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Rune Aakvik Pedersen

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NTNU
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Thesis for the Degree of
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Trondheim, May 2021

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Norsk sammendrag

Utfordringer i oppfølgingen av pasienter med hjerneslag i allmennpraksis

Hjerneslag kan beskrives som plutselig innsettende nevrologiske utfall grunnet en forstyrrelse i hjernens blodsirkulasjon. Det kan dreie seg om en blødning eller iskemi. Iskemi, altså en lokal blodmangel, ligger til grunn for størstedelen av slagene. Den lokale blodmangelen skyldes i sin tur at en blodåre som fører til den aktuelle delen av hjernen, har blitt tilstoppet av for eksempel en blodpropp. Hjerneslag er en hyppig forekommende lidelse som har store personlige og samfunnsmessige konsekvenser. I Norge rammes årlig om lag 13 000 personer av hjerneslag og på verdensbasis er det den nest vanligste årsaken til død og den tredje vanligste årsaken til invaliditet.

Personer som har gjennomlevd ett hjerneslag har økt risiko for et nytt, ofte kalt residivslag. Hvert fjerde hjerneslag er et residivslag og dødeligheten ved residivslag er spesielt høy. Oppfølging av pasienter med hjerneslag i allmennpraksis retter seg blant annet mot forebygging av slike nye slag. I 2010 kom det en nasjonal faglig retningslinje for behandling og rehabilitering ved hjerneslag som gir råd for oppfølgingen. Det har vært lite forskning på oppfølging av pasienter med hjerneslag i allmennpraksis og på betingelser for etterlevelse av retningslinjen.

Denne avhandlingen består av to studier med til sammen tre artikler som utforsker etterlevelsen av retningslinjen i allmennpraksis og enkelte av betingelsene for etterlevelse av retningslinjen i allmennpraksis. Til den første studien hentet vi materialet fra fastlegekontorene og til den andre studien fikk vi materialet fra sykehusene.

Den første studien ledet til to publiserte artikler. Artikkel I er en prospektiv kohortstudie på etterlevelse av retningslinjen når det gjelder oppfølging av pasienter med hjerneslag i allmennpraksis. Materialet bestod av fastlegenes journalnotater fra det første året med oppfølging i allmennpraksis etter hjerneslag. Vi studerte om retningslinjens anbefalinger ble fulgt og hvor ofte pasientene konsulterte sine fastleger i perioden. I

Artikkel II undersøkte vi omfanget av multimorbiditet blant pasientene. Multimorbiditet ble definert som to eller flere samtidige kroniske sykdomstilstander fra en tidligere publisert liste med 40 tilstander. På denne bakgrunnen modellerte vi tre hypotetiske eksempelpasienter, hver med et representativt antall kroniske tilstander, basert på det som viste seg å være hyppige forekommende kroniske tilstander blant pasientene med hjerneslag. Vi analyserte hva det innebar å følge de samlede retningslinjene for de ulike tilstandene i form av behov for konsultasjoner hos fastlege og spesialist, samt supplerende undersøkelser slik som blodprøver eller røntgenundersøkelser.

I denne første studien fant vi at pasienter med hjerneslag hadde hyppige konsultasjoner med sine fastleger, men likevel ble retningslinjen i liten grad etterlevd. I de tilfellene der retningslinjen ble fulgt, betydde det likevel ikke nødvendigvis at retningslinjens målverdier for eksempelvis blodtrykk ble oppnådd. Alle pasientene fylte kriteriene for multimorbiditet, og i gjennomsnitt hadde pasientene 4,7 kroniske tilstander inklusive hjerneslag fra listen med 40. Analysen viste at det krevde mange besøk i helsetjenesten for å etterleve retningslinjenes samlede anbefalinger. For en pasient med et gjennomsnittlig antall kroniske tilstander, krevdes 10 til 11 konsultasjoner i året for å kontrollere tilstandene i stabil fase. Flere konsultasjoner ville vært behøvelig ved avvikende funn, forverring av en eller flere sykdommer eller ved interkurrent sykdom i perioden.

Studie 2 var en analyse av epikrisene fra sykehusopphold for pasientene i studie 1. Vi benyttet en diskursanalytisk tilnærming. I Artikkel III utforsket vi om epikrisene inneholdt de elementene som retningslinjen anbefalte, og hvorvidt epikrisene ble brukt som verktøy for kunnskapsoverføring og samarbeid. Vi fant at epikrisene ikke inneholdt alle de elementene som retningslinjene anbefalte. Det var en klar tendens til at forhold av betydning for behandling på sykehus ble omtalt, mens forhold av betydning for den videre oppfølgingen i allmennpraksis i større grad ble utelatt. Epikrisene inviterte ikke til samarbeid om pasientene etter utskrivelse og hadde et uforløst potensial innen kunnskapsoverføring fra spesialist- til primærhelsetjenesten.

Samlet sett belyser studiene flere forhold som er utfordrende i oppfølgingen av pasienter med hjerneslag etter behandling i sykehus. Etterlevelse av retningslinjen er svak, og samtidig er de samlede retningslinjene ikke mulig å etterleve for pasienter med kompleks multimorbiditet. Vi har også påvist svakheter innen kunnskapsoverføring og samarbeid på tvers av nivåene i helsetjenesten. Hvis mål om sømløse overganger innen helsetjenestene for pasienter med hjerneslag skal oppnås, må disse utfordringene håndteres. Dette prosjektet har hatt som mål å beskrive og å analysere den nåværende situasjonen, og har ikke tatt mål av seg å komme fram til nye løsninger. Det er likevel klart at mer kunnskap kreves for å løse utfordringene knyttet til oppfølging av pasienter med hjerneslag i allmennpraksis.

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English summary

Challenges in the follow-up of patients with stroke in general practice

Stroke can be described as a sudden onset of neurological symptoms due to a disturbance in the blood circulation of the brain. It could be a bleed or ischemia. Ischemia, a deficient supply of blood, is the cause of most strokes. This is in turn due to a blood vessel leading to the affected part of the brain being blocked by, for example, a blood clot. Stroke is a common disorder that has major personal and societal consequences. In Norway, about 13,000 people a year are affected by stroke and worldwide it is the second most common cause of death and the third most common cause of disability.

People who have experienced a first stroke have an increased risk of a recurrent stroke. Every fourth stroke is a recurrent stroke and the mortality rate from recurrent strokes is particularly high. Follow-up of patients with stroke in general practice is aimed, among other things, at the prevention of such recurrent strokes. In 2010, Norwegian national guidelines for treatment and rehabilitation in stroke were issued. They provide advice for the follow-up. There has been little research on the follow-up of patients with stroke in general practice and on conditions for adherence to the guidelines.

This dissertation consists of two studies with a total of three papers that explore adherence to the guideline in general practice and some of the conditions for adherence to the guideline in general practice. For the first study, we obtained the material at the general practitioners' (GPs') offices and for the second study, we obtained the material from the hospitals.

The first study led to two published papers. Paper I is a prospective cohort study on adherence to the guideline regarding follow-up of patients with stroke in general practice. The material consisted of GPs' medical records from the first year with follow-up in general practice after stroke. We studied whether the recommendations in the guidelines were followed and how often patients consulted their GPs during the period. In Paper II, we studied the extent of multimorbidity among patients. Multimorbidity was defined as two or more concomitant chronic disease states from a previously

published list of 40 conditions. Against this background, we modeled three hypothetical patients, each with a representative number of chronic conditions, based on the common chronic conditions found among the patients. We analyzed what it meant to follow the overall guidelines for the various conditions in the form of the need for consultations with a GP and specialist, as well as supplementary examinations such as blood tests or X-ray examinations. We found that patients with stroke had frequent consultations with their GPs, however, the adherence to the guideline was limited. In those cases where the guideline was followed, it did not necessarily mean that the target values for, for example, blood pressure were reached. All patients met the criteria for multimorbidity, and on average the patients had 4.7 chronic conditions including stroke from the list of 40. The analysis showed that considerable effort was necessary in order to adhere to the overall recommendations in the different guidelines. For a patient with an average number of chronic conditions, 10 to 11 consultations annually were required to check the conditions in the stable phase. More consultations would be necessary in the event of deviating findings, exacerbation of one or more diseases or in the case of intercurrent illness during the period.

Study 2 was an analysis of the hospital discharge summaries for the patients in study 1. We used a discourse analytical approach. In Paper III, we explored whether the discharge summaries contained the elements recommended by the guidelines, and whether the discharge summaries were used as tools for knowledge transfer and collaboration. We found that the discharge summaries did not contain all the elements recommended by the guidelines. There was a clear tendency for matters of importance for hospital treatment to be discussed, while matters of importance for the further follow-up in general practice were to a greater extent omitted. The discharge summaries did not invite to collaboration on patients after discharge and had an untapped potential in knowledge transfer from specialist to primary health care.

Overall, the studies shed light on several factors that are challenging in the follow-up of patients with stroke in general practice. Adherence to the guidelines in general practice was weak, and at the same time the overall guidelines were not possible to adhere to for patients with complex multimorbidity. We also identified weaknesses in knowledge

transfer and collaboration across the levels in the health care service. If goals of seamless transitions within the health care services for patients with stroke are to be achieved, these challenges must be addressed. This project has aimed to be descriptive analytic of the existing situation and has not aimed to come up with new solutions. However, it is clear that more knowledge is required to solve the challenges associated with follow-up of patients with stroke in general practice.

Acknowledgements

This research project was made possible with the help of many persons, each contributing in their individual way. I therefore would like to thank my main supervisor Irene Hetlevik for including me in her research team and for her dedicated support and guidance. She has continuously been encouraging in all stages of the research project. I am also extremely grateful for all inspiration and all insights she has provided me with. I would also like to thank my co-supervisors Halfdan Petursson and Henriette Thune. Halfdan – thank you for all your valuable input. Without your sharp academic gaze, this project would have been a lot poorer in many dimensions. Henriette – thank you for introducing me to the world of meaning production and communication, and for our long and inspiring talks online, in Oslo and in Copenhagen.

The traditional African proverb "It takes a village to raise a child," leaps to mind when I think of Allmennmedisinsk forskningsenhet (AFE) Trondheim and Nasjonal forskerskole i allmennmedisin (NAFALM). The enthusiastic and dedicated people I have met there all deserve my gratitude for contributing to a milieu where a PhD-candidate can grow in a safe and intellectually stimulating environment. Thanks to NAFALM for supporting my academic visit to the Primary Care Unit at the University of Cambridge, and to Jonathan Mant and Ricky Mullis for accepting and including me there.

I would like to thank all the general practitioners who participated and let me in to their clinics and facilitated data collection. Thanks to all the patients who participated in the project. This thesis is dedicated in particular to you. I thank Møre og Romsdal Hospital Trust for helping in identifying patients for the projects, and Helfo (The Norwegian Health Economics Administration) for help in identifying the general practitioners. My gratitude also goes out to the Faculty of Medicine and Department of Public Health and Nursing for giving me this opportunity.

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I am grateful for the understanding from friends and relatives who have accepted my absence and absentmindedness in periods of this project.

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List of publications

This thesis is based on the following original research papers:

Paper I:
Pedersen RA, Petursson H, Hetlevik I: "Stroke follow-up in primary care: a prospective cohort study on guideline adherence". *BMC Family Practice* 2018; 19: 179.

Paper II:
Pedersen RA, Petursson H, Hetlevik I: "Stroke follow-up in primary care: a Norwegian modelling study on the implications of multimorbidity for guideline adherence". *BMC Family Practice* 2019; 20: 138.

Paper III:
Pedersen RA, Petursson H, Hetlevik I, Thune H: "Stroke follow-up in primary care: a discourse study on the discharge summary as a tool for collaboration and knowledge transfer". *BMC Health Services Research* 2021; 21: 41.

Abbreviations

ASA	Acetylsalicylic Acid
BP	Blood Pressure
CEUS	Contrast-enhanced ultrasonography
CK	Creatine Kinase
COPD	Chronic Obstructive Pulmonary Disease
CNS	Central Nervous System
EBM	Evidence Based Medicine
GP	General Practitioner
HELFO	The Norwegian Health Economics Administration
HUNT	Helseundersøkelsen I Nord-Trøndelag [The Nord-Trøndelag Health Study]
ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10th revision
IOM	The US Institute of Medicine
LDCT	Low-dose computed tomography
LDL-C	Low-Density Lipoprotein Cholesterol
mmHg	Millimetre of Mercury
NAFALM	Nasjonal Forskerskole i Allmennmedisin [Norwegian Research School in General Practice]
NTNU	Norwegian University of Science and Technology
NR	No Recommendations
RA	Rheumatoid Arthritis
RCT	Randomized Controlled Trial
REK	Regional Committee for Medical and Health Research Ethics
RGP	Regular General Practitioner
SD	Standard Deviation
SIGN	Scottish Intercollegiate Guidelines Network
STROBE	Strengthening the Reporting of Observational studies in Epidemiology
TIA	Transient Ischemic Attack

WHO	World Health Organization
WONCA	World Organization of Family Doctors

Prologue: The development of this project.

Becoming a researcher in general practice

The general practice perspective and a holistic approach to the patient has always intuitively appealed to me as a physician. After completing medical school at the University of Bergen in 2000 and the following 18 months mandatory internship, I nonetheless chose differently. In 2002 I began to work in neurology. The cause of this choice was in part chance, in part a genuine interest for the discipline, and in part a feeling that I was not ready for the independent role as a general practitioner (GP). Eight years later, I was a qualified neurologist with experience ranging from internship in local hospitals to consultant in the largest university hospital in Norway. This was the point where I chose to become a GP. I was offered the opportunity to take part in establishing a new surgery in my hometown, Kristiansund. In 2010, we welcomed our first patients. While general practice offered many new challenges, something was missing. During my years in hospital medicine, especially at the University Hospital in Oslo, I had learned to appreciate being a part of a research orientated team of colleagues. Whereas earlier, I could draw on the research efforts of my colleagues, I soon realized that I now had to do research myself. This was the obvious way to get in touch with academic medicine, the part that was missing in my new life as a GP.

Finding my research project

It was clear to me from the beginning, that I wanted to ground my research in my own self-perceived strengths: the general practice perspective and an in-depth knowledge of neurological disorders. The same year as I began my career as a GP, the Norwegian Directorate of Health issued national guidelines for treatment and rehabilitation in stroke. This presented an opportunity for my research project. With the introduction of new treatments, such as thrombolysis, and new forms of management in specialized stroke units in hospitals, there was a strong focus on the acute treatment of stroke. The follow-up of stroke survivors in general practice did not achieve the same attention. This was well illustrated by the implementation efforts made for the new guidelines in

2010. While grants were distributed to projects with the aim of making the guidelines known in specialized care, the implementation efforts in primary care were less vigorous and consisted of presenting the new guidelines on a stand in a primary care conference. I was curious if other GPs knew the recommendations in the guidelines at all and if they adhered to them in their follow-up of stroke survivors.

From idea to study protocol

I was not convinced that the recommendations for the follow-up of stroke survivors were adhered to in general practice. Stroke is a serious condition, and if guidelines for stroke were not adhered to, this might also be true for other and possibly less serious conditions. Perhaps a project on stroke could also illuminate some public health issues. At that time, I was taking courses in public health medicine, and the idea of a project that matched several of my professional interests emerged. I discussed my thoughts with friends and colleagues in general practice as well as in academia. One of my previous colleagues from the department of neurology advised me to contact the General Practice Research Unit at The Norwegian University of Science and Technology (NTNU) in Trondheim. There I met Irene Hetlevik, who was later to become my mentor and main supervisor. With her help, a vague idea was transformed into a research protocol.

1. Background

1.1 Overview of this thesis

Stroke is a frequent cause of death and disability. In recent years, we have seen major improvements in the acute treatment of stroke (1). The subsequent follow-up of stroke survivors has not achieved the same attention (2-4). In 2010, Norwegian national guidelines for treatment and rehabilitation in stroke were issued, providing advice for the entire process from the prehospital acute phase, via hospital treatment, rehabilitation, and to the follow-up in primary care (5). These different phases are tied together with advice for interaction and collaboration (5).

This thesis includes three papers focused on the follow-up of stroke survivors in primary care. Paper I investigates the extent to which patients who have suffered a stroke are followed up in general practice, if procedures recommended in the guidelines have been applied, and whether patients achieve the treatment goals set in the guidelines. Paper II investigates the implications of multimorbidity for follow-up of stroke in general practice. Paper III explores the hospital discharge summaries after hospitalization for stroke with the aim of assessing the discharge summaries as tools for knowledge transfer and collaboration within the health care services after patients' discharge from hospital.

Later in this background chapter, I will introduce the central themes for this thesis, such as stroke, recurrent stroke, secondary prevention, general practice, clinical practice guidelines, evidence-based medicine, and multimorbidity. In accordance with a Norwegian recommendation for the contents of medical theses (6), I have included only references published prior to our papers in the background. Hence, the background is an outline of what was already known when I embarked on this project.

Chapter 2 presents a theoretical framework for this thesis that incorporates theories from different academic disciplines. The theoretical framework is connected to the nature of

general practice, to language in use, and to collaboration. In Chapter 3, I describe the present study. After a presentation of aims and a description of the study sample and recruitment, the material and methods of each paper is presented individually. Finally, a summary of results is presented.

In Chapter 4, I discuss important aspects of the methodology and reflect on the researcher's role, validity, transparency and trustworthiness. In the following discussion of results, newer literature is also added (6). After providing the conclusions in Chapter 5, I will present some reflections on implications and future perspectives in Chapter 6.

1.2 Stroke and recurrent stroke

The term "stroke" originated as a predominantly lay term and has been in use for over 400 years. Physicians, on the other hand, preferred the word "apoplexy" until the first half of the 20th century (7). Typically, stroke is characterized by the sudden onset of focal neurological signs and symptoms, resulting from disturbances in the circulation of blood to the brain in the form of brain hemorrhage or ischemia. The World Health Organization (WHO) defines stroke as *"rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin"* (8) (p.114). This definition dates from the 1970s and in the decades since, knowledge and technology have evolved. The need for an updated definition of stroke has therefore emerged. In 2013, the American Heart Association/American Stroke Association presented an updated definition of stroke based on expert consensus (9). According to this statement, the term "stroke" includes ischemia and hemorrhage, as well as silent ischemia and silent hemorrhage; lesions found on imaging or neuropathological examination without a history of attributable acute neurological dysfunction. Ischemic stroke is defined as: *"An episode of neurological dysfunction caused by focal cerebral, spinal, or retinal infarction"* and CNS infarction is defined as *"brain, spinal cord, or retinal cell death attributable to ischemia, based on 1. Pathological, imaging, or other objective evidence of cerebral, spinal cord, or retinal focal ischemic injury in a defined vascular distribution; or 2. clinical evidence of cerebral, spinal cord, or retinal focal ischemic*

injury based on symptoms persisting ≥24 hours or until death, and other etiologies excluded" (9) (p.2066). There is, however, still no universally endorsed updated definition of stroke. Approximately 80 – 90% of strokes affecting the brain are cerebral infarctions (5, 10).

Globally, stroke is the second most common cause of death (11) and the third most common cause of disability (12). At the time of the planning of this project, in 2013, about 15,000 persons suffered a stroke in Norway each year, and a 50% increase was expected in the period 2007-2030 (5, 13). The community's use of resources on stroke care is extensive. There are no exact calculations of the costs of a stroke in Norway, but lifetime expenses for one stroke have been suggested to be around NOK 600,000 (2006) (14).

Having suffered a first stroke, the person has an increased risk of further strokes. The risk is particularly high in the early post stroke period, but also remains high the following years (15). Estimates of stroke recurrence vary. In a meta-analysis from 2011, Mohan et al. found a cumulative risk of stroke recurrence of 11% within 1 year, 26% within 5 years and 39% within 10 years (16). Rates have been falling, but recurrent stroke remains a major clinical problem (17) and one in four strokes is a recurrent stroke (18). Compared to patients with a first-ever stroke, patients suffering recurrent strokes more often have adverse outcomes and costs are higher (19). Recurrent stroke is associated with a high mortality (20). This underlines the importance of secondary prevention.

1.3 Secondary prevention

In stroke, the term secondary prevention refers to the treatment of risk factors in persons who have already suffered a stroke. This treatment aims to prevent a recurrent stroke. There are many causes of stroke and modifiable risk factors are well known. They include atrial fibrillation, hypertension, diabetes mellitus, smoking, dyslipidemia, obesity, and lifestyle (21-23).

Long-term antiplatelet treatment is well established as a cornerstone of secondary prevention of stroke. Antiplatelet drugs primarily have their effect through inhibition of platelet activation and aggregation (24). Aspirin, also known as acetylsalicylic acid (ASA), has been a standard treatment, and used for decades (25). In a cumulative metanalysis from 1999, Algra and van Gijn found a relative risk reduction of 13% for new vascular events in patients with ischemic stroke when treated with aspirin (26). This represents a somewhat more modest therapeutic effect than some previous findings (27, 28). Further effects can be achieved by combining aspirin with dipyridamole or by clopidogrel in monotherapy, the guidelines therefore recommend this (5).

Arterial hypertension is regarded the most important single risk factor for stroke (29). Because it might affect cerebral perfusion, the effect of lowering blood pressure (BP) after a stroke was for a long time uncertain. In recent years, it has been documented that lowering BP is associated with significant reduction in stroke both in the context of primary, as well as secondary prophylaxis (30, 31). In the Norwegian guidelines from 2010, a treatment goal for BP of <140/90 mmHg in general and <130/80 mmHg for younger patients and patients at particularly high risk is recommended (5).

The association between hypercholesterolemia and vascular risk is well established. In Norway, this was pointed out as early as in 1937 by Carl Müller (32, 33). It has later been established that low density lipoprotein cholesterol (LDL-C) plays an important part in atherogenesis (34) and thus in the resulting atherosclerotic disease. Lipid-lowering treatment with statins reduces the risk of stroke (35-37). In 2006, the Stroke Prevention by Aggressive Reduction in Cholesterol Levels (SPARCL) trial, a multi-centre randomized controlled trial (RCT) evaluated the effect of statin treatment in secondary stroke prevention, and found that recurrent strokes and cardiovascular events were reduced after a first stroke or transient ischemic attack (TIA) with 80mg of atorvastatin daily (38).

Diet, smoking, alcohol intake, exercise and obesity are lifestyle factors connected to the risk of stroke in general (39-41). Information about lifestyle given as a part of secondary prevention can help people to achieve changes (42).

An association between high salt intake and increased incidence of stroke has been documented (43). In the Northern Manhattan Stroke Study in 2003, Suk et al. found abdominal obesity to be an independent risk factor for ischemic stroke (44). In a large standardised case-control study with 3000 cases with a first ever stroke recruited from 22 countries and 3000 controls, the 2010 Interstroke study, O'Donnell et al. (29) documented that high consumption of red meat, salty snacks, fried foods, and alcohol was associated with higher risk of stroke, in contrast to the lower risk associated with the consumption of fish and fruit. In the same study, the risk of stroke among current smokers increased with the daily number of cigarettes smoked. Regular physical activity, on the other hand, was associated with a reduced risk for stroke in general. However, no RCT has demonstrated the same for exercise in secondary prevention of stroke (45). There has been an uncertainty as to whether different risk factors have the same significance in the primary and secondary prevention of stroke. Guidelines' recommendations on lifestyle in secondary prevention of stroke are to some extent based on research in connection to primary prevention rather than in populations selected on the basis of symptomatic cerebrovascular disease (5, 45).

Handling the modifiable risk factors with effective treatment can provide substantial gains in preventing cerebrovascular disease and death (46, 47). Still, to provide the necessary regular follow-up and to adhere to recommendations for secondary prevention is a challenge for the health care services (46). Development and implementation of clinical practice guidelines is one way to solve this challenge.

1.4 Evidence-based medicine

Evidence-based medicine (EBM) has its philosophical origins in mid-19th century Paris and also before that (48), but the term was first launched in medical literature in the early 1990s by Gordon Guyatt from McMaster University in Canada (49, 50). EBM started as a movement to increase the use of best available evidence from research as a basis for decision-making in clinical practice. In 1996, Sackett et al. defined EBM, and described its practice, as following:

"Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research" (48) (p. 71).

The critics of EBM point to scientific dilemmas when evidence is weak, and to the problematic effects at the local level where EBM can shift focus away from clinical experience and replace it with a "cookbook medicine" (51, 52). One worry has been that clinicians are encouraged to follow the protocol instead of using clinical judgement, which paradoxically may lead to poorer standards in health care (52). In a 1997 article with the title *"Restoring the balance: evidence-based medicine put in its place,"* one of the critics, Bruce G. Charlton, concluded: *"The core of clinical medicine is, and should remain, the provision of personal medical services by means of a consultation. And the place of EBM must be subordinate to this."*(53) (p. 97).

In a later definition, its combination with clinical skill and the patient's situated position is emphasized, and EBM is defined as *"healthcare practice that is based on integrating knowledge gained from the best available research evidence, clinical expertise, and patients' value and circumstances"*(54).

A common strategy for implementation of EBM is through the development of clinical practice guidelines (52).

1.5 Clinical practice guidelines

There are different definitions of clinical practice guidelines, also known as clinical guidelines, or "guidelines". In 1990, a committee appointed by the US Institute of Medicine (IOM) issued a report on clinical practice guidelines, and defined them as *"systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances"* (55) (p.38). This definition has been much used later, and in 2011, the IOM updated its definition to: *"Clinical Practice guidelines are statements that include recommendations intended to optimize*

patient care. They are informed by a systematic review of evidence an assessment of the benefits and harms of alternative care options" (56) (p.25-26). This definition is also used by The Guidelines International Network, an international association of persons and organizations involved in the development and use of guidelines, and of which the Norwegian Directorate of Health is a member (57, 58).

Over the last decades, the number of guidelines has increased substantially (56). They are developed in different countries by various organizations. The quality and the process of development varies (59). Stakeholders internationally such as the US IOM (56), The Scottish Intercollegiate Guidelines Network (SIGN) (60), the UK National Institute for Health and Clinical Excellence (NICE) (61), and the Directorate of Health in Norway (62), have developed standards for guideline developers. Principles from EBM are central in the development of guidelines (63).

In order for a guideline to contribute in achieving aims of optimizing patient care in clinical practice, physicians are expected to adhere to the recommendations in the guideline. Passive methods of implementation, such as distribution of guidelines, is in itself not sufficient and it is therefore recommended use of more active methods of implementation (64). However, there is an uncertainty about which strategies are appropriate under different circumstances (65), and even comprehensive active implementation-strategies do not necessarily lead to adherence to the clinical guidelines (66, 67).

Lack of awareness of guidelines, lack of familiarity with guideline recommendations, lack of agreement with guideline recommendations, lack of outcome expectancy, practice inertia, and lack of self-efficacy – the personal judgement that one can execute a course of action (68) – are all among the various identified reasons for physician non-adherence to guidelines (69). It has, however, been suggested that GPs who do not adhere to guidelines may act on a professional rationale that has not yet been sufficiently identified, understood, and described in the in biomedical research that forms the basis of the guidelines (70). The workload generated in general practice from implementation of guidelines has also been subject of criticism. For example,

guidelines on hypertension have been estimated to impose a workload that exceeds the total working capacity of Norwegian GPs (71).

In Norway, the Directorate of Health has the responsibility for developing national clinical practice guidelines. The national clinical practice guidelines are normative, and they provide a basis for interpreting legislation in the health care services. Health care practitioners are obliged by law to provide "sound health care" and guidelines are part of the accepted grounds for assessing what is academically sound (62).

1.6 Norwegian national guidelines for treatment and rehabilitation in stroke

The Norwegian national guidelines for treatment and rehabilitation in stroke were issued in 2010. They were developed by a multidisciplinary group appointed by the Norwegian Directorate of Health after suggestions made by the regional hospital administrations. The ambitions of the project are stated in the preface of the final product: "these guidelines shall contribute to a science based, effective treatment of good quality for all stroke patients in Norway, regardless of age, sex and place of residence" (5)(p.1). Recommendations in the resulting guidelines were given according to modified version of a methodology developed by SIGN. In this methodology for guideline development, the recommendations were graded depending on the quality or strength of the evidence supporting the individual recommendations. Systematic reviews of RCTs had the highest rating as support or evidence (5).

1.6.1 Recommendations in the guidelines on secondary prevention in general practice

The Norwegian national guidelines for treatment and rehabilitation in stroke state that the GPs should be a key worker in the follow-up of stroke survivors. They include a section dedicated to the follow-up in primary care, in effect in general practice. The GP is supposed to provide follow-up of "optimal secondary prevention". The following items are presented in a list of important tasks for the GP to focus on in the follow-up:

- Hypertension. The treatment goal for BP is <140/90 mmHg
- Smoking cessation
- Statins. Patients with stroke should generally be treated with statins. The follow-up is meant to secure that the LDL-C treatment goal of <2,0 mmol/L is achieved, and to detect any side effects that require action. Blood lipid values, creatine kinase (CK) and transaminases should be controlled.
- Diabetes mellitus
- Atrial fibrillation

Antithrombotic treatment and habits of life such as physical activity, obesity and diet are also pointed out as topics for an optimal secondary prevention of stroke.

1.6.2 Recommendations on collaboration, knowledge transfer and discharge summaries in the guidelines

The guidelines also emphasize the importance of collaboration within the health care systems. Regarding communication and knowledge transfer from secondary to primary care, the guidelines provide a list of recommendations for the contents in the hospital discharge summary. The following elements are recommended:

- The kind of stroke and its localization in the brain
- The cause of the stroke
- A short description of the treatment and the diagnostic investigation
- Complications (if applicable)
- The patient's level of function on discharge
- Prognosis, including prognosis for driver's license and work
- Assessment of the necessity for further diagnostic investigations
- Medication at discharge
- Further treatment and treatment goals for the blood pressure and blood lipid values
- Plans for the follow-up

1.7 General practice and the Norwegian health care context

1.7.1 General practice

General practice has slightly different roles in different parts of the world, depending on assets, tradition and the structure of the health care system. General practice, or family medicine, is by its nature context-specific (72). In the 2002 World Organization of Family Doctors' (WONCA's) European definition, general practice/ family medicine is "*an academic and scientific discipline with its own educational content, research evidence base and clinical activity, and a clinical specialty oriented to primary care"*(73) (p. 4).

In its definition of general practice, WONCA has also stated a set of core competencies and characteristics of the GP. These competencies and characteristics of general practice and the GP are visualized as branches and leaves in the "WONCA tree". Among the characteristics are longitudinal continuity and a patient and context centered care. Communication with patients is at the tree's trunk and the tree is rooted in attitude, science and context.

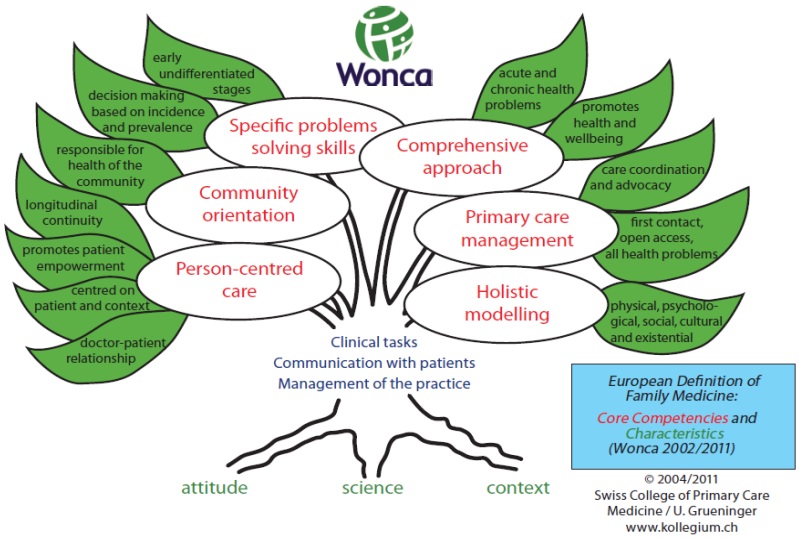

Figure 1.1. "The WONCA Tree." Reproduced with permission of the Swiss College of Primary Care Medicine.

In the following, I will present three selected characteristics that are of special relevance to this thesis; a person-centered approach, longitudinal continuity, and a comprehensive approach.

A person-centered approach

One characteristic of the discipline of general practice is that it practices a person-centered approach. The focus is on the individual in the context of life circumstances, family, and community (73). A patient-centered clinical method is meant to understand the patient as well as his or her illness and stands as a contrast to a disease-centered clinical method. In 1986, Levenstein et al. introduced a patient-centered method for general practice (74). In this approach, the physician tries to access the world of the patient by behaving in a way that invites to openness from the patient. Hence, the physician can obtain an understanding of the context of the illness that can be crucial to understanding the whole illness. A patient-centered method is especially central to general practice because to many of the problems presented in general practice, a

pathological diagnosis is not always the most relevant. Furthermore, the criteria of success are not necessarily the same in general practice as in other fields of medicine. Arriving at a precise diagnosis in general practice may implicate an earlier missed opportunity to prevent the illness. Furthermore, there are many ways of managing an illness, and therefore the GP must know the patient as an individual (74). Later, it has been documented that a patient-centered approach in general practice leads to fewer diagnostic tests, lower costs, and increased patient satisfaction (75, 76).

Longitudinal continuity

Another characteristic of general practice as a discipline is the relationship with the patient over time, where each consultation can draw on prior consultations. General practice is responsible for providing longitudinal continuous care and follow the patients through their whole life (73). Continuity of care improves preventive care and adherence to treatment (77), and personal and continuous care is associated with higher patient satisfaction (78, 79). Continuity of care in general practice is also associated with reduction in long-term mortality among older adults (80), and with fewer hospitalizations and a lower probability of using outpatient specialist services (81).

A comprehensive approach

The third and last characteristic to be presented here, is that general practice deal with all kinds of health problems for each individual patient. This means that the GP manages acute and chronic conditions of the patients and often multiple problems at same time or in the same consultation. Therefore, it is necessary to make choices. Such choices must be based on both the physician's and the patient's priorities (73).

1.7.2 General practice in Norway

The health care system in Norway is divided into primary health care and specialist health care. The municipalities are responsible for the primary health care service, while the state is responsible for the specialist health care service. In the Norwegian system, hospital services are provided by the local health trusts, which in turn are owned by four state owned regional health trusts.

In 2001, the regular general practitioner (RGP) scheme ("Fastlegeordningen") was introduced in Norway. The purpose of the RGP scheme was to ensure that everyone receives the necessary GP services of good quality at the right time, and that persons residing in Norway have one specific RGP to consult (82). In this scheme, RGPs have lists of regular patients for whom they have a special responsibility, and each individual resident has the right to be on the list of one RGP. Limited to twice a year, it is possible for the patient to change RGP if another RGP has a vacancy on his or her list. Although voluntary, participation in the scheme is high among residents in Norway. In 2012, about 99% of the Norwegian population was registered with an RGP (83).

1.7.3 Stroke follow-up in General practice

It has previously been documented that primary care is associated with lower mortality of stroke (84). In the description of different medical specialties, The Norwegian Medical Association states that the GP must have a broad and comprehensive knowledge about examination, treatment and prevention of disease, and be experts in follow-up of patients with chronic and complex conditions (85). General practice is well positioned to provide follow-up for stroke patients residing in the communities, but its potential is not necessarily fulfilled (86, 87).

1.8 Multimorbidity

There are different definitions of multimorbidity. However, multimorbidity is most often defined as the presence of two or more simultaneous chronic medical conditions in the same person (88, 89).

Almost 90% of first-ever strokes affect patients aged 65 or older (18) and most persons over the age of 65 have two or more chronic conditions, defined as multimorbidity (90). A Norwegian study based on the HUNT health survey 2006-2008 (91) has shown that at the age of 65, seven of 10 are affected by multimorbidity (92). Patients with multimorbidity have clinical needs that may differ from those of patients suffering from one single condition (93). Most patients with one chronic condition have multimorbidity, but clinical practice guidelines largely focus on single conditions (94).

Among patients in general practice, multimorbidity represents the rule rather than the exception (88, 92, 95). Treatment of patients with multiple concurrent diseases in accordance with the relevant guidelines can give undesirable results (96, 97). One example is polypharmacy which is associated with increased risk of adverse effects (98, 99). GPs can therefore experience situations where adherence to guidelines is incompatible with a patient centered approach to the patient with multimorbidity (100). With multiple coexisting morbidities, multiple guidelines must be applied to the individual patient. In such situations, benefits and harms associated with combining treatments become unclear and priorities become uncertain (101). For the patient, the management burden can become considerable with a resulting chaotic experience of care (102). Multimorbidity and polypharmacy is more common among persons with stroke than among those without (103).

2. Theoretical framework

When new knowledge is to be created, it is necessary to define what is to be studied and in which context. We also need to be clear on the purpose or aim of the study, why it is conducted. Furthermore, we need to define the tools of inquiry. Finally, we need to have some basis upon which the new knowledge can be built. The field of study for this thesis was presented in Chapter 1. The aims of the study and the scientific tools or methods are presented in Chapter 3. In this chapter, the focus is on the theoretical framework.

A theory is in a scientific sense a system of assumptions and statements that enable the derivation of new statements within the field the system is meant to apply (104). A theoretical framework is in other words a basis upon which new knowledge can be built. This thesis is concerned with developing knowledge in the field of general practice about topics ranging from the science on which the guidelines draw, to the communication and collaboration necessary to provide follow-up for stroke survivors. A theoretical framework for this thesis must therefore consist of inputs from the basis of knowledge in general practice as well as contributions from theory on language in use and on collaboration. This is in sum a large theoretical field. The presentation in this chapter is therefore limited to some core theoretical inputs for this thesis.

2.1 Theoretical aspects of general practice; basis of knowledge and continuity of care

The Merriam- Webster Online Dictionary (105) defines medicine as *"the science and art dealing with the maintenance of health and the prevention, alleviation, or cure of disease."* In our part of the World, contemporary Western medicine is often called *"conventional medicine" or "biomedicine",* the latter a term that links the understanding of medicine to biology. Biomedicine can be defined as *"medicine based on the application of the principles of the natural sciences and especially biology and biochemistry"* (105).

The basis of knowledge in general practice differs somewhat from other parts of medicine. While other medical disciplines can focus on one particular organ, condition or technology, general practice is meant to practice an integrated approach. Combining knowledge from the natural sciences and the humanities is not unique to general practice (106), but possibly especially central to this discipline. In a Norwegian textbook of general practice, Kirkengen et al. discuss the basis and limits of clinical knowledge and describe how a mismatch between biomedicine and clinical reality is particularly noticeable in general practice. A key point is that the biomedical understanding is based on a methodology that consists of biology, pathology, objective measurements, and standardization. This framework, however, leaves little room for psychological and social phenomena. In turn, this is particularly challenging for the GP, who is supposed to provide holistic help to the patient over time, and not just deal with disease processes of individual organs (107).

Most medical disciplines define themselves on the basis of clinical content and the doctor- patient relationship is therefore often limited in time and space, depending on the patient having a disease covered by the clinician's specialty (108). Doctors in general practice is to a greater extent concerned with the patient as a person (109), and the continuous relationship with the patient is essential to the practice (108, 110) and fundamental to the ideology and teaching in this discipline (111). As mentioned before, continuity of care by doctors has been documented to give better patient satisfaction, fewer acute admissions in hospitals and lower mortality rates (112). The clinical practice of general practice can only to a limited extent be based on science (110), and biomedicine alone is an insufficient theoretical basis for understanding the clinical practice of this discipline (107). In addition to the role as clinical practitioner, the GP, at least in Norway, is meant to have other roles in the health care services. The role as a coordinator of health care makes collaboration and communication essential.

2.2 A theory on language in use and a method for analysis

Language makes it possible to share information with other people. Communicating information is, however, not the only function of language. Language also helps us to be things and to do things. In fact, *"saying things in language never goes without also doing things and being things"* (113) (p.2). Put another way, using language means saying, being (113), and doing things with words (114).

Discourses

When we talk or write, we adapt our language to the specific setting. We take part in practices that belong to certain social groups, institutions, or cultures (113). We could also refer to this by saying that we take part in a discourse. "A cognitive and normative community expressed in language", is one way of understanding a discourse (115) (p.29). On this basis, there is no limit to the number of discourses, and we can identify different discourses within the health care services and within the medical profession. Discourses do not only reflect social realities, but they also construct them and maintain them (116) and research on discourses often investigates how social realities are constructed in language (117).

Discourse analysis

James Paul Gee has developed an interdisciplinary theory and method of discourse analysis (113, 118). In Norway, this theory and method has become central to the teaching of discourse- and text analysis for PhD students in literacy studies (119). The theory focuses on the structure of language and the basis for the theory is the assumption that when we use language, we construct areas of reality. These areas of reality are referred to as the "building tasks" of language. One such building task is *significance* – when we express ourselves through language, some things are made more significant than other things. A second building task is *practices* or *activities* – by speaking or writing we enact a practice and language is used to make others understand what activity or practice is going on. A third building task is *identities* – language helps us to get recognized as playing a certain role ourselves, but also to attribute identities to others. The fourth building task of language, Gee calls *relationships* – signaling the kind

of relationship we have or want to have to others. *Connections* is also among the building tasks – we use language to build connections or to disconnect things. By doing this, we make things more or less relevant to each other. The last building task to be mentioned here, is what Gee calls *sign systems and knowledge* – we can use language to privilege some kind of sign system (e.g., medical language over everyday language). We also use language to make claims to knowledge, or to privilege some form of knowledge.

It is on the basis of this theory of language in use, Gee develops his methodology for a discourse analysis. Each of the "building tasks" can be analyzed through several dimensions. Each way of analyzing the building tasks is referred to as a "tool of inquiry". Each "tool" can be formulated as a specific question to ask of the data. S*ocial languages* is one example of the tools of inquiry – different styles of language are used for different purposes. The *social languages* tool of inquiry is to investigate how this is done. A discourse analytical question could be "How does this communication use words and grammatical structures to signal and enact a given social language?" *Figured worlds* is another example. This tool of inquiry is based on the often unconscious theories about reality, that are taken for granted and used to get on efficiently in daily life. Other terms for the same phenomenon include "cultural model", "discourse model", "frame", and "folk theory". Gee's example of a discourse analytical question for the figured worlds tool is this: *"For any communication, ask what typical stories or figured worlds the words and phrases of the communication are assuming and inviting listeners to assume. What participants, activities, ways of interacting, forms of language, people, objects, environments, and institutions, as well as values, are in these figured worlds"* (118) (p.177).

2.3 A theory on collaboration

The guidelines are a knowledge base for different levels in the health care service and they also provide recommendations on the organization of the treatment and on collaboration (5, 120). The guidelines state that "It is important to have a structured collaboration between the specialist health care services and primary health care

services and other service providers in order to be able to offer a continuous chain of treatment" and that the different participants in this collaboration "must work towards common aims" (5) (p.25). In 2014, I wrote my master's thesis in social studies (121). I was then introduced to a theory of collaborative advantage, developed by Vangen and Huxham (122). This theory also informs the parts of this thesis concerned with the topic of collaboration. In the following, I will therefore present some key parts of Vangen and Huxhams theory.

The theory of collaborative advantage illustrates the complexity of collaborations and provides pointers to aspects that are challenging in collaborative situations. Agreement on aims, trust-building, cultural diversity and attitudes to knowledge transfer are four such aspects that need consideration for collaborations to be successful.

Agreement on aims

Common or agreed aims are essential to a collaboration, and this is in itself paradoxical. The paradox lies in the fact that the potential for a collaboration to achieve advantage, comes from drawing on heterogenous participants with different background and expertise but these differences are at the same time connected to different visions. Agreement on aims can therefore be problematic. To better understand this problem, the authors suggest analyzing aims in several dimensions.

For example, aims can vary at different levels and aims of individuals can differ from the aims of organizations. Therefore, the behavior of participants in a collaboration can be affected by individual aims as well as aims at organizational levels. Also, aims can be formulated or influenced by stakeholders (e.g. governments) external to the collaboration. Another dimension for analysis is therefore the different origins of aims or mandate that can have different implications on the collaboration.

A third dimension is authenticity. Aims stated may be genuine but they may also be pseudo-aims invented to e.g. satisfy an external stakeholder or aims that have been forced upon the participants. These are some dimensions of aims that illustrate how complex this one aspect of collaboration may be.

Trust

"Trust is a prerequisite for successful collaboration yet many situations are characterized by suspicion and mistrust" (122) (p.168). In collaborations, trust must be built and maintained. Imbalance in power is among the possible threats to trust.

Cultural diversity

A part of the difference between participants that provide the potential to draw benefits from a collaboration, comes from the differences in culture. Differences in culture can, however, cause tensions. Encountering otherness makes it necessary to build awareness to avoid pitfalls such as unrealistic expectations and illusions of superiority.

Attitudes to knowledge transfer

There may be various reasons for setting up a collaboration, but sharing knowledge and work is a key aspect of all collaborations. However, *"attitudes to knowledge-sharing vary"* (122) (p.174). Participants in collaborations take various stances to both giving knowledge and taking knowledge. E.g., participants can be protective or unconfident and seek to avoid sharing knowledge. Participants can also be passive towards knowledge transfer and not think of it, described as "sidelining".

In collaborative situations there exists a tension between "Collaborative Advantage" on one side and "Collaborative Inertia" on the other side. With the term "Collaborative Advantage", the authors mean the synergy that can be created by working together, while "Collaborative Inertia" refers to the tendency collaborations have, to be "*slow to produce output or uncomfortably conflict-ridden".* In fact,*"…left to their own devices, collaborations are much more likely to reach collaborative inertia than collaborative advantage"* (122) (p. 180).

3. The present study

3.1 Aims

A starting point for the present project was the assumption that guidelines for the follow-up of stroke in general practice were not sufficiently adhered to. When we constructed the protocol, we wanted to elucidate and explore the follow-up of stroke survivors residing in the communities. Those are the ones who have their follow-up of stroke in general practice. First, we had to map the follow-up visits to see if our initial assumption was correct. We then chose to follow two tracks in the search for possible explanations of why the clinical reality may differ from a theoretically expected pattern of action as described in the guidelines. One track was patient complexity, or more precisely patients' multimorbidity. The second track was connected to collaboration between primary and secondary health care services.

The overarching aim of this thesis has been to develop knowledge about the follow-up in general practice after stroke. More specifically to develop knowledge on the adherence to the national guidelines for the follow- up after stroke in general practice and to explore two specific topics that may have implications for the follow-up of stroke survivors in general practice: patients' multimorbidity and collaboration between secondary and primary care after hospital discharge for stroke.

The overarching aim was reached by conducting studies with the following more detailed aims:

- To investigate to what degree patients who have suffered stroke are followed up in general practice, if recommendations in the national guidelines are adhered to, and if patients achieve the treatment goals recommended in the guidelines (Paper I).
- To investigate the extent of multimorbidity among stroke survivors residing in the communities, with the purpose of assessing the implications of multimorbidity for the follow-up of stroke in general practice (Paper II).

- To map the degree to which the hospital discharge summaries contain elements recommended in the guidelines and to assess to what degree the discharge summaries invite to a post discharge collaboration on the patient (Paper III).

3.2 Methods and material

This thesis has been developed from a study consisting of one sub-study on data collected in general practice (Study 1) and one sub-study on data extracted from hospital discharge summaries (Study 2). These sub-studies were on the same study population. The general practice study was presented in two papers, Paper I and Paper II. The discharge summary study was presented in Paper III.

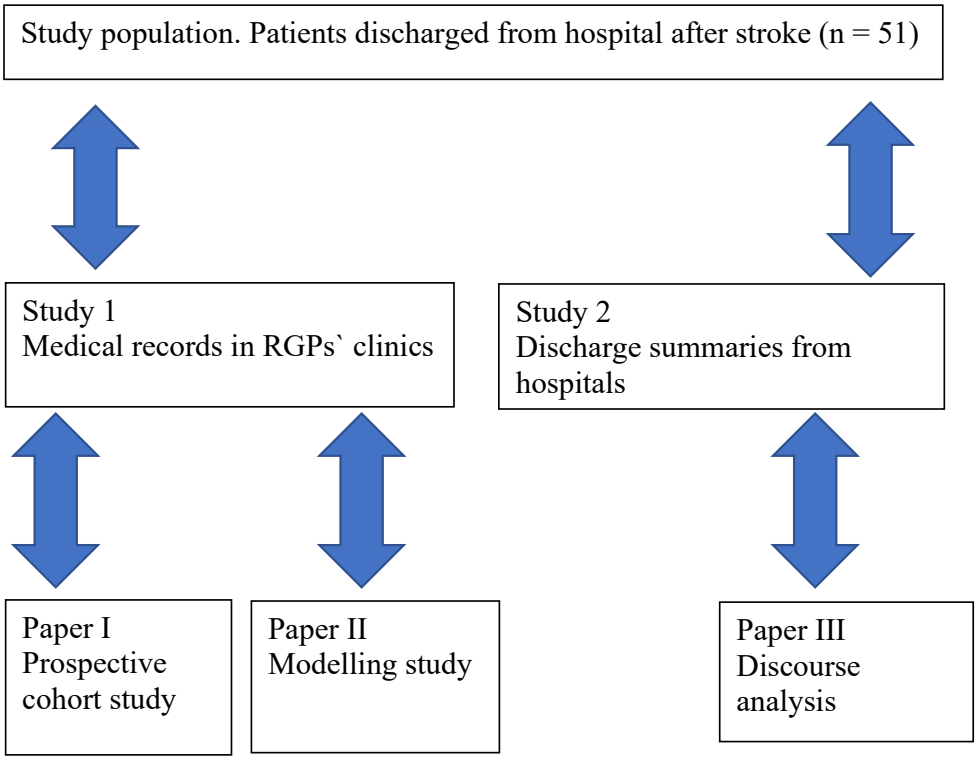

Figure 3.1: Flowchart showing material and methods in sub-studies and papers

3.2.1 Study sample and recruitment

We wanted to examine how stroke survivors residing in the communities were followed up in general practice and whether patients' complexity exemplified by multimorbidity may have implications for the basis of the follow-up. To investigate how follow-up actually took place, we needed access to the GPs' medical records. Furthermore, to assess the implications of multimorbidity for the follow-up in general practice, we needed to be able to see the same picture as the GPs. Hence, it was essential to map the extent of patients' multimorbidity in the GPs' own documentation; the medical records in the RGPs' clinics.

After approval by the Regional Committee for Medical and Health Research Ethics (REK), the Helse Møre og Romsdal Hospital Trust provided a list of patients discharged with ischemic cerebral stroke (ICD- 10 diagnosis I63 (I63.0 through I63.9)) as a primary or secondary diagnosis from 01.01.2011 to 31.12.2011 from two local hospitals in Møre og Romsdal County in Western Norway; the hospital in Molde and the hospital in Kristiansund. We did not include patients with hemorrhagic stroke, as the guidelines did not apply to all subgroups of hemorrhagic stroke. As the plan was to collect the material for Study 1 at each participating RGP clinic, the travel distance had to be limited. These two hospitals had a combined admission area of about 9,500 square kilometers with close to 120,000 inhabitants. With this choice of hospitals, it was possible for me to reach any of the RGP clinics in the admission area by car within a three to four-hour drive each way. We deemed longer travel distances to be unfeasible for this project.

We examined the hospital discharge information for each patient. Patients who had died (group 0) and patients discharged to permanent nursing home stay (group 1), were excluded. The remaining patients were discharged to follow-up by their RGP (Group 2), to rehabilitation stays (group 3) or to outpatient follow-up at the hospital (group 4). Date of discharge was registered, and for group 4 patients, the time of the last outpatient consultation at the hospital was registered.

The Norwegian Health Economics Administration (HELFO) provided a list of the RGPs for each individual patient. This information excluded patients who had died after discharge from hospital. Furthermore, patients who had changed RGP were excluded. This was done by cross checking the recipient of the discharge summaries (RGP at the time of discharge) with the RGP in the list from HELFO (RGP at the time of inclusion). The RGPs with patients on the remaining list with practice address in Møre og Romsdal County were invited to participate in the study. RGPs with practice address outside Møre og Romsdal were excluded. Only patients living in their own homes with RGPs who had accepted participation were subsequently invited to participate (group 5). All patients from group 5 who gave their written consent were included in the study.

The first inclusion process resulted in 26 written patient consents and is illustrated in figure 3.2.

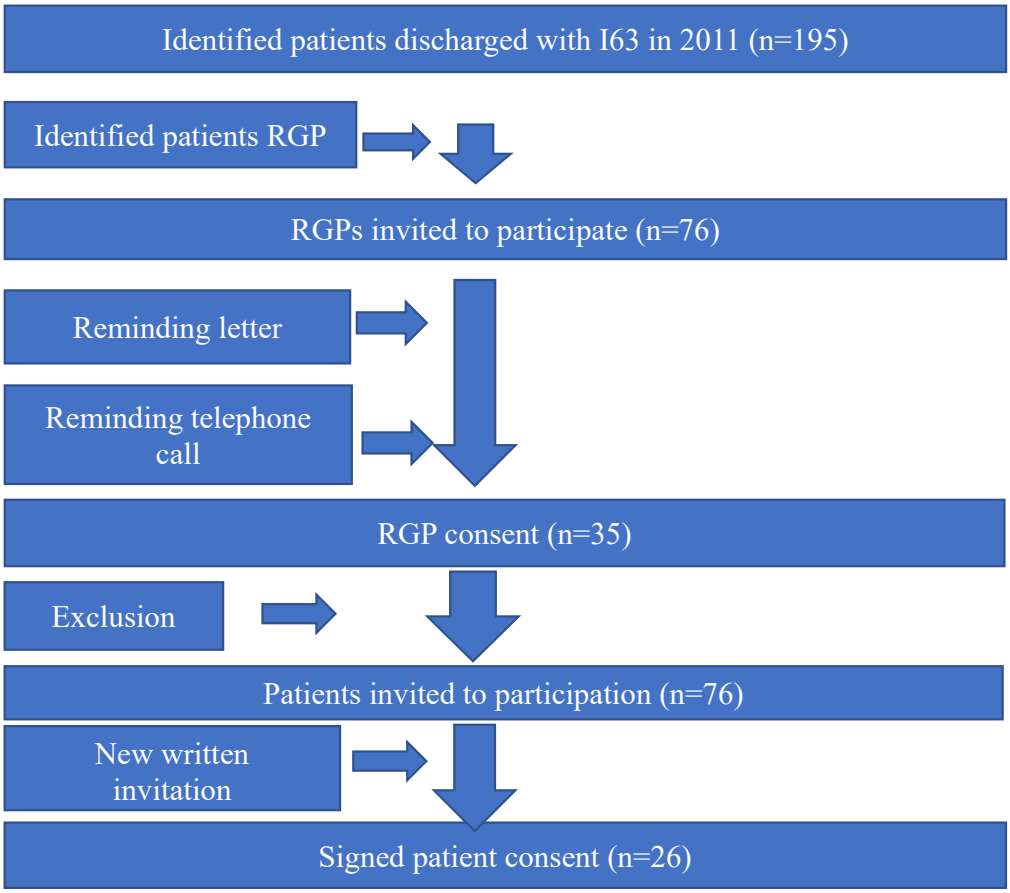

Figure 3.2: Flowchart showing the first round of inclusion

We deemed this study population to be too small, and therefore applied to REK for an extension of the inclusion period from 01.01.2012 to 31.12.2012. REK accepted the extension, and a new, supplementary inclusion was carried out. The second inclusion process is illustrated in figure 3.3.

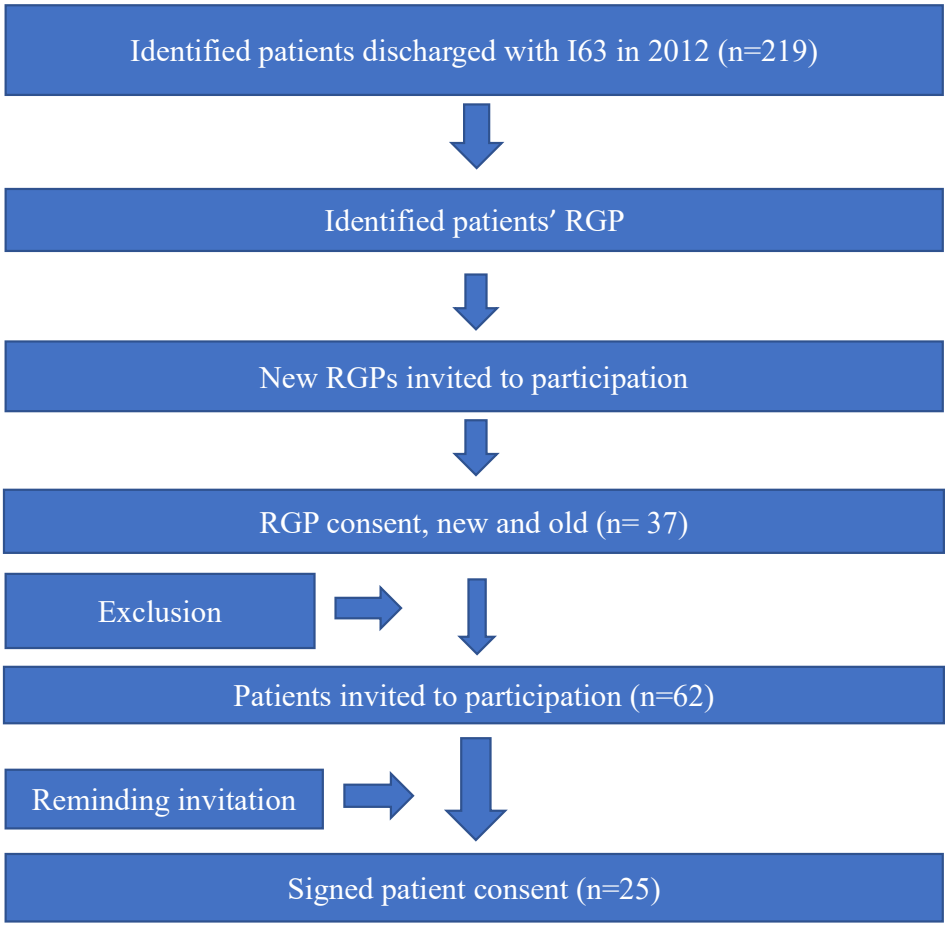

Figure 3.3: Flowchart showing the second round of inclusion

Figure 3.4 illustrates the combined inclusion for the entire inclusion period from 01.01.2011 to 31.12.2012.

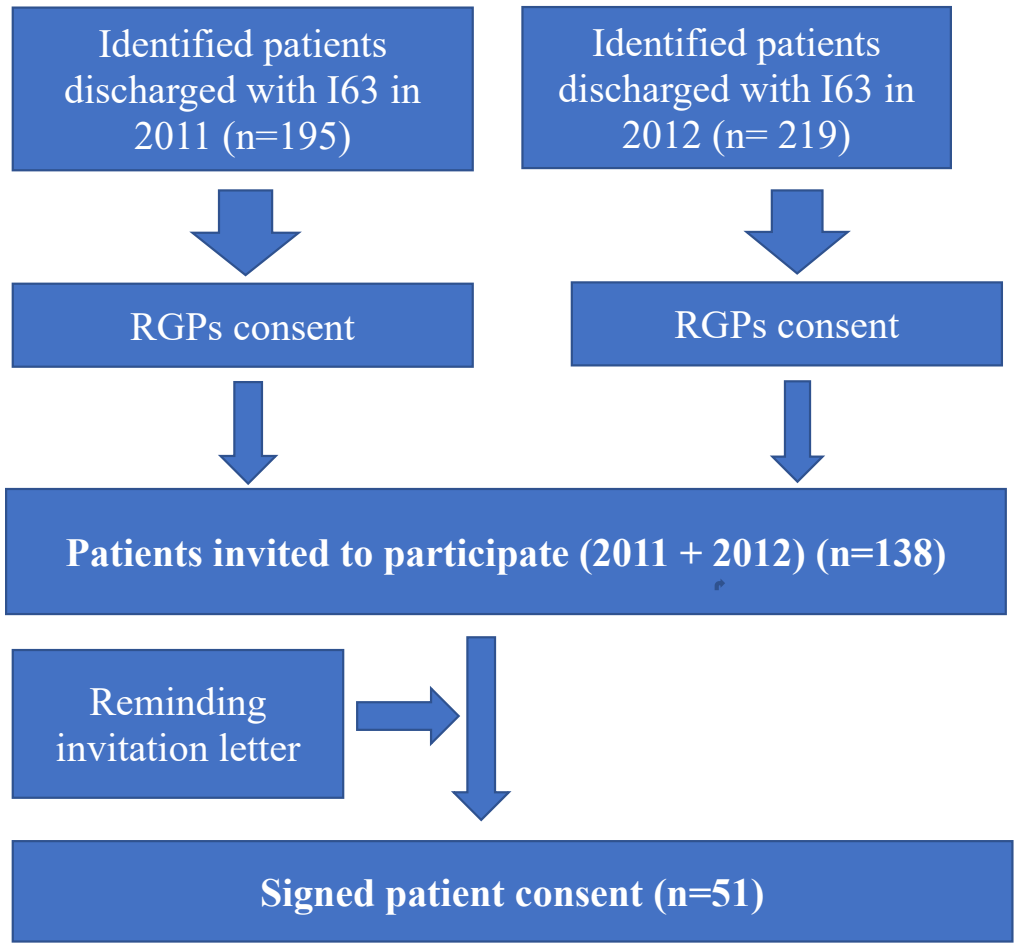

Figure 3.4. Flowchart showing the combined inclusion for the study

The data collection process varied somewhat between the different papers and is therefore described in more detail in the presentation of each paper below.

3.2.2 Participating patients and clinics

A total of 37 GPs gave their written informed consent to participation. From the patient lists of these 37 GPs, 138 patients were invited to participation and 51 gave an informed written consent. The patients' age varied from 38 to 90 years at the time of the stroke (mean 68.5 years). Thirty were male (59%) and 21 were female (41%). The patients had RGPs in 18 different clinics spread across the northern half of the county of Møre og Romsdal. The clinics were localized in the countryside and in two towns. All clinics kept electronic medical records. They were all available for wheelchair users and had secretaries available by phone.

3.2.3 Study 1- Paper I. Guideline adherence

Design and data collection

All data were collected and processed by RAaP. Patients discharged with ischemic stroke were identified in the hospital files, and our first aim was to investigate the follow-up in general practice. For this purpose, we designed a prospective cohort study. Data for Paper I was obtained by personally visiting each of the 18 clinics where the participating RGPs practiced. The clinics facilitated the data collection by providing a workstation and access to the electronic medical records. The GPs used three different electronic medical record systems (System X, Winmed and Profdoc vision). These are record systems widely used in Norwegian general practice, and I had previously been trained in all these systems.

For each participating patient, the complete medical records from the RGPs' surgery was read for the first year after discharge for stroke or the first year after the last outpatient control at the hospital in the case the patient had such a control. Each consultation was evaluated according to a list of elements adapted from the guidelines and supported by an operational definitions list. The list of elements was made to standardize the data collection and the operational definitions was made to standardize the data coding. The operational definitions list is provided in the appendix. Beside the

main written text for each consultation, all other written documentation in the electronic medical records was also read. This included the record's diagnosis registry, laboratory results, and prescribing registries and notes from other contacts than consultations, e.g. phone calls. All consultations were registered. Consultations that – according to the preset definition – had stroke as a topic and those that had stroke as a main topic were counted. Furthermore, it was registered if lifestyle advice were given and what form of lifestyle advice (e.g. diet, physical activity or smoking). It was also registered if the recommended blood tests were taken, if BP was measured and if the treatment goals for these tests were reached.

Analysis and interpretation

Complete and unedited patient records from the RGPs' clinics were not collected. The reasons for this are discussed in the ethics chapter below. Therefore, the first analysis and the first interpretations had to be made there and then in the RGP's clinic while retrieving data. Notes of the number of all consultations, the number of consultations with stroke a topic and the number of consultations with stroke as the main topic were made. It was easy to identify a consultation and to differentiate consultations from other notes in the written text, because these notes were explicitly marked in all three electronic record systems. This is due to the financial system for general practice in Norway, where consultations are coded to trigger a specific tariff that is different from the tariffs of other types of contact.

Any consultation where stroke was mentioned in the medical records, was defined as a consultation with stroke as a topic. Consultations where a measurement relevant to stroke was made without it being assessed in the context of stroke were not counted. E.g.: BP measurement outside the context of stroke was not counted as a consultation with stroke as a topic.

To find consultations with stroke as the main topic, the written text of the medical record for the consultation was assessed and consultations where stroke was the most prominent issue were counted. This was an individual assessment of each text. Consultations where more than half of the text was concerning the stroke were included,

and so were also consultations where the text pointed to stroke as the main topic without the subject of stroke necessarily constituting one half of the words. A fictional example could be: “Long conversation about stroke and secondary prevention. She also needs a prescription for paracetamol and a referral to a physiotherapist for her chronic back problem.” Here it appears that the main content of the consultation was stroke, although most words are about other topics. Consultations were also counted when stroke was one of two prominent issues and it was reason to believe that at least half of the time spent in the consultation could be occupied with the issue of stroke.

The data collection resulted in 51 completed forms with information on the follow up of each stroke survivor in the study population the first year after discharge from hospital or the first year after the last outpatient consultation at the hospital where applicable. Information from the forms was summed up and the number of consultations in the study period calculated. The material covered a total of 381 consultations with the GPs. We compared the recommendations for follow up of stroke in general practice in the national guidelines with real life clinical practice as documented in the medical records.

3.2.4 Study 1- Paper II. Multimorbidity

Design and data collection

This study was designed as a cross sectional analysis of the prevalence of multi morbidity in our study population. Barnett et al. had previously published a list of 40 chronic conditions in an epidemiological study on multimorbidity (90). This list of chronic conditions was used to identify conditions to include in our multimorbidity count. Aided by this list, RAaP reviewed the medical records for each patient at the RGPs’ office. In the reviewing process, the written texts of the records, the prescribing registry, and the diagnosis registry were read. Notes were made of every condition corresponding to the definitions of the 40 conditions on the list. This resulted in 51 lists of chronic conditions, one for each participating stroke survivor.

Analysis and interpretation

The 51 lists of chronic conditions formed the basis for our following analysis. The number of morbidities for each patient was counted and the mean burden of morbidities; the number of chronic conditions, was calculated. We also made a list of the co-existing chronic condition found among the patients, ranging from the most to the least frequent. Based on this information, we constructed three example patients. The example patients were to be representative for the study population in age, sex and the number and kind of chronic conditions. We chose a number of chronic conditions corresponding to below the average for one example patient, about average for the second example patient and above average for the third example patient. All conditions chosen were among the 20 most frequent conditions found among the participants, and only conditions with clinical guidelines or similar formal recommendations were chosen.

For each of the three example patients, a follow-up regimen was constructed based on the recommendations in the different guidelines for the chronic conditions of each example patient. In this follow-up regimen, we noted the number of consultations recommended with the GP, with different organ specialists, and with other health care providers. We also made notes where laboratory tests or special procedures were recommended. This was the basis for the analysis of the total health care burden for the patients.

3.2.5 Study 2- Paper III. The discharge summary study

Design and data collection

The material for this study consisted of discharge summaries for the hospital stay that resulted in the diagnosis of stroke. The hospital administration provided access to the patient files so that we were able to extract the discharge summaries of the hospital stay in question for all 51 participants. The texts in the discharge summaries were the data for our following discourse analysis.

Analysis and interpretation

As earlier referred to: a discourse analysis is a study of language in use (123). When using language, for example in writing a discharge summary, we do things with words (114) and we take part in a practice that belongs to a social group or culture (113).

The guidelines recommended that certain content should be included in the discharge summaries. We read each discharge summary aided by a list of these elements and registered content recommended by the guidelines. In the next phase of the analysis, we used a selection of tools for discourse analysis adapted from Gee's approach to discourse analysis (113, 118). We utilized these tools for each discharge summary and noted answers to the questions posed by each tool. Table 3.1. present all the 10 tools we used and their operational definitions. Tools 1-7 are fetched directly from Gee, while tools 8-10 are my formulations of relevant tools for the material, inspired by Gee.

Tools	Operational definition
1) The Subject Tool	Ask why the authors have chosen the subject/topic and what are they writing about the subject. Ask also if and how they could have added more topics and why they did not.
2) The Doing and Not Just Saying Tool	Ask not just what the authors are writing, but also what they are trying to do. Accept that they may be trying to do several things.
3) The Significance Building Tool	Ask how language is being used to build up or lessen significance/ importance/ relevance for certain things, but not for others.
4) The Activities Building Tool	Ask what activity (practice)/ activities (practices) the text is building/ enacting. What activity/ activities is the text seeking to get others to recognize.
5) The Identities Building Tool	Ask what identity or identities the author is enacting or trying to get others to recognize.
6) The Relationships Building Tool	Ask how language is being used to build, sustain, or change relationships of various sorts among the authors, other people, groups or institutions.
7) The Figured Worlds Tool	Ask what typical figured worlds the words or phrases of the text are assuming and inviting readers to assume. Especially, how is the GPs' situation in this figured world?
8) The Collaboration Tool	Ask in what way are words and grammatical devices being used to make the text invite to collaboration. Ask also if there are signs of the opposite in the text.
9)The Patient's Voice Tool	Ask if the patient's voice (questions, utterances, opinions, wishes or preferences) are commented on (other than indirectly in the anamnesis).
10) The Recipient Tool	Ask what recipient the author most likely had in mind when writing, based on the subject, contents, words and phrases in the text.

Table 3.1. Tools for discourse analysis with operational definitions

3.2.6 Ethics

Approvals

The study was approved by REK with the reference number REK midt 2013/1501. All participants – both patients and GPs – were informed about the study and its purpose. All participants gave their written consent. Both GPs and patients were anonymized.

Ethical considerations

Paper I

We did not bring with us complete and unedited patient records from the RGPs clinics. We considered that the benefits of this did not justify such extensive data retrieval, which would necessarily include data not relevant to the study. We therefore did not apply to REK for permission to do so.

Paper II

In this paper, we used hypothetical example patients instead of real patients. We considered using real patients in the examples and found that this would set the anonymity of the participants at risk.

3.3 Summary of results

3.3.1 Synopsis of the papers I – III

Paper I

Stroke follow-up in primary care: a prospective cohort study on guideline adherence

Pedersen RA, Petursson H, Hetlevik I: *BMC Fam Pract* 2018; 19: 179.

This paper investigated the follow up in general practice of patients with stroke residing in the communities. We focused on whether the follow-up in general practice was in accordance with the recommendations in the national guidelines for treatment and rehabilitation in stroke. We assessed whether treatment goals were reached and investigated to what degree the patients consulted their RGPs – for the stroke and for other topics – the first year after hospital treatment for stroke. We performed a prospective study of a cohort of stroke survivors identified in the hospital files (n=51).

Results

We identified a total of 381 consultations the first year after discharge from hospital with stroke as a diagnosis or the last outpatient consultation for stroke. In 148 of these consultations (39%), it was documented that stroke had been a topic. We assessed that stroke was the main topic in 71 consultations (19%). BP was measured in 46 patients (90%) and the treatment goal was reached in 24 (47%). LDL-C was measured in 28 patients (55%) and the treatment goal was reached in 14 (27%). We found it documented that a total of 16 patients (31%) received some kind of lifestyle recommendation. BMI was calculated for 12 patients (24%), 6 (12%) got advice on physical activity and none of the patients got advice on alcohol consumption.

Conclusion

The stroke received limited attention in general practice in the first year of follow-up. The guidelines were often not adhered to. Many consultations were concerned with other topics than the stroke, indicating that there must be other reasons than just lack of access to the RGP as explanation for the weak guideline adherence. Such reasons may be found in the complexity of general practice.

Paper II

Stroke follow-up in primary care: a Norwegian modelling study on the implications of multimorbidity for guideline adherence

Pedersen RA, Petursson H, Hetlevik I: *BMC Fam Pract* 2019; 20: 138.

This paper investigated the extent of multimorbidity among stroke survivors residing in the communities in a county in Western Norway. We performed a cross sectional study of the prevalence of multimorbidity among the patients and mapped the most common co-morbidities. On this basis, we estimated the implications of the overall guideline-recommendations in terms of need for follow-up consultations and investigations of different kinds for representative hypothetical patients.

Results

The number of chronic conditions corresponding to a predefined list of 40 conditions was in the range of two to 10 for all participants. All participants met the criteria for multimorbidity, defined as two or more chronic conditions or morbidities. On average, patients had 4,7 (SD: 1.9) morbidities, 46 (90.2%) had three or more morbidities, and ten (19.6%) had seven or more morbidities. The most prevalent co-morbidities to stroke were hypertension, coronary heart disease, rheumatic disease as a group and diabetes. The analysis of the health care burden showed that a high number of annual consultations with the GP were necessary in order to adhere to the different guidelines' recommendations for the follow-up in stroke patients with multimorbidity. We modelled the implications for an average patient and found that 10-11 consultations were needed annually to follow up the stable state of the chronic conditions. The need for follow-up consultations increased with increasing complexity of multimorbidity. While an increase in the need for consultations with intermitting disease or unstable chronic conditions was foreseeable, this increase was not calculated.

Conclusion

Adhering to the guidelines for each condition was challenging for the stroke patients with the fewest co-morbidities. For patients with complex multimorbidity, adhering to the combined guidelines for the different conditions seemed unmanageable.

Paper III

Stroke follow-up in primary care: a discourse study on the discharge summary as a tool for collaboration and knowledge transfer

Pedersen RA, Petursson H, Hetlevik I, Thune H: *BMC Health Serv Res* 2021; 21: 41.

This paper investigated to what degree the discharge summaries for patients with stroke adhered to the guideline-recommendations for discharge summary contents. It explored whether the discharge summaries invited to the prescribed collaboration between secondary- and primary care, and if the potential for knowledge transfer in this communication was fulfilled. We performed a discourse analysis. The study population was the same as in Paper I and Paper II. The data for this paper was collected in the hospitals and not in general practice as was the case with the previous two papers.

Results

We found varying adherence to the different recommendations for content in the discharge summaries. The discharge summaries often described the treatment and diagnostic investigation (98%), the kind of stroke and its localization in the brain (87%), and the cause of the stroke (80%). Descriptions of the patients' level of function at discharge were provided by 63% of the discharge summaries and multidisciplinary assessments by 31%. In total 12 (23.5%) of the discharge summaries provided plans or advice of any kind for the follow-up in primary care. In the interpretative discourse analysis, we did not find indications of invitations to collaboration on the patient after discharge.

Conclusion

One tendency was clear: the discharge summaries focused on the fragments of health care provided there and then in the hospitals and omitted other relevant topics. In this way the discharge summaries contributed to maintain the fragmentation of the post stroke health care. The discharge summaries were to a limited extent used as tools for knowledge transfer. Collaboration is prescribed by the health authorities as a necessity for seamless and integrated health services. In this study, we found that the hospital discharge summaries did not fulfill their potential to facilitate such a collaboration.

3.3.2 Key findings

Study 1 (Paper I and Paper II)

Adherence to the Norwegian national guidelines for treatment and rehabilitation in stroke was weak in general practice. This may be due to patient complexity. Patients' multimorbidity is a part of this complexity.

All participants met the criteria for multimorbidity. Multimorbidity had clear implications for the basis of the follow-up of patients with stroke in general practice due to the health care burden the combined recommendations of the different guidelines imposed on patients with multimorbidity.

Study 2 (Paper III)

The discharge summaries had a fragmented focus on certain topics while omitting others. Typically, the focus was on the health care provided there and then, in the hospital. While a focus on the health care provided in itself is necessary, the omittance of other relevant topics such as plans, advice, collaboration, or knowledge transfer contributes to maintaining a fragmented health care service. A potential in the discharge summaries to contribute to seamless transfer of care and follow-up of high quality was not fulfilled.

4. Discussion

Previous sections have described the process of developing this project from a vague idea to a research project, the background, how data have been collected, the tools used, and the results or findings. In this chapter, I will present reflections on this research project and the choices I have made from the beginning to the completion. I will present strengths and weaknesses of the project, discuss ethical aspects, researcher bias, and other factors that may affect the results. First, I will present a reflection of the relevance of the topic today.

This project was planned in 2013. In our study we included patients with ischemic stroke, as the guidelines do not apply to all types of hemorrhagic stroke. A study from 2019 showed that the number of ischemic strokes in Norway in the period 2010 to 2015 was declining, despite a growth and ageing of the population (124). In contrast, in a recent systematic review of population-based stroke incidence studies from high-income countries, Li et al. found that the incidence of stroke is falling, but not the absolute number per year (125). A study from England in 2020 by Clery et al., has added that the proportion of stroke survivors discharged to their own home has increased significantly over the last two decades, from 72% in 1995 – 2000 to 92% in 2013 – 2018 (126). This may indicate that the follow-up in general practice of stroke survivors residing in the communities is still as relevant today as it was at the beginning of this project.

4.1 Discussion of methods

This thesis comprises three papers with different methods, but the same study sample when it comes to patients involved. The sources of data have been the patients' medical records at the RGPs' offices for Study 1 (Paper I and Paper II) and their hospital discharge summaries after hospitalization with stroke as a primary or secondary diagnosis in Study 2 (Paper III). I will therefore first present reflections on the recruitment of participants for the entire project, before further describing reflections and critiques of the methods for each paper individually.

4.1.1 Reflections on recruitment

There were limits in time as well as in space for the choice of study sample. The patients had to have at least one year of follow-up by the RGP after a hospitalization and a possible outpatient follow-up for stroke at the hospital. The hospitalization had to occur after the introduction of the guidelines in 2010. The planning of this study took place in 2013 with the ambition of collecting material from 2014 onwards. In order to have had one year of follow-up with the RGP before the data collection, the participants could therefore have been hospitalized in 2011 or 2012.

The study took place in Møre og Romsdal county. As the plan was to collect data from the RGPs' own documentation, this involved personal attendance by the researcher at each RGP clinic. Therefore, the study also had to be limited in space. By limiting the geographical area to the admission area for the local hospitals in Kristiansund and Molde, I could reach any of the RGP clinics within a three to four-hour drive. We considered three to four hours of driving each way to be the maximum acceptable, it was therefore not an option to include the admission areas of more than the two local hospitals.

The local hospitals in Kristiansund and Molde had an admission area with about 116,000 inhabitants in 2011. Based on Norwegian incidence of stroke (18), we expected about 270 ischemic strokes, corresponding to the ICD-10 – diagnosis I63, annually in a population of this size. We estimated that about 70% of these patients were eventually discharged to their own homes (14, 18, 127) and to a follow-up by the RGP. This gave us a theoretical study population of 190 persons in 2011. We needed enough patients for the descriptive quantitative parts of the project, but at the same time not more than we could analyze in the qualitative part of the project. We deemed it likely that we could recruit a suitable number of participants among 190 stroke survivors residing in their own homes, hence we started out with inclusion of patients treated for stroke in 2011.

We underestimated the challenges of recruiting participants in our double inclusion design. First, the relatively low number of GPs responding, limited our possibility to invite patients to participate. Second, we had a low response rate from the patients we

did invite. We therefore had to repeat the inclusion for patients surviving a stroke in 2012. In retrospect, it can be argued that it would have been easier to have a longer inclusion period from the start. However, at the time we could not predict that the participation would be so low. On the other hand, a very high participation from a long inclusion period could have exceeded our capacity for qualitative analysis of the discharge summaries.

4.1.2 Reflections on design, study sample, data collection, and analysis

Study 1; Paper I and Paper II

Reflections on design and study sample

We wanted to investigate if the recommendations in the national guidelines were adhered to and if patients reached the treatment goals stated in the guidelines. The point of departure was a group of stroke survivors identified in the hospital files and residing in the communities. To investigate the follow-up, we could have designed a questionnaire and performed a survey among the participating GPs, among the participating patients, or both. This, however, would be an investigation of thoughts and opinions on the subject, while we wanted to examine the situation as it was recorded in the patients' medical records by their RGPs. We could also have used the discharge summaries as a source of data for the multimorbidity count in Paper 2, but this information would be filtered by the hospital physician and would not allow us to take part in the GPs view on the extent of multimorbidity for each of the patients. To get as close as possible to the situation as it was, we therefore needed to perform an observational study where I personally visited each of the clinics to collect the information directly from the RGPs' own electronic medical records. Using the RGPs' medical records as source of data and designing a prospective cohort study for the follow-up and a cross sectional study for the multimorbidity count, allowed us to do just that. This is a strength of the study.

Reflections on data collection

I personally visited each clinic, and I was given access to the electronic medical records. There and then, I assessed the records and made notes of the number of consultations,

results of procedures, and number of concurrent chronic conditions. The data collection for Paper I was guided by an operational definitions list, presented in the appendix. When we constructed the operational definitions list, we tried to make the criteria for registering lifestyle advice as wide as possible, in order to not miss out any advice given. For example, we included all BMI calculations found in the medical records of the patient, also those made before the stroke, and we included any note on alcohol in the study period. This approach carries with it an inherent possibility of overestimating the amount of advice given. While the fact that only one researcher assessed the medical records rules out the possibility of inter-observer bias, it does not rule out the possibility of intra-observer bias. There is also a possibility that the GP does not document all aspects of the consultation. Alternatively, recording the consultations would introduce the possibility of an observer effect.

Visiting 18 different clinics with up to a four-hour drive each way, must necessarily be done over some time. During this time, and with increasing experience, it is not unlikely, or even rather to be expected, that changes occur in the way the observer assesses the material. Also, there is a possibility of incorrect recordings. As the assessments were made there and then in the clinics, there was no way of revising this part of the process afterwards except for repeating the whole data collection process. Such a revision would be very resource demanding, and in practice unfeasible. This may be regarded as a weakness.

For the multimorbidity count, we needed to define what conditions to include. Definitions of multimorbidity were not uniform at the onset of this project (128), but multimorbidity was widely defined as the coexistence of two or more chronic conditions in the same individual (129). However, there was no internationally accepted standard for defining or counting chronic conditions. Definitions of these terms remained diverging through the project period (130). We therefore had to make a pragmatic choice for the definition of multimorbidity and for which conditions to include in the multimorbidity count. Barnett et al. had recently presented a list of 40 chronic conditions used in a multimorbidity count in an epidemiological study on multimorbidity (90). We found that this list could also be used in a study in Norwegian

general practice and assessed it a strength to use a pre-defined list of conditions already published in the same research field. We therefore chose this list to define what conditions to include in the count of chronic conditions and defined multimorbidity as the presence of two or more concurrent chronic conditions from the same list. The list is included in the appendix.

Reflections on analysis

In Paper I, we compared the recommendations in the national guidelines with the clinical practice as documented in the medical records of the GPs. We used simple frequency analyzes to shed light on the degree of adherence to the guidelines.

A starting point for Paper II was that perhaps the sum of recommendations for different conditions was not compatible with the capacity of the GP, the patient, or both. If so, this could provide a new dimension of understanding lack of adherence to guidelines in general practice. It was known that multimorbidity was the rule rather than the exception in general practice (88). We therefore wanted to model the practical implications for patients posed by adhering to the recommendations in the guidelines for their various chronic conditions. To achieve this, we had to find the number of concurrent chronic conditions among the stroke survivors. We also had to map the most common chronic conditions. On this basis, we could calculate the number of consultations, procedures and examinations. We made a pragmatic choice of using three hypothetic example patients. The use of hypothetic patients had the advantage that the examples could be designed to complement each other and at the same time fit well into the list of the most common chronic conditions. We also used some of the same conditions in more than one example; chronic obstructive pulmonary disease (COPD), diabetes, colorectal cancer and thyroid disorder were all used in two examples. This led to fewer descriptions of recommendations from the guidelines and might be regarded a weakness. The reason, however, was to avoid exhausting the reader with too many excerpts from the various guidelines.

Study 2; Paper III

Reflections on design and study sample

"In planning a research design, the researcher in quest of new knowledge cannot be shackled by discipline-specific methodological restraints"(131) (p. 74).

In Study 2, We wanted to examine the "conversation" between doctors in hospitals and doctors in general practice at the time of discharge from hospital. The discharge summaries are essential in this conversation, and we wanted to find out if the discharge summaries included the topics recommended by the health authorities in the national guidelines for treatment and rehabilitation in stroke and if they invited to the prescribed collaboration within the health care services (5). The intention was to illuminate new dimensions in the understanding of follow-up of patients with stroke in general practice. Therefore, we assessed the study sample from Study 1 to be suited for this study as well. By designing a discourse analysis, we chose a design that was not common in the medical research I had seen so far. However, we found it necessary to examine the language of the discharge summaries to achieve the new insights we were looking for. For a part, I could draw on my background from the social sciences, but I soon realized that I lacked the necessary knowledge from discourse analysis. The solution was a course in text and discourse analysis at the University of Stavanger and a co-supervisor from the field of meaning production and communication. Alternatively, we could have designed a focus group study among GPs and hospital doctors. A strength of the text analysis approach was that the material gave direct access to the conversation I wanted to investigate. Other approaches would cause me to miss this direct access to the conversation.

Reflections on data collection

One advantage in the choice of a discourse analysis design was that the data collection was very much straightforward. The Helse Møre og Romsdal hospital Trust provided electronic access to the discharge summaries. Each of the discharge summaries were printed on paper for analysis. In this process, the documents were de-identified in accordance with the ethics committee's approval. Some of the patients had been discharged from hospital with a stroke diagnosis more than one time in the study period, and therefore the total number of discharge summaries was 54.

Reflections on analysis

While the data collection for Study 2 was straightforward compared to that of Study 1, the subsequent analysis of 54 discharge summaries in Paper III was more extensive than the analyzes in the previous two papers. There are many ways of analyzing a text. Looking back, my choice of a discourse analytical approach adapted from that of J. P. Gee (113), was pragmatic. This approach to discourse analysis was a central part of the curriculum in the PhD course in text and discourse analysis at the University of Stavanger (132). I could therefore assume that this approach to discourse analysis was acknowledged among academics within the field in Norway. Furthermore, the theory and method were more operationalized than other discourse analytical approaches I had seen. This gave me ideas to how the work could be organized and helped me getting started. After initiating analysis, I nevertheless realized the need for guidance from a person with expertise in this research method. Much fell into place when Henriette Thune joined this part of the project as my co-supervisor.

An analysis of large amounts of text must be organized in a way that provides overview and structure. Also, choices must be made concerning which tools to use or what questions to ask of the texts. After an initial explorative analysis, I chose a selection of seven analytical tools directly adapted from J. P. Gee (118); The Subject Tool, The Doing and Not Just Saying Tool, The Significance Building Tool, The Activities Building Tool, The Identities Building Tool, The Relationships Building Tool, and The Figured Worlds Tool. Furthermore, I developed three analytical tools strongly inspired the same approach. The latter three were The Cooperation Tool, The Patients Voice Tool and The Recipient Tool. I could have chosen other tools, but at this stage of the project, these were the tools that I considered best suited for the material and the aims. For overview in the process, I constructed a 10 (number of tools) x 54 (number of discharge summaries) matrix for plotting results of the analysis as the work progressed.

4.2 Reflections on the researcher's role and reflexivity

A researcher has previous personal and professional experiences and will therefore bring preconceptions into a research project. His or her background and position may

affect the research process – at the very least for instance in terms of what seems the relevant questions to ask. Reflexivity involves acknowledging and assessing how a researcher's background, preconceptions, position, and perspectives may influence every step of the research process (133). This is by no means something new, the history of reflexivity in qualitative research spans at least a century and involves a range of research traditions (134).

I started my PhD project after three years of clinical practice as a GP, following almost 10 years as a hospital physician. During the project period, I first worked part-time as a GP. Later, I worked part-time as a neurologist. In the same period, I have also worked part time as a medical advisor to the regional branch of the Norwegian Labor and Welfare Administration and taken courses to qualify as a specialist in Public Health Medicine. This means that I have had numerous different positions as a physician in different parts of the health care services studied in this project. I have used different clinical practice guidelines as a practitioner in hospitals as well as in general practice, including the guidelines for stroke after they were issued in 2010. The practitioner-researcher position of the clinician who also conducts research is valuable in developing insights (135). On the other hand, proximity can also make critical reflection difficult (136). By conducting research on colleagues, there is always a risk of choosing sides, of losing the academic distance - what social anthropologists call "to go native" (116).

As stated in the prologue to this thesis, I was not convinced that the guidelines for stroke were adhered to in general practice. This preconception was central to some of the choices made early in this project. I was also skeptical to whether the same guidelines were adhered to in hospitals, but intuitively perhaps thought that guidelines in general were more known and more adhered to in hospitals than in general practice.

I embarked on this PhD project about the same time as I was finishing my master's thesis in social sciences. Input from the social sciences is therefore also likely to have been a part of my perspectives when I first started this project. My master's thesis was on collaboration within the health care services. One of the conclusions was that the concept of collaboration elicits generally positive associations, but people nevertheless

tend to see problems when positive attitudes are to be translated to concrete situations in their own field of practice (121). An assumption on my part, therefore, was that collaboration within the health services was not necessarily practiced the way the guidelines prescribed.

The scientific environment that I became a part of as a PhD candidate, had previously debated and published papers on different aspects of clinical practice guidelines. Even though the specific guidelines in focus of this project had not previously been subject to critical review by my colleagues at the NTNU General Practice Research Unit (AFE) this scientific environment had openly criticized aspects of other clinical guidelines.

4.3 Reflections on validity, transparency, and trustworthiness

Regardless of the methodology chosen, the validity of a research study must be considered (131). The validity of a research project can be addressed by asking questions concerning whether the conclusions drawn are warranted by the data (internal validity), and whether the results can be used to make generalizations beyond the context of the specific research project (external validity) (131). The terms internal validity and external validity originated in connection to quantitative research (131, 137, 138). Qualitative research is based on different philosophical perspectives, and the relevance and use of criteria from quantitative research have been debated (116). Criteria tailored to qualitative research have been suggested (139), but internal validity and external validity is still used as criteria to assess the quality of qualitative research (116). In a textbook of qualitative methods in medical research (136), Malterud asks this question regarding internal validity: "what it is true about"? (p. 22) and for external validity, she asks "In which contexts can our findings apply beyond the context in which we have mapped them?" (p. 22).

Triangulation is an ideal for qualitative research in general (140). It can be part of a strategy for validation (136) and can strengthen the internal validity of a project (131). In this project, I have used mixed methods. Study 1 was a quantitative study and the GPs' medical records were the source of data. Study 2 was a qualitative study with

discharge summaries from the hospitals as the source of data. A main advantage of using multiple methods is that it makes triangulation possible (137). Even though the sources, theories, methods or investigators in each individual paper cannot be said to be triangulated, the project as a whole is triangulated by the use of different sources, methods and theories. Further triangulation could have been possible. For example, I could in addition have performed surveys or interviews among participating patients or participating physicians. However, I found this to require too much time and resources. Utilizing a variety of tools from different disciplines for interpretation of texts in a discourse analysis is in agreement with this approach. Transdisciplinary convergence in discourse analysis occur when interpretations based on inputs or tools from different disciplines converge, and has been proposed as a way to validate discourse analytical approaches to research (141). The tools applied in the discourse analysis in Study 2, are based on perspectives from different disciplines and a variety of approaches (113).

Transparency has been an ideal at every stage of this research process. The form and content of the present dissertation is part of this transparency. Earlier in the dissertation, I have presented my background and preconceptions. Theoretical framework is also accounted for. In study 1, reporting was guided by the STROBE (Strengthening the Reporting of Observational studies in Epidemiology) statement. The STROBE statement is a 22-item checklist with recommendations for transparent reporting of observational research (142, 143). The checklist is endorsed by several biomedical journals (142, 144).

4.4 Discussion of ethics

The study was approved by REK (Reference number: REK midt 2013/1501). Beyond the ethical considerations in connection to the formal approval in REK, planning and conducting this project raised ethical issues worth discussing.

The order in which the invitations to participation were sent, for instance, had an ethical dimension. We needed signed consent from patients as well as from GPs. After identifying the patients, we could have sent invitations to them first. However, we

deemed this to be ethical problematic. A consent from a patient could put pressure on the GP to participate. This could be a strain on the relationship between GP and patient. We therefore decided to invite the GPs first, and only patients listed with GPs who had accepted participation were subsequently invited.

While I have already discussed the practical implications of choosing hypothetical rather than real example patients in Paper II, the choice also had an ethical dimension. We considered it to be possible that patient anonymity could be compromised if actual patients were used in the examples.

4.5 Discussion of results

Our studies have shown that stroke survivors residing in the communities had many consultations with their RGPs during the first year of follow-up after stroke, but that most consultations were on topics other than the stroke. Adherence to the guidelines was weak (Paper I). All patients met the criteria for multimorbidity, defined as the presence of two or more chronic conditions from a previously published list of 40 conditions. Adhering to the sum of recommendations from different guidelines was challenging, and obviously unmanageable for patients with many concurrent chronic conditions (Paper II). The discharge summaries did not meet the authorities' ambitions of continuity of care across different parts of the health care service. They did not fulfill their potential as tools for collaboration, knowledge transfer and guideline implementation in general practice (Paper III).

In the following, I will discuss the results from the thesis in more detail and in light of current knowledge.

4.5.1 Access to the RGPs and follow-up for stroke survivors residing in the communities

When I was collecting the material to the first study (Paper I and Paper II), I personally visited each of the 18 participating RGP surgeries. All were available by phone and all clinics were available for wheelchair users. Altogether, the 51 patients had 381

consultations with their RGP the first year of follow-up after stroke, an average of 7.5 annual consultations per patient (SD = 4.5). On average, Norwegians had 2.6 consultations with their RGPs in 2012 (145). The patients in this study had almost three times as many consultations with their RGPs as average Norwegians. From this point of view, access to the RGP seems to have been good. Even if the patients had relatively many annual consultations with their RGPs compared to the general population, this may still not be sufficient for stroke follow-up in agreement with the guidelines. This depends on how time-consuming adherence to the specific guideline is and to what extent other health issues must be addressed in the consultations.

We found stroke mentioned as a topic in the medical records for 148 of 381 consultations (39%). Regarding consultations with stroke as a main topic, we found this documented for 71 consultations (19%). Most consultations the first year of follow-up after a stroke, were therefore on topics other than the stroke.

Some priorities must have been made in the meeting and the dialogue between patient and physician, leading to this result. Such priorities may be based on professional assessments by the physician, the patient's wishes or perceptions, or both. In our studies, we have not examined this decision-making process further. However, we have investigated how some premises may be of significance for the priorities made in general practice. The impact of patients' multimorbidity for the follow-up of stroke in general practice was explored in Paper II and results are discussed later in this section.

4.5.2 Adherence to guidelines and attainment of treatment goals in stroke follow-up in general practice

Clinical practice guidelines provide maps to assist or guide clinical decisions. They seek to translate advances in research to clinical practice and in this way to reduce the evidence-practice gap and to optimize patient care. In the background section of this dissertation, I have discussed clinical practice guidelines in more detail. In Paper I, we examined the follow-up of stroke survivors in general practice in light of the guidelines.

We mapped the follow-up and compared our findings with the recommendations in the guidelines (5).

When we compared clinical practice as documented in the medical records with the recommendations in the guidelines, we found that the recommendations were often not adhered to. Advice on physical activity was recorded for six patients (12%), advice on diet for three (6%), we found no record of advice on alcohol consumption for any of the patients. However, the fact that a topic is not documented in the medical record for the consultation, does not necessarily mean that it has not been discussed.

Adherence to the guidelines, on the other hand, does not necessarily mean that treatment goals are attained. The Norwegian guidelines recommend a BP target value of < 140/90 mmHg (5). We found that BP was measured with 46 patients (90%), whereas the treatment goal was reached by 24 patients (47%). The latter corresponds well with a new Irish study from general practice, finding that 63.1% of patients with a previous stroke or TIA had BP < 140/90 mmHg (146) and a recent Norwegian study where 40.7% and 47% of stroke survivors reached the same recommend target values for BP at 3-month and 18-month follow-up, respectively (147). The recommendation for LDL-C was < 2.0 mmol/L. In our study LDL-C was measured with 28 patients (55%), and the treatment goal was documented to be attained by 14 (27%). The recent Norwegian study mentioned above (147) found LDL-C control, defined as attainment of the same treatment goal as in our study, with 48.4% and 44.6% at 3 and 18 months follow-up. Our numbers for treatment goal attainment refer to the proportion that has been documented, and not to an absolute proportion. Our figures for goal attainment are therefore not necessarily directly comparable with those from other studies.
Lack of treatment goal attainment for LDL-C is not specific to stroke or to Norwegian general practice. It is known that attainment of treatment goals for LDL-C is low also for other conditions where LDL-C target values are defined. Suboptimal attainment of LDL-C target values has been documented beyond diagnosis and beyond geographic borders (148, 149).

Non-adherence to guidelines in general practice is well known (70), and has also been documented in connection to stroke prevention (66, 150). Barriers to guideline adherence have been identified, including lack of knowledge, lack of agreement with the guidelines' recommendations, factors connected to patients' preferences and ability, and unclear or confusing recommendations in the guidelines (151, 152). Dilemmas in applying guidelines designed for managing single diseases in the care for older patients with multimorbidity has also previously been shown (96). The weak adherence to the guidelines combined with the many consultations for other topics than the stroke found in our study provided an extra incentive to study the implications of patients' multimorbidity for the follow-up of stroke.

4.5.3 What are the implications of patients' multimorbidity for the follow up of stroke in general practice?

In Paper II, we examined the implications of multimorbidity for the follow-up of patients with stroke in general practice. All patients met the criteria for multimorbidity. Patients on average had 4.7 chronic diseases (SD = 1.9), ranging from two to 10. The most common coexisting chronic conditions were hypertension, coronary heart disease, rheumatoid arthritis and other inflammatory polyarthropathies and systemic connective tissue disorders, diabetes, atrial fibrillation, prostate disorders, hearing loss, treated dyspepsia, anxiety and other neurotic stress related and somatoform disorders, asthma, painful conditions, depression, chronic obstructive pulmonary disease, blindness or low vision, new diagnosis of cancer in the last 5 years, and epilepsy. All these conditions affected 10% or more of the patients. A complete list of coexisting chronic conditions is provided in the appendix.

When we modelled our example patients, we made one table with recommended follow-up activity for each patient. The recommendations are taken from the guidelines for each individual condition. They represent the minimum recommended follow-up activity for a period of 12 months, provided that all conditions are clinically stable and that no unexpected abnormalities are found in the tests.

Example patient 1, a male smoker, 74 years, who recently suffered a minor stroke with full recovery. He had COPD and 1 year before the stroke, he was treated for colorectal cancer. The cancer treatment was curative. He was now motivated to cease smoking. Three chronic conditions, including the stroke is about one standard deviation below average among the patients in this study.

Table 4.1. Example patient 1

	Consultations with the GP	**Consultations with specialists**	**Other recommended health care providers**	**Laboratory tests**	**Special Procedures**
COPD	1–2	NR	Physiotherapist (limited to 40 annual treatments), two supervised workouts a week	NR	Spirometry Vaccination
Colorectal cancer	2	NR	NR	yes	2 x CEUS and 1 x LDCT
Smoking	4	NR	NR	NR	NR
Driver's licence	1	NR	NR	NR	NR
Stroke	1	1	NR	yes	NR
Total	9–10	1	yes	yes	5

Abbreviations: *COPD* Chronic obstructive pulmonary disease, *CEUS* Contrast-enhanced ultrasonography, *LDCT* Low-dose computed tomography, *NR* No recommendations

Example patient 2 was a 68-year-old woman who recently suffered a stroke. She had thyroid disorder, asthma, type 2 diabetes and rheumatoid arthritis (RA). Five chronic

conditions, including the stroke, corresponds to the average among the patients in our study. Women in her age group are included in a national screening program.

Table 4.2. Example patient 2

	Consultations with the GP	**Consultations with specialists**	**Other recommended health care providers**	**Laboratory tests**	**Special procedures**
Asthma	1	NR	physiotherapist		Spirometry
Diabetes	2	1–2	NR	yes	NR
RA	4	1	NR	yes	NR
Thyroid disorder	2	NR	NR	yes	NR
Screening	0–1	NR	NR	yes	Gynecological examination. Mammography
Stroke	1	1	NR	yes	NR
Total	10–11	3–4	yes	yes	3

Abbreviations: *RA* Rheumatoid arthritis, *NR* No recommendations

Example patient 3 was a 65-year-old woman who recently suffered a stroke. She was curative treated for colorectal cancer two years ago. She also had type 2 diabetes, COPD, a painful condition in the back, thyroid disorder and she was mildly depressed. In total she had seven chronic conditions and represented the patients with the most complex multimorbidity, about 1 standard deviation above average. We assumed her to be a smoker.

Table 4.3. Example patient 3

	Consultations with the GP	Consultations with specialists	Other recommended health care providers	Laboratory tests	Special procedures
Diabetes	2	1–2	NR	yes	
COPD	1–2	NR	Physiotherapist (limited to 40 annual treatments), two supervised work-outs a week	NR	Spirometry. Vaccination
Colorectal cancer	2	NR	NR	yes	2 x CEUS and 1 x LDCT
Depression	6	NR	NR	NR	NR
Painful condition	6	NR	NR		NR
Thyroid disorder	2	NR	NR	yes	NR
Screening	0–1	NR	NR	yes	Gynecological examination. Mammography
Smoking	4	NR	NR	NR	NR
Stroke	1	1	NR	yes	NR
Total	24–26	2–3	yes	yes	7

Abbreviations: *COPD* Chronic obstructive pulmonary disease, *CEUS* Contrast-enhanced ultrasonography, *LDCT* Low-dose computed tomography, *NR* No recommendations

The sum of guideline recommended follow-up does for each of our three example patients necessitate a number of consultations that exceeds the relatively high average annual number of consultations with the RGP that the patients in this study had. This may be challenging for the patients with the smallest burden of chronic conditions, and more problematic those with the most complex multimorbidity. Our findings indicate that stroke patients' multimorbidity has crucial implications for the premises for guideline adherence in general practice. It has previously been pointed out that guideline adherence may have undesirable effects when caring for older persons with multimorbidity (96). We have not examined whether guideline adherence in the follow-

up of stroke survivors with multimorbidity can have other undesirable effects than those affecting capacity.

In a large national representative study in Scotland, Gallacher et al. found that multimorbidity and polypharmacy was more common in patients with stroke than in those without (103). The treatment burden of patients with multimorbidity can be high, and the capacity of patients is limited (153). A high treatment burden induces low adherence and poor outcomes, and better coordinated and more patient-centered health care, especially for patients with complex conditions, has therefore been called for (154). The results of our study shows that this is still relevant to stroke patients in Norway.

4.5.4 Knowledge transfer and collaboration within the health care services

The guidelines emphasize the importance of collaboration and knowledge transfer and state that "From the patient's perspective it is important that the chain of care functions and is experienced as a continuous process regardless of which level of administration is responsible." (5) (p.101). The follow-up in general practice is a part of this continuous chain of care. Bridging the different elements of care provided by different healthcare providers is necessary to achieve continuity of care (155). The chain of care must therefore be held together by collaboration and the transfer of information. Lack of communication from the hospital to the GP, on the other hand, has been found to contribute to preventable adverse events after discharge (156). In the transition of care from hospital to general practice in Norway, discharge information is passed in the discharge summaries, written reports sent from the hospital to the RGP at the end of the patients' stay. In Paper III, we investigated knowledge transfer and collaboration within the health care services in this transition by analyzing the discharge summaries after hospitalization for stroke.

Routines of transition from hospital to primary care with descriptions of treatment targets and recommendations for the follow-up are proposed to be essential to the

follow-up of stroke in primary health care (147). When we explored the adherence to the guidelines' recommendations for content in the discharge summaries, we found a clear tendency; matters close to the clinical situation in the hospital were often included, while topics mainly relevant to the subsequent follow-up in primary care to a larger degree were omitted. For example, a description of treatment and diagnostic investigation at the hospital was provided by 98%, a treatment goal for BP was provided by 11%, and a treatment goal for blood lipid values was provided by 13% of the discharge summaries. This compares well with the findings in a review article from 2007 by Kripalani et al., where substantial deficits in communication and information transfer between physicians in hospitals and primary care at hospital discharge were highlighted (157). A recent review from 2020 by Kattel et al., showed that discharge summaries often lacked important information and that despite recommendations and guidelines for care transition, processes to improve quality of discharge information are still lacking (158). In an American survey on information transfer and the hospital discharge summary in general, Robelia et al. in 2017 found that only 25% of the primary care physicians reported that the discharge summary contained all the information they needed more than 80% of the time (159). This is in line with findings in an English study by Weetman et al. from 2020, where GPs reported that discharge summaries often lacked content they assessed to be important (160).

It has been proposed that the cause of shortcomings in discharge summaries may be linked to limitations in the intra-professional understanding between hospital physicians and GPs (161). In Study 2 (Paper III), we found that the figured worlds of the hospital physicians sometimes differ from the reality of the GPs. This finding corresponds to a limitation in the intra-professional understanding of the GPs situated position.

In Chapter 2 of this dissertation, I presented theoretical perspectives on how attitudes to sharing knowledge vary. Knowledge transfer is part of the interorganizational learning in collaborations. Vangen and Huxham (122) list different stances towards learning in collaborations. In their theory, "sidelining" is the term for a passive stance where learning or knowledge transfer is not something we think about. The results from Paper III may be interpreted as a sidelining of the need for learning in primary care. Lack of

information in the transfer of care contributes to a breach of continuity in the chain of care and to the fragmentation of the health care services. Discontinuity of care from an inpatient setting to an outpatient setting is related to medical errors (162). In our first study (Paper II), we found that the community-dwelling stroke patients often had complex multimorbidity. It has previously been pointed out that patients with complex health problems are especially vulnerable to the effects of suboptimal transition of care (163).

A main finding in Paper III was the lack of post discharge collaboration initiatives expressed in the discharge summaries. Instead, we found a that the doctors in hospitals were often trying to end the relationship with the patients. This corresponds well with previous descriptions of situations where patients are “pushed” between different institutions or different levels of the health care system instead of being “pulled” (2). In light of Vangen and Huxham’s theory of collaborative advantage (122), this finding may be interpreted as an expression of collaborative inertia rather than as an expression of collaborative advantage.

5. Conclusion

This thesis has explored new terrain in the field of stroke follow-up in general practice.

I began by studying the follow-up of patients with stroke in Norwegian general practice and the adherence to the Norwegian national guidelines for treatment and rehabilitation in stroke. I found that patients had many consultations with their RGPs, but that these consultations were often on other topics than the stroke. The guidelines were often not adhered to, and adherence to the guidelines did not necessarily mean that treatment goals were reached. In order to find new dimensions to the understanding of these findings, this thesis has explored the implications of patients' complexity for the follow-up.

In the following study on multimorbidity among stroke patients residing in the communities, I found that all patients met the criteria for multimorbidity, defined as two or more chronic conditions. On average patients had 4.7 chronic conditions from a predefined list of 40. I modelled example patients based on the profiles of chronic conditions found among the actual patients and calculated the number of consultations needed if all recommendations from the different relevant guidelines for each patient were adhered to. The results showed that it was challenging to adhere to the sum of recommendations for the patients with the lowest burden of chronic conditions. For patients with complex multimorbidity it was obviously unmanageable.

Finally, I explored the hospital discharge summaries to see to what extent they contained the elements recommended in the guidelines and if they invited to a post discharge collaboration. I found that the discharge summaries often included some kinds of recommended content, while often omitting other kinds of content. Content relevant to the follow-up in primary care such as plans for the follow-up and treatment goals were often omitted. Knowledge transfer was suboptimal and collaboration initiatives lacked.

The Norwegian national guidelines for treatment and rehabilitation in stroke are supposed to provide a map to aid the clinicians in hospitals as well as in general practice. This thesis, however, has shown that this map is not followed in the transition of care from hospitals to primary care or in the follow-up of home-dwelling patients with stroke that takes place in general practice. The hospital discharge summaries have a potential to serve as tools for knowledge transfer and collaboration that was not fulfilled. The form of communication found in the discharge summaries may instead contribute to maintaining the gap between hospitals and general practice. The thesis has also shown how the sum of advice from different guidelines together form a map that is not suited for navigation in general practice when the patients' conditions are complex.

This thesis contributes with a critical view of the feasibility of implementing stroke specific guidelines in general practice where the norm is that patients' complexity is high. It also contributes in illuminating that health services are fragmented for this group of vulnerable patients. Even though the focus of this thesis has been patients residing in the communities after a stroke, several of the issues identified as problematic for the follow-up, may be of a more general nature.

6. Implications and future perspectives

Through working with this project, I have encountered several issues that should have implications for the development of clinical guidelines, for the training of physicians, for clinical practice, for standards of hospital discharge summaries and for collaboration across the boundaries within the health care services.

Implications for development and implementation of clinical guidelines

Clinical guidelines recommend a collaboration between the different professional participants in the continuous chain of care. Collaborative themes such as agreed aims are, however, not necessarily sufficiently operationalized (5) and this thesis has shown that operationalized plans for knowledge transfer such as the recommendations for discharge summary contents are not necessarily adhered to. In this thesis, I have presented a theory on collaborative advantage that states that a failure to focus on certain aspects of collaboration will make collaborative inertia more likely than collaborative advantage. In other words, some of the findings in this study are in agreement with an established theory on collaboration. Guideline developers should therefore to a greater extent take theory on collaboration into account, at least in situations where collaboration is regarded a prerequisite for success. Furthermore, this thesis has shown that the combined recommendations from different guidelines is not necessarily implementable in general practice for patients with complex multimorbidity. As multimorbidity is the rule rather than the exception in general practice, this must also be taken into account in the development of guidelines.

Implications for education and clinical practice

This thesis has shown that communication and collaboration – at least as expressed in the discharge summaries – between physicians in hospitals and in primary care is weak for stroke patients residing in the communities. If the authorities' ambitions of continuous care across the boundaries within the healthcare services are to be fulfilled, it may be useful to have a greater focus on training in collaborative situations in the medical education. It may also be useful to have formalized collaboration in the

transition of care, for example where GPs and hospital doctors can achieve agreement on templates for information transfer such as the hospital discharge summaries.

Implications for future research

This thesis has shown that adhering to several guidelines for different chronic conditions at the same time may be unmanageable for patients with complex multimorbidity. Little is known about how GPs handle such complex situations, on what background priorities are made, and which solutions are optimal. Future research should explore how priorities are made in general practice in complex situations with conflicting interests. This may contribute in forming a basis for a better understanding of non-adherence to guidelines, and also a basis for better formalized training in such complex situations. Future research should also further explore the collaboration and communication between different parts of the health care services.

There is no tradition for utilizing discourse analysis on discharge summaries or other parts of the communication between physicians in primary and secondary care. I therefore believe that this approach may yield valuable new insights from this field in the future.

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8. Appendix

8.1 Invitation and consent to participate, patients

Det medisinske fakultet
Institutt for samfunnsmedisin

Deres dato

Deres referanse

Forespørsel om deltakelse i forskningsprosjektet «Oppfølging av pasienter med hjerneslag i allmennpraksis.»

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie. Studien skal undersøke hvordan pasienter som har hatt hjerneslag følges opp hos fastlegen. Videre skal studien gi kunnskap om kvaliteten på den informasjonen som sykehusene gir til fastlegene om den enkelte pasient som har vært innlagt for hjerneslag. Studien skal også belyse hvilke andre sykdommer som hjerneslagpasientene har og hvordan disse sykdommene kan innvirke på oppfølgingen av hjerneslaget. Du er valgt ut til å forespørres på bakgrunn av at du har fått diagnosen hjerneslag i forbindelse med sykehusopphold ved Kristiansund sykehus eller Molde sjukehus i løpet av 2011 eller 2012.

Forskningsprosjektet utgår fra Allmennmedisinsk forskningsenhet (AFE), Institutt for samfunnsmedisin (ISM), NTNU, Trondheim.

Studien er godkjent av Regional komité for medisinsk og helsefaglig forskningsetikk.

Hva innebærer studien?

En forsker (Rune Aakvik Pedersen) vil lese gjennom din journal ved sykehuset fra sykehusoppholdet du hadde for hjerneslag for å undersøke den informasjonen som er sendt om deg til din fastlege. Forskeren vil også notere blodprøveresultater av betydning for hjerneslag. Kun slike prøver blir registrert. Deretter vil forskeren oppsøke fastlegekontoret og gjennom innsyn i fastlegens journal undersøke hvordan du har blitt fulgt opp, resultat av undersøkelser som har med slaget å gjøre, og om du har andre sykdommer som kan være av betydning for oppfølgingen av hjerneslaget. Deltagelse i studien innebærer derfor at man også gir tillatelse til at forskeren henter opplysninger fra fastlegejournalen.

Deltagelse i studien innebærer ikke at det blir tatt noen ekstra prøver eller undersøkelser av deg. Du må heller ikke møte opp til noen avtaler eller på annen måte engasjere deg personlig.

Mulige fordeler og ulemper

Deltagelse i studien vil ikke gi muligheter for medisinske fordeler eller ulemper for deg personlig, men det vil bli skapt kunnskap som kan komme framtidige pasienter med hjerneslag til gode. Du personlig vil ikke motta noen annen medisin eller annen form for behandling som et resultat av deltagelse i studien.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Etter at forskeren har undersøkt oppfølgingen av deg hos din fastlege vil resultatene registreres, men ditt navn vil slettes og erstattes med en kode i det videre forskningsprosjektet. Denne koden vil ikke på noe senere tidspunkt kunne identifiseres med deg eller din lege.
Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen nedenfor. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Rune Aakvik Pedersen på følgende måte:

E- post: rune.pedersen@ntnu.no

Post: Rune Aakvik Pedersen, AFE, Institutt for samfunnsmedisin, NTNU, 7489 Trondheim

Ytterligere informasjon om studien finnes i kapittel *A* – *utdypende forklaring av hva studien innebærer.*
Ytterligere informasjon om personvern finnes i kapittel B – *Personvern og økonomi.*

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

--------- (Signert av prosjektdeltaker, dato)

Kapittel A - utdypende forklaring av hva studien innebærer

Bakgrunn

I Norge rammes omlag 15 000 personer av hjerneslag årlig, og hjerneslag er dermed blant de vanligste alvorlige sykdommene i vårt samfunn. Grunnet befolkningsutvikling ventes antallet pasienter å vokse i de kommende år, og det er anslått en 50% økning de neste 20 år.

Enkelte kan oppleve at hjerneslag oppstår på nytt, og det er derfor grunn til å tro at det er nyttig med god oppfølging etter hjerneslaget. En god oppfølging kan både lindre plager fra det første slaget og bidra til å redusere sjansen for et nytt. Hvordan pasientene faktisk følges opp i allmennpraksis er likevel ikke kjent.

Det finnes retningslinjer for hvordan oppfølgingen bør være, og disse retningslinjene er basert på vitenskapelige undersøkelser. Spørsmålet om disse vitenskapelige undersøkelsene er dekkende for de norske pasientene som følges opp av sin fastlege er likevel ubesvart.

Retningslinjene anbefaler at sykehusene skal gi fastlegene råd om den videre oppfølgingen av pasienten med hjerneslag etter utskrivning fra sykehus. Det er imidlertid ikke kjent om sykehusene faktisk gir fastlegene slike råd.

Nærmere 90% av pasientene er 65 år eller eldre når de opplever å få hjerneslag første gang. De fleste personer over 65 år har 2 eller flere kroniske eller langvarige sykdomstilstander, multimorbiditet. Det er likevel ikke gjort noen kartlegging av andre langvarige sykdomstilstander blant norske pasienter med gjennomgått hjerneslag. Det er derfor heller ikke kjent hvilken betydning slike andre langvarige sykdomstilstander kan ha for oppfølgingen av pasienter som har hatt hjerneslag.

Hvilke opplysninger registreres i dette prosjektet?

Opplysninger som registreres om deg er tidspunkt for utskrivelse fra sykehus, eventuell kontroll ved sykehus, resultat av blodprøver med relevans for hjerneslag og hvilke råd og anbefalinger som ble gitt i epikrisen fra sykehus til fastlege. Disse opplysningene hentes ut av sykehusjournalen. Fra fastlegens journal hentes det ut opplysninger om hvor ofte du har vært til kontrollert i forbindelse med hjerneslaget, funn ved blodtrykkskontroll før og etter hjerneslaget, hvilke blodprøver som er tatt i forbindelse med oppfølgingen av hjerneslaget og resultatet av disse. Det vil også bli registrert om de undersøkelser og tiltak som anbefales i nasjonal retningslinje har blitt gjennomført. Til sist noteres eventuelle andre diagnoser fra fastlegejournal som regnes som kroniske eller langvarige etter en liste på om lag 40 vanlige kroniske sykdomstilstander.

Kapittel B - Personvern og økonomi

Personvern

Etter at informasjonen er hentet ut og opplysninger fra fastlegens journal er koblet sammen med informasjonen fra sykehusets journal, slettes navnet ditt og erstattes med en kode som ikke vil kunne identifiseres med deg eller din lege.

NTNU ved administrerende direktør er databehandlingsansvarlig.

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du

trekker deg fra studien, kan du kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede avidentifisert, er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi

Studien er finansiert ved forskningsmidler fra Allmennmedisinsk forskningsfond, og forprosjektet har vært finansiert ved midler fra Allmennmedisinsk forskningsutvalg og Nasjonalt senter for distriktsmedisin.

Informasjon om utfallet av studien.

Det vil bli lagd vitenskapelige artikler og holdt foredrag om resultatene fra studien.

8.2 Invitation and consent to participate, GPs

Forespørsel om deltagelse i forskningsprosjektet

«Oppfølging av pasienter med hjerneslag i allmennpraksis.»

Dette er et spørsmål til deg om å delta i en forskningsstudie for å undersøke om pasienter som har hatt hjerneslag følges opp i allmennpraksis i henhold til Nasjonal retningslinje for behandling og rehabilitering ved hjerneslag.

Du er som fastlege valgt ut til å forespørres på bakgrunn av at du har listepasient(er) som har fått diagnosen hjerneslag i forbindelse med sykehusopphold ved Kristiansund sykehus eller Molde sjukehus i 2011.

Ansvarlig for forskningsprosjektet er Institutt for samfunnsmedisin ved NTNU, Trondheim.

Studien er godkjent av Regional komité for medisinsk og helsefaglig forskningsetikk.

Hva innebærer studien?

Deltagelse i studien vil ikke kreve ekstra oppfølging av enkeltpasienter eller annet merarbeid fra fastlegens side.

En forsker (Rune Aakvik Pedersen) vil på bakgrunn av pasientlister fra sykehusene i Kristiansund og Molde identifisere pasienter med gjennomgått hjerneslag i 2011. Etter skriftlig samtykke fra pasient og godkjenning fra regional etisk komite, vil så epikriser gjennomgås for å kartlegge hvilken informasjon og eventuelle konkrete råd som er oversendt fastlege. Etter dette vil forskeren oppsøke fastlegekontoret og se inn i den enkelte pasients journal. Antallet konsultasjoner registreres, det registreres også verdier av blodtrykk og relevante klinisk kjemiske prøver. Til slutt registreres diagnoser på andre kroniske lidelser fra journalhistorikk. Etter dette arbeidet er gjennomført anonymiseres opplysningene, slik at verken lege eller pasient blir identifiserbare.

Bakgrunn

Hjerneslag er en hyppig forekommende lidelse med omfattende personlige og samfunnsmessige konsekvenser. I den vestlige verden regnes hjerneslag som den tredje største årsak til død. I Norge rammes omlag 15 000 personer av hjerneslag årlig.

I løpet de første 5 årene etter første gangs hjerneslag vil 30% av en ellers uselektert populasjon oppleve recidivslag, en risiko 9 ganger høyere enn normalbefolkningen.

Nasjonal retningslinje for behandling og rehabilitering ved hjerneslag ble utgitt i april 2010, og kan lastes ned elektronisk fra helsedirektoratets hjemmesider. Retningslinjen gir blant annet råd for sekundærforebygging. Hvorvidt rådene følges er ukjent.

I den grad retningslinjer ikke følges, er årsakene til dette ukjent. I den grad retningslinjene følges, er det ikke kjent i hvor stor grad man lykkes i å nå anbefalte behandlingsmål.

Nasjonal retningslinje for behandling og rehabilitering ved hjerneslag anbefaler at epikriser skal inneholde tverrfaglige vurderinger og konkrete råd og planer for oppfølging, rehabilitering og sekundærforebygging. Det er ikke kjent hvorvidt spesialisthelsetjenesten benytter epikriser til å formidle slike råd til fastlegene, eller om epikrisen brukes til å formidle retningslinjens anbefalinger for sekundærforebygging.

Nærmere 90% av førstegangs hjerneinfarkt rammer pasienter som er 65 år eller eldre og de fleste mennesker over 65 år har 2 eller flere kroniske eller langvarige sykdomstilstander, multimorbiditet. Det er likevel ikke gjort noen kartlegging av multimorbiditet blant norske pasienter med gjennomgått hjerneslag, det er ikke kjent hvilken betydning multimorbiditet har for oppfølgingen av disse pasientene eller hvilke spesielle kliniske utfordringer allmennlegen står overfor i møtet med sine multimorbide hjerneslagpasienter.

Prosjektplan
Studien skal gi kunnskap om primærhelsetjenestens håndtering av pasienter med gjennomgått hjerneslag. Den skal belyse i hvilken grad slagpasientene følges opp i allmennpraksis, om nasjonal retningslinje for behandling og rehabilitering ved hjerneslag følges og i hvilken grad man når behandlingsmål som anbefalt i retningslinjen. Studien skal gi kunnskap om hvorvidt epikriser fra sykehus brukes som implementeringsverktøy for de nasjonale retningslinjene, om forekomsten av multimorbiditet i pasientgruppen og hvordan dette kan ha betydning for oppfølging, måloppnåelse og retningslinjens relevans.

Med hilsen

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Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av fastlege, dato)

8.3 Operational definitions list for Paper I

Operational definitions list

1) **Study period:**

Read date of last outpatient control for stroke. Read date of discharge if no outpatient control was made.

2) **Number of consultations:**

All consultations: Read number of all consultations the first year after the last outpatient control or the first year after discharge if no outpatient appointment was made.
Consultations with stroke as a topic: Count any consultation where stroke is mentioned in the medical records. Do not count a consultation where a measurement relevant to stroke is made without it assessed in the context of stroke. E.g: BP measurement outside the context of stroke is not counted as a consultation with stroke as a topic.
Consultations with stroke as the main topic: Assess the written text of the medical record for the consultation. Count consultations where stroke is the most prominent issue, do also count consultations where stroke is one of two prominent issues and it is reason to believe that at least half of the time spent in the consultation was occupied with the issue of stroke.

3) **Lifestyle advice**

Period of study: from discharge to one year after last outpatient control for stroke.
Diet: Read any advice on diet recorded.
Physical activity: Read any advice on physical activity recorded.
Smoking: Read any advice on smoking recorded.
Alcohol: Read any note on alcohol recorded
BMI: Read any registration of BMI recorded. Extended period: Any time up to one year after last outpatient control. Include before the stroke.

4) **Recommended blood tests**

Period: One year from last outpatient control or one year from discharge if no outpatient appointment for stroke was made.
LDL: Read any LDL measurement in the period.
ASAT: Read any ASAT measurement in the period.
ALAT: Read any ALAT measurement in the period.
CK: Read any CK measurement in the period.

5) **Blood pressure**

Period: One year from last outpatient control or one year from discharge if no outpatient appointment for stroke was made.
BP: Make note of all blood pressure measurements in the period.

6) **Goals reached**

BP: Assess the last recording in the period. If this measurement shows BT < 140/90 mmHg, goal is reached.
LDL: Assess the last recording in the period. If this measurement shows LDL<2,0 mmol/L, goal is reached.

8.4 Predefined list of chronic conditions used for Paper II

List of chronic conditions with operational definitions

Hypertension - Read code ever recorded.

Depression - Read code recorded in last 12 months OR ≥4 anti-depressant prescriptions (excluding low dose tricyclics) in last 12 months.

Painful condition - ≥4 prescription only medicine analgesic prescriptions in last 12 months OR ≥4 specified anti-epileptics in the absence of an epilepsy Read code in last 12 months.

Asthma (currently treated) - Read code ever recorded AND any prescription in last 12 months.

Coronary heart disease - Read code ever recorded**.**

Treated dyspepsia - ≥4 prescriptions in last 12 months BNF 0103

Diabetes - Read code ever recorded.

Thyroid disorders - Read code ever recorded**.**

Rheumatoid arthritis, other inflammatory polyarthropathies & systematic connective tissue disorders - Read code ever recorded.

Hearing loss - Read code ever recorded**.**

Chronic obstructive pulmonary disease - Read code ever recorded**.**

Anxiety & other neurotic, stress related & somatoform disorders - Read code in last 12 months OR ≥4 anxiolytic/hypnotic prescriptions in last 12 months OR ≥4 10/25mg amitriptyline in last 12 months & do not meet the criteria for 'Pain'.

Irritable bowel syndrome - Read code ever recorded OR ≥4 prescription only medicine antispasmodic prescription in last 12 months**.**

New diagnosis of cancer in last five years - Read code first recorded in last 5 years.

Alcohol problems - Read code ever recorded**.**

Other psychoactive substance misuse - Read code ever recorded.

Treated constipation - ≥4 laxative prescriptions in last year.

Stroke & transient ischemic attack - Read code ever recorded.

Chronic kidney disease - Read code ever recorded.

Diverticular disease of intestine - Read code ever recorded.

Atrial fibrillation - Read code ever recorded.

Peripheral vascular disease - Read code ever recorded.

Heart failure - Read code ever recorded.

Prostate disorders - Read code ever recorded.

Glaucoma - Read code ever recorded.

Epilepsy - Read code ever recorded AND antiepileptic prescription in last 12 months.

Dementia - Read code ever recorded.

Schizophrenia (and related non-organic psychosis) or bipolar disorder - Read code ever recorded/recorded in last 12 months (code dependent) OR Lithium prescribed in last 168 days.

Psoriasis or eczema - Read code ever recorded AND ≥4 related prescriptions in last 12 months (excluding simple emollients).

Inflammatory bowel disease - Read code ever recorded.

Migraine - ≥4 prescription only medicine anti-migraine prescriptions in last year.

Blindness & low vision - Read code ever recorded.

Chronic sinusitis - Read code ever recorded.

Learning disability - Read code ever recorded.

Anorexia or bulimia - Read code ever recorded.

Bronchiectasis - Read code ever recorded.
Parkinson's disease - Read code ever recorded.
Multiple sclerosis - Read code ever recorded.
Viral Hepatitis - Read code ever recorded.
Chronic liver disease - Read code ever recorded.

8.5 Coexisting chronic conditions among the patients

Condition	n	%
Hypertension	28	55
Coronary heart disease	24	47
Rheumatoid arthritis, other inflammatory polyarthropathies & systematic connective tissue disorders	13	25
Diabetes	11	22
Atrial fibrillation	10	20
Prostate disorders	9	18
Hearing loss	9	18
Treated dyspepsia	8	16
Anxiety & other neurotic, stress related & somatoform disorders	7	14
Asthma	7	14
Painful condition	7	14
Depression	6	12
Chronic obstructive pulmonary disease	6	12
Blindness & low vision	6	12
New diagnosis of cancer in last five years	5	10
Epilepsy	5	10
Thyroid disorders	4	8
Chronic kidney disease	4	8
Peripheral vascular disease	3	6
Heart failure	3	6
Alcohol problems	2	4
Migraine	2	4
Psoriasis	2	4
Diverticular disease of intestine	2	4
Learning disability	1	2
Inflammatory bowel disease	1	2
Chronic sinusitis	1	2
Other psychoactive substance misuse	1	2

8.6 Operational definitions list for Paper III

Operational definitions list:

1) *The kind of stroke and its localization in the brain:* Count discharge summaries that include a description of the kind of stroke *and* its location in the brain. The localization of the stroke is provided when either clinically or radiologically described. Count also when not applicable, e.g. a new admission for the same stroke.
2) *The cause of the stroke:* Count discharge summaries that provide a description of the cause of the stroke, count also discharge summaries that provide an assessment of risk factors. Count also when not applicable (see also 1)).
3) *A short description of the treatment and the diagnostic investigation*: Count discharge summaries with any description of the treatment *and* the diagnostic investigation.
4) *Complications (if applicable):* Refer to page 48 of the National Guideline for stroke. Count discharge summaries with new diagnosis of: Seizures, Raised Intracranial Pressure, Infections, Venous thrombosis, Cardial arrythmia, Risk of falls, Pain, Psychiatric symptoms, Stress Ulcer or any Gastrointestinal bleeding, or Dysphagia.
5) *The patients` level of function on discharge:* Count discharge summaries that provide any information on the patient´s level of function on discharge.
6) *Prognosis, including prognosis for driver`s license and work:* Count discharge summaries that provide a prognosis *including* prognosis for driver`s license and work. Count discharge summaries also when driver`s license and work is not applicable.
7) *Assessment of the necessity for further diagnostic investigations:* Count discharge summaries with any assessment of the necessity for further diagnostic investigations
8) *Medication at discharge:* Count discharge summaries that provide an overview of medication at discharge.
9) *Further treatment and treatment goals for the blood pressure and blood lipid values:* Perform separate counts: I) Count discharge summaries that provide treatment goals for blood pressure and II) Count discharge summaries that provide treatment goals for blood lipid values.
10) *Plans for the follow-up:* Count discharge summaries that provide any plan for the follow-up in general practice.

9. Papers I-III

Paper I

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BMC Family Practice

RESEARCH ARTICLE Open Access

Stroke follow-up in primary care: a prospective cohort study on guideline adherence

Rune Aakvik Pedersen*, Halfdan Petursson and Irene Hetlevik

Abstract

Background: After a stroke, a person has an increased risk of recurrent strokes. Effective secondary prevention can provide significant gains in the form of reduced disability and mortality. While considerable efforts have been made to provide high quality acute treatment of stroke, there has been less focus on the follow-up in general practice after the stroke. One strategy for the implementation of high quality, evidence-based treatment is the development and distribution of clinical guidelines. However, from similar fields of practice, we know that guidelines are often not adhered to. The purpose of this study was to investigate to what degree patients who have suffered a stroke are followed up in general practice, if recommendations in the national guidelines are followed, and if patients achieve the treatment goals recommended in the guidelines.

Methods: The study included patients with cerebral infarction identified by the ICD-10 discharge diagnoses I63.0 trough I63.9 in two Norwegian local hospitals. In total 51 patients participated. They were listed with general practitioners in 18 different clinics. The material consists of the general practitioners' (GPs') medical records for these patients in the first year of follow-up; in total 381 consultations.

Results: Of the 381 consultations during the first year of follow-up, 71 (19%) had stroke as the main topic. The blood pressure (BP) target value < 140/90 mmHg was reached by 24 patients (47%). The low density lipoprotein (LDL) cholesterol target value < 2.0 mmol/L was reached by 14 (27%) of the 51 patients. In total six patients (12%) got advice on physical activity and three (6%) received dietary advice. No advice about alcohol consumption was recorded.

Conclusions: The findings support earlier claims that the development and distribution of guidelines alone is not enough to implement a certain practice. Despite being a serious condition, stroke gets limited attention in the first year of follow-up in general practice. This can be explained by the complexity of general practice, where even a serious condition loses the competition for attention to other apparently equally important issues.

Keywords: Stroke, Practice guidelines, General practice, Secondary prevention

Background

Stroke

Ischemic stroke is a frequent disorder with extensive personal and social consequences. In the Western world, stroke is regarded the third most common cause of death [1]. In Norway, about 15,000 persons suffer a stroke each year, and a 50% increase is expected in the period 2010–2030 [2]. The average cost of an acute ischemic stroke hospitalization in Europe has been estimated to $11,900 (2013) and one-year follow-up is estimated to an average of $3720 [3]. Patients with recurrent strokes have more adverse clinical outcomes and costs are higher compared with patients suffering first-ever strokes [4].

Recurrent stroke and secondary prevention

Having had a first stroke, a person has an increased risk of recurrent strokes; 11% within 1 year, 26% within 5

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years and 39% within 10 years. The numbers refer to all strokes [5]. The mortality after a recurrent stroke is particularly high [6, 7].

Risk factors for recurrent cerebrovascular events are well known. Handling these with effective individualized secondary prevention can provide substantial gains in preventing cerebrovascular disease and death [8]. Based on estimates of the benefits from preventive measures for heart attack, it has been suggested that the various secondary preventive measures in combination can reduce the risk of recurrent stroke with up to 70% [1].

Adherence to recommendations for such secondary prevention and to offer the patients the necessary follow-up is a challenge for the health services [8]. Although management of secondary prevention for stroke and transient ischemic attack (TIA) may differ [9], reports on follow-up of TIA may indicate that many patients do not receive secondary prevention at all [10]. Considerable under-treatment with statins in patients with prior cardiovascular disease is documented [11] as is diminishing compliance over time [11, 12]. One answer to such challenges has been development and implementation of clinical guidelines.

Follow-up in primary care

General practice is well placed to provide follow-up of stroke patients, but this potential is not necessarily fulfilled [13]. Norwegian National guidelines for treatment and rehabilitation of stroke patients [2] were issued in 2010. According to these guidelines, the general practitioner (GP) is supposed to play a key role in the follow-up of patients who have suffered a stroke. Furthermore, the guidelines provide specific advice on the content of the follow-up. It is recommended that patients with stroke should usually be treated with lipid-lowering medication in the form of statins, and that creatine kinase (CK) and transaminase blood samples are taken to control possible side-effects of this treatment. The recommended target value for low-density lipoprotein (LDL) is < 2.0 mmol/L. For blood pressure (BP), the recommended target value is < 140/90 mmHg. Diet, body mass index (BMI), physical activity, alcohol consumption and smoking affect the risk for stroke and recurrent stroke. These lifestyle factors should therefore also be part of the post-stroke follow-up. In the Netherlands, it was found that advice in a protocol corresponding to the Norwegian guidelines is followed only to some extent. As an example, lifestyle advice was offered to only one in four patients [14]. After the introduction of the Dutch protocol, only minimal impact was noted on clinical practice and no major changes in survival or secondary outcomes were found [15].

However, it is still not known to what degree the patients are followed up in general practice in Norway, nor is it known if the follow-up is in accordance with the guidelines. It is known that development and distribution of guidelines alone is not sufficient for implementation in general practice [16]. It is therefore recommended to make use of more active methods for implementation [16], but even comprehensive active implementation does not necessarily lead to adherence to the clinical guidelines [17, 18].

In this study, the aim was to investigate the extent to which patients who have had a stroke are being followed up in general practice, if the recommended procedures have been applied and whether or not patients achieve the treatment goals recommended in the national guidelines.

Methods

Design and setting

The study took place in Møre og Romsdal County in Western Norway. This is an affluent area with good access to primary and secondary health care. In 2016 the county had the highest life expectancy for boys and the second highest for girls among all 19 Norwegian counties [19]. In Norway, all residents are entitled to a regular general practitioner (RGP). When a resident is registered on a GP's list of patients, the GP has the medical responsibility for this person. At the time of this study, about 99% of the Norwegian population was registered on GPs' patient lists [20]. When a person registered on a GP's list is discharged from hospital, the GP normally receives a discharge summary. The discharge summary is a transfer of information from the hospital to the GP, not a formal referral. The guidelines [2] state that discharge summaries of good quality sent to the RGP is a prerequisite for the follow-up of stroke patients.

The study included patients treated for ischemic stroke in two Norwegian local hospitals in 2011 and 2012. Patients with hemorrhagic stroke were not included. The reason for this was that the guidelines do not apply to all forms of hemorrhagic stroke. A search for the ICD-10 discharge diagnosis I63.0 trough I63.9 identified patients with cerebral infarction in the hospital files. The patients' RGPs were identified by The Norwegian Health Economics Administration (Helfo). All patients identified in the hospital files were registered with an RGP, and all patients included had active practicing RGPs in clinics with regular office hours and availability. All clinics were available for wheelchair users, and all clinics had secretaries available by phone. All clinics also had laboratory services including availability of blood investigations such as CK, transaminases and cholesterol. The costs of laboratory services are covered by the National Insurance Scheme. Residents in Norway have compulsory membership in this scheme. None of the

clinics had dietitians or rehabilitation therapists as part of their staff.

Invitation to participate in the study was sent to each of the GPs identified as described above. Only patients living in their own home and registered with an RGP who accepted participation, were subsequently invited to participate in the study. Patients in nursing homes were excluded.

One of the authors (RAaP) visited each clinic personally. All clinics kept electronic medical records, and each clinic provided access for the researcher. The GPs used three different electronic medical record systems. We evaluated the records of each consultation ($n = 381$) in the RGPs' clinic the first year after the hospital stay or the last outpatient hospital consultation. The record's laboratory results, prescribing registries and diagnosis registries were all used to support the evaluation of the written text record of each individual consultation. An operational definitions list was used to standardize the coding of data (Additional file 1).

We noted the number of consultations with any content relevant for stroke follow-up, as was the number of consultations mainly concerning stroke. A note was made where we found that any of the lifestyle factors diet, BMI, physical activity, alcohol consumption or smoking had been addressed in the consultation. We chose to include those who had a recorded BMI, also when recorded before the specific follow-up year. Furthermore, we recorded whether or not the recommended blood tests were taken and the results of blood pressure measurements and LDL laboratory results, as these tests have specified targets in the guideline, expected to be reached.

Results

Among 100 invited GPs, 37 agreed to participate. These 37 GPs had a total of 138 stroke patients from 2011 and 2012 on their lists. We invited all these 138 patients to participate in the study, and 51 gave their written consent. Age varied from 38 to 90 years (mean 68.5 years). Thirty (59%) were male and 21 (41%) female. These 51 patients had RGPs in 18 different clinics.

In total 46 patients (90%) had suffered from an acute stroke. Among these, 40 had their first-ever stroke, and 6 had a recurrent stroke. The rest of the patients in the total group of 51 patients had TIA following a previous stroke or previous stroke with new symptoms not classified as TIA, and where new stroke could not be detected. In one patient, we found that the stroke diagnosis was used, but not further discussed in the discharge summary. Five patients got acute thrombolytic treatment and 19 of the patients were discharged with an outpatient control appointment.

Consultations

These 51 patients had 381 consultations with their RGP the first year after discharge from hospital, an average of 7.5 (0–24) consultations.

Stroke follow-up

In 148 consultations (39%), stroke was documented as a topic. We found that 71 (19%) of the consultations had stroke as the main topic. The medical record in these cases was primarily concerned with stroke, although other issues also were discussed. On average, each patient had 1.4 (0–7) consultations mainly concerning stroke during the first year of follow up in general practice.

Adherence to the most central advice for the follow-up

Table 1 gives information about the number (percentage) of relevant lifestyle information registered in the patient records, as well as procedures performed (BP and LDL-cholesterol) in addition to the number of patients where the recommended goals were reached.

Other recommendations

On discharge from hospital, 45 of the 51 patients were treated with statins. In the GPs' medical records, we found confirmation of ongoing statin treatment in 39 patients. In our material, CK and transaminase blood samples were taken in 8 (16%) of the 51 patients, and in 7 of the 39 patients where we could find confirming

Table 1 Variables registered and goals reached

	Women ($n = 21$)		Men ($n = 30$)		Total ($n = 51$)	
	N	%	n	%	n	%
Variables registered						
Lifestyle[a]	7	33	9	30	16	31
BMI[b]	6	29	6	20	12	24
Diet[c]	2	10	1	3	3	6
Physical activity[d]	4	19	2	7	6	12
Smoking[e]	1	5	3	10	4	8
Alcohol[f]	0	0	0	0	0	0
BP[i]	20	95	26	87	46	90
LDL[h]	13	62	15	50	28	55
Goals reached						
BP[i]	11	52	13	43	24	47
LDL[j]	7	33	7	23	14	27

[a]Patients with any notes on lifestyle made the first year of follow-up. [b]Patients with a BMI measure made before or the first year after the stroke. [c]Any notes on diet during the first year of follow-up. [d]Any notes on physical activity the first year of follow-up. [e]Any notes on smoking the first year of follow-up. [f]Any notes on alcohol consumption the first year of follow-up. [i]Blood pressure measured the first year of follow-up. [h]LDL measured the first year of follow up. [i]BP < 140/90 mmHg in the last registration in the study period. [j]LDL < 2.0 mmol/L

information about ongoing statin treatment in the GPs' medical records.

Discussion

Main findings

In this study we examined the follow-up of patients with stroke in general practice. We compared the recommendations in the national guidelines with clinical practice in real life. Nearly all patients had their blood pressure measured within the first year of follow-up in general practice. Despite this, only about half of the patients had reached the blood pressure target value. Fewer patients had their LDL-cholesterol level measured, and the LDL-cholesterol target value was reached by less than one third of the patients. We found limited information on diet and physical activity and none about alcohol consumption in the medical records.

Patients residing in the community had on average consulted their GP more than seven times the first year after being discharged from hospital with a stroke diagnosis. In 2012, Norwegians on average consulted their RGP 2.6 times [21]. However, in our material we also found that stroke was not necessarily the foremost concern in the consultations with the GP in this period. In fact, stroke was not documented as an issue at all in most of these consultations. The findings reveal that the median number of consultations mainly concerning stroke was one in the first year of follow up. Stroke got limited attention in the consultations with the GP the first year after the incident, even though it is a serious condition. This may be because the stroke diagnosis faced competition from other issues that were perceived as equally important by the patient or by the GP at the moment of consultation.

The guidelines give evidence-based advice on the follow-up of stroke survivors. They are based on a thorough review of an extensive amount of research and are intended to ensure good clinical practice. They can be regarded as a map that gives direction and guides the most important clinical decisions for the treatment of patients who have experienced stroke. Our study, however, shows that this map is not in accordance with the terrain in general practice.

Strengths and weaknesses

Based on the GPs' medical records, this study investigates how the follow-ups of the patients have been recorded. It does not involve any form of possible biased self-reporting. The inclusion of patients started out wide, and although the participation rate was low, the researchers did not make any selections. All data collection was done by the same person. In this way, there were no different practices in the review of the medical records or data registration. The possibility of intra-observer variations is nevertheless still present.

We found a low degree of adherence to the guideline. We have no reason to believe that the GPs who accepted participation in this study have a less optimal practice than those who rejected the request. On the other hand, we have some indication of the opposite. When we made reminding telephone calls to all the invited GPs that did not respond to our invitation letters one GP admitted that it was scary to have her practice investigated by researchers.

Still, there are several limitations to this study. There were relatively few patients included, and although the GPs are practicing in 18 different clinics, the clinics are all in the same county. In addition to a low rate of participation among of GPs, there was also a low degree of participation among patients. Possible explanations for this could be poor health, high age and impaired physical and mental functioning in the patients. We needed, for example, to exclude a patient because this persons' partner had signed a declaration of consent, without documentable transfer of authority for consent. The experienced treatment burden among those with stroke is shown to be considerable [22] and combined with the reduced patient capacity, this may also be the reason for the low degree of participation among the invited patients. While the chosen method of reading medical records has its strengths, it also carries with it some weaknesses. There is a possibility of making incorrect recordings. To check this, one would have to visit the clinics again to read the records once more. Given the geographical spread, this would be very resource-demanding.

Furthermore, physicians do not necessarily document every topic of the consultation. Therefore, it is possible that the GP or the patient have addressed topics without it being included in our counts. Despite these weaknesses, we claim the findings to be valid for the performance of secondary stroke-prevention in general practice.

Findings in the light of current knowledge

We have found that the patients often consult their GPs in the period after having had a stroke. In this way, our study is consistent with previous claims that general practice is well placed for the follow-up of patients who have had a stroke [12]. The reasons for lack of guideline adherence are largely unknown. It could be that the GPs do not know the recommendations for secondary prevention after stroke [16], that the guidelines do not fit in with the patients` complexity [23] or that the guidelines are poorly adapted to general practice in other ways [24]. There are also critical questions as to whether the theoretical basis for clinical guidelines is good enough as guidelines are mostly organ-specific. This results in a high degree of complexity in general practice where

patients often have many diseases at the same time [25]. International expert guidelines are also documented to be non-implementable in Norwegian general practice because of the resource utilization recommended is not compatible with the resources available. For example, international guidelines on high blood pressure alone have been estimated to impose a workload that exceeds the total working capacity of Norwegian GPs [26]. To the extent that the guidelines are followed with respect to recommended procedures being carried out, it is nevertheless a recognized problem that this does not have to significantly affect health goals for patients [17, 18].

It is known that the risk of stroke can be reduced by adjustments in lifestyle and that lack of knowledge is a main obstacle for patients in achieving this benefit [27]. The guidelines [2] are explicit on lifestyle advice; they give recommendations on physical activity, diet and alcohol consumption in addition to BMI. One prominent finding in this study is the absence of such lifestyle advice, and especially advice on diet and alcohol consumption. This corresponds to previous findings, pointing out that patients report having received little or no information about lifestyle following a stroke [28].

We recommend future research to explore reasons for non- adherence to guidelines. Other studies point out that the majority of patients with a chronic disease in primary care, also have other chronic diseases; multimorbidity [29]. Also, most persons aged 65 and older are multimorbid [30, 31]. In our research group, we will therefore conduct further research on stroke follow-up in the presence of multimorbidity. General practice is not meant to focus on one single disease, but practices an integrated approach. An understanding of this complexity might give answers to why the follow-up of patients who have had a stroke seems to be so limited in general practice.

Conclusions

Although patients frequently consulted their GPs in the first year after a stroke, most consultations were concerned with issues other than the stroke. When stroke was an issue, the recommendations in the guidelines were often not adhered to. This means that even a medical condition considered to be serious, may receive only limited attention in general practice. As the access to the GP did not seem to be limited, the results may rather be caused by the complexity of general practice. Other complaints may be regarded as equally important by the patient or by the GP. This complexity should be considered in the development of clinical guidelines.

Additional file

Additional file 1: Operational definitions list. List of definitions used when registering data from the medical records. (DOCX 13 kb)

Abbreviations

BMI: Body mass index; BP: Blood pressure; CK: Creatine kinase; GP: General practitioner; Helfo: The Norwegian Health Economics Administration; LDL: Low-density lipoprotein; REK: Regional committees for medical and health research ethics; RGP: Regular general practitioner; TIA: Transient ischemic attack

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Availability of data and materials

Data could be available from the corresponding author on reasonable request.

Authors' contributions

RAaP, HP and IH took part in the planning of the study. RAaP registered data from the medical records and wrote the first draft of the manuscript. HP and IH read the paper and made improvements of the content and wording. RAaP, HP and IH have read and approved the final manuscript.

Authors' information

RAaP is a neurologist, a former family doctor and holds a masters' degree in social studies. HP is a family doctor and PhD. IH is a Professor of General practice at NTNU.

Ethics approval and consent to participate

The study was approved by the regional committee for medical and health research ethics (REK) (Reference REK midt 2013/1501). All participants gave their written informed consent.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Paper II

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RESEARCH ARTICLE Open Access

Stroke follow-up in primary care: a Norwegian modelling study on the implications of multimorbidity for guideline adherence

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Abstract

Background: Specialized acute treatment and high-quality follow-up is meant to reduce mortality and disability from stroke. While the acute treatment for stroke takes place in hospitals, the follow-up of stroke survivors largely takes place in general practice. National guidelines give recommendations for the follow-up. However, previous studies suggest that guidelines are not sufficiently adhered to. It has been suggested that this might be due to the complexity of general practice. A part of this complexity is constituted by patients' multimorbidity; the presence of two or more chronic conditions in the same person. In this study we investigated the extent of multimorbidity among stroke survivors residing in the communities. The aim was to assess the implications of multimorbidity for the follow-up of stroke in general practice.

Methods: The study was a cross sectional analysis of the prevalence of multimorbidity among stroke survivors in Mid-Norway. We included 51 patients, listed with general practitioners in 18 different clinics. The material consists of the general practitioners' medical records for these patients. The medical records for each patient were reviewed in a search for diagnoses corresponding to a predefined list of morbidities, resulting in a list of chronic conditions for each participant. These 51 lists were the basis for the subsequent analysis. In this analysis we modelled different hypothetical patients and assessed the implications of adhering to all clinical guidelines affecting their diseases.

Result: All 51 patients met the criteria for multimorbidity. On average the patients had 4.7 (SD: 1.9) chronic conditions corresponding to the predefined list of morbidities. By modelling implications of guideline adherence for a patient with an average number of co-morbidities, we found that 10–11 annual consultations with the general practitioner were needed for the follow-up of the stable state of the chronic conditions. More consultations were needed for patients with more complex multimorbidity.

Conclusions: Multimorbidity had a clear impact on the basis for the follow-up of patients with stroke in general practice. Adhering to the guidelines for each condition is challenging, even for patients with few co-morbidities. For patients with complex multimorbidity, adhering to the guidelines is obviously unmanageable.

Keywords: Stroke, General practice, Practice guidelines, Multimorbidity

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Background

Stroke follow-up in general practice

Each year about 15,000 persons suffer a stroke in Norway. The acute treatment most often takes place in specialized stroke-units in hospitals, but the follow-up of survivors residing in the communities takes place in general practice. This is in accordance with the national guidelines for treatment of stroke [1] which state that general practitioners (GPs) should play a key role in the follow-up of stroke survivors. All residents in Norway are entitled to a regular general practitioner (RGP) and at the time of the study, about 99% of the Norwegian population were registered on RGP's lists [2].

The guidelines give normative advice on the contents of the follow-up in general practice. They recommend that patients with stroke should normally be given lipid-lowering treatment in the form of statins. Creatine kinase (CK) and transaminase blood samples should be taken to control possible side-effects of this medication. The target value for low-density lipoprotein (LDL) should be < 2.0 mmol/L, and the target value for blood pressure should be < 140/90 mmHg. Diet, body mass index (BMI), physical activity, alcohol consumption, and smoking affect the risk for stroke and recurrent stroke. These lifestyle factors should therefore also be part of the post-stroke follow-up. However, an increasing amount of evidence suggests that the follow-up in general practice is not in accordance with clinical guidelines [3–7]. This includes previous analysis of data on the same participants as the present study, where we found that most consultations with the RGP the first year after a stroke were concerned with issues other than the stroke, and that guidelines were often not adhered to [3]. Multiple factors can explain non-adherence to clinical guidelines, such as lack of familiarity with the recommendations, but complexity of patient situations has also been identified as a barrier to the implementation of clinical guidelines [8, 9].

Multimorbidity

There is no international consensus on a standardized list of chronic conditions or a standard for the measurement of multimorbidity [10–13]. Therefore there is a need to operationally define which conditions to include in a multimorbidity count [14]. Definitions of multimorbidity vary in the number and kinds of conditions included. Most often, multimorbidity is defined as the presence of two or more chronic medical conditions in the same person [12, 13, 15–17]. Recent publications point out that the GPs are situated in a landscape that is more complex than what is reflected by organ-specific guidelines, and that this landscape is dominated by multimorbidity. According to Tomasdottir et al. "the disease clusters typically transcend biomedicine's traditional demarcations between mental and somatic diseases and between diagnostic categories within each of these domains" [18]. In general practice, multimorbidity is the rule rather than the exception [15, 18, 19].

Multimorbidity poses a challenge to patient safety, in part due to the complex management regimens [20]. It has been documented that when the treatment of patients who have multiple concurrent diseases is in accordance with the relevant guidelines, this can give unfortunate results [21, 22]. An example is polypharmacy with significantly increased risk of drug side effects and interactions [23]. Hence, GPs can experience situations where adherence to guidelines is incompatible with a patient-centered approach to the patient with multimorbidity [24]. Furthermore, in the presence of multiple coexisting conditions, the benefits and harms associated with the combination of recommended treatments become unclear and priorities become uncertain [25]. Multimorbidity and polypharmacy have been documented to be more common among persons with stroke than those without [26].

The aim of this study was to assess the implications of multimorbidity on the follow-up of stroke in general practice. More detailed aims were:

- To investigate the extent of multimorbidity among patients who had suffered an ischemic stroke.
- To map the most common co-morbidities.
- To estimate the annual number of guideline-recommended investigations and follow-up visits to the GP or other healthcare providers for a stroke survivor with a typical combination of chronic conditions.

Methods

This study was designed as a cross-sectional analysis of prevalence of multimorbidity in patients with stroke in Norway, and assessment of the implications of adherence to clinical guidelines. We used the STROBE statement [27] to guide our reporting of the study. Multimorbidity was defined as the presence of two or more chronic medical conditions in the same person. A pre-specified list of 40 conditions (see: Additional file 1), developed by Barnett and colleagues [11], was used as a frame for the morbidity-count. We included patients treated for ischemic stroke in two local hospitals in Mid-Norway in 2011 and 2012. All patients with the discharge diagnosis I63.0 trough I63.9 according to the International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10), were identified in the hospital files. The Norwegian Health Economics Administration identified the RGP for each of the patients. Each of these GPs were invited to participate. Subsequently, identified stroke patients were invited if

they were living in their own home and registered with an RGP who had accepted participation. Patients in nursing homes were excluded.

Data collection

One of the authors (RAaP) personally visited each clinic and reviewed the continuous text of the medical records, the diagnosis records, laboratory records, and the prescribing registries for each individual patient. Diagnoses that met the pre-specified diagnostic criteria (Additional file 1) were registered, resulting in a list of chronic conditions for each participant.

Analysis

The number of chronic conditions was counted for each participant and the frequency of each condition registered (Table 1).

To assess the implications for the follow-up of stroke, we constructed three follow-up situations, representative for the study population, that typical patients would find themselves in if all isolated conditions were to be followed up according to "best practice", i.e., in accordance with all relevant guidelines. The constructions were hypothetical examples representative regarding number and type of chronic condition. Hypothetical rather than real patients were chosen to eliminate the risk of identification of specific participants. First, we defined age, gender and number of chronic conditions for the hypothetical patients. To reflect the different grades of multimorbidity among the patients, we chose different numbers of conditions for each of the examples. The number of conditions for each example was selected based on the spectrum we found among the participants. The first example represented the patients with the least complex multimorbidity among the stroke survivors (Example 1: a patient with three morbidities including stroke). The number of chronic conditions for this example was below average. The second example represented an average number of chronic conditions (Example 2: a patient with five morbidities including stroke). The third example represented the patients with the most complex multimorbidity, with a number of chronic conditions above average (Example 3: a patient with seven morbidities including stroke). For each example we chose the defined number of conditions among the 20 most frequent conditions (Table 1). In this way, only conditions affecting several patients in our study were taken into account.

Only conditions with national clinical guidelines or similar formal recommendations were selected. Recommendations on follow-up were extracted from relevant guidelines and the number of recommended follow-ups with the GP and organ-specific specialists was registered into a table for each example (Tables 2, 3 and 4). Recommendations regarding treatment by other health care providers, laboratory tests and special procedures were also recorded.

Table 1 Co-existing chronic conditions among the 51 patients with stroke

Condition	N	%
Stroke	51	100
Hypertension	28	55
Coronary heart disease	24	47
Rheumatoid arthritis, other inflammatory polyarthropathies & systematic connective tissue disorders	13	25
Diabetes	11	22
Atrial fibrillation	10	20
Prostate disorders	9	18
Hearing loss	9	18
Treated dyspepsia	8	16
Anxiety & other neurotic, stress related & somatoform disorders	7	14
Asthma	7	14
Painful condition	7	14
Depression	6	12
Chronic obstructive pulmonary disease	6	12
Blindness & low vision	6	12
New diagnosis of cancer in the last 5 years	5	10
Epilepsy	5	10
Thyroid disorders	4	8
Chronic kidney disease	4	8
Peripheral vascular disease	3	6
Heart failure	3	6
Alcohol problems	2	4
Migraine	2	4
Psoriasis	2	4
Diverticular disease of intestine	2	4
Learning disability	1	2
Inflammatory bowel disease	1	2
Chronic sinusitis	1	2
Other psychoactive substance misuse	1	2

Results

We identified 414 patients with the discharge diagnosis I63.0 trough I63.9 according to ICD-10 in the hospital files. They were listed with 100 different GPs. Among 100 invited GPs, 37 in 18 different clinics agreed to participate. In total 138 patients were invited to participate in the study, 51 gave their written consent and were included. Thirty (59%) were male and 21 (41%) were female, aged 38 to 90 years (mean 68.5 years).

With the range of 2–10 chronic conditions, all participants met the criteria for multimorbidity. On average the

Table 2 Patient 1: Recommended annual follow-up activity

	Consultations with the GP	Consultations with specialists	Other recommended health care providers	Laboratory tests	Special Procedures
COPD	1–2	NR	Physiotherapist (limited to 40 annual treatments), two supervised work-outs a week	NR	Spirometry Vaccination
Colorectal cancer	2	NR	NR	yes	2 x CEUS and 1 x LDCT
Smoking	4	NR	NR	NR	NR
Driver's licence	1	NR	NR	NR	NR
Stroke	1	1	NR	yes	NR
Total	9–10	1	yes	yes	5

Minimum follow-up activity recommended for a period of 12 months, given that all conditions are clinically stable, and no new abnormalities are found in the tests
Abbreviations: *COPD* Chronic obstructive pulmonary disease, *CEUS* Contrast-enhanced ultrasonography, *LDCT* Low-dose computed tomography, *NR* No recommendations

patients had 4.7 (SD: 1.9) chronic conditions corresponding to the list of 40 (Additional file 1), stroke included.

Analysis of the health care burden

Among the participants, 46 (90.2%) had three or more morbidities (see Fig. 1). Ten (19.6%) had seven or more morbidities. In the first example, we chose three chronic conditions including the stroke. This is about one standard deviation (SD) below average.

Example 1: a patient with three morbidities including stroke

> A male smoker, 74 years, recently suffered a minor stroke with full recovery. He has chronic obstructive pulmonary disease (COPD) and 1 year before the stroke, he was treated for colorectal cancer. The cancer treatment was curative. He is now motivated to cease smoking.

Norwegian national guidelines for the follow-up of patients with COPD [28] were issued in 2012. It is recommended that patients with stable mild or moderate COPD have follow-up consultations with their GPs at least once a year, minimum twice if the COPD is severe. Annual controls should include spirometry, body mass index (BMI) registration, measurement of oxygen saturation, grading of dyspnea according to the British Medical Research Council (BMRC) scale, COPD questionnaire, mapping of physical activity, mapping of the number of exacerbations, evaluation of comorbidities, evaluation of each of the prescribed drugs, assessment of the need for rehabilitation, assessment of the need for specialized healthcare and advice on vaccination.

In the case of hospitalization it is recommended to have an additional consultation within 4 weeks of discharge. Smokers should be encouraged to cease smoking, motivation should be explored and help to cease smoking offered at every suitable consultation. Orientation on medication aided smoke cessation should be given. If motivated for cessation, the patient should be followed-up closely the first months. If cessation is initiated at the hospital, the GP must be involved by making an appointment for follow-up.

Patients with moderate to severe COPD should be referred to a physiotherapist for exercises regarding muscular

Table 3 Patient 2: Recommended annual follow-up activity

	Consultations with the GP	Consultations with specialists	Other recommended health care providers	Laboratory tests	Special procedures
Asthma	1	NR	physiotherapist		Spirometry
Diabetes	2	1–2	NR	yes	NR
RA	4	1	NR	yes	NR
Thyroid disorder	2	NR	NR	yes	NR
Screening	0–1	NR	NR	yes	Gynecological examination. Mammography
Stroke	1	1	NR	yes	NR
Total	10–11	3–4	yes	yes	3

Minimum activity recommended for a period of 12 months for the patient in example 2, given that all conditions are clinically stable, and no new abnormalities are found in the tests
Abbreviations: *RA* Rheumatoid arthritis, *NR* No recommendations

Table 4 Patient 3: Recommended annual follow-up activity

	Consultations with the GP	Consultations with specialists	Other recommended health care providers	Laboratory tests	Special procedures
Diabetes	2	1–2	NR	yes	
COPD	1–2	NR	Physiotherapist (limited to 40 annual treatments), two supervised work-outs a week	NR	Spirometry. Vaccination
Colorectal cancer	2	NR	NR	yes	2 x CEUS and 1 x LDCT
Depression	6	NR	NR	NR	NR
Painful condition	6	NR	NR		NR
Thyroid disorder	2	NR	NR	yes	NR
Screening	0–1	NR	NR	yes	Gynecological examination. Mammography
Smoking	4	NR	NR	NR	NR
Stroke	1	1	NR	yes	NR
Total	24–26	2–3	yes	yes	7

Minimum activity recommended for a period of 12 months for the patient in example 3, given that all conditions are clinically stable, and no new abnormalities are found in the tests
Abbreviations: *COPD* Chronic obstructive pulmonary disease, *CEUS* Contrast-enhanced ultrasonography, *LDCT* Low-dose computed tomography, *NR* No recommendations

strength, endurance, mobility, training in breathing techniques and secretive mobilization techniques. The patient should work out at least three times a week, two of which under supervision. The national health insurance scheme supports up to 40 annual treatments with physiotherapist. An annual influenza vaccination should be given.

There are national guidelines for the follow-up of colorectal cancer [29]. These guidelines provide an established form for the follow-up. The controls are performed by the patient's GP, but the first check after surgery is to be performed by a surgeon. The second year of follow-up includes carcinoembryonic antigen (CEA) blood samples at 18 and 24 months after the surgery. Every 6 months a contrast-enhanced ultrasonography (CEUS) of the liver is to be performed. A low-dose computed tomography (LDCT) of the thorax is recommended every 12 months.

The national guidelines for smoking cessation [30] recommend that a structured aid for smoking cessation should include at least four meetings or consultations with the addition of follow-up according to need.

To continue driving at the age of 75, a person in Norway must undergo a health check with the GP. A person who has suffered a stroke can meet the health requirements after 3 months provided complete recovery. This can be assessed by the specialist at an outpatient control after the

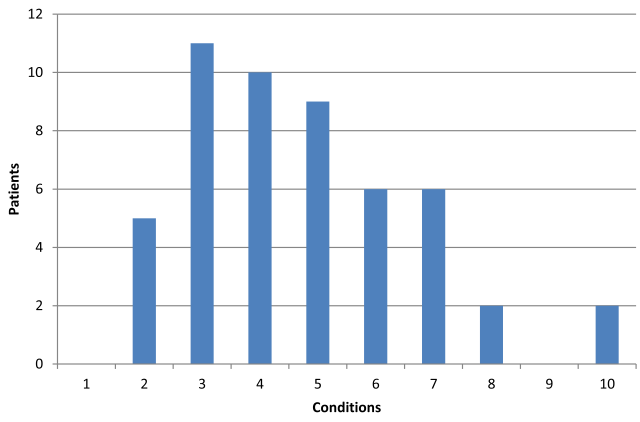

Fig. 1 shows the distribution of patients with 0–10 chronic conditions. The number of patients with 0–10 chronic conditions.

stroke, but an assessment of the combined health requirements for the driver's license is more comprehensive and includes all aspects of health with potential impact on road safety. There is a separate form for the health certificate [31] and the health requirements for driver's license are specified in guidelines issued in 2016 [32].

Example 2: a patient with five morbidities including stroke

> A 68-year-old woman recently suffered a stroke. She also has the combination of thyroid disorder, asthma, type 2 diabetes and rheumatoid arthritis (RA).

The second example represents the average stroke survivor residing in the community.

Norwegian guidelines for asthma in general practice were issued in 2015 [33]. According to these, asthma is to be checked in an annual control. This control should include lung function measurements with a liberal use of reversibility testing, referral to physiotherapist and an assessment of the need for referral to a specialist or to a rehabilitation institution. Newly diagnosed patients should normally come to a control within 3 months after the first consultation and thereafter every 3–6 months. After an exacerbation, it is important to offer follow-up after 2–4 weeks. For patients with stable and good disease control, follow-up once a year is considered sufficient.

The national guidelines for diabetes [34] recommend one extensive control annually with the GP. Between the annual controls it is recommended to have at least one consultation for diabetes if it is well-regulated. More if needed. Patients with type 1 diabetes should in addition have interdisciplinary follow-up in the specialist health service at least once a year, patients with type 2 diabetes should be referred to an interdisciplinary team in the specialist health service in the case of coexisting complicating disease. The patient should be referred to an ophthalmologist at the time of diagnosis. If there is no sign of retinopathy, controls every 2 years is sufficient.

Regarding the RA, there is currently no national guideline for the follow-up in general practice, but the University hospital for the study region, St. Olavs Hospital in Trondheim, has issued recommendations for the follow-up in general practice [35], and these recommendations are published online at legehandboken.no, an evidence-based clinical decision support online resource used by more than 90% of Norwegian GPs [36]. Patients with disease modifying antirheumatic drugs (DMARDs) or biological medication are to be checked at the hospital's outpatient clinic annually, and if necessary, more often. The GP should conduct a regular clinical examination with joint examination and blood pressure measurement. It is important to be aware of infectious diseases, and in the case of persistent airway symptoms, chest x-ray and spirometry should be taken. Laboratory tests should be taken every third month when clinical presentation and laboratory tests are stable.

Advice on follow-up of thyroid disorders is also available online in evidence-based clinical decision support resources. Patients with maintenance treatment need follow-up 1–2 times a year, more often when medication is adjusted.

Women in Norway are at the time of this study generally recommended to follow the cervical cancer screening program with screening every third year through age 69 years and the breast cancer screening program with screening every second year through age 69 years. The breast cancer screening takes place in radiology departments and does not necessarily involve the GP. The cervical cancer screening involves a gynecological examination, usually performed by the GP.

Example 3: a patient with seven morbidities including stroke

> A 65-year-old woman who recently suffered a stroke. 2 years ago, she was curative treated for colorectal cancer. She has type 2 diabetes, COPD, a painful condition in the back, thyroid disorder and she is mildly depressed.

In the third example, we chose seven chronic conditions, including stroke. This corresponds with one SD above average.

The national guidelines for use of opioids with long lasting non-malignant pain [37] recommends careful follow-up in general practice. Patients with opioids for non-malignant pain should have control appointments with the GP at least every second month. The aim of these consultations is to control and prevent side-effects such as addiction and obstipation.

In Norway, a clear majority of patients with depression have their treatment exclusively in primary care. This is mainly people suffering from mild to moderate depression [38]. National guidelines for treatment of adults with depression states that these patients may benefit from short-treatment in primary care. It is recommended to consider counseling in relation to everyday problems, short-term cognitive therapy or interpersonal counseling with six to eight treatments over a period of 10 to 12 weeks. Antidepressants should be considered if the depression does not respond to non-medication attempts [38].

Discussion

With a mean of 4.7 (SD: 1.9) chronic medical condition, none of the participants of the study had fewer than two morbidities, including stroke. Hypertension, coronary heart disease, rheumatic diseases as a group, and diabetes being the most prevalent co-morbidities. Multimorbidity had a clear impact on the basis for the follow-up of patients with

stroke in general practice. We found that the overall follow-up regimen implicated by the different guideline recommendations can be challenging even for those patients in our study who had the fewest co-morbidities. Norwegian GPs find the workload heavy and increasing. Concern is expressed that this may compromise patient safety and recruitment of GPs [39]. In this context, the total regimen for the patients with the most complex multimorbidity is evidently unmanageable for the GPs. It must also be overwhelming for the patients.

We found that a high annual number of consultations with the GP were required for patients with multimorbidity, according to guideline recommendations. This cannot necessarily be solved by doing several things at the same time or in the same consultation, as the consultations are time-limited. In Norwegian general practice, a consultation is normally limited to 15–20 min [40]. Some of the procedures recommended by guidelines are so time consuming that there is hardly sufficient time for one procedure in the consultation. The annual diabetes control is an example of such a time consuming procedure [34]. Multimorbidity adds to the complexity of the consultations the increased risk of drug-drug and drug-disease interactions [41].

Our findings represent the recommendations provided that all conditions are clinically stable, and no new abnormalities are found in the tests. It is foreseeable that all conditions in patients with multimorbidity are not clinically stable along the timeline, this is a logical foundation for the guidelines. Abnormal findings in tests, clinical exacerbations of chronic conditions, or intercurrent diseases along the timeline will necessitate further procedures and hence further consultations.

Findings in the light of current knowledge

In a previous study [3], we have shown that stroke survivors residing in the communities often consult their GPs, but also that adherence to guidelines for stroke follow-up [1] is limited. Multimorbidity is a part of the complexity of general practice, and findings in our present study provide an explanation of why the combined recommendations of guidelines may be too challenging to adhere to.

The complex topic of the doctor-patient relationship is well described in several dimensions. Structure, communication, and patients' perspectives have been among the areas of research [42–44]. Time constraints has been identified among the systemic factors that affect this relationship [45].

There is no tradition for the use of modelling studies in assessing the consequences of guideline development before implementation is initiated. However, research of this kind has documented that guideline implementation can destabilize the health care service. For example, the monitoring and follow-up of blood pressure according to international expert guidelines may alone require more resources than available in general practice [46].

While much is known about what constitutes a good doctor-patient relationship, little is known about the capacity of this relationship. There must exist some limit to the extent of follow-up in general practice. We suggest that this limit is determined by the capacity of the doctor-patient relationship. This is obviously no fixed entity. It must depend on the patient capacity combined with that of the patient's GP. With the term patient capacity, we mean the patient's willingness and ability to participate in consultations, procedures, examinations and treatments. The doctor capacity may be determined by workload among other possible factors. We have no measure for the capacity of the doctor-patient relationship in general practice. However, a previous study by our research group showed that stroke survivors on average consulted their GPs 7.5 times the first year after the stroke [3]. This is not sufficient to control the stable state of the morbidities of any of our example-patients if the guidelines were adhered to. The patient in example 1 had below average complexity and the patient in example 2 had the same level of complexity as the average stroke survivor. This fact may indicate that the capacity of the doctor-patient relationship is exceeded even among those patients with the least co-morbidities. Simplifying treatment regimens as a strategy for safer care for people with multimorbidity has been previously suggested [20], and the findings in our study adds to the knowledge supporting such a view. More resources might solve problems related to doctors' capacity, but they would not necessarily solve problems related to patients' capacity.

Guidelines are usually developed according to international standards [47]. Our findings point out a substantial weakness in the guideline development. Their combined recommendations for the follow-up are not sustainable when it comes to patients with multimorbidity. As multimorbidity is the rule rather than the exception in general practice [15, 18, 19], guidelines, at least in Norway, are poorly adapted to patients' clinical reality even if they comply with Norwegian guidelines for guidelines [48]. It has previously been raised critical questions as to whether the theoretical basis for the guidelines is good enough [5]. The findings in this study show that such questions are still relevant.

The general practice perspective tends to be inadequately addressed in guidelines, with factors such as workload and resources insufficiently taken into account. Partly, we believe this is due to inadequate involvement of GPs in guideline panels. Furthermore, recommendations on the frequency of follow-up visits is usually based on expert opinion, as there is rarely any direct evidence available to support these recommendations [1, 38].

We recommend future research to further explore undesired consequences of adherence to clinical guidelines in general practice. We also recommend the theoretical basis for guideline development to be scrutinized.

Strengths and limitations

With the aim to assess the possible implications of multimorbidity for the follow-up of stroke in general practice, we see it as a major strength that we analyzed data from the GPs' own documentation, rather than self-reported disease counts, for instance. In this way, we could assess the extent of multimorbidity from the GP's point of view. All data collection was done by the same person, eliminating the risk of inter-observer differences in the review of the medical records or data registration, although intra-observer variations cannot be excluded. The retrospective nature of the medical records bares the risk of overestimating disease counts by including outdated diagnoses. However, the chronicity of most of the conditions considered makes this a minor source of potential bias. On the other hand, there may be some diagnoses missing in the GPs' documentation.

We found a high degree of multimorbidity among stroke survivors. There was no reason to believe that the patients in this study had particularly many co-morbidities compared with other stroke survivors. On the other hand, there were some reasons to assume the opposite. We excluded patients in nursing homes. It is a fair assumption that these were the patients with the greatest burden of disease.

The inclusion of patients started out wide. There was, however, a low degree of participation among invited patients. Possible explanations for this could be poor health and impaired physical and mental functioning among the patients. Impaired physical and mental functioning is associated with stroke as well as with multimorbidity [49–51]. It is therefore possible that the patients with the most complex multimorbidity were excluded in our study.

It may be regarded a weakness that the patient examples were hypothetical and not real patients. However, presenting real patient cases was deemed to risk the anonymity of the participants. Instead, a representative combination of conditions was strived for in the examples. The combinations of chronic conditions for the analysis were not influenced by the complexity of the relevant guidelines, i.e., there was no preference for conditions with comprehensive follow-up regimens. The criteria were that the condition was relatively frequent among the participants and that there should be specific guidelines for the condition. However, the combinations of conditions are to a large extent consistent with known patterns of co- and multimorbidity. Example 1 features the combination of stroke and COPD. The association between these conditions is previously described [52]. The association between stroke and RA in example 2 is also previously described [53, 54]. A disease cluster of cardiovascular diseases, metabolic diseases and mental health problems similar to that used in example 3, has previously been pointed out in a Norwegian population-based study on multimorbidity [18]. Associations between musculoskeletal problems and mental health problems and between musculoskeletal problems and cardiovascular problems was also identified in the same study [18].

Despite weaknesses, we claim the findings to be valid for the extent of multimorbidity among stroke survivors residing in the communities in this county.

Conclusions

This study included stroke survivors residing in the communities. The GPs play a key role in the post-stroke follow-up of these patients. While guidelines for the follow-up exist, we have previously documented that adherence to these guidelines is weak [3]. In the present study, we have documented that all participants met the criteria for multimorbidity. Furthermore, we have demonstrated how adhering to the guidelines for each condition is a challenge, even for patients with few co-morbidities. For patients with more complex multimorbidity, adhering to the guidelines must be overwhelming and unmanageable for the GP. In this way, multimorbidity had a clear impact on the basis for the follow-up of patients with stroke in primary care. The findings provide new dimensions to the understanding of non-adherence to guidelines which should have implications for development of future guidelines.

Supplementary information

Supplementary information accompanies this paper at https://doi.org/10.1186/s12875-019-1021-9.

Additional file 1. List of chronic conditions with operational definitions.

Abbreviations

BMI: Body mass index; BMRC: British Medical Research Council; CEA: Carcinoembryonic antigen; CEUS: Contrast-enhanced ultrasonography; COPD: Chronic obstructive pulmonary disease; DMARD: Disease modifying antirheumatic drug; GP: General practitioner; ICD-10: International Statistical Classification of Diseases and Related Health Problems, 10th revision; LDCT: Low-dose computed tomography; NR: No recommendations; RA: Rheumatoid arthritis; RGP: Regular general practitioner; SD: Standard deviation

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Authors' contributions

RAaP, HP and IH took part in the planning of the study. RAaP registered data from the medical records and wrote the first draft of the manuscript. HP and IH read the paper and made improvements of the content and wording. RAaP, HP and IH have read and approved the final manuscript.

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RAaP is a neurologist, a former family doctor and holds a masters' degree in social studies. HP is a family doctor and PhD. IH is a Professor of General practice at NTNU.

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Availability of data and materials
Data could be available from the corresponding author on reasonable request.

Ethics approval and consent to participate
The study was approved by the Regional Committee for Medical and Health Research Ethics (REK) (Reference number: REK midt 2013/1501). All participants gave their written informed consent.

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

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RESEARCH ARTICLE Open Access

Stroke follow-up in primary care: a discourse study on the discharge summary as a tool for knowledge transfer and collaboration

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Abstract

Background: The acute treatment for stroke takes place in hospitals and in Norway follow-up of stroke survivors residing in the communities largely takes place in general practice. In order to provide continuous post stroke care, these two levels of care must collaborate, and information and knowledge must be transferred between them. The discharge summary, a written report from the hospital, is central to this communication. Norwegian national guidelines for treatment of stroke, issued in 2010, therefore give recommendations on the content of the discharge summaries. One ambition is to achieve collaboration and knowledge transfer, contributing to integration of the health care services. However, studies suggest that adherence to guidelines in general practice is weak, that collaboration within the health care services does not work the way the authorities intend, and that health care services are fragmented.
This study aims to assess to what degree the discharge summaries adhere to the guideline recommendations on content and to what degree they are used as tools for knowledge transfer and collaboration between secondary and primary care.

Methods: The study was an analysis of 54 discharge summaries for home-dwelling stroke patients. The patients had been discharged from two Norwegian local hospitals in 2011 and 2012 and followed up in primary care. We examined whether content was according to guidelines' recommendations and performed a descriptive and interpretative discourse analysis, using tools adapted from an established integrated approach to discourse analysis.

Results: We found a varying degree of adherence to the different advice for the contents of the discharge summaries. One tendency was clear: topics relevant here and now, i.e. at the hospital, were included, while topics most relevant for the later follow-up in primary care were to a larger degree omitted. In most discharge summaries, we did not find anything indicating that the doctors at the hospital made themselves available for collaboration with primary care after dischargeof the patient.

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(Continued from previous page)
Conclusions: The discharge summaries did not fulfill their potential to serve as tools for collaboration, knowledge transfer, and guideline implementation. Instead, they may contribute to sustain the gap between hospital medicine and general practice.

Keywords: Stroke, Primary care, Practice guidelines, Fragmented care, Collaboration, Knowledge transfer, Discourse analysis

Background

Stroke follow-up

Stroke is one of the major causes of death and disability worldwide [1, 2]. About 13,000 patients are registered annually with acute stroke as primary or secondary diagnosis in Norwegian hospitals [3]. Most patients are discharged to their own home after the acute hospitalization for stroke [4] and the follow-up of patients residing in the communities takes place in primary care. Norwegian national guidelines for treatment of stroke, issued in 2010, state that general practitioners (GPs) should play a key role in the follow-up of stroke survivors [5]. After the introduction of the Regular General Practitioners System in 2001, all inhabitants in Norway are entitled to a regular general practitioner (RGP). At the time of this study, about 99% of the Norwegian population was registered on RGP's lists [6].

After a first stroke, people have an increased risk of recurrent strokes [7] which are associated with particularly high mortality [8, 9]. Individualized secondary prevention is meant to reduce mortality and morbidity from stroke and can provide substantial gains [10]. Secondary prevention is part of the follow-up in primary care.

The discharge summary and collaboration within the health care services

To ensure optimal post stroke care after discharge from hospital, collaboration within the public health care is vital [11]. The guidelines' developers acknowledge that collaboration and knowledge transfer within the health care service are important factors for the optimal treatment and follow-up of patients. Therefore, they provide specific advice on how collaboration and knowledge transfer should take place, while emphasizing the importance of establishing chains of care that are continuous within and across organizational boundaries in health care [5].

The discharge summary is a written report from the responsible physician at the hospital, generated at the end of the patient's hospital stay. In Norway, this report is primarily sent to the patient's RGP. This information transfer is essential to the smooth transition from inpatient to outpatient care [5]. The guideline recommends that discharge summaries describe multidisciplinary assessments and provide specific advice on follow-up, rehabilitation and secondary prevention. Furthermore, ten recommended elements are listed (Table 1).

By adhering to this part of the guidelines, the discharge summary is meant to serve as a tool for knowledge transfer and collaboration within the health care services. When these recommendations are adhered to, the discharge summary can also serve as a tool for guideline implementation in general practice, e.g. by setting treatment goals for blood pressure and blood lipid values.

However, an increasing amount of evidence suggests that the follow-up in general practice is not in accordance with clinical guidelines [12–16] and that collaboration within the health care services does not necessarily work as intended [17]. Instead, fragmentation and inadequate integration of health services are obstacles in ensuring that the scientific advances in prevention, treatment and rehabilitation are translated into clinical practice [18]. From similar fields of practice, we know that there is a gap between evidence-based recommendations and real-world management [19, 20]. Deficits in communication and information transfer in discharge summaries may adversely affect patient care [21].

It is not known whether the secondary health services use the discharge summaries to provide the GPs with multidisciplinary assessments or specific advice on the follow up, as recommended by the guidelines. Nor is it known whether the discharge summary is used to spread knowledge about the guidelines' specific recommendations on secondary preventive measures. Furthermore, it is not known to what degree the discharge summary

Table 1 Elements of the discharge summary, recommended in the guidelines

- The kind of stroke and its localization in the brain
- The cause of the stroke
- A short description of the treatment and the diagnostic investigation
- Complications (if applicable)
- The patient's level of function on discharge
- Prognosis, including prognosis for driver's license and work
- Assessment of the necessity for further diagnostic investigations
- Medication at discharge
- Further treatment and treatment goals for the blood pressure and blood lipid values
- Plans for the follow-up

provides an invitation to the recommended collaboration within the health services.

Discourses

A study of discharge summaries is a study of language in use in a specific setting. Language in use is about saying, but also about being [22] and doing things with words [23]. When saying – or writing – something, we adjust our language to the setting. We enact a practice that belongs to a social group or a culture, and by doing this, we sustain this culture [22]. We take part in the discourse. A discourse can be defined as a cognitive and normative community that is expressed in language [24]. Hence discourses can have different sizes, and there is no end to their numbers [22]. One can talk about a medical discourse, but there are also numerous discourses even within medicine and they are dynamic in time and place. On this basis, it is reasonable to distinguish between the current discourses of specialized medicine or hospital medicine and medicine in general practice or primary care. Hospital medicine and primary care medicine use different diagnostic systems. At the time of this study, hospitals in Norway used International Classification of Diseases and Related Health Problems, 10th revision (ICD 10) [25] while primary care used International Classification of Primary Care, 2nd edition (ICPC-2) [26]. These coding- and classification systems have different backgrounds and different developers. The base version of ICD 10 was published by World Health Organization (WHO) and ICPC-2 was developed by World Organization of Family Doctors (WONCA). The different diagnostic systems are examples of a gap between two discourses, expressed in sign systems and language.

Discourse analyses are qualitative and interpretative analyses. They are concerned with studying language in use. Significance, identities or relationships are examples of what we build in language. It is possible to analyze each of the language constructions by asking predefined questions. As an example, we can ask not just what the author is writing, but also what he or she is trying to do [22]. Discourse analysis consists of a wide range of qualitative analytical approaches from which the researcher must choose one.

Aims

This study aims to assess possible obstacles to guideline adherence and collaboration within the health care service expressed in the discharge summaries for stroke survivors. More detailed aims were:

- To explore the extent to which the discharge summaries contain the elements recommended by the guidelines.
- To assess to what degree the discharge summaries provided an invitation to a post discharge collaboration.

Methods

Design and setting

This study was part of a larger project on stroke follow-up in primary care. In this project we examined adherence to the guidelines [12], and assessed the implications of multimorbidity for the follow-up of patients with stroke in general practice [27]. We found weak adherence to the guidelines in general practice [12] and saw the need to have a closer look at aspects of collaboration.

We included patients treated for stroke in two Norwegian local hospitals in 2011 and 2012. In order to study the follow-up in general practice and the collaboration between hospital and general practitioner, it was essential to identify patients discharged to their own homes. In Norway, these are the patients who are followed-up by their RGPs. While for the previous parts of the project, the material has consisted of the RGPs' medical records, the material for this study consists of hospital discharge summaries provided by the hospitals. RAaP personally visited each participating RGP clinic in order to collect the material for the first parts of the project, therefore the admission area of the hospitals had to be limited and so the number of hospitals also had to be limited. The two hospitals had a total admission area of about 9500 km^2 with close to 120,000 inhabitants. The choice of hospitals made it possible to reach any of the RGP clinics within a four-hour drive each way. We considered that longer travel was not feasible. After ethics approval was granted, the hospitals provided lists of patients with discharge diagnoses I63.0 trough I63.9 according to ICD 10, and provided access to the patient files. The patients' RGPs were identified by The Norwegian Health Economics Administration (Helfo), and invitations to participate in the study were sent to each of these RGPs. The contribution of the RGPs was to facilitate the collection of data in the first part of the project. Only patients living at home and registered with an RGP who accepted participation, were subsequently invited to participate in the study. Written, informed consents were obtained from all participating patients. Participation meant allowing the researchers access to their medical records and nothing else. Patients not able to consent and patients in nursing homes were excluded.

Discourse analysis

RAaP initially read all the discharge summaries aided by the list of guideline-recommended content categories (Table 1) and registered content recommended in the guidelines. Complications were defined based on the

guidelines' description of common and important complications. Furthermore, the number of discharge summaries that provided multidisciplinary assessments was counted. An operational definitions list is provided in Additional file 1.

In the following discourse analysis, that was performed by RAaP and HT, we used analytical tools adapted from J. P. Gee's interdisciplinary approach to discourse analysis [22]. He describes a general overarching system with 28 tools for the analysis, while emphasizing the need for adapting tools from any theory to the needs and demands of the individual study and that some tools will be more useful for some kinds of data than for other kinds of data [28]. In practice, we therefore do not use all the tools available but select the ones that appear most suitable for our purpose. We initially conducted an explorative analysis with a wide range of the available tools. Tools that did not provide answers that illuminated our aims were excluded. In this way, we subsequently narrowed down our approach with the tools most suitable for our aims. This approach resulted in the identification of what we at this point in the process regarded the most relevant tools for this material and this study. The selected tools and their operational definitions are presented in Table 2.

Results

Description of the selection and material

A total of 100 RGPs were invited, and 37 agreed to participate. They had 138 patients with stroke as a discharge diagnosis in 2011 or 2012 on their lists. We invited all these 138 patients to participate, and 51 gave their written consent. Age on the date of discharge from hospital varied from 38 to 90 years (mean 68.5 years). Thirty (59%) were male and 21 (41%) were female. The material consisted of 54 discharge summaries. For some of the patients, more than one discharge summary was included. Additional discharge summaries were included for new admissions when stroke was the diagnosis. Three discharge summaries were excluded in the analysis stage of the project. One discharge summary was excluded because the content revealed that the correct diagnosis was transient ischemic attack (TIA) rather than stroke and two were excluded because the content revealed that the patients were treated as outpatients, even though the patients were all registered as inpatients with ischemic stroke in the hospital's own system.

The patients were treated in two different clinics in different geographic locations. The clinics shared the same administration and offered equal services to stroke patients in their respective geographic areas. They were located in two neighboring towns of equal size in mid-Norway, separated by a distance of about 75 km. In total 28 different physicians were involved in the production of the discharge summaries, that most often were written and signed by a subordinate doctor before they subsequently were approved and counter-signed by a senior doctor; a specialist in neurology or internal medicine. Eight of the texts were written and signed by only one physician, in these cases the physicians were all specialists in neurology or internal medicine.

Table 2 Tools for the discourse analysis adapted from J.P. Gee

Tools	Operational definition
1) The Subject Tool	Ask why the authors have chosen the subject/topic and what are they writing about the subject. Ask also if and how they could have added more topics and why they did not.
2) The Doing and Not Just Saying Tool	Ask not just what the authors are writing, but also what they are trying to do. Accept that they may be trying to do several things.
3) The Significance Building Tool	Ask how language is being used to build up or lessen significance/ importance/ relevance for certain things, but not for others.
4) The Activities Building Tool	Ask what activity (practice)/ activities (practices) the text is building/ enacting. What activity/ activities is the text seeking to get others to recognize.
5) The Identities Building Tool	Ask what identity or identities the author is enacting or trying to get others to recognize.
6) The Relationships Building Tool	Ask how language is being used to build, sustain, or change relationships of various sorts among the authors, other people, groups or institutions.
7) The Figured Worlds Tool	Ask what typical figured worlds the words or phrases of the text are assuming and inviting readers to assume. Especially, how is the GPs situation in this figured world?
8) The Collaboration Tool	Ask in what way are words and grammatical devices being used to make the text invite to collaboration. Ask also if there are signs of the opposite in the text.
9) The Patient's Voice Tool	Ask if the patient's voice (questions, utterances, opinions, wishes or preferences) are commented on (other than indirectly in the anamnesis).
10) The Recipient Tool	Ask what recipient the author most likely had in mind when writing, based on the subject, contents, words and phrases in the text.

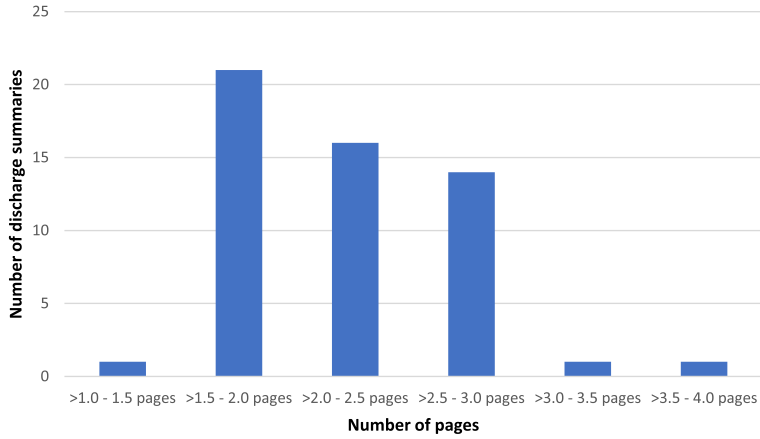

Fig. 1 The text lengths of the 54 discharge summaries

Figure 1 illustrates the lengths of the discharge summary texts that varied from approximate one A4 page to four A4 pages.

All discharge summaries included date of admission and date of discharge. The duration of hospitalization varied from 1 day to 20 days and is illustrated in Fig. 2.

Description of guideline recommended content categories found in the discharge summaries

We found varying degrees of adherence to the different recommendations for content in the discharge summaries (Fig. 3). The discharge summaries often described the kind of stroke and its localization in the brain (87%), the cause of the stroke (80%), medication at discharge (98%) and the treatment and diagnostic investigation (98%).

We found a description of the patient's level of function on discharge in 34 of the discharge summaries (63%), assessment of the necessity for further diagnostic investigations in 29 (54%), a description of complications in 22 discharge summaries (41%), advice on treatment goals for blood pressure in six discharge summaries (11%) and advice on treatment goals for blood lipid values in seven (13%). Multidisciplinary assessments were provided by 17 (31%) of the discharge summaries.

We used the 10 tools presented in Table 2 on each of the 54 discharge summaries. We present the results

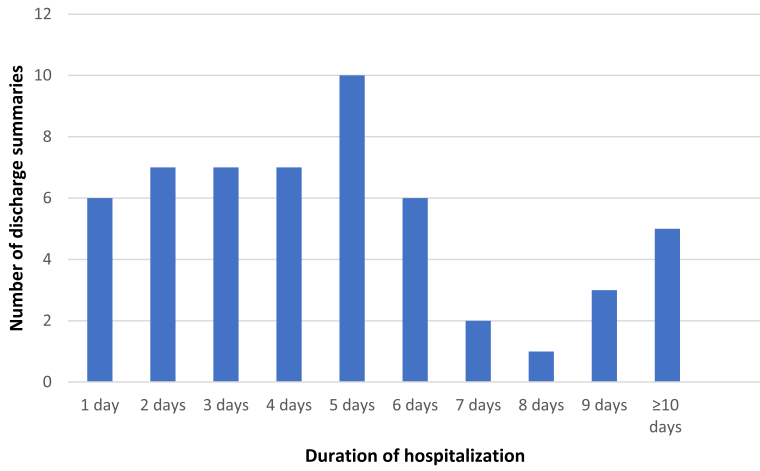

Fig. 2 The duration of hospitalization

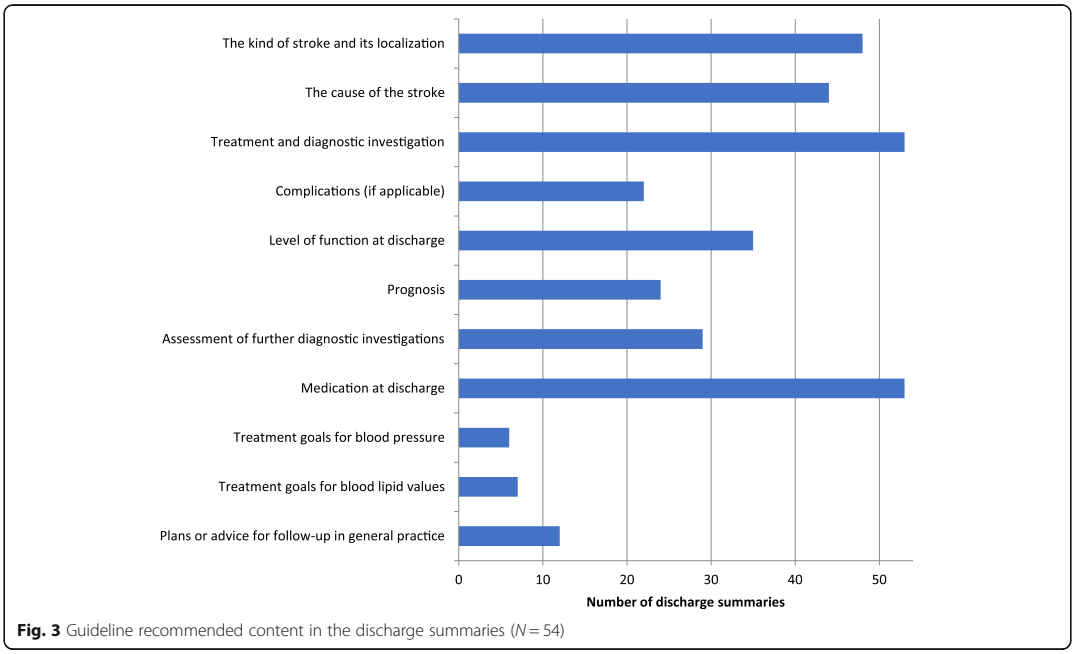

Fig. 3 Guideline recommended content in the discharge summaries ($N = 54$)

divided into those of a descriptive discourse analysis and an interpretative discourse analysis.

Descriptive discourse analysis

Tool 1. The subject tool

When we were working with "The Subject Tool," we asked what the topic of the text was, if the authors could have made other choices of subject or topics and why they did not. Before presenting the main topic, most discharge summaries provided a brief description of the patients' background with selected information on past and present illnesses, work, social conditions, family and heredity. Usually this description was kept within a few lines. Some discharge summaries, however, had longer descriptions of the background information. The two longest had respectively 9 and 14 lines devoted to this background information. The shortest descriptions merely stated that the patient was previously healthy before moving on to the next topic:

> ***Discharge summary 17:*** *"Previously healthy man who (time and date) noticed a numb feeling …".*

The background description could also be kept short in cases where the patient was suffering from multimorbidity:

> ***Discharge summary 8:*** *"63-year-old man, with known diabetes mellitus, insulin treated from (year). ACB- operated (year). Woke up (time and date) with numbness and a loss of strength in the right …".*

The main topic was typically initiated with a brief description of the patients' symptoms, followed by clinical findings:

> ***Discharge summary 9:*** *"The patient is admitted with acute difficulties in controlling the right arm, first registered at 06.45 am on the day of admission. On examination a distal loss of strength is registered and loss of tempo in the right arm, dysmetria on finger-nose test. NIHSS score 1p.*

After presenting the clinical findings, most summaries presented findings from supplemental examinations, such as x-rays, CT-scans, MRI-scans, or blood samples. The main topic was then concluded in a chapter on progress, assessment and treatment. In addition to this overarching main theme, sometimes other themes emerged. Examples of such other themes were the patient's social situation or why a certain treatment was not given.

Tool 2. The doing and not just saying tool

When we applied "The Doing and Not Just Saying Tool, " we asked not just what the authors were writing, but

also what they were trying to do. Showing that the investigation at the department was finished and complete, and that relevant treatment was initiated was central in all discharge summaries, but the authors often tried to do other things in the same texts. This could be to refer the patient to another department:

> ***Discharge summary 5:*** *"We find a closer cardiac examination indicated and the discharge summary applies as referral to …".*

Or to formalize the suspension of a driver's license:

> ***Discharge summary 2:*** *"4 weeks suspension of driver's license after TIA/ stroke without motor/ visual sequela."*

The texts often made it clear that no further appointments were made. Some were specific and clear about transfer of responsibility to the GP and some established a system for follow-up where the hospital took on a further responsibility for the patient.

Much used, however, were some forms of these short phrases:

> *"No further follow-up at our department."*
> or
> *"Follow-up by the RGP."*

Tool 3. The significance building tool

This tool is meant to help us identify how words and grammatical devices are used to build up or lessen the importance of certain things. Foregrounded information is given extra importance or relevance in language. We can also build or lessen significance or importance with the words we use. In the discharge summaries, we found that technical investigations were often foregrounded. By the use of specialist language, they were presented in a way that made them seem important:

> ***Discharge summary 5:*** *"MRI Caput. Sagittal T1, transversal T2, coronal FLAIR, transversal BOLD, and diffusion. Confluent high signal changes around the ventricles, compatible with chronic circulatory changes."*

However, we also found examples where clinical findings or assessments were made more significant than technical radiological findings. In these cases, the assessments were made by doctors.

> ***Discharge summary 41:*** *"The patient has clinically had a stroke on an atherosclerotic basis".*

Assessments from other health care personnel, e.g. physiotherapists were reported summarily and with the use of everyday language:

> ***Discharge summary 38:*** *"Has received guidance from a physiotherapist who does not see need for physical follow-up beyond self-training."*

> ***Discharge summary 29:*** *"She has been assessed by a physiotherapist in the ward, and is considered not to need specialized rehabilitation after discharge."*

In one of the discharge summaries, we found that language was used in different ways when referring to conversations with respectively a cardiologist and a dietitian:

> ***Discharge summary 21*** *"Secondary stroke prophylaxis was discussed with a cardiologist".*

Whereas, from the same discharge summary:

> *"the patient (…) got to have a chat with the dietitian..."*

Tool 4. Activities building tool

We asked what activity or practice the texts were seeking to get others to recognize. The activities described were the clinical examination at admission, the further diagnostic investigations, clinical assessment, clinical decision-making, and treatment.

Tool 5. The identities building tool

When we read the texts aided by "The Identities Building Tool", the presumed identities enacted might have been the ones of dedicated clinicians at hospitals, carrying out clinically and technically advanced hospital activities. While this often may be the case, we also found examples where the authors enacted other identities:

> ***Discharge summary 6:*** *"For the sake of order, one reminds that when acute stroke/ TIA is suspected, the patient should be referred to the neurological department for acute assessment."*

Tool 6. The relationships building tool

When we explored how relationships were built, sustained or changed in the discharge summaries, we primarily focused on relationships between doctors in primary and secondary health care and between doctors and patients. We found few indications of relationship building, most often the relationship was changed or ended. Frequently, we found variations of phrases like.

"No further appointments in the neurological department." (For instance, in **discharge summaries 2, 6, 7, 12,** and **17**).

Tool 7. The figured worlds tool

We assessed what typical assumptions that were made in the discharge summaries with a focus on identifying assumptions about further treatment in primary care.

Discharge summary 1: *"The patient has a 4-week suspension of driver's license after discharge, after which a new assessment must be performed by the GP."*

Discharge summary 9: *"Requesting the GP to perform follow-up within 4-6 weeks..."*

Discharge summary 48: *"Hb control in about two weeks."*

Tool 8. The collaboration tool

We asked in what way the texts invited to a further collaboration on the patients' care after discharge from the hospital. In some of the texts, we found advice on what tests should be performed by the GP or a request to the GP to check an abnormal finding made at the hospital.

Discharge summary 14: *"We ask the RGP to control kidney function."*

Discharge summary 24: *"One asks the RGP to follow up with regular check-ups of blood pressure and lipid status."*

We did not find direct invitations to further collaboration beyond this in any of the discharge summaries.

Tool 9. The Patient's voice tool

Most texts did not include the patient's voice. A few included the patients' views:

Discharge summary 21: *"Patient feels he does not function as normal yet, although he has an apparently good motor function, normal speech and no more reported visual problems."*

Discharge summary 44: *"The patient was offered a rehabilitation stay at* (place) *but had a strong desire to return home."*

Tool 10. The recipient tool

Sometimes a colleague in another department in secondary care was asked for an assessment or to perform some sort of further treatment or diagnostic investigation. In these cases, the rationale was thoroughly explained.

This was a contrast to cases where the authors concluded that no further follow-up in specialized care was necessary. Then the referral to the colleague in primary health care could be made short:

Discharge summary 43: *"Follow-up of blood pressure by the RGP."*

Discharge summary 52: "*Further follow-up by the RGP as well as physical therapy training."*

Interpretative discourse analysis

The topic (Tool 1) most often seemed to be what has happened there and then; diagnostic investigations and medical treatment. They could also have added other topics, such as collaboration or advice for the follow-up in primary care, but this rarely happens. Considering what the authors were trying to do (Tool 2), an obvious interpretation would be that authors were often trying to do other things than inviting to collaboration or reporting on the elements recommended by the guidelines. A possible interpretation is clearly that they were often trying to end their responsibility for the patients.

Our findings when working with "The Significance Tool" (Tool 3) can be interpreted as gradients in significance. We found traces of a hierarchy. In this hierarchy, technical findings were given high priority, but doctors' assessment could nevertheless in some cases set the technical findings aside. In some of the texts there was an obvious gradient of significance between different types of health care professionals.

The activities going on (Tool 4) are not necessarily only the activities first assumed. We found a strong focus on what happened there and then in terms of different kinds of examinations, assessments and treatment. These findings correspond with an interpretation that authors to a large extent were seeking to get others to recognize a responsible medical practice or a technically advanced hospital activity. However, the activity was often described with a brief introduction and without linking the activity to what will happen later. In this way, the activity is isolated in time and space, and may be perceived as a breach of continuity.

The identities enacted (Tool 5) were often the ones of trustworthy and dedicated clinicians, but in some cases the author may also assume the role of a normative authority.

Texts can affect or alter relationships (Tool 6). The use of specialist language, the focus on technical procedures and investigations and the omission of topics relevant to the follow-up in primary care and future collaboration, may be seen as effectively maintaining a

distant relationship between the hospital physician and colleagues in primary health care.

The GP is in the figured worlds (Tool 7) of the authors sometimes situated quite differently from his or her position in real life. The previously mentioned and much used phrase "further follow-up by the GP" implies an assumption that such follow-up would take place, even if no appointment was made and also where it was not clear that the patient had been instructed to book an appointment with his or her RGP. In some cases, a deadline was also set for when a follow-up consultation with the GP should occur. In addition to the assumption that the GP can prioritize such a consultation within the specified deadline, this also implies an assumption that the GP has a way of summoning the patient at relatively short notice.

The discharge summaries did not often invite to a collaboration (Tool 8) and we could not find anything indicating that the doctors at the hospital made themselves available for collaboration on the patient care after discharge. On the other hand, we found that the hospital doctors sometimes delegated tasks to the GPs, asked the GPs to complete some investigation or check deviating findings made at the hospital.

The patient's voice (Tool 9) was given little priority in most texts. Complaints or description of symptoms on admission were referred to, but wishes, preferences, concerns or thoughts beyond this were usually not mentioned. One discharge summary included the patient's as well as the closest relatives' worries about functioning, but this seemed to be an exception.

The recipients (Tool 10) were listed in the heading of the discharge summaries, but authors could also have other readers in mind when writing the texts. Examples of this could be the patients themselves, patients' relatives, a senior countersigning physician, a lawyer, or some authority.

When we combined the "Recipient Tool" with "The Significance Tool," it became clear that some recipients stood out as more significant than others. Colleagues in other departments in hospitals were given a higher priority than colleagues in primary care.

Discussion

Based on the discharge summaries for patients with stroke, this study has identified several obstacles to knowledge transfer and collaboration within the health care services. The absence of post discharge collaboration initiatives expressed in the discharge summaries stands out as a main finding.

The breach of continuity is another main finding. The mapping of guideline recommended content categories in the discharge summaries showed that some forms of content were more often omitted than other forms of content. The material had a clear tendency; matters close to the actual work situation of the author of the discharge summaries are mentioned, while matters more distant are omitted. This is in agreement with the findings and interpretations in the part of the discourse analysis where we applied "The Subject Tool" and found that the topic seemed to be what happened there and then. Possible reasons not to include certain topics could be that they do not seem relevant, that they are regarded to be the responsibility of primary health care, that the specialist opposes the recommendations of the guidelines, or that such topics may generate undesired extra work or responsibility here and now or after discharge.

The fact that the described activities focused on what happened there and then is not necessarily problematic in itself, one of the main functions of any discharge summary must be to communicate what has happened during the stay. The fact that there often was a lack of connection to what was going to happen after discharge, may be more problematic. In this way, the hospital activities are disconnected from the continuous care of the patient. In addition, we found that the hospital doctors were often trying to end their responsibility for the patients and that the patient's voice most often was absent.

The discharge summary is a text written in one discourse and often, if not always, read in another. Being the only document carrying medical information concerning the individual patient, as the responsibility for treatment and care passes from the hospital to the RGP, it is an essential part of the conversation between the discourses. The health authorities are clear on what themes they want to have included in this conversation. However, our study shows that this conversation is broken. The discharge summaries omit many of the elements that the health authorities have prescribed as important parts of the communication [5].

Findings in the light of current knowledge

The discharge summaries are tools for communication at a point where the responsibility for the treatment of the patients is handed over from the hospital to the GP. At this point, three stakeholder organizations and their respective discourses meet. The first is the discourse of the health authorities, influenced by current evidence base and scientific insights in the field of stroke research and by national health politics. This discourse is here represented by the normative guideline for treatment and rehabilitation after stroke [5].

The second is the specialized clinical medicine practiced in hospitals. The clinical discourse is also influenced hypotheses about life and death, of ethical choices and of therapeutic decisions [29] but still with a focus on the one illness at hand. Traces of this social practice can be found in the text of the discharge summaries [30].

The third is the discourse of general practice. In contrast to other parts of medicine, where the doctor is concerned with one particular organ or technology, doctors in general practice are to a greater extent concerned with the patient as a person [31, 32]. In other parts of medicine, the doctor-patient relationship most often is of short duration. In general practice, the continuous relationship with the patient is essential, the GP must be pragmatic and the clinical practice can only to a limited extent be based on science [33, 34].

Controversies between these discourses sometimes lead to open confrontations and protests, as in the case of WONCAs (The World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians) protest against new and stricter guidelines on treatment of hypertension [35].

Our study revealed that the figured worlds in the discharge summaries sometimes situated the GPs quite differently from their positions in real life and that tasks were delegated to the GPs. Delegation of tasks from hospital doctors to GPs has recently led to controversies in Norway. Some GPs have even expressed that they are expected to do secretarial work for the hospital doctors [36]. It has previously been pointed out that poor communication and poor understanding of each other's role are barriers of interprofessional collaboration within the health care systems [37]. The finding relates to an area where Vangen and Huxhams theory on collaborative advantage [17] is meant to apply. This general theory on collaboration describes how collaborations can reach *"Collaborative advantage – the synergy that can be created through joint working"* or *"Collaborative inertia - the tendency for collaborative activities to be frustratingly slow to produce output or uncomfortably conflict-ridden"* (p.163). Collaborative situations necessitate a focus on aspects such as collective aims, trust, cultural differences, and knowledge transfer. A lack of focus on these challenges in collaborative situations, makes a collaboration more likely to reach "collaborative inertia" than "collaborative advantages."

In 2014, Hammad et al. found frequent omissions in adherence to UK national guidance for the content of discharge information [38]. This corresponds well with the findings in our present study on discharge summaries for stroke survivors in Norway. In a previous study on the same cohort, we also found that adherence to the guidelines for follow-up of stoke survivors in general practice is weak [12] and also dependent of the degree of multimorbidity among patients who suffers from stroke [27].

We have identified omissions of guideline recommended content and obstacles to collaboration in the discharge summaries. However, we have no reason to believe that hospital specialists in general are unwilling to collaborate with GPs. On the contrary, available knowledge suggests the opposite. In a Norwegian qualitative study on the referring process [39], Thorsen et al. found that all the interviewed hospital doctors emphasized the importance of good communication and cooperation with GPs. Berendsen et al. found that hospital specialists in The Netherlands were positive to knowledge transfer to GPs as well as to collaboration with GPs [40].

It has previously been pointed out that differences in discourses provide difficulties in aspects of communication between hospital physicians and GPs [41]. Although there is no tradition for employing methods from literacy on patient records, it has been done before [42]. Discourse analytical methods have also been utilized on other material in health services research, e.g. on recorded conversations between health care workers in different settings [43] and on interviews with clinicians [44]. It has, however, been suggested that discourse analysis is an underutilized methodology within health care system research [45], and a search in PubMed performed in September 2019, using the phrase "discharge summary discourse analysis" did not return any results. We were therefore not able to compare the findings in the discourse analysis part of this study with previous findings from the same field.

Strengths and limitations

To our knowledge, this is the first study involving discourse analysis of discharge summaries for patients with stroke. We examined the discharge summaries, utilizing tools built on perspectives from different approaches and disciplines [22]. A discourse analysis is used to make claims about for example written texts, such as discharge summaries, based on interpretations. Transdisciplinary convergence is proposed to validate discourse analysis approaches to research. When interpretations based on the use of tools of analysis that go beyond one discipline converge, claims of validity can be made [46]. We claim this was the case in our present study.

One could argue that another selection of tools may have led to other conclusions. This is a consequence of the discourse analysis as a method. Nevertheless, the tools applied are acknowledged tools of discourse analysis, they are available to the reader, and as far as we could see in the process, they were the best tools available to provide information on the topics we were exploring in this study.

It may be argued that the perspective of the discharging physician is only represented in the discharge summary and not through for example interviews or focus groups. Although the aim of this study has been to assess the discharge summaries and not the authors' perspectives, research on the perspectives of both the authors and recipients of the discharge summaries could

contribute to a better understanding of the communication between the various parts of the health care system.

The material in this study consists of hospital discharge summaries for patients discharged in 2011 and 2012. It may be considered a weakness that discharge workflow and discharge summaries may have evolved since then, and that lack of knowledge transfer and collaboration initiatives may be less common in different settings, in other hospitals and in other countries. However, the findings in this study are reported in the context of the guideline recommendations for the discharge summaries at the time of study. More research on the discharge summaries may broaden the empirical basis and provide more nuance in the understanding of the communication between hospitals and primary care.

The situated position as reader, analyst and interpreter is continually changing during the process of this project. This means that the researchers probably will emphasize other things at the beginning of the project than at the end of the project. Different readers of the summaries will represent different situated positions that will lead to different interpretations of the text [47]. Despite these weaknesses, we claim that the findings are valid for the discharge summaries in this study.

Conclusions

This study has shown that the discharge summaries for stroke survivors residing in the communities did not include all the content recommended by the Norwegian national guideline for the treatment and rehabilitation in stroke. The discharge summaries have the potential to serve as tools for collaboration across boundaries within the health care services. They can also be utilized for knowledge transfer, and guideline implementation in general practice. This study, however, pointed out that the discharge summaries were not optimized for such purposes. The discharge summaries focused the fragments of the health service provided by the hospital. In this process, they also disconnected the hospital, its doctors and other groups of health care professionals from the continuous care for the patients. By doing this, they may contribute in sustaining the gap between the discourse in hospital medicine and the discourse in general practice.

Health services are not a seamless continuum, they are still fragmented. One explanation lies in the broken conversation between the different discourses in research, hospital medicine and primary health care. The guidelines express ambitions of collaboration and continuous chains of care across boundaries between secondary and primary health care services. These ambitions were not reflected in the discharge summaries for stroke survivors. We believe that further research on the perspectives of the different stakeholders in this collaboration is necessary to identify ways of bridging the gaps between the discourses involved and contribute to continuous health care services.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-020-06021-8.

Additional file 1.

Abbreviations

GP: General Practitioner; Helfo: The Norwegian Health Economics Administration; ICD 10: International Classification of Diseases and Related Health Problems, 10th revision; ICPC-2: International classification of primary care, 2nd revision.; RGP: Regular general practitioner; WHO: World Health Organization; Wonca: World Organization of Family Doctors

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Authors' contributions

RAaP, HP and IH took part in the planning of the study. RAaP registered data from the discharge summaries and wrote the first draft of the manuscript. HP, IH and HT read the paper and made improvements of the content and wording. RAaP, HP, IH and HT have read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

The study was approved by the regional committee for medical and health research ethics (REK) (Reference REK midt 2013/1501). Møre og Romsdal Hospital Trust provided access to the medical records after approval by REK. All participants gave their written informed consent.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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