complex chronic health conditions achieves better continuity of care and therefore achieves better quality of services.

The term *integrated care* quickly becomes more complex when discussing the magnitude of different *types and forms* of integration that exist. Integration can be understood by its *process* (the means to achieving integration), the *degree* of integration (full integration vs. linkages that support cooperation), the *breadth* (targeted toward a specific patient group vs. the entire population), the *type* (organizational, professional, cultural, etc.), the *time-span* (lifelong vs. episode of care), and *level* (macro, meso, micro) (Goodwin et al., 2017). Additionally, integrated care has a variety of labels, such as: horizontal, vertical, sectoral, professional, clinical, functional, organizational, and whole system, among others (Goodwin et al., 2017; Toth, 2020; Valentijn et al., 2013). Toth (2020) and Fares et al. (2018) point to the fact there is little consensus or consistency surrounding the appropriate use of each of these labels/concepts, which again, complicates the understanding of integrated care and has led to the absence of one, universally accepted framework that can be applied to integrated care. Leijten and associates (2018) state that the absence of a general framework (especially one that is suited for multi-morbidity care) makes it challenging to compare integrated initiatives. Valentijn et al. (2015a) suggest creating a common taxonomy to “move toward a clearer operational consensus regarding integrated care as a whole” (Valentijn, 2015, p. 42).

For the purpose of this thesis, I believe it is important to define horizontal and vertical integration (system integration), organizational and clinical integration, and the levels of integration (macro, meso, micro). To do so, I will use definitions found in recent literature. Goodwin et al. (2017) define *horizontal integration* as integrated care “between health services, social services and other care providers that is usually based on the development of multidisciplinary teams and/or networks that support a specific client group (e.g. for older

people with complex needs)” (p. 12). Valentijn et al. (2013) further state that this applies to services that are found in the same “level” of care – i.e. primary care or secondary care. *Vertical integration* can be understood as integrated care that spans across sectors, in a vertical manor, across “levels of specialization” (e.g. primary, community, hospital, tertiary) (Goodwin et al., 2017; Valentijn et al., 2013). Vertical integration is often designed as “care-pathways” for specific patient groups who require services from different levels of care throughout their disease trajectory. From a system perspective (i.e. integration of an entire health system), both vertical and horizontal integration are needed to lessen fragmentation.

Toth (2020) provides a clear distinction between clinical and organizational integration. He states that *organizational integration* is concerned with “formal contractual agreements that bind health care providers together [and that it] therefore applies to the theoretical structure of the health care provision system” (Toth, 2020, p. 161). Additionally, he states that *clinical integration* “evaluates to what extent different providers treating the same patient coordinate their efforts [and that it] refers to the actual interaction of individual professionals, to the operational methods used – in practice – to deliver care to patients” (Toth, 2020, p.161). Valentijn et al. (2013) state that inter-organizational integration is needed to provide population-based care as this requires collective action across organizations (both horizontal and vertical). To illustrate this, they created a continuum on inter-organizational integration, seen in figure 3, which was adopted from Gomes-Casseres (2003) and Ahgren and Axelsson (2005). In this figure, they demonstrate a segregated scenario (on the left), where market competition leads to short-term contractual agreements and little shared decision-making, and a fully integrated scenario (on the right) that is characterized by top-down coordination.

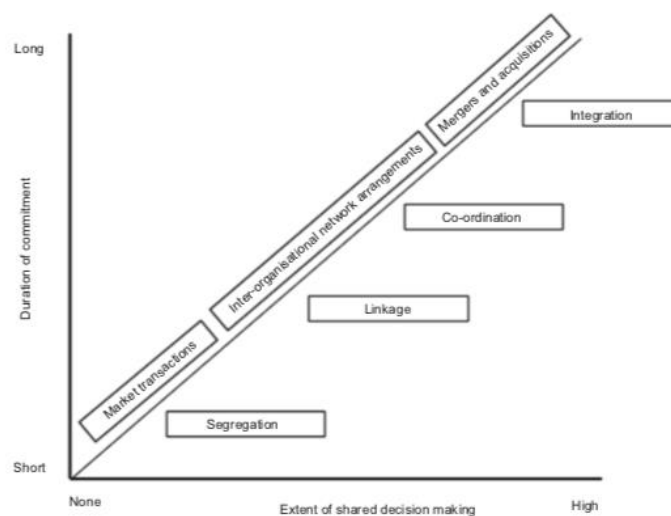


Figure 3. Continuum on inter-organization integration (Valentijn et al., 2013)

Finally, reference is often made to levels of integration, that is, micro, meso, and macro levels of integration. Valentijn et al. (2013) state that integration on these levels often play complementary roles. They define micro level integration as “clinical integration”, meso level integration as “professional and organizational integration”, and macro level integration as “whole-system integration”. Fares et al. (2018) build upon this definition and further explain that micro level integration (clinical integration) is the “extent to which person-focused care is coordinated,” meso level integration (professional integration) is “the sharing of roles, competencies and responsibilities” and (organizational integration) is “collaboration through contracting and alliance,” and finally, that macro level integration (system integration) is “the linkages of healthcare services through rules and policies” (Fares et al., 2018, p. 2). Table 1 under provides a quick reference to these definitions.

Table 1. Types of integration. Own illustration based on works from (Fares et al., 2018; Goodwin et al., 2017; Toth, 2020; Valentijn et al., 2013).

Horizontal integration	Integration of services that are found in the same “level” of care – i.e. in primary care or secondary care. Usually based on the development of multidisciplinary teams and/or networks that support a specific client group (e.g. for older people with complex needs)
Vertical integration	Integrated care that spans across sectors (primary, community, hospital, tertiary). Often designed as “care-pathways” for specific patient groups who require services from different levels of care throughout their disease trajectory
Organizational integration	Concerned with the formal contractual agreements that bind health care providers together; the theoretical structure of the healthcare system
Clinical integration	Evaluates to what extent different providers treating the same patient coordinate their efforts; the actual interaction of individual professionals, to the operational methods used – in practice – to deliver care to patients
Micro level	“clinical integration” - the extent to which person-focused care is coordinated
Meso level	“professional integration” - sharing of roles, competencies and responsibilities “organizational integration” - collaboration through contracting and alliance
Macro level	“system integration” - the linkages of healthcare services through rules and policies

When searching for appropriate frameworks on integrated care to give my study scientific justification, Henry Mintzberg and Sholom Glouberman’s work on differentiation and integration from the early 2000’s (that we covered in HMAN4210) remains very much relevant, and many new publications on integration continue to refer to their explanation of “silo-based working”. Mintzberg and Glouberman (2001a & 2001b) developed an integrative framework to explain the complexity of healthcare systems, depicting, what they call, the “four worlds” of healthcare. On a macro level (i.e. the society at large) these “four worlds” are represented by community care, acute care, public control, and community involvement (Glouberman & Mintzberg, 2001a). Community *care* represents all primary care services that are delivered in the community (including GP and homecare services). The *cure* is

represented by acute care hospitals. *Public control* is represented by public groups and regulatory agencies, such as the Norwegian directorate of health and the ombudsman's role as they organize, implement, and make decisions for the better of the society. And *community involvement* is represented by elected individuals and groups, i.e. politicians, trusts, and boards, elected by the population to make decisions on society's behalf. Mintzberg and Glouberman stress the importance of integrating these "worlds", as fragmentation and specialization has contributed to making these worlds operate highly differentiated from each other, creating what is known as "silos of professions". With the increasing complexity of disease and increasing economic deficits, the differing interests represented by these four worlds need to be integrated and aligned in order to avoid health care and disease cure from "spinning out of control" (Glouberman & Mintzberg, 2001a).

Furthermore, Glouberman & Mintzberg (2001b) describe, what they call, "curtains" between the different levels of specialization, which inhibit integration. The curtains exist vertically, between acute care (hospitals) and community care (community physicians, other healthcare professionals, and "alternative" practice) and horizontally between GPs and other healthcare professionals in the community. These so-called "curtains" create and maintain silos. The metaphor "silo" is used here to describe the phenomenon of each professional group only being concerned with their own tasks, and not with the holistic needs of patients or society as a whole. This representation of fragmentation in the healthcare system fits well within the Norwegian reality, where GPs are separate entities from other community care providers, and where there is a municipal and state division of responsibility between primary and secondary care. I have decided to include this framework in my thesis as a means to visualize the fragmentation in the primary care sector that I am addressing.

Glouberman & Mintzberg (2001b) further discuss various methods to facilitate coordination in and between the "four worlds". Here, they make a distinction between acute care and community care. This is where the model may begin to show its age, as higher acuity of care is now provided at the community level. Nonetheless, I believe their "problem solving web" for geriatrics (coordination by open discussion) can be applied to the community level instead of the acute care level. Here, the point is that multidisciplinary teams, working with complex patients (multimorbidity) should form a web configuration to facilitate information sharing and joint decision making. This web configuration is thought to flatten hierarchical structures and "puts everyone in charge." A web configuration requires mutual adjustment, and

Glouberman & Mintzberg (2001b) state that consideration should be given to how physicians divide their time and how they relate to other health care professionals. When addressing community care directly, Glouberman & Mintzberg (2001b) acknowledge that achieving coordination across the vast and varied professions and organizations is challenging. They suggest care-coordinators, cross-cutting teams, and state that information technology will become more important and will therefore impose a more centralized form of coordination. Although some of what these authors describe is now outdated, much of what they discuss in terms of coordination and organizational design remains true today.

More recently, there has been various attempts to create conceptual frameworks to describe and evaluate integrated care (programs). Valentijn et al.'s (2013) *conceptual framework for integrated care based on integrated functions of primary care* was constructed to facilitate a simplified understanding of the complex phenomenon of integrated care from a primary care perspective. The authors suggest that integrated care must be designed in a cross-sectoral manner, spanning all levels of the health and social system, in order to achieve continuous and comprehensive coordination of service delivery. Furthermore, they state that how integration is achieved in and between these levels is context dependent. This model can be used to “identify the optimal scenario for integration and the contribution of the different integration mechanisms” (Valentijn, 2015, p. 32). This model was further developed in 2015 and coined the *Rainbow Model of Integrated Care (RMIC)* (Valentijn et al., 2015a). The RMIC model addresses six dimensions of integrated care, describing the interconnectedness between micro, meso, and macro level integration. Integration can be achieved in any one of these levels. The authors propose that functional and normative enablers can facilitate integration in and between these levels. Table 2 provides a description of the dimensions of integrated care proposed in the RMIC framework. Valentijn et al. (2015a) state that the distinctions between micro, meso, and macro levels allow for comprehensive insight into the entities, processes, and structures needed to achieve integration.

Table 2. Dimensions of integrated care proposed in the RMIC framework (Valentijn et al., 2015a).

Level	Dimension	Description
Micro	Clinical integration	The coordination of person-focused care in a single process across time, place and discipline.
Meso	Professional integration	Inter-professional partnerships based on shared competences, roles, responsibilities and accountability to deliver a comprehensive continuum of care to a defined population.
Meso	Organisational integration	Inter-organisational relationships (e.g. contracting, strategic alliances, knowledge networks, mergers), including common governance mechanisms, to deliver comprehensive services to a defined population.
Macro	System integration	A horizontal and vertical integrated system, based on a coherent set of (informal and formal) rules and policies between care providers and external stakeholders for the benefit of people and populations.
Micro, Meso, Macro	Functional integration	Key support functions and activities (i.e. financial, management and information systems) structured around the primary process of service delivery to coordinate and support accountability and decision making between organisations and professionals in order to add overall value to the system.
Micro, Meso, Macro	Normative integration	The development and maintenance of a common frame of reference (i.e. shared mission, vision, values and culture) between organisations, professional groups and individuals.

Adopted from Valentijn et al. (2013) ^[6]

There was an additional Delphi study published in 2015 that resulted in a refinement of the taxonomy used by Valentijn and associates (2015a). Here, the original six dimensions of integrated care (as seen in table 2) were expanded upon to include person-focused integration and population-based integration, resulting in a total of eight domains (Valentijn, Vrijhoef, Ruwaard, Boesveld, Arends, & Bruijnzeels, 2015c). These domains were organized into three categories: *scope* (person-focused vs. population-based), *type* (clinical, professional, organizational and system) and *enablers* (function vs. normative). Valentijn et al. (2016c) argue that the refinement of their taxonomy was an essential step “toward establishing an instrument that can measure a broad range of integrated service models”. Furthermore, they state that including the scope (person-focused vs. population-based) can help to achieve a balance in integrated initiatives, that is, between “public health services, which are more orientated on the population, and medical-oriented services, which are more focused on the individual” (Valentijn, 2015, p. 99). The final taxonomy produced as a result of this study can be seen in table 3. This taxonomy will be applied to differentiate, clarify, and interpret the findings in my study. It will help me to describe the situation as it is now, using a theoretically grounded approach.

Table 3. Final taxonomy of key features (Valentijn et al., 2015).

Main categories and domains	Description
Scope of integrated care	
<i>Person-focused care</i>	
Centrality of client needs	The principle of integrated service delivery is to address the needs of individual clients in terms of medical, psychological and social aspects of health
<i>Population based care</i>	
Centrality of population needs ^b	The principle of integrated service delivery is to address the dominant needs of well-defined populations
Type of integration processes	
<i>Clinical integration</i>	
Case management	Coordination of care for clients with a high risk profile (e.g. identifying risks, developing policies and guidance)
Continuity	Integrated service delivery aims to provide fluid the processes of care delivery for an individual client
Interaction between professional and client	Attitude and behavioural characteristics between professional and client regarding all health needs of the client
Individual multidisciplinary care plan	Implementation and application of a multidisciplinary care plan at the individual client level
<i>Professional integration</i>	
Inter-professional education	Inter-professional education for professionals focused on interdisciplinary service delivery and collaboration
Agreements on interdisciplinary collaboration	Agreements on the establishment of interdisciplinary service delivery and collaboration between the professionals
Value creation for the professional	The value added by the integrated service delivery approach for the individual professional
<i>Organisational integration</i>	
Inter-organisational governance ^b	The governance of the integrated service model is focused on openness, integrity and accountability between the involved organisations and professionals (e.g. joint accountability, appeal on pursued policies and responsibilities)
Inter-organisational strategy	Collective elaborated strategy between the organisations involved in the integrated service model
Trust	The extent to which those involved in the integrated service model trust each other
<i>System integration</i>	
Alignment of regulatory frameworks ^a	Alignment of regulatory frameworks for teamwork, coordination and continuity of care
Environmental climate ^a	Political, economic and social climate in the environment of the integrated service model (e.g. market characteristics, regulatory framework, and competition)
Enablers for integration	
<i>Functional integration</i>	
Learning organisations	Collective learning power between the organisations involved in the integrated service model (e.g. joint research and development)
Information management	Aligned information management systems within the integrated service model (e.g. monitoring and benchmarking systems)
Regular feedback of performance indicators	Regular feedback of performance indicators for quality improvement and self-reflection
<i>Normative integration</i>	
Shared vision ^b	Collectively shared long-term vision among the people who are involved in the integrated service model
Reliable behaviour	The extent to which the agreements and promises within the integrated service model are fulfilled
Visionary leadership	Leadership based on a vision that inspires and mobilizes people within the integrated service model
Linking cultures	Linking cultures (e.g. values and norms) with different ideological values within the integrated service model

^a Features were added at final taxonomy during the review and synthesis process

^b Features were merged due to identical or nearly identical content

An additional study by Valentijn, Ruwaard, Vrijhoef, de Bont, Arends & Bruijnzeels (2015b) addresses *how* integrated care can be successfully implemented in primary care. The authors discuss centralized top-down and collaborative bottom-up approaches. Based on recent literature, the authors hypothesized that bottom-up collaborative approaches are more successful as they are linked to “trust-based” strategies (e.g. shared values and mutual respect) rather than “control based” mechanisms (e.g. formal rules and structures). The authors state that “within a primary care context, trust-based collaboration approaches from the bottom-up are considered essential for stimulating the integration of different services because they have traditionally been delivered by professionally-owned, disjointed, small-scale practices” (Valentijn, 2015, p. 133). Valentijn and associates (2015b) state that identifying the collaboration practices between professional and organizational groups can help us to understand the critical mechanisms for success or failure of integrated approaches. In this study, Valentijn and associates (2015b) found that integrated initiatives are improved (more effective) when all stakeholders are committed and their perspectives are aligned. Furthermore, they identified that both trust -and control mechanisms are needed to facilitate a

common ground between stakeholders on professional and organizational levels. That is, that both bottom-up and top-down approaches are needed. These trust -and control mechanisms are discussed as functional and normative enablers for integrated care. These enablers can be embedded into the micro (clinical), meso (professional and organizational), and macro (system) levels of integration, and are crucial for the success and sustainability of integrated processes (Valentijn et al., 2015a). Functional enablers refers to “key support functions and activities (i.e. financial, management and information systems) structured around the primary process of service delivery to coordinate and support accountability and decision making between organizations and professionals in order to add overall value to the system” (Valentijn et al., 2015a, p. 3). Whereas normative enablers refers to “the development and maintenance of a common frame of reference (i.e. shared mission, vision, values, and culture) between organizations, professional groups and individuals” (Valentijn et al., 2015a, p. 3). Functional enablers can be understood as *technical processes*, whereas normative enablers can be understood as *cultural processes*. These enablers help to clarify and interrupt the technical and cultural processes needed to achieve an integrated effort. In this regard, trust-based normative enablers can be understood as bottom-up approaches, and control-based functional enablers can be understood as top-down state driven approaches.

In my study, I am addressing *how* Norwegian municipal health and care services cooperate with primary care physicians in a healthcare system that on the surface appears to lack integrative mechanisms (both organizational and financial). I will use Valentijn and associates conceptual framework (2015c) – RMIC – to describe my study setting, and (2015b) to identify and discuss the various functional and normative enablers that are currently being used to facilitate integration across the clinical, professional, and organizational levels in the primary care sector.

2.2 Integrated dementia initiatives in Norway

2.2.1 Systematic follow-up after a dementia diagnosis (SOED) models

One of the measures in Dementia Plan 2020 (for the period 2016-2020) was to initiate a three-year program to develop models for systematic post-diagnostic follow-up for patients newly diagnosed with dementia (SOED). By the year 2020 the goal was to have various models developed and tested and to begin adapting successful models in other municipalities. The SOED models can help to reduce variation between municipalities by means of

standardization; this is an example of a current centralized initiative. The models can be adapted to fit the local municipal context but provide a means for ensuring consistency in the availability and quality of services (Kirkeland, 2020). The Norwegian National Advisory Unit on Aging and Health (Aging and Health) has now published an evaluation report on the process of developing and testing the SOED models. There were fourteen models developed and tested in twenty-one Norwegian municipalities (Kirkeland, 2020, p. 9). The project was focused on improving the structure for systematic diagnostic work, identifying patients early in the disease pathway, building knowledge and competency in dementia care for healthcare professionals, and improving cooperation between the different care providers (GPs, care coordinators/ memory team and other municipal care providers) (Kirkeland, 2020, p. 18). Cooperation between GPs and municipal care providers was identified as crucial for program success. The goal of this project was to develop and assess various methods for systematically delivering appropriate support/ services to patients and their family members after receiving a dementia diagnosis. The focus was on providing appropriate information and offers for the right services at the right time throughout the disease trajectory. The SOED models focused specifically on the time after receiving a diagnosis until the patient required other healthcare services, at which point the municipal home care service providers would continue the coordination / follow-up.

A work group of relevant governmental stakeholders, consisting of Norwegian Directorate of Health, the National Competency Agency for Aging and Health, and the National Association for Public Health was developed to provide the municipalities with methodological and professional support throughout the process and to give guidance in areas such as content, organization, methods, and evaluation. The SOED models were derived from five already existing programs/ methods for delivering follow-up care and were adapted to fit the local municipal context. The SOED models were informed by: the five pillars model, DAISY, “tiltaksplan demens” [care package dementia], “oppfølging etter demensdiagnose” [follow-up after a dementia diagnosis], and “hva er viktig for deg?” [what’s important for you?].

The five pillars model was developed by Alzheimer’s Scotland and is a part of Scotland’s national dementia strategy (Kirkeland, 2020, p. 6). It is designed to provide patients and family members with tools, connections, resources, and plans (Alzheimer’s Scotland, Action on Dementia, 2020). In Scotland, every person newly diagnosed with dementia is entitled to

support for at least one year following the diagnosis. The five pillars in this model are: planning for future decision making, supporting community connections, peer support, planning for future care, and understanding the illness and managing symptoms.

DAISY is a model that was developed through a Danish study (Kirkeland, 2020, p. 6). Here, the focus is on preventing depression and improving quality of life for patients and their family members by providing multifaceted and semi-adapted intervention programs. Through this program participants are offered advice, provided with support networks and written information, offered courses, and followed-up with regularly planned telephone calls.

“Tiltakspakke demens” [care package dementia] is a Norwegian model for systematic follow-up care for home-dwelling patients with a dementia diagnosis and their family members (Kirkeland, 2020, p. 7). This is a municipal care service where patients and family members are provided with a primary contact person with whom they have monthly meetings. During these visits the contact person uses a checklist to identify important areas for the patient’s (and family member’s) health and the care pathway. The contact person is responsible to inform the patient’s GP about any changes in the patient’s condition.

“Oppfølging etter demensdiagnose” [follow-up after a dementia diagnosis] is a model that was developed by the Norwegian National Association for Public Health that focuses on how patient’s needs should be evaluated and appropriate measures implemented (Kirkeland, 2020, p. 7). This model identifies five areas for follow-up: ability to perform ADLs; family, friends and networks; planning for the future, physical and mental health; environment and society. In this model patients also receive a contact person who is responsible for identifying the patient’s needs and providing them with information regarding availability of services. This program incorporates the perspective “What’s important for you?”

“Hva er viktig for deg?” [what’s important for you?] is not a model specifically designed for follow-up care, but a tool for patient involvement which allows patients to develop their own priorities for care (Kirkeland, 2020, p. 8). This approach is often used in “everyday rehabilitation” models but has also been applied to follow-up care for dementia patients. The Danish designed “conversation wheel” is a tool to help the patient identify and set priorities. Patients are involved in planning how to reach their goals and evaluating their results (Folkehelseinstituttet, 2019). This tool can be useful for ensuring patient involvement and individualized care in SOED models (Kirkeland, 2020, p. 8).

All of the SOED models described the patient's GP as an extremely important stakeholder (Kirkeland, 2020, p. 21). Referrals from GPs to the SOED program and cooperation in follow-up care were crucial for program success. Cooperation with GPs was therefore described as a goal in many of the projects. How GPs were included in the SOED program differed among municipalities – some included GPs in their steering team or work group, and others involved GPs at the beginning of the project to help to develop methods for cooperation. All municipalities provided GPs with information about how to refer patients to the programs, either by providing written information, meeting GPs in person at their offices, arranging a common information meeting, or a combination of these methods. Patients could also be referred to the programs from specialist care or in some municipalities could refer themselves (Kirkeland, 2020, p. 25).

All SOED models included a contact person or coordinator for the patient and specified that at least one home visit would be arranged (and what this should entail). How often contact took place between the coordinator and patient, and how this was arranged, varied between models (Kirkeland, 2020, p. 24). All municipalities incorporated the “what's important for you” framework and all models ensured that the patient/family was provided with information on municipal services and activities and underwent a functional assessment to identify needs for follow-up health care.

2.2.1.1 Evaluation and recommendations from SOED project

An external evaluation of the SOED project was conducted to identify which models are the most useful for delivering systematic follow-up after a dementia diagnosis (Kirkeland, 2020, p. 12). The evaluation aimed to describe municipalities experiences in working with the models, what was perceived as useful, what conditions must be met in order to benefit from the models, and what problems had to be solved for successful implementation. The “RE-AIM” (reach, effectiveness, adoption, implementation, maintenance) tool was used to measure effectiveness. Additionally, municipalities and participants were asked to complete evaluation reports/surveys at the end of the project. This was important to draw conclusions around efficacy – if the models actually contributed to better services for users, from the perspective of the municipalities and the patients/families.

During the evaluation of the projects almost all municipalities identified that there is a need to develop better methods for cooperation between the different actors (GPs, memory team/ coordinator, and the rest of the municipal care services) to improve quality (Kirkeland, 2020, p. 18). Municipalities also expressed that communication between these different actors was difficult/challenging – especially with GPs – and that it is important to have good routines in place for collaboration and communication.

One of the main challenges to providing SOED is to detect patients early in the disease trajectory; this requires a timely diagnosis from GPs/the specialist sector (Kirkeland, 2020, p. 33). After a diagnosis is in place, the patient can be referred to the SOED program. Many models were also designed so that patients could refer themselves, but it was reported that very few actually did. Therefore, the most important actors for referral to SOED programs are GPs and specialist care providers (Kirkeland, 2020, p. 29). Having a member of the SOED project group who was aware of the GPs daily routines, that is, including a GP in the planning process, meant that they could take this into account when developing routines for cooperation with GPs – this is recommended. However, it was also stated that it was difficult to find GPs that had time to participate in developing the models (Kirkeland, 2020, p. 29). Many municipalities also stated that they received fewer referrals from GPs than expected and that even though GPs were provided with the same information as the specialist sector, getting referrals from GPs was challenging (Kirkeland, 2020, p. 34). This could be because GPs were not aware of the program or because they didn't understand the advantages of the program. This problem could possibly be avoided by ensuring that all partners understand the impact of the program, that is, that patients and family members experience better, safer care with improved continuity, and GPs experience an eased workload (Kirkeland, 2020, p. 36).

The most important obstacle identified throughout this process was getting partners (GPs and the specialist sector) familiar with the models – this can help also to explain why stakeholders did not fully follow the procedures set out in the SOED models (Kirkeland, 2020, p. 35). Challenges with electronic documentation systems were also identified as a barrier to good communication.

Many municipalities reported that the SOED projects helped them to develop better routines to collaborate with GPs, but there remains a need to develop this further (Kirkeland, 2020, p. 29). Specifically, it was stated that these projects have improved the collaboration between

memory teams and GPs and that these projects have started an important process in developing better methods for cooperation (Kirkeland, 2020, p. 29). Some municipalities reported that SOED projects have made transitions between services in the municipality more seamless throughout the entire care pathway. Using already established services (like homecare or a memory team) makes the programs more resilient (less fragile), can lead to greater flexibility in services for clients, and can reduce the need to hire more employees (less resource demanding). For SOED to be successful it should be made part of the existing structure within the municipality (Kirkeland, 2020, p. 35).

Based on recommendations from the EU-project *Act on Dementia*, it is recommended that municipal care providers and GPs have a mandatory face-to-face meeting with the patients/family members after a diagnosis is in place (Kirkeland, 2020, p. 36). This is the best way to ensure clarity of roles/tasks, set goals, and create a tailored plan for follow-up care. This is also recommended in the Norwegian national guidelines on dementia. In the SOED evaluation report, it is stated that municipalities found it was challenging to arrange this face-to-face meeting. This could be because it was perceived as time consuming for both GPs and other healthcare professionals or because GPs and other healthcare providers were not clear over the relevance/importance of such meeting (Kirkeland, 2020, p. 36). Furthermore, many GPs only meet a few patients per year with suspected dementia, so it is possible that they lack the volume of patients required to develop good routines for follow-up care. This can also impact how effective SOED models are, not only between municipalities, but also within the municipality itself.

Finally, to ensure good cooperation between GPs and municipal healthcare providers in delivering SOED it was identified that both actors should have: general knowledge about dementia and the specific patient, good routines and procedures for collaboration, an understanding of each other's roles and tasks, formal and informal methods for discussion, competence in communication, routines for exchanging necessary information and relevant forms to input information in the patients journal (Kirkeland, 2020, p. 36). This is in line with Valentijn and associates (2015b) findings that both trust -and control (bottom-up and top-down) facilitators are needed to successfully implement integrated approaches. These findings were used to guide the development of the interview guide for my study.

3. Research Methods

3.1 Background

This thesis has been written as part of the result evaluation of Care Plan 2020 being carried out by the Department of Health Management and Health Economics (HELED) at the University of Oslo (UiO). The evaluation is a collaboration between the Institute for Health and Society at UiO, The Center for Care Research in Østlandet og Vest (SOF) and with the Norwegian Social Research (NOVA). The evaluation project is organized into three work packages; my work is relevant for part C: evaluating of innovations in the service provision for specific groups: people with needs for rehabilitation and dementia. The goal for this part of the evaluation is to research how services for people living with dementia and services connected to everyday rehabilitation have been developed and which effects they have had.

The research strategy planned for part C of the evaluation project is grounded in case studies set in seven Norwegian municipalities. Municipalities of different size and location were chosen to participate to give a good representation of the reality experienced by Norwegian municipalities. The research partners (will) explore various conditions related to satisfaction, mobility, and health with approximately 6-8 people per municipality on two separate occasions. Phase one of data collection took place in spring 2018 and phase two has recently began, this was delayed due to the COVID-19 situation. Interviews were conducted with employees working directly with these patient groups and with the care service leaders. In phase one of the project interviews were also conducted with patients and family members.

I developed my research plan in collaboration with our partners at UiO and SOF to allow for shared data collection. We developed a question guide that was relevant for phase two of the evaluation project, and at the same time worked to address the questions relating directly to my research topic, collaboration in the primary care sector. This was a means to save resources and time for our interview subjects. Municipalities that participated in phase one of the evaluation project already agreed to participate in phase two. Therefore, the municipalities included in my part of the project were already selected during phase one. Our research partner at SOF and I shared responsibility for conducting the interviews. This project was approved by NSD (project number 61395).

As there was much uncertainty regarding availability of municipal employees for interviews due to the COVID-19 situation, we developed several back-up strategies for this thesis work. One of these strategies was to examine the transcripts from phase one of the data collection to identify and extract relevant information to address my research question. This provided me with a relatively good understanding of the municipalities situations prior to beginning with my own interviews, and helped me to understand the coding system that was used to ensure anonymity. Another strategy was to use documentary analysis to address my research questions, which led me to an in-depth analysis of SOED report from Aging and Health. Through this analysis, my topic of interest became more clear and profound.

3.2 Study design

Qualitative methods were used to collect and analyze data for this thesis. Qualitative research allows researchers to observe and explore the direct experience of a phenomenon (Tong, Sainsbury & Craig, 2007; Trochim, 2020). It generates detailed information which can be used to thoroughly describe the phenomenon of interest, using the language of the participants. It “tells the story” from the participants point-of-view and provides rich detail about the lived experience. Qualitative research is individualizing, it assumes that relations between units are internal, meaning that they encompass conscious or subconscious meaning/logic which others can identify with (Sturm, 2019, p. 46; Green & Thorogood, 2014). For this thesis, qualitative methods were applied to understand how collaboration between municipal healthcare providers and primary care physicians is achieved to ensure holistic and continuous care for home-dwelling dementia patients. I am trying to understand how collaboration is realized in a fragmented system where GPs are private enterprise owners and home healthcare services are organized through municipalities.

In this thesis, my units of analysis are people working within the municipal health and care services sector. The different groups include healthcare professionals (nurses, physiotherapists and occupational therapists) and managers. It is important to recognize that the perspectives of managers and care providers may also represent an institutional viewpoint as these groups of employees often identify with the organizational identity. This can be an important distinction in qualitative research as it can result in a sort of “double identity”.

Prior to the interviews being conducted, interview partners were contacted by phone and received a formal invitation letter via e-mail. This letter contained information regarding the

goal of the research, how the research was designed, how data would be used and protected, the participant's rights, among others. This letter ended with an informed consent form which was signed and sent back to me prior to beginning the interviews.

Interviews were conducted using zoom, an on-line platform used for video and audio conferencing. Interviews were recorded using a dictaphone application that immediately uploads audio files to TSD, a service for sensitive data. TSD is "a platform for collecting, analyzing and sharing sensitive data in compliance with the Norwegian privacy regulation" used by researchers at UiO and other public research institutions (University of Oslo, n.d.). Once the audio files were uploaded to TSD, they were immediately erased from my recording device. We also recorded audio files on Zoom as a back-up in case there was a problem with the dictaphone files. These files were also immediately uploaded to TSD and erased from the computer. Interviews were stored, transcribed and analyzed in TSD.

Interviews and transcripts were also assigned an ID-number to ensure anonymity. This ID number was used to classify the type of interview, the type of participant, the municipality, and the research topic (dementia or everyday rehabilitation). Interviews were *semi-structured* and were organized either as focus groups with 3-4 participants (with healthcare professionals) or as one-on-one interviews (with managers).

Interviews are often categorized according to the extent of their structure (Green & Thorogood, 2014). They can either be fully structured, semi-structured, in-depth, narrative or informal. Semi-structured interviews explore participant's experiences surrounding a particular theme, and meanings that they associate with them (Tong, Sainsbury & Craig, 2007). Interviewers use open-ended questions to encourage participants to elaborate on issues related to their research question. Exploring experiences or meanings related to healthcare delivery, for example, can help to identify areas for improvement.

There are also four main types of group interviews: consensus panels, focus groups, natural groups and community interviews (Green & Thorogood, 2014). Focus groups usually include 4-10 participants and use a semi-structured approach to explore a certain issue, or set of issues (Tong, Sainsbury & Craig, 2007). Focal questions are asked to individuals, but participant interaction is encouraged. This stimulates participants to explore shared or individual perspectives.

3.2.1 Strength of the study design

A qualitative research design allows for an open dialog with participants to generate an understanding of their perspectives of a given situation. Including various healthcare professionals and managers helped to create a holistic understanding of how municipalities cooperate with GPs to ensure continuity of care for home-dwelling dementia patients. This study also included participants from five different municipalities. This is important because service provision is organized on a municipal level and therefore there can be significant differences in and between municipalities. Furthermore, the result evaluation of Care Plan 2020 is being conducted as a collaboration between three different research institutes. As challenges in care services affect many sectors of society, this allows the evaluation to include several dimensions and environments and to use various subjects and approaches.

3.2.2 Weaknesses of the study design

In general, qualitative research allows for the possibility of selection bias when choosing interview partners, researcher's confirmation bias when researchers interpret the results, and social desirability bias when interviewees want to please the researcher or other participants. Generalizability may be another limitation to this study. There were five municipalities included in the study, but due to the vast variation between municipalities it may be difficult to generalize the results to the entire country without having a larger sample size.

3.3 Interview guide

I developed my part of the interview guide in collaboration with our research partners at SOV to allow for a shared data collection. My section was largely based on the prerequisites for good cooperation between GPs and other healthcare providers for systematic follow-up after a dementia diagnosis as highlighted in the SOED report. These include: "general knowledge about dementia and the specific patient, good routines and procedures for collaboration, an understanding of each other's roles and tasks, formal and informal methods for discussion, competence in communication, routines for exchanging necessary information and relevant forms to receive information from the patients journal" (Kirkeland, 2020, p.36). The questions in the interview guide directly related to my research question can be seen in Appendix 2, questions 17-22. The interview guide was created with the intent to direct the discussions throughout the interviews. I received feedback regarding my part of the interview

guide from my research partners at UiO and SOF and made appropriate adjustments. It was developed using non-leading, open-ended questions, to allow interview participants to answer honestly without being nudged or biased by the way the question was asked. I tried to ask each question as it was written, to avoid changing the meaning or possible interpretation of the questions. All questions were also asked in the order they were written in the interview guide to avoid omitting questions. This can sometimes happen if an interviewer believes that a question was answered earlier in the interview, so they skip a question; This can lead to information voids and should therefore be avoided (Trochim, 2020). Participants were allotted adequate time to answer questions and silence was permitted and used as a means to encourage participants to share.

3.4 Data analysis

All interviews were transcribed verbatim using f4 transcription software in TSD. The transcripts were analyzed and coded by means of a thematic content analysis, using NVivo 12 software. A thematic content analysis is used to identify reoccurring themes in a data set and helps to systematically summarize participant's perspectives (Green & Thorogood, 2014). As interviews were analyzed and new topics emerged, initial codes were created and grouped together in themes. Matrix coding queries was used to verify that the emerging themes were representative across the various interviews. Figure 4 displays Braun and Clarke's (2006) steps for conducting a thematic analysis. This was used to guide my analysis.

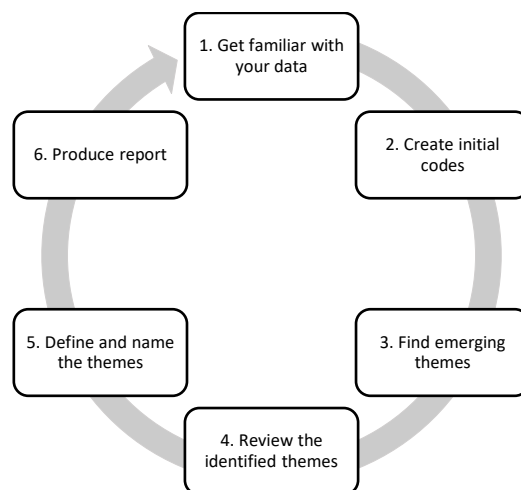


Figure 4. Own representation of Braun and Clarke's (2006) steps for conducting a thematic analysis.

3.5 Validity and reliability

To ensure validity and reliability in my research, I have used the *consolidated criteria for reporting qualitative studies* (COREQ) to report the characteristics of my research team, the study design, and my analysis and findings (Tong, Sainsbury & Craig, 2007). This is a 32-item checklist that has been developed to improve reporting of data from in-depth interviews and focus groups, methods which are commonly used in qualitative research. “The checklist aims to promote complete and transparent reporting among researchers and indirectly improve the rigor, comprehensiveness and credibility of interview and focus-group studies” (Tong, Sainsbury & Craig, 2007, p. 350). The complete checklist can be seen in Annex 1.

4. Results/ Findings

The focus of this thesis is to investigate how Norwegian municipal health and care service providers cooperate with primary care physicians to ensure continuity of care across disciplines for home-dwelling dementia patients in a healthcare system that is challenged by fragmentation. Three major themes were extracted from my data using the thematic analysis framework from Braun & Clarke (2006): Interdisciplinary cooperation, communication, and organization.

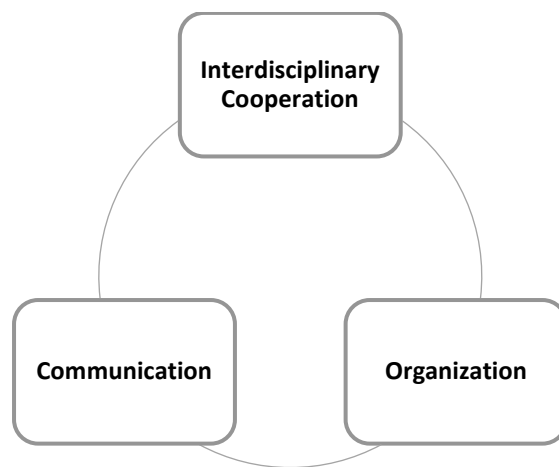


Figure 5. Major themes extracted from my data. Own representation

These themes were created as a result of identifying and linking similar *codes* in my data analysis. This chapter will provide a summary of my participant's statements as they relate to these identified themes. Interviews were conducted and transcribed in Norwegian, but have been translated to English for the purpose of this section. The translations had to be slightly adjusted to ensure comprehensiveness as direct translation can create statements that are difficult to understand.

4.1 Interdisciplinary cooperation

Participants identified that cooperation with GPs was an important aspect of the patient pathway. However, methods for cooperation and perceptions surrounding how well cooperation works was varied among participants. Organizational structure, physician reimbursement methods, time and routines for cooperation were addressed in all interviews. Table 4 provides a summary of the sub-themes relating to interdisciplinary cooperation.

Table 4. Summary of the sub-themes for Interdisciplinary cooperation

GP variation
Patient pathways
Routines
Payment schemes

Many stakeholders identified that cooperation with GPs varies depending on their individual interest for dementia, experience with the diagnostic process and time constraints. A common point-of-view was that there is a generational shift among GPs, where younger or newly educated GPs have a better understanding the disease and are therefore willing to invest more time in the development of multidisciplinary routines in order to provide more holistic care. One participant stated that:

I believe that there is a generational difference among GPs. Given that such a big portion of the population is diagnosed with dementia, I believe that ... this makes them [GPs] interested in finding the triggers for the disease, what causes it, what are the best treatments, and the desire and ability to create a better way for follow-up of dementia patients with a holistic approach.

Interdisciplinary cooperation typically begins with the referral process, this can sometimes happen before the municipal care providers meet the patient. The need for cooperation depends on the patient's individual needs, but in acute cases with a fast progressing disease, tight cooperation is paramount. One stakeholder expressed:

[In difficult cases] we are totally dependent on the GP supporting and helping us. Some are very good at joining us at home visits and some are a bit harder to engage. That's just how it is, and we are used to it.

There is a broad consensus that routines for cooperation between municipal care providers and GPs exist, but there often remains confusion surrounding who is responsible for what given the extensive needs for this patient group. In order for routines to be effective, all parties must have a common understanding of each other's tasks and responsibilities. Prior to referring patients to a memory team in the municipality, for example, GPs must have

adequate information regarding this service offer. This can be difficult to ensure given the large number of GPs working within one municipality or borough.

Some participants identified that GP payment methods prohibited them from using adequate time with the multidisciplinary team. One method to address this issue was the municipal care provider booking an appointment with the GP using the patient's national insurance number so that the GP could be reimbursed for the appointment time, insuring that they get paid for their work. Another participant stated that appointments at the GPs office are typically allotted 15 minutes, and this is inadequate to thoroughly discuss a complex patient case. One participant stated:

I don't know if this model of activity-based financing for GPs is the optimal model to give good healthcare services to patients with big and complex needs [and for those who] require coordinated services.

4.2 Organization

Organization in the primary care sector varies greatly between municipalities and boroughs. How municipal care providers cooperate with GPs is therefore dependent on the organization within the municipality. Optimal organization of healthcare services for dementia patients is rooted in strong local leadership and the political climate. This theme was discussed in-depth in all interviews. The sub-themes related to this theme are summarized in table 5.

Table 5. Summary of the sub-themes for Organization

Organizational structure

Preventative care

Interdisciplinary development

Organizational structure, that is, how municipal health care providers cooperate with GPs, differs between municipalities and boroughs. Some stakeholders discussed dementia coordinators and memory teams, while others discussed interdisciplinary teams focused on preventative care. Some stated that a shared education or knowledge surrounding each other's daily work routines would facilitate a better cooperation with GPs. All stakeholders identified that communication was challenged by organizational structure (where GPs are typically not

a part of the municipal interdisciplinary team) and lack of an integrated patient journal system. One participant stated:

If the GP could just log in and see what services the patient receives from the municipality, I'm sure that would be very beneficial for them. And on the other hand, it would be very beneficial for us if we always had access to an updated diagnosis and medication list.

Many stakeholders mentioned that they have very little face-to-face contact with GPs and that most communication is done through electronic means. Some indicated seeing each other in person more often would stimulate a better overall service because they would be able to discuss the general organization/cooperation, instead of only having time to focus on one patient. One stakeholder expressed that they wished they had better arenas where they could share information and experiences with other service providers.

Maybe the most important [for a good cooperation] would be to reduce the administrative tasks and create areas where we meet more often.... There is something in having seen each other, know a little about each other. And that we can also inform them [GPs] on what initiatives are taking place in the municipality at the moment.

Preventative care has been identified as an important aspect of caring for dementia patients. Interdisciplinary teams (often including physiotherapists, occupational therapists and nurses – but not GPs) work together to deliver the necessary preventative services. Stakeholders working on these teams state that it is important that GPs are aware of the services that are available so that they can inform their patients (if they are not already referred to the municipality). One stakeholder stated that it may be difficult for GPs to stay up-to-date on the wide range of services that municipalities offer as most GPs operate as separate entities.

One stakeholder identified the importance of having political leadership engaged in preventative care for dementia patients as it signals a shift from *cure to care* (away from a strictly biomedical perspective to allow for a more holistic approach to patient care). This can affect how resources are distributed and prioritized (and which state-driven initiatives are mandated). Another stakeholder identified that the shift towards preventative care is also seen

in education across disciplines, that is, that nursing education to a larger extent now includes a more holistic approach that also focus' on prevention of disease. An additional stakeholder implied that municipalities should employ more physiotherapists and occupational therapists if they wish to achieve better preventative care, and that the current system is dominated by nurses who often have other focuses. In order to achieve a joint understanding of each other's work across disciplines, some municipalities arrange interdisciplinary annual meetings. Public interest meetings are also arranged in order to engage and inform members of society about different aspects of dementia. One stakeholder stated that it can be difficult to get GPs to engage in these meetings because they lack incentives to participate. They stated:

We invited children of dementia patients to share their experiences in growing up with a parent who has dementia. Here we also invited all GPs to this meeting, and only two showed up, not more. There is surely a reason for that.

4.3 Communication

Communication was identified as one of the most important aspects for good cooperation with GPs. Most communication takes place over digital platforms. This can sometimes be challenging, as communication systems are not integrated. Flow of information between care providers is crucial for ensuring holistic and efficient services. Currently, there are several initiatives working to achieve better communication between disciplines and sectors. Table 6 summarizes the sub-themes relating to communication.

Table 6. Summary of the sub-themes of Communication

Digital communication

Information flow

Innovation

Many stakeholders identified that their primary means of communication with GPs takes place over an digital platforms. Most municipalities use the electronic patient journal system *Gerica*, while GPs can choose their preferred journal system (that is not integrated with *Gerica*). This means that municipal care providers do not have access to the GPs journal system, and vice versa, which leads to a fragmentation in information flow and communication between the different care providers. To partially address this issue, e-link

can be used as a type of messaging service, where the different care providers can message each other through their preferred journal system. Many stakeholders discussed their experiences with using e-link as a means of communication with GPs. Some stated that this system works relatively well, while others were dissatisfied with the amount of time it may take to receive a response from the GP. One stakeholder stated:

[e-link] has its limitations, that's obvious. I mean the way that we are not notified when we receive an e-link. We don't get a direct message when we have received a response from a question we have asked ... and on the GPs side there is a lack of sorting so they get everything in one big batch, regardless if it's an urgent message or an epicrisis that they can read in 14 days.

Another stakeholder also addressed this issue, but stated that e-link should not be used in urgent cases; instead, GPs should be contacted directly by telephone at their office. This represented an issue for other stakeholders where they identified that it is difficult to contact GPs by phone due to their limited office hours and high demand.

It is very difficult to get a hold of them [GPs] outside of the e-link system because when we call them they don't have time for us, and they usually don't call back. So e-link is the answer, that's what we use.

One stakeholder stated that they sometimes need to physically go to the GPs office if they have not received an answer on e-link. They stated:

Some of them are very good and answer in the same day, or the day after. But others don't answer and we often need to remind them. And very often I've had to drive to the GPs office to remind them of a task. You have to facilitate for them because they are always so busy.

Another issue that was addressed in regard to information flow was information sharing from the municipality to the GP. One stakeholder stated they could be better at giving feedback to the GP about a successful patient treatment. Information in one journal system does not automatically get up-dated in another. One participant stated:

Everything needs to be manually written in the different systems. It's not really connected, so it's not like if you change something in one place it changes in another place also. It's not automatic.

To address some of the issues relating to information sharing and communication between care providers, Health Norway is piloting a new journal system that will operate across sectors and disciplines. The new common platform will work to facilitate cooperation between GPs, primary care and specialist care. This journal system is expected to be implemented in some municipalities in autumn 2021. Although this initiative is still being developed, many stakeholders discussed how they believe it will help to create a better integrated system and will lead to more holistic care for patients. One stated:

I hope that the new health platform will revolutionize our communication issues with one common journal system for the entire region, and maybe for the whole of Norway afterwards.

5. Discussion and Conclusions

In response to a shifting governmental focus toward better integration of care services, as seen through e.g. Dementia Plan 2020, I hypothesized that municipal care providers and GPs have developed routines and procedures to facilitate better cooperation. Through this thesis I have investigated how Norwegian municipal healthcare providers cooperate with primary care physicians to provide holistic and continuous care for home-dwelling dementia patients in a system that, on the surface, appears to lack integrative mechanisms. In this chapter, I will first use Mintzberg and Gluberman's (2001) work on specialization and integration to explain, in simple terms, the complex reality of *the world of community care*. I will then apply the conceptual framework by Valentijn and associates (2015c) – RMIC – to elaborate on the processes and enablers for integration that being are currently being used to achieve cooperation between municipal care providers and primary care physicians.

The research question I have addressed is:

How do Norwegian municipal care providers cooperate with primary care physicians to ensure continuity of care across disciplines in the primary care sector for home-dwelling dementia patients?

As stated in my theoretical framework, *the silos of professions* coined by Mintzberg and Gluberman (2001) provides a relatively good description of the reality for my stakeholders. In the world of primary care (or community care as they call it), the medical curtain, between community doctors and other healthcare providers, inhibits integration. This is the result of the organizational design in the primary care sector. Many of my stakeholders described interdisciplinary teams designed for the holistic delivery of dementia care. These teams often included physiotherapists, occupational therapists and nurses, but did not include GPs. The stakeholders stated that they had very little face-to-face contact with GPs and this make it difficult to discuss methods for creating better routines for cooperation, as well as keeping GPs informed about new programs being offered in the municipality. Stakeholders also indicated that communication is one of the most important factors for a good cooperation with GPs. However, most communication takes place on less-than-optimal digital platforms where again, professions work in “silos” each using their own electronic patient record (EPR) system. This inhibits information sharing, communication, and joint-decision making as

municipal healthcare providers do not have access to the GPs notes in the patients EPR, and vice versa.

Mintzberg and Gluberman (2001) state that these structurally developed “silos” result in each professional group only being concerned with their own tasks, and not with the holistic needs of patients or society as a whole. In the Norwegian primary care sector, GPs and municipal care providers are organizationally and financially separated; this challenges coordination/cooperation across disciplines. Some of my stakeholders identified that they wished to have better systems in place to facilitate better cooperation with GPs, that is, that they wished to eliminate the “medical curtains” in order to provide better integrated and holistic care. To do this, GPs should perhaps be included in the municipal interdisciplinary team or be provided with the proper incentives (i.e. financial reimbursement). Although I did not include GPs in my stakeholder group, a study by Vassbotn, Sjøvik, Tjerbo, Frich & Spehar (2018) identified that Norwegian GPs also experience organizational barriers to being involved in the planning of care coordination. They identify lack of informal arenas for communication with the municipal interdisciplinary team and lack of financial incentives for participating in interdisciplinary meetings as inhibitors to their involvement. This corresponds with the results from my study, where many participants identified GPs time constraints and financing scheme as barriers to cooperation. Mintzberg and Gluberman (2001b) state that in order to facilitate coordination for complex patients (e.g. geriatrics), *coordination by open discussion* can be used in multidisciplinary teams and that consideration should be given to how physicians use their time. The problem here is that GPs are not included in the municipal multidisciplinary team. Moreover, the lack of informal arenas for communication and challenges with the current EPR systems, hinders this type of coordination (specifically, between GPs and the municipal multidisciplinary team).

In light of the above mentioned absence of system integration (organizational and financial fragmentation), are there perhaps other mechanisms for integration in place that facilitate cooperation between municipal care providers and primary care physicians? Valentijn and associates’ Rainbow Model of Integrated Care (2015c), and their taxonomy of terms for integrated care, has been applied to help me clarify and interpret the findings in my study. I have focused on the *enablers for integration* (functional and normative) to try to identify how cooperation actually happens between disciplines in the primary care sector.

Functional and normative enablers for integrated care can be embedded into the micro (clinical), meso (professional and organizational), and macro (system) levels of integration (Valentijn et al., 2015a). They are crucial for the success and sustainability of integrated processes in and between all levels in the healthcare system. Functional enablers refers to “key support functions and activities (i.e. financial, management and information systems) structured around the primary process of service delivery to coordinate and support accountability and decision making between organizations and professionals in order to add overall value to the system” (Valentijn et al., 2015a, p. 3). Whereas normative enablers refers to “the development and maintenance of a common frame of reference (i.e. shared mission, vision, values, and culture) between organizations, professional groups and individuals” (Valentijn et al., 2015a, p. 3). Functional enablers can be understood as *technical processes*, whereas normative enablers can be understood as *cultural processes*. These enablers help to clarify and interrupt the technical and cultural processes needed to achieve an integrated effort.

5.1 Functional enablers

Functional enablers can be understood as the “hard” mechanisms that assist in achieving an integrated effort, such as IT or financial incentives (Valentijn et al., 2015a). In my study, several stakeholders identified functional enablers that promote improved cooperation with GPs. The most commonly mentioned functional enabler was e-link. As stated earlier, e-link is a digital communication tool that allows care providers to share patient information and communicate with each other through a messaging service through their preferred EPR system. Stakeholders identified several issues with this functional tool, such as a lacking notification and sorting system, the amount of time it may take to receive a response, and that the disconnected EPR systems do not automatically up-date. However, other stakeholders indicated that they were relatively satisfied with the e-link system and stated that this tool has led to better communication and cooperation with GPs. Many stakeholders acknowledged that there is variation among GPs; some are quicker to respond through the e-link system than others. This can perhaps be expected when working with many disconnected enterprises. Although there are several challenges with the e-link system it provides a means for communication, and therefore cooperation, between municipal care providers and GPs. This may indicate that this functional enabler facilitates clinical and professional integration (on the micro and meso level) by improving communication. This tool is a state-driven initiative

and is used in all municipalities. It is now an integrated part of many EPR systems in Norway, and does not need to be actively pursued by care providers (Helsedirektoratet, 2014). In order to protect patient data while using e-link all organizations and private enterprise owners using the various EPR systems must have an agreement with Norwegian Health Net, this provides a secure method for sharing sensitive patient data (Norsk Helsenett SF., 2019).

Stakeholders also mentioned the pilot project being developed by Health Norway to initiate one integrated patient journal system, *Health Platform*, across sectors and disciplines. Although this is still being developed, stakeholders believe that it will enable better communication and cooperation with GPs. This functional enabler may represent an attempt toward better integration on a systems (macro) level. Again, this can be seen as a state-driven initiative.

Another functional enabler that was identified by my stakeholders was the possibility to book an appointment with the GP (using the patients national identification number) to discuss a patient case. This is a means to addressing the lack of financial integration between municipal care providers and GPs. By booking an appointment, the GP is able to use the normal reimbursement mechanism (through HELFO) to ensure they are paid for their work. It is unclear if or how the GP is paid the co-payment in this case. One stakeholder identified that this method can be problematic if the GP has a long waiting time and that the allotted 15 minute appointment is not adequate for discussing complex patient cases. In light of these problems, this functional enabler may facilitate clinical and professional integration (on the micro and meso level) by addressing financial and time related barriers to cooperation. It is unclear if this enabler is a state driven initiative, or if it was a creative solution designed by municipalities themselves; it is clear, however, that this solution must be actively pursued by municipal care providers in order for it to work. A report by the Directorate of Health (2020) states that GPs also have the possibility to send a refund request to HELFO for participating in interdisciplinary meetings for home-dwelling dementia patients. However, in 2018 only 12.5% of all GPs in Norway sent such requests, perhaps indicating (or confirming the statements from my stakeholders) that there is a low participation rate among GPs at these interdisciplinary meetings. This functional enabler also needs to be actively pursued by GPs in order to be effective.

As seen in table 7 many of the functional enablers for integrated care that are being used to achieve interdisciplinary cooperation in the primary care sector are state-initiated (centralized). This may confirm my hypothesis that in response to a shifting governmental focus toward better integration of care services, GPs and municipal care providers have developed routines and procedures to facilitate better cooperation. In the case of functional enablers, the initiatives appear to be top-down and state-driven. An interesting result from my study is that these functional enablers also appear to be either active or passive in nature. This was not a finding in Valentijn and associates (2015c) work. “Active” functional enablers, such as E-link and the Health Platform, do not require active pursuit by care providers. Whereas “passive” functional enablers, such as municipalities booking appointment time with GPs to ensure GPs are paid for their work and GPs needing to apply to HELFO for reimbursement for attending interdisciplinary meetings, require an active action in order to happen. This may indicate that there can be a normative aspect to “passive” functional enablers which can impact the effectiveness of such enablers (as seen through e.g. low GP participation rate at interdisciplinary meetings).

Table 7. Summary of functional enablers for interdisciplinary cooperation (own representation)

<i>Functional Enablers</i>	<i>State Initiated</i>	<i>Locally Initiated</i>	<i>Unclear</i>	<i>Active</i>	<i>Passive</i>
E-link	X			X	
Health platform	X			X	
GP appointment reimbursement			X		X
Interdisciplinary meeting reimbursement	X				X
<i>Normative enablers</i>		X			

5.2 Normative enablers

Valentijn and associates (2015c) identify a shared vision, values, norms, and reliable behaviour as *normative enablers* for integrated care. Normative integration is non-tangible, but these informal mechanisms are often essential for effective inter-sectoral collaboration. In my study, many stakeholders identified a shared vision and values with GPs as important for good cooperation. Many stakeholders experience that the newer generation of GPs generally

have more interest for this patient group and that they are therefore willing to invest more time/effort into the development of multidisciplinary routines to provide more holistic care. This may imply that normative enablers, in the form of a shared vision and values, especially with newly educated and engaged GPs, can contribute to improved cooperation across disciplines, and therefore improved professional (meso level) integration.

Valentijn and associates (2015c) state that the success of integration is largely shaped by professionals' behaviours and attitudes. Many of my stakeholders pointed to the variation among GPs and stated that cooperation is often affected by the GPs individual interest for dementia, experience with the diagnostic process and time constraints. This may present a challenge for normative enablers of integrated care as the GPs behavior or willingness/ability to fulfil agreements may be unpredictable. GPs attitudes related to the importance of a diagnosis and follow-up for this patient group can therefore negatively or positively affect cooperation with municipal care providers.

Valentijn and associates (2015c) state that “*the clashing of cultures* (e.g. between medical and non-medical professionals) is one of the reasons why many integration efforts fail”. The fragmentation in the Norwegian primary care sector between *cure and care*, that is, between municipal care service providers and GPs, may inhibit the development of a shared culture. Stakeholders discussed that the lack of informal arenas for communication and lack of face-to-face meetings with GPs makes them feel disconnected to the other care providers (GPs). Without the possibility to discuss each other's work, know about each other's daily routines, or develop a personal relationship with each other, it may be difficult to establish a joint vision and work culture.

As opposed to the top-down functional enablers for integrated initiatives, normative enablers appear to be bottom-up and local. This is likely due to their informal and individualistic nature. Valentijn and associates (2015b) assumed that bottom-up collaborative approaches are more successful for achieving integration as they are linked to “trust-based” strategies (e.g. shared values and mutual respect) rather than “control based” mechanisms (e.g. formal rules and structures). Meanwhile, this study has identified several challenges to achieving a shared vision and work culture between municipal care providers and GPs in the Norwegian context. Due to organizational design it can be argued that centralized approaches may be more effective in establishing better methods for cooperation.

5.3 Limitations

This study has several limitations. First, I have focused solely on the perspectives of municipal care service providers and have not incorporated reflections from the GPs side. Including GP perspectives would allow for a more holistic understanding of the mechanisms for cooperation being used in the primary care sector, as well as a better understanding of the shared values system, which is an importance aspect for normative integration. Second, as my study was a part of a larger project I would have liked to include more of the interviews into my analysis. This was not possible due to time constraints, and has possibly limited the generalizability of my findings. With a larger sample size I would have hopefully achieved data saturation where I could be more certain that my findings represent the reality for Norwegian municipalities in general.

5.4 Conclusion

Dementia Plan 2020 highlights the importance of strong cooperation between primary care physicians and municipal care providers to deliver good follow-up care for people living with dementia. In 2015, when the plan was developed, many health personnel identified poor communication between the different service providers as a challenge to providing good follow-up care, and acknowledged the need for better coordination and cooperation between the various actors. In this study I have attempted to investigate how this cooperation happens and which mechanisms are currently being used to facilitate a better cooperation between primary care physicians and municipal care providers to ensure appropriate follow up for home-dwelling dementia patients. I was able to identify various functional and normative enablers that are currently used to facilitate clinical and professional integration (on the micro and meso level) between these independent entities, such as e-link to address better communication, booking appointment time to address financial and time related barriers, and a shared vision between care providers. The functional enablers that have been identified appear to be top-down and state driven (centralized), whereas normative enables appear to be bottom-up and individualistic in nature (decentralized). Furthermore, functional enablers appear to be either active or passive in nature – suggesting that there may also be a normative aspect to functional enablers. These attempts to improve cooperation come with their limitations, and it is evident that the *professional curtain in the world of community care* that results in *soils of professions* is still very much relevant today. In my research I have not

identified any changes to the organization or financing systems in the Norwegian healthcare system that facilitates better cooperation on a systems level. However, the report from Aging and Health on the development of models for systematic follow-up after a dementia diagnoses (SOED) and the development of an integrated EPR system, as discussed by my stakeholders, signals that attempts toward better integration on a systems (macro) level are currently being developed. The development of SOED models are a direct result of Dementia Plan 2020.

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Appendices

Appendix 1: Consolidated criteria for reporting qualitative studies (COREQ)

Appendix 2: Interview guide

Appendix 1: Consolidated criteria for reporting qualitative studies

Table 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>
Participant selection		
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>
11.	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? <i>e.g. participant number</i>
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

(Tong, Sainsbury & Craig, 2007).

Appendix 2: Interview guide

Vi skal så til slutt stille noen spørsmål om samarbeidet mellom dere og fastlegene.

Fastlegene kjenner jo som regel brukerne dere gir tjenester til på forhånd og deres sykdomsutvikling. De kan foreta konsultasjoner på legekantorene, sykebesøk i hjemmet, årlig fullstendig undersøkelse, legemiddelgjennomgang, deltakelse på tverrfaglige møter og/eller samtale med pårørende.

13. Når/hvor tidlig eller sent i pasientforløpet starter vanligvis samarbeidet mellom fastlegene og dere?

14. Hvordan endres behovet for samarbeid gjennom pasientforløpet?

15. Hvilke rutiner og prosedyrer har dere for samarbeid? (Henvisning; ansikt-til-ansikt møte for å planlegge oppfølging, osv.)

16. Hvordan er rutinene og kommunikasjonen mellom kommunen og fastlegen i dag? Er de gode nok?

Skaper det noen utfordringer at fastlegene (vanligvis) ikke er ansatte i kommunen, men som selvstendig næringsdrivende?

17. Har du tanker om hvordan rutinene og kommunikasjonen med fastlegene kan bli enda bedre?

18. Hva tenker dere er det viktigste for et godt samarbeid?