Medication communication with older adults experiencing chronic illness and polypharmacy

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Licentiate Thesis

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Contents

Abstract

Background: Populations in many high-income countries are ageing, with an ever-increasing proportion of the population aged 65 years or older. Despite increasingly better health in older people, susceptibility to chronic illness increase with age. As life expectancy increases, the length of time people can live with chronic illness increases correspondingly, mainly due to improved medication treatments.

Decreased number of hospital beds per capita and length of stay in hospital has gained primary care an increasing role in the healthcare system, with higher demands on patients and their knowledge and abilities to manage medications and self-management.

Aim: The overarching aim of this thesis was to explore how medication regimens are communicated in primary care consultations and in written discharge letters.

Methods: In Study I, passive participant observations of primary care consultations were audio-recorded, transcribed and analysed using content analysis.

Study II had a convergent mixed methods design. An assessment matrix, constructed based on previous research, was used to assess and quantify discharge letter content. The quantified discharge letter content, questionnaires and register data were used to calculate correlations between discharge letter content and readmission rate as well as self-rated quality of care transition. Finally, associations between discharge letter content and time to readmission were calculated both univariable and multivariable. In addition to discharge letter content, several other potential independent variables were included in the multivariable analysis.

Results: Both studies show that physicians were prone to give information about medications and blood-samples or other examinations performed in advance to the consultation (Study I) or during the hospital admission (Study II). The physicians were, however, less prone to inform patients about self-management and lifestyle changes, symptoms to be aware of, and what to do in case they would appear.

Communication was occasionally hindered by misunderstandings, e.g., when vague expressions or words with ambiguous meaning was used. Ambiguities e.g., arose due to dialectal disparity. Although physicians mainly communicated in plain language with patients, medication names

imposed a significant problem for patients and in communication about medications.

Discharge letter content was not associated to readmissions, the only significant predictor variables for time to readmission were previous admission the past 180 days and birth outside the Nordic countries. Discharge letters with more content were, on the other hand, correlated to worse self-estimated quality of care transition from hospital to home (Study II).

Conclusions: Physicians informed patients about tests and examinations performed in the past time, and comprehensive information was provided about medications, both during consultations and in discharge letters. However, information about symptoms to be aware of and measures to take in case they would appear was scarce in consultations and discharge letters. In conversations where lifestyle changes were raised, the topic was quickly dropped without recommendations or offering support if the patient showed unconcern. Lifestyle changes in relation to chronic illness and medications were rarely discussed. Improved lifestyle as a means of reducing the need for medications was not discussed or informed about in discharge letters. Discharge letter content did not have any impact on readmissions.

Sammanfattning

Bakgrund: Många höginkomstländer har en åldrande befolkning, där andelen av befolkningen som är över 65 år ständigt ökar. Trots att hälsan hos äldre har blivit bättre, ökar risken för kroniska sjukdomar med åldern. I takt med den ökande medellivslängden har också den tid människor kan leva med kronisk sjukdom ökat, något som till stor del beror på förbättrade läkemedelsbehandlingar.

Antalet vårdplatser per capita och den genomsnittliga vårdtiden på sjukhus har minskat de senaste decennierna, medan primärvården har fått en allt större roll i hälso- och sjukvården. Detta ställer allt högre krav på patienter och deras kunskaper och förmåga att hantera mediciner och egenvård.

Syfte: Det övergripande syftet med denna uppsats var att undersöka kommunikation om läkemedelsbehandlingar vid årliga besök i primärvården och i skriftliga utskrivningsmeddelanden.

Specifika syften med studierna var att:

Studie I: Utforska kommunikation om läkemedelshantering under årliga läkarbesök i primärvården för patienter med kronisk sjukdom och polyfarmaci.

Studie II: Avgöra vilken effekt innehållet i utskrivningsmeddelanden har för oplanerad återinläggning på sjukhus inom 30 eller 90 dagar, samt att identifiera korrelation mellan innehållet i utskrivningsmeddelanden och självskattad kvalitet på vårdövergången.

Metoder: I Studie I genomfördes passiva deltagarobservationer av årliga läkarbesök med kroniskt sjuka äldre som behandlas med polyfarmaci. Ljudinspelningar gjordes vid besöken, och dessa transkriberades och analyserades genom innehållsanalys.

Studie II hade en design med mixade metoder. Patientkaraktäristika, skattningsskalor, registerdata och utskrivningsmeddelanden för patienter med hjärtsvikt eller kronisk obstruktiv lungsjukdom som skrevs ut från inneliggande sjukhusvård ingick i analyserna. För att kunna bedöma och kvantifiera innehållet i utskrivningsmeddelanden konstruerades en bedömningsmatris med utgångspunkt i tidigare forskning. Det kvantifierade innehållet i utskrivningsmeddelanden, frågeformulär och registerdata användes för att beräkna korrelation mellan innehåll i utskrivningsmeddelanden och återinläggningar samt självskattad kvalitet på vårdövergången från sjukhus till eget boende. Slutligen undersöktes om

innehållet i utskrivningsmeddelanden påverkade tid till återinläggning, med en icke-parametrisk metod (Kaplan-Meier) och en semi-parametrisk (Cox proportional hazards model). I den semiparametriska modellen ingick förutom det kvantifierade innehållet i utskrivningsmeddelanden även flera andra potentiella förklarande variabler från patientkaraktäristika, frågeformulär och registerdata.

Resultat: Båda studierna visar att läkarna var benägna att ge information om läkemedel, blodprover och andra undersökningar som gjorts inför läkarbesöket (Studie I) eller under sjukhusinläggningen (Studie II). Läkarna var dock mindre benägna att informera patienter om egenvård och livsstilsförändringar, och symtom som patienterna ska vara uppmärksamma på och vilka åtgärder som patienterna i så fall skulle vidta (Studie I; Studie II).

Kommunikationen under läkarbesöken hindrades ibland av missförstånd, vaga uttryck eller när ord med tvetydig betydelse användes. Tvetydigheter kunde till exempel uppstå på grund av dialektala skillnader. Trots att läkarna kommunicerade i klartext med patienterna medförde läkemedelsnamn ett betydande problem för patienterna och i kommunikationen om läkemedel (Studie I).

Utskrivningsmeddelandets innehåll påverkade inte risken för återinläggning inom 30 eller 90 dygn, och påverkade inte heller tiden till återinläggning, de enda signifikanta förklarande variablerna för tid till återinläggning var tidigare sjukhusinläggning de senaste 180 dagarna och att vara född utanför Norden. Mer innehåll i utskrivningsmeddelanden var däremot korrelerat till sämre självskattad kvalitet på vårdövergången från sjukhus till eget boende (Studie II).

Slutsatser: Läkarna informerade sina patienter om blodprover och undersökningar som gjorts inför läkarbesöket, och gav omfattande information om de läkemedel som patienten använde, både vid årliga läkarbesök i primärvården (Studie I) och i utskrivningsmeddelanden (Studie II). Information om symtom som patienterna skulle vara uppmärksamma på, och vilka åtgärder som patienterna i så fall skulle vidta var dock knapphändiga, både vid de årliga besöken och i utskrivningsmeddelanden. I samtal där livsstilsförändringar togs upp lämnades ämnet oftast snabbt om patienten visade ointresse, utan att rekommendationer eller erbjudande om stöd från vårdcentralen gavs. Livsstilsförändringar i relation till kronisk sjukdom och läkemedel diskuterades sällan. Förbättrad livsstil som ett sätt att minska behovet av

mediciner diskuterades eller informerades inte om i utskrivningsmeddelanden. Utskrivningsmeddelandets innehåll påverkade inte heller risken för, eller tiden till, återinläggning.

List of scientific papers

I: Communication about medication management during patient-physician consultations in primary care: a participant observation study. Igor Adelsjö, Lina Nilsson, Amanda Hellström, Mirjam Ekstedt, Elin Christina Lehnbom. BMJ Open. 2022 Nov 3;12(11):e062148. doi: 10.1136/bmjopen-2022-062148.

II: The impact of discharge letter content on self-rated quality of care transitions, patient activation, and unplanned hospital readmissions within 30 and 90 days in patients with chronic illness. Igor Adelsjö, Elin Christina Lehnbom, Amanda Hellström, Lina Nilsson, Maria Flink, Mirjam Ekstedt (submitted).

List of abbreviations

CHF – Congestive heart failure
COPD – Chronic obstructive pulmonary disease
OECD – Organization for Economic Cooperation and Development
GP – General practitioner
MI – Multiple imputations
CTM – Care Transition Measure
PAM – Patient Activation Measure
RCT – Randomised controlled trial
PIM – Potentially inappropriate medications
ATC – Anatomic Therapeutic Chemical classification system
ICD-10 – International Classification of Diseases, 10th revision
ADL – Activities of daily living

Background

Introduction

The population in many countries, especially in the OECD-countries [Organization for Economic Cooperation and Development], are ageing due to rising life expectancy and declining fertility rates (Rouzet et al., 2019, p. 8). The proportion of people aged 65 years or older in relation to the entire population has almost doubled in the last 60 years and will continue to increase in the coming 30 years according to a recent prognosis (OECD, 2021, pp. 250-251). Chronic illness increases with age and people, particularly in high-income countries who have access to high quality healthcare, live longer with chronic illness.

The Swedish healthcare system, designed to manage critical injuries and acute communicable illnesses, is not fit to manage the healthcare needs of the growing number of individuals with chronic illness (Bodenheimer et al., 2002). People with chronic illness are best managed in primary care, by a team of healthcare providers who know the patient. Despite a national priority (Statens offentliga utredningar, 2016) to strengthen primary care to improve patient outcomes and reduce the need for inpatient care, it is still riddle with understaffing resulting in a high workload for remaining staff, poor availability and lack of continuity. People are thus required to learn to live with their chronic illness and become 'experts' in self-management i.e., follow lifestyle advice, adhere to often complex medication regimens, know what symptoms to monitor for and what to do in case of deterioration.

This thesis examines how medication information is communicated to older adults living with chronic illness and polypharmacy, to examine the extent of support they receive in becoming experts of self-management and identify how the medication management of chronic illness can be improved.

Chronic illness

The definitions of chronic illness differ considerably between countries and organisations. Internationally, the term non-communicable disease is often more common than chronic illness. Non-communicable diseases are described as illnesses with long duration and are the result of a combination of genetic, physiological, environmental and behavioural factors. They

share four major risk factors: tobacco use, physical inactivity, the harmful use of alcohol and unhealthy diets (WHO, 2002).

In this thesis, chronic illness is defined as an 'illness that in most cases can be expected to last for at least five years, or until the patient dies from another cause. No distinction is made between communicable and non-communicable diseases' (Swedish Agency for Health and Care Services Analysis, 2014, p. 40).

Chronic illnesses that are common in the Swedish population include cardiovascular disease, diabetes mellitus type 2, chronic respiratory diseases and cancer (Swedish Agency for Health and Care Services Analysis, 2014).

Medication management

Medications are among the most common treatments for several illnesses. Many persons with chronic illness have more than one disease, hence, are treated with multiple medications. A treatment with five or more regular medications is often referred to as 'polypharmacy', although this definition is arbitrary (Masnoon et al., 2017). Five or more medications daily will be used as definition of polypharmacy in this thesis. The prevalence of polypharmacy in Sweden was recently assessed to be 19 % (Zhang et al., 2020). In people 75 years or older, 45% experienced polypharmacy (Wastesson et al., 2018).

In this thesis, the concept *adherence* will be used to describe whether a patient follows *the agreed* medication regimen or not. Polypharmacy can make it especially challenging for people to understand all the medication information provided and remember what medications they are taking, when to take them and why, resulting in both intentional and unintentional non-adherence (Pérez-Jover et al., 2018).

With increasing age comes not only increased morbidity but also altered pharmacokinetics and pharmacodynamics (Mangoni & Jackson, 2004). Many medications may therefore be inappropriate for older adults (Holt et al., 2010). Using potentially inappropriate medications (PIM), may be associated with poor health outcomes and result in greater risk of adverse drug events or greater harm than the expected benefits with the treatment for older adults (American Geriatrics Society, 2015). There is no global definition of PIM:s, there are however a number of lists, including a list of inappropriate medications published by the Swedish National Board of Health and Welfare (Socialstyrelsen, 2017a).

In Sweden, patients 75 years of age or older who are experiencing polypharmacy should be offered a medication reconciliation when visiting a primary care physician, at admission to hospital, when starting with home healthcare or when moving into care facilities (Socialstyrelsen, 2017b). The purpose of a medication reconciliation is to obtain a complete and accurate list of a patients' current medications and to detect and resolve any discrepancies. In a Swedish study comparing medication lists from pharmacies with the medication used by patients, discrepancies were found in two thirds of the cases (Hammar et al., 2022). To address the issue of multiple different medication lists, a national medication list is being implemented. Such a list has the potential to offer a complete medication list available for all healthcare professionals involved in the patient's medication and healthcare (Hammar et al., 2022). Even with such a list available, it still requires that all prescriptions and changes in the medication are documented in the patient's medication list, otherwise inaccuracies will continue to occur.

The healthcare system in Sweden

Like many other high-income countries, healthcare costs are predominately publicly financed in Sweden (Anell et al., 2012; Blümel et al., 2020; Boyle, 2011; Marchildon et al., 2020; Ringard et al., 2013). Nearly 80% are tax-funded and users contribute almost 20% of the cost (Anell et al., 2012). The responsibility for providing healthcare is divided between the regions and the municipalities. The regions are responsible for the largest part of healthcare delivery which includes health promotion, prevention, diagnosing and treating diseases and injuries, as well as provide inpatient hospital care. Responsibility for primary care provision is divided between regions and municipalities. The Swedish parliament provides the framework for healthcare in the form of legislation and decides on financial grants via the state budget.

Since the 1990s, there has been a focus on shifting inpatient hospital care to primary care, hospital outpatient care or day care (e.g., day surgery) (Anell et al., 2012, pp. 88, 90). Providing inpatient care is costly for regions, hence there has been a move to shorten the length of stay in hospitals; from 5.0 days in 1998 to 3.9 days in 2019 (Socialstyrelsen, 2020). Decision to discharge a patient from hospital is often made on the same day as the discharge, even for multimorbid patients experiencing polypharmacy (Flink

& Ekstedt, 2017). This can reduce the possibility for staff to prepare the discharge and follow-up care properly.

Hospital readmissions

A considerable proportion of patients with chronic illnesses are readmitted shortly after hospital discharge. Readmission can be measured as a rate at a certain time e.g., 30 days or 90 days, or time to readmission at a certain time point, e.g., 90 days or 180 days (Khan et al., 2021; Saxena et al., 2022; Wideqvist et al., 2021). A distinction is often made between all-cause readmissions (i.e., readmission diagnosis does not have to be related the diagnosis at index admission) and disease-specific readmissions (e.g., in patients admitted for congestive heart failure [CHF] at the index admission, only readmissions related to CHF are included when readmission rate is calculated).

Many physicians consider readmissions to be related to patient factors such as poor understanding and lack of ability to self-manage their illnesses (Herzig et al., 2016). This is supported by patients who report not feeling ready for discharge, often because patients felt that their symptoms had been adequately resolved (Howard-Anderson et al., 2016). A mismatch between the patient's needs of healthcare and the available healthcare services, as well as poor communication between healthcare professionals and healthcare facilities were identified by patients as additional contributing factors to their readmission (LeClair et al., 2019).

Transitional care

A widely used definition of transitional care is 'a set of actions designed to ensure the coordination and continuity of healthcare as patients transfer between different locations or different levels of care within the same location' (Coleman & Boult, 2003).

Transitional care is a comprehensive approach to ensure continuity of care for vulnerable individuals who are affected by changes in where care is provided, and by whom. The methods and elements of transitional care have evolved and expanded over time. Bradway et al. (2012) and Naylor and Keating (2008) defined it as a successful model that encompasses a wide range of services, with an emphasis on providing safe and appropriate care during transitions between care settings. Discharge from hospital has been associated with adverse drug events (Forster et al., 2004), unintended

medication discontinuation (Redmond et al., 2019) and uncertainty about the medication regimen (Meyer-Massetti et al., 2018). Care transitions are critical processes and approximately 20% of discharged patients are readmitted within 30 days of discharge (Jencks et al., 2009). Older adults (65 years or older) are particularly vulnerable to adverse events following hospital discharge because of the high prevalence of comorbidity, polypharmacy and frailty in this population. Many patients experience a loss of function in activities of daily living (ADLs) during an hospital admission (Buurman et al., 2011) and require care or assistance at home. To reduce the risk of adverse events following discharge, the discharge process of older adults should be well-structured and planned from the admission (Zurlo & Zuliani, 2018).

To improve the transition of care numerous interventions have been evaluated. Interventions have been provided in hospitals (e.g., geriatric assessment, discharge planning, or medication review) or at home after discharge (e.g., follow-up by telephone, rehabilitation, or home safety assessment). Different healthcare professionals have provided the interventions, such as, nurses, geriatricians, or occupational therapists. One commonly used intervention is the Care Transition Intervention which consists of four pillars: assistance with medication self-management, patient centred record owned and maintained by the patient, timely follow-up with primary or specialty care and use of red flags indicative of a worsening condition and instructions on how to respond to them (Coleman et al., 2006).

Eight reviews of transitional care interventions for people with chronic illness were reviewed by Joo and Liu (2021). The goal of all the transitional care interventions included in this review was to decrease disjointed care and hospital readmissions and improve health outcomes for patients with chronic illnesses. After analysing and combining the data, four key outcomes were identified: hospital readmissions, quality of life, mortality, and cost savings. While there was evidence that transitional care can lead to cost savings, the results for the other outcomes were inconsistent.

Transitional care interventions for frail older adults, either starting at the hospital admission, starting at home or starting in hospital and continuing at home after discharge, were studied in another recent review (Lee et al., 2022). In seven of the thirteen studies that examined readmission rates, no effect on readmissions were reported at any of the studied time points (8 days, 1, 2, 3, 6, 12 or 24 months after discharge). Despite occasional studies reporting lower readmission rate for intervention group at some of

the time points, the only time point where the pooled result was significant in the review was at six months (Lee et al., 2022). No reduction was observed regarding mortality rate (Lee et al., 2022).

A systematic review (Coffey et al., 2017) to synthesise and present findings regarding the transitional care interventions to community nursing in supporting the coordination and integration of health care for older adults with increasing levels of dependency found that most interventions were nurse-led, consisted of home visits, rehabilitation, advanced care management, telephone support, clinic-based heart failure care, patient education, support and coordination.

Another important aspect to consider in care transitions is the communication between healthcare providers and with patients. Discharge communication is often relayed in written form either as a discharge summary to the next healthcare provider or a discharge letter provided to the patient. Communication between healthcare professionals; preparation of patient; medication reconciliation; follow-up plan; and patient education about self-management has been identified as essential parts of transitional care (Coleman & Boult, 2003). Protocols including, among other things, visiting the patient in the hospital and recurring home visits during the first three months after discharge, education for patients and their family members, coordinating with home care and primary care physician and care planning (Centeno & Kahveci, 2014).

Coleman and Boult (2003) emphasised the importance of coordination and continuity of care in transitional care. There is some overlap in the terms and concepts used in transitional care, such as 'continuity of care', 'discharge planning' and 'care coordination', which are often used interchangeably. However, to effectively implement transitional care across different populations and cultures, a common set of attributes in terms of their causes, effects and outcomes should be described (Coleman & Boult, 2003). Transition of care from hospital to home is a period of increased vulnerability, especially for patients with multimorbidity (Coleman, 2003). Altogether, this indicates that the problems are complex and that there are difficulties to design interventions that provide successful results in patients with chronic and multiple illnesses.

Self-management of chronic illness

Self-management is defined by Audulv et al. (2012) as 'the strategies individuals undertake to promote health (e.g., healthy living, exercising), manage an illness (e.g., manage symptoms, medication and lifestyle changes) and manage life with an illness (e.g., adapt leisure activities or deal with losses caused by illness)'.

For patients living with chronic illness, it can be very demanding to manage symptoms, disabilities and complex medication regimens on their own (Barnett et al., 2012; Bodenheimer et al., 2002; Jaarsma et al., 2021). Multiple studies have shown that patients receive little attention regarding their priorities, skills and understanding of self-management needs (Daker-White et al., 2015; Hesselink et al., 2012; Vashi & Rhodes, 2011).

At discharge from inpatient hospital care in Sweden, most patients are provided with a discharge letter, containing plain language information, for example, about their disease, the care during their hospital stay and instructions for how to handle their medication and self-management at home after discharge (Flink & Ekstedt, 2017). Understanding and execution of discharge instructions is important for patients' self-management and can reduce the need for unplanned readmission within 30 days of discharge (Regalbuto et al., 2014). After discharge, a considerable deficit of understanding has been found in studies, for example, 40% of patients in a study of Horwitz et al. (2013) had deficit understanding regarding reason for admission.

Successful self-management of chronic illnesses requires high poly-literacy (e.g., health, medications and healthcare system), the ability to take medications as prescribed, store them safely and know what symptoms to be aware of, and when and where to seek appropriate medical advice (Lang et al., 2015). Poor understanding of medication information may lead to poor adherence, suboptimal patient outcomes and readmission (Boyde et al., 2018; Glick et al., 2019; Schönfeld et al., 2021).

Self-management in most cases includes medication management. In the two studies included in this thesis, medication management and self-management are studied separately and thus will medication management not be included in the concept 'self-management'.

Failure to recognise symptoms as deterioration in the illness is common and may also result in avoidable hospitalisation as demonstrated by Reeder et al. (2015). More than nine out of ten patients with congestive heart failure

admitted to inpatient hospital care in a study did not realise that their symptoms were indications of deterioration. Recognising symptoms of deteriorating chronic illness enabled patients to use the self-management skills they had to reduce symptoms (Riegel et al., 2022).

Theoretical framework

Communication has a multifaceted role that is not only about gathering or providing information, but also fostering relations, enabling decision-making and disease and treatment-related behaviour and responding to emotions (de Haes & Bensing, 2009; Xue & Heffernan, 2021). The patient's narrative and the patient-healthcare professional's communication have a particularly significant role in nursing theories (Fredriksson, 2003) and in avoiding non-participation (Eldh et al., 2008). Non-participation was a result of lack of appropriate information and not being listened to or lacking recognition as a person with individual needs and concerns (Eldh et al., 2008). Communication thus has a key role in healthcare, especially by enabling patients to take an active part in their self-management.

The origin of the word communication is, at least partly the Latin words *communicare* meaning 'to share' and *communis* meaning 'common' (Oxford English Dictionary). Communication can be regarded as merely a process of information exchange, described in the sender-receiver model by Berlo (1960). In a conversation, the communication does not consist of the *meaning,* only the sender's interpretation of the meaning, called a message. When the message reaches the receiver, the message is interpreted into a meaning, however, not necessarily the same meaning as the sender once intended. According to Berlo (1960), it is emphasised that the sender and the receiver should be on the same level for communication to be effective. In healthcare, Berlo's model implies that the asymmetrical level of knowledge, communication skills and attitudes in a patient-physician consultation may impair communication with a significant risk of misinterpretations.

Communication can, however, also be regarded more as an interpersonal process of developing shared understanding (Manojlovich et al., 2015). From that point of view, communication always entails several other aspects such as being relational, multi-layered, contextual and more than just language (Jacobi, 2011). Communication as a process of developing a shared understanding corresponds better to the Latin origin than that of information exchange.

Self-management of chronic illness requires poly-literacy about illness and medications as well as an understanding of how to navigate the healthcare system. Information from healthcare professionals and through patient education play a vital role in preparing patients for self-management.

When patients have deficient understanding of their illness and medication regimens this might impair their health status (Boyde et al., 2018; Glick et al., 2019; Schönfeld et al., 2021). This highlights the need for effective relationships between proactive informed healthcare professionals and informed and activated patients and their families. A critical element of self-management is to activate patients by teaching them the skills, providing the knowledge, address beliefs and support motivation to participate as an integral member of the care team (Hibbard & Greene, 2013; Wagner et al., 2001).

For patients to gain sufficient knowledge and skills for self-management, and to handle medication regimens, communication between patients and healthcare professionals plays a crucial role (Hibbard & Greene, 2013). Improved communication skills have been identified to enable several favourable outcomes, that can improve patient self-management (Levinson et al., 2010).

Healthcare professionals discussing a patient, use a highly specialised, medical, professional language, but when speaking to patients, communication need to be adapted to the patient and the context (e.g., communication in plain language) (Jones & Watson, 2009). Manojlovich et al. (2015) suggest that a multi-dimensional view of communication is needed, that acknowledges the social and relational nature of communication, developing a shared understanding which enables co-creation of knowledge.

In respect to this thesis, two different kinds of communication appear: synchronous and asynchronous communication (Pirnejad et al., 2008). Synchronous communication is when all parts of communication are present, for example, in a patient-physician consultation in primary care. Synchronous communication can take place face-to-face or remotely such as in telephone calls or video meetings. Synchronous communication is interruptive, i.e., the parties in the communication have, for example, the opportunity to interrupt and ask for clarification about things they do not understand (Pirnejad et al., 2008). Asynchronous communication is when one part is communicating, without all parts being present at the same time (in the same place or, for example, over the telephone). Written communication, such in an e-mail or in a letter are examples of asynchronous communication.

Rationale

As we age, the cumulative effect of our lifestyle choices regarding tobacco use, alcohol intake, nutrition and physical activity along with our genetic predisposition makes us more susceptible for chronic illnesses. With the advancement in medical care and the discovery of novel drug therapies, it is now possible to live a long life despite having multiple chronic illnesses. Patients with chronic illness are required to self-manage their illnesses to prevent deterioration, avoidable hospital admissions and remain independently at home for as long as possible. It is thus especially important that patients understand their illness, medication regimens and adheres the treatment plan to avoid side effects or deterioration of their illness. This can be particularly challenging for individuals with polypharmacy. To facilitate self-management and support adherence, healthcare providers should embrace all opportunities to engage with patients and clearly communicate the information patients need.

Aims

The overarching aim of this thesis was to explore how medication regimens are communicated in primary care consultations and in written discharge letters.

Specific aims of the studies were to:

Study I: Explore communication about medication management during annual consultations in primary care.

Study II: Determine the impact of discharge letter content on unplanned 30-day and 90-day hospital readmissions, and to identify correlations between discharge letter content and patients' self-rated quality of care transitions in patients with chronic illness.

Methods

Design

An explorative observational design was used in Study I, to investigate verbal communication during annual consultations in primary care. Passive participant observations were used to gather information about the communication. Passive observations mean that the observer does not interact at all with the people being studied during the observation (Spradley, 1980).

To determine the impact of discharge letter content on unplanned hospital readmissions, to identify correlations between the discharge letter content and quality of care transitions, mixed methods were used. Mixed methods studies could be defined as 'research in which the investigator collects and analyses data, integrates the findings and draws inferences using both qualitative and quantitative approaches or methods in a single study' (Tashakkori & Creswell, 2007). In Study II, qualitative data was transformed into quantitative data using an assessment matrix and used together with additional quantitative data to make statistical inferences. The study has a convergent, mixed methods design and the analysis was performed in three phases (Creswell & Creswell, 2018, pp. 217-221).

An overview of the included studies is presented in Table 1.

Study I

Setting and participants

The study was conducted at two primary care centres, purposefully chosen to reflect areas with different socio-cultural environments. Both primary care centres were publicly operated.

Patients aged 60 years or older, with chronic illness and experiencing polypharmacy (i.e., five or more regular medications), with a scheduled visit for an annual consultation were invited together with their general practitioner (GP) to be observed during the consultation. Eligible consultations were selected by the respective primary care centres manager, based on the inclusion criteria. In total, 18 consultations were observed. A relative (i.e., a spouse or an adult child) participated in four of the consultations.

Table 1: Overview of included studies

	Study I	Study II
Study design	Descriptive explorative observational approach	Mixed methods design, with qualitative and quantitative approach
Setting and participants	Patients (n = 18) 60 years or older with chronic illness and polypharmacy, scheduled for an annual consultation in primary care	Patients (n = 154) 18 years or older with CHF[a] and/or COPD[b], living in their private homes
Data collection	Participant observation of patient-physician consultations	Data from an RCT[c]: Patient characteristics Questionnaires: -CTM-3[d] -PAM[e] Register data: - hospital admissions - prescribed medications - diagnoses Discharge letters
Data analysis	Inductive content analysis	Qualitative content analysis and descriptive, correlational (Pearson's correlation coefficient) and time-to-event analyses (Kaplan-Meier and Cox proportional hazards model)

[a]Congestive heart failure [b]Chronic obstructive pulmonary disease [c]Randomised controlled trial [d]Care transition measure, 3-items [e]Patient activation measure

Data collection

Data was collected by passive participant observations of annual, scheduled patient-physician consultations that were audio-recorded. The observations were performed by either a male intensive care nurse specialist and doctoral student or a female sociologist with a PhD in applied health informatics experienced in participatory observations). During the consultations, the observer took field notes based on an observation guide. Passive participant observations imply that the observer would not interact with patients or physicians in any way during the consultation (Spradley, 1980).

Data analysis

Depending on the aim of a study, content analysis as method is open to different theoretical approaches, and can be anywhere on the continuum between descriptive and interpretative (Lindgren et al., 2020). The level of abstraction can be low or high as well as anywhere in between. The analysis was performed inductively, using qualitative content analysis (Graneheim et al., 2017; Graneheim & Lundman, 2004), with a low abstraction level and

a low degree of interpretation (Lindgren et al., 2020). In the current study, the manifest content, meaning visible, obvious components of data (Graneheim & Lundman, 2004) and more concrete descriptions and interpretations was analysed (Graneheim et al., 2017). Patient–physician (GP) consultations were the unit of observation (Graneheim & Lundman, 2004).

The transcribed data was sorted into meaning units, which were later condensed with a low degree of interpretation and labelled with codes (Graneheim et al., 2017; Graneheim & Lundman, 2004). The transcripts from the first six observations were coded by all the researchers to create a coding scheme, taking advantage of the authors respective perspectives (nursing: ME, AH and IA; sociology: LN; and pharmacy: ECL). The two observers coded the remaining transcripts. When all the transcripts had been coded, one author (IA) grouped the initial codes manually into eleven tentative subcategories based on similarities and differences in the data. All authors, with their respective perspectives were involved in the analysis, during the creation of categories and the inclusion of codes and quotations from the original text (Graneheim et al., 2017). These discussions continued until consensus was reached, and the eleven subcategories were abstracted into four main categories, still close to the data.

Study II

Setting and participants

Data was collected at four medical care wards in two hospitals in Stockholm, Sweden, that were included in a randomised controlled trial (RCT), that investigated the effect of a care transition intervention (sPATH – Supporting Patient Activation in Transition to Home) (Kaltenbrunner et al, submitted). The sPATH intervention was developed to support patient activation after hospital discharge and to reduce readmission rates. Patients randomised to the intervention group received support in one face-to-face encounter and four telephone calls from a medical social worker or a nurse, trained in motivational interviewing, to increase their motivation to be active in their self-management post discharge. Patients in the control group received care as usual. For details see study protocol (Flink et al., 2017).

Patients with congestive heart failure (CHF) and/or chronic obstructive pulmonary disease (COPD) at one of four medical wards were invited to participate. Most patients were multimorbid (and thus had additional

diagnoses) and experienced polypharmacy. Inclusion criteria were age at least 18 years and living in their private homes. Patients with cognitive impairment, need of interpreter or with a statement of 'do-not-resuscitate' in the record were excluded. Of the 207 patients included in the RCT, discharge letters were missing for 53 of the patients. Consequently, they were excluded from the present study, resulting in 154 patients being included in the analyses.

Data collection

Study II used discharge letters, patient characteristics, questionnaires and register data previously collected for a RCT.

Patient characteristics
Baseline data on patient characteristics were used, including age, sex, educational level, living arrangements, income level and country of birth. Clinical data regarding unplanned hospital admissions, prescribed medications and multimorbidity were also collected.

Questionnaires
To measure patients' self-rated knowledge, skills and confidence in self-management, the Swedish translation of the 13-item Patient Activation Measure (PAM) was used (Hellström et al., 2019; Hibbard et al., 2005). The raw scores of PAM can be converted into four activation levels on a scale ranging between 0-100, where higher scores indicate greater patient activation. Level 1 ($\leq$ 47.0) indicates not believing activation important, level 2 (47.1–55.1) a lack of knowledge and confidence to take action, level 3 (55.2–67.0) indicates beginning to take action and level 4 ($\geq$ 67.1) implies taking action (Hibbard et al., 2005).

To measure patients self-rated quality of care transitions, the Swedish translation of the 3-item version (CTM-3), i.e., items 2, 9 and 13 of the original 15-item Care Transition Measure (CTM), was used (Coleman et al., 2002; Flink et al., 2018). The three items are: 'The hospital staff took my preferences into account in deciding what my healthcare needs would be when I left the hospital', 'When I left the hospital, I had a good understanding of the things I was responsible for in managing my health' and 'When I left the hospital, I clearly understood the purpose for taking each of my medications'. Higher scores on CTM-3 have been shown to be associated with a lower risk of hospital readmission within 30 days

(Goldstein et al., 2016). Patients were given the CTM-3 questionnaire at discharge from hospital and were asked to fill it out at home and return by mail within one week.

For both the CTM-3 and PAM questionnaires, patients rate each item from 1 = 'strongly disagree' to 4 = 'strongly agree', or 'not applicable', and answers are converted into a scale of 0–100.

Register data

Data regarding healthcare consumption 180 days before and 90 days after study inclusion was used and included unplanned hospital admissions as well as prescribed medications dispensed from pharmacies (identified using codes in the Anatomic Therapeutic Chemical (ATC) classification system). Diagnoses at discharge from index admission (identified using codes in the International Classification of Diseases, 10th revision) were used to calculate Charlson Comorbidity Index. All register data was collected from the Stockholm region's Register for Healthcare Encounters.

Data analysis

The analysis was performed in three phases, an initial literature review to create an assessment matrix, a deductive content analysis of discharge letters using the matrix and statistical analyses of discharge letter content and other data.

Firstly, a literature review was performed to identify evidence for content in discharge letters that has been identified in previous research as important for successful discharge and care transition. Studies were searched in the databases PubMed, Cinahl and Cochrane using the phrases 'Discharge communication', 'Discharge information', 'Discharge instructions', 'Discharge letter' and 'Discharge summary'. The literature search yielded 30 studies (Appendix 1). Key elements that were identified in two or more studies, in total 36 key elements, were categorised and sorted into a coding scheme consisting of 11 key elements. The minimum required content in the discharge letter for each key element was defined in the coding scheme.

A deductive content analysis of the discharge letters was conducted using the coding scheme as a template for assessment of the content of key elements, as a lens for analysing the texts (Appendix 2). Deductive content analysis is useful when prior research would benefit from further description and in cases of retesting existing data in a new context (Elo & Kyngäs, 2008). The coded key elements were transformed into a quantitative variable

labelled 'discharge letter score' which was combined with the dataset from the RCT (Creswell & Creswell, 2018, p. 220).

Lastly, the combined data was analysed with statistical methods and jointly visualised in the results. Patient characteristics and the discharge letter content were described and summarised by frequencies and percentages or means and standard deviations.

Bivariate correlations between discharge letters (key elements and discharge letter score), and CTM-3, 30-day and 90-day readmission rates, respectively, were examined using Pearson's correlation coefficient, with 2-tailed significance (Sedgwick, 2012).

In contrast to bivariate correlations, in which only the proportion readmitted at a certain point in time, e.g., 30 days or 90 days, is of interest, time-to-event analyses also take in account *when* during the 30-day or 90-day period patients are readmitted and the possibility that not all patients have experienced the event of interest (e.g., a readmission) at the end of the study period (Bewick et al., 2004; Sedgwick, 2013).

In the univariable Kaplan-Meier analysis, patients were first divided into three groups according to the discharge letter score: below the median score (< 8, n = 36), median score (8, n = 63) and above median score (> 8, n = 55) and a Kaplan-Meier analysis was performed. Significant difference between three groups was tested using log-rank test (Schober & Vetter, 2021).

To identify the association between discharge letter score and time to readmission, adjusted for other possible independent predictors of time to readmission at 90 days, a stepwise multivariable Cox proportional hazards analysis was applied. The model included the following variables: intervention/control group, age at inclusion, sex, education level, married/living with partner or living alone, income level, country of birth, CTM-3 score, PAM score, Charlson Comorbidity Index, number of medications (by ATC codes), length of stay during index admission and any unplanned admission within 180 days before index admission. Stepwise elimination was used in the Cox proportional hazards model, and the results are presented as hazard ratios. The adjusted hazard ratio in the multivariable model compares the readmission rate at any time during follow-up within each explanatory variable when all other explanatory variables are constant (Sedgwick, 2011, 2013).

To take advantage of all available data in the Cox proportional hazards model regardless of missing items, multiple imputation was used (Newman, 2014). Missing data were replaced with five imputed datasets in addition to

the original dataset. Variables corresponding to those used in the subsequent analysis were used for multiple imputation (Black et al., 2011; Newman, 2014). The Cox proportional hazards model was also performed without imputed data to verify the multiple imputation model.

The significance level was set to < 0.05 for all tests. All statistical analyses were performed using SPSS 27.0.1.0.

Ethical considerations

Both studies in this thesis were approved by the Regional Research Ethics Committees, Study I in Linköping (Reg no 2018/109-31) and Study II in Stockholm (Reg no 2014/1498-31/2). Ethical principles according to the Helsinki Declaration (World Medical Association, 2001) and the Swedish legislation on research involving human subjects (Utbildningsdepartementet, 2003) have been followed during the entire research process. All participants were provided written and verbal information about the studies, to enable participants to make informed decisions regarding their participation. The right to decline participation, even without giving any reason for this, was respected during the data collection. Data was managed to uphold confidentiality throughout the research project and the individual participant's identity will not be evident in articles or other forms of dissemination.

All participants (i.e., patients, physicians and family members when they intended to participate) were provided with verbal and written information about the study. Information about the study and that participation is voluntary was included in the written material, as were information about confidentiality and handling of data. When data was collected, names were replaced with coded numbers and names of persons, roads and other personal information that could increase the risk of identification of participants were removed when the recorded consultations were transcribed.

Seven of the 25 eligible patients chose to decline participation in Study I. It is possible that the dropouts may to some extent have been systematic (e.g., based on background factors, diagnoses or the questions that would be raised during the consultation). The conversations nevertheless contained a range of different issues that might arise in patients with polypharmacy.

As part of the ethical considerations for Study I, a risk/benefit discussion was held. Participant observation invades the life of the informant and sensitive information is frequently revealed (Spradley, 1980). Identified possible harm of the patients was the risk of them feeling inhibited in the conversation, due to the presence of an observer was discussed. When the benefits of the research were weighed against the risks, considering the limited alternatives for alternative data collection any risks were deemed reasonable in relation to the benefit.

Participants in Study II provided written informed consent prior to being included and randomised in the study. The collected data contained personal data, including names, social security numbers and diagnoses. Coded numbers already existing for the included patients were used in all further analysis of the material, to minimise the risk of any patient being identified. In the dataset, individual code numbers are linked to data regarding ratings in questionaries and healthcare utilisation. Data presented in the result section in Study II do not include individual measures, only averages (or equivalent) are presented, hence, no values that can be linked to names or social security numbers, or even to individual code numbers are available in the article.

Results

Study I

Four categories were revealed in the communication during annual patient-physician consultations: communication barriers, striving for a shared understanding of medication management, evaluation of the current medication treatment and the plan ahead and behavioural changes in relation to medication management (Table 2). Several things posed problems in the conversations: ambiguous in the language, medication names that are complicated, sound similar, are poorly adapted to the languages in which they are used, and medications often switched to a generic substitution.

Table 2: Summary of categories

Categories	Characteristic features
Communication barriers	GPs flexible and adapting, miscommunication due to vague or ambiguous words/expressions
Striving for a shared understanding of medication management	GPs tried to clarify uncertainties, deficient documentation and communication between healthcare professionals Medication reconciliation reveals inaccuracies, patient the carrier of information
Evaluation of the current medication treatment and the plan ahead	GPs evaluated treatments together with the patient, side effects, generic substitutions
Behavioural changes in relation to medication management	Lifestyle changes discussed but dropped if patient resisted

Medication lists often contained inaccuracies and would be difficult to ascertain if the patient would not even recognise the names of their medications. Information transfer between healthcare providers seemed to be deficient, for examples failure to report changes in the medication treatment between healthcare professionals. Difficulties in remembering or recognising medication names appeared to be most pronounced regarding generic substitutions. Even GPs occasionally mentioned a similar medication name instead of the intended one. In addition to the difficulties posed by the names, generic substitutions also presented problems when new side effects started to appear after generic substitutions or when different management instructions complicated patient's strategies to manage medication adherence. Alternatives to medications, e.g., lifestyle

changes and the fact that the need for medications could be reduced with improved lifestyle were rarely discussed. In conversations where lifestyle changes were raised, the topic was often quickly dropped without recommendations or offering support (e.g., regarding smoking cessation) when the patient showed unconcern. Information about what to be aware of and self-management measures in case of deterioration was also rarely provided during consultations, and patients did not either ask about specific symptoms to be aware of or any measures to take.

Study II

The discharge letters contained between five and eleven key elements, and the mean number of key elements was 8.3. Most key elements were present in more than four fifths of the discharge letters. However, three of the key elements were present in less than one third of the discharge letters: 'Expected course and complications' (32.5%), 'Measures in case of deterioration' (28.6%) and 'Advice about lifestyle and self-management' (10.4%). There was no correlation between any of the key elements and 30-day or 90-day readmission rate. However, both the key element 'Reason for admission' and discharge letter score were negatively correlated to self-rated quality of care transition (CTM-3) (Table 3).

Table 3: Correlations between discharge letters content and CTM-3[a], 30-day or 90-day readmission rate (Pearson's correlation coefficient)

Key elements/Discharge letter score	CTM-3[a]	30-day read-mission rate	90-day read-mission rate
Reason for admission	-.28**	.13	.05
Progress during care	.02	.10	.09
Diagnosis stated	.13	- .13	- .09
Medication list attached	-.00	.04	.06
Explanation of the medication list	-.09	.03	- .03
Advice about lifestyle and self-management	-.12	.05	.14
Follow-up	-.14	- .03	- .12
Contact information	N/A	N/A	N/A
Expected course and complications	-.10	.04	- .02
Measures in case of deterioration	-.16	- .06	- .10
Patient-friendly discharge letter	-.06	- .05	.01
Discharge letter score	-.23*	.03	- .02

[a]Care Transition Measure, 3 items * $P < .05$ ** $p < .01$

Discharge letter score was not correlated to either 30-day or 90-day readmission rate (Table 3) or associated with time to readmission at 90 days

(Table 4). Of the variables included in the stepwise Cox proportional hazards model (background factors, questionnaires and discharge letter score), the only variables that were significantly associated with time to readmission were a previous admission the past 180 days and country of birth (Table 4).

Table 4: Time to readmission at 90 days. Last step in a stepwise Cox proportional hazards model (pooled results)

	Variable		HR[a]	95% CI[b]	p -value
13	Country of birth	Sweden	1.00		
		Other Nordic country	1.61	0.57–4.52	.37
		Outside the Nordic countries	2.88	1.31–6.34	.01
	Unplanned admission within preceding 180 days[c]		2.47	1.40–4.37	< .01

[a]Hazard ratio [b]Confidence interval [c]Within 180 days before index admission

To verify the multiple imputation model, an additional Cox proportional hazards model was performed without imputed data. This analysis yielded a similar result in the 13th iteration: being born outside the Nordic countries (hazard ratio: 2.94, $p = .05$) and having an unplanned hospital admission within 180 days before the index admission (hazard ratio: 2.39, $p = .03$) remained significant. However, in the model without imputed data, an additional, 14th iteration indicated that only a previous unplanned hospital admission within 180 days before index admission was significantly associated with time to readmission at 90 days (Table 5). There were no statistically significant differences in time to readmission between intervention and control patients in either model.

Table 5: Time to readmission at 90 days. Last steps in a stepwise Cox proportional hazards model (model without imputed data)

	Variable		HR[a]	95% CI[b]	P -value
13	Country of birth	Sweden	1.00		
		Other Nordic country	0.97	0.23–4.18	.97
		Outside the Nordic countries	2.94	0.99–8.72	.05
	Unplanned admission within preceding 180 days[c]		2.39	1.09–5.22	.03
14	Unplanned admission within preceding 180 days[c]		2.22	1.03–4.80	.04

[a]Hazard ratio [b]Confidence interval [c]Within 180 days before index admission

Results Study I and II

The results in Study I and II show that physicians inform patients about medications to a large extent, however, information about lifestyle changes is rarer and less complete. Medications were discussed in all consultations (Study I) and information about medications was present in almost all discharge letters (Study II).

Three topics were present in less than one third of the discharge letters: 'Expected course and complications', 'Measures in case of deterioration' and 'Advice about lifestyle and self-management'. The six remaining key elements were present in more than four fifths of the discharge letters (Study II). In the consultations, discussions about lifestyle changes and self-management also appeared to a small extent. When the subject was discussed, physicians in most cases dropped the topic when the patient showed unconcern, often without recommendations or offering support (e.g., regarding smoking cessation). Lifestyle changes were rarely discussed in relation to medication, and the fact that improved lifestyle could reduce the need for medications was also not discussed.

The key elements 'Expected course and complications' and 'Measures in case of deterioration' were included in less than one third of the discharge letters (Study II). Although several of the patients were encouraged to contact the physician before the next annual consultation in case of problems, worsened symptoms or if they would need new prescriptions, however, no information was provided on *how* to self-manage worsening symptoms or *when* to seek medical attention.

When physicians encouraged patients to use their home monitoring equipment to check their blood pressure or blood sugar levels regularly, several patients stated that they rarely or never used their equipment. As was the case with the topic lifestyle, discussions about home monitoring were dropped when patients showed unconcern (Study I).

The majority of the discharge letters were written in a patient-friendly manner without abbreviations or medical terms (Study II). The conversations in the annual consultations were also conducted without the involvement of medical or technical terms in most cases. An exception was names of medications, which often proved to impose problems for patients, and resulted in physicians occasionally mentioning medications with a similar name instead of the one under discussion. Ambiguous words or

phrases occurred but could in most cases be clarified by taking advantage of the synchronous communication in a consultation (Study I).

The comprehension of the discharge letter was not found to affect either 30-day or 90-day readmission rate, nor was it associated to time to readmission at 90 days. In contrast, discharge letters including more key elements were correlated to *worse* self-rated quality of care transition (Study II).

Discussion

The overarching aim of this thesis was to explore how medication regimens are communicated in primary care consultations and in written discharge letters.

The communication in annual consultations (Study I) and discharge letters (Study II) took place in plain language, largely without unnecessary medical or technical terms. Medication names was an exception from the plain language used otherwise, which imposed difficulties for many patients. Even when discussing medications, physicians tried to use a language intelligible to their patient, e.g., using the shape or purpose of a medication rather than complicated generic names.

In previous research, communication barriers have often referred to deficient language skills (Clarke et al., 2019; Karliner et al., 2012) or certain disabilities (Agaronnik et al., 2019). In Study I, use of vague expressions or words with ambiguous meaning could lead to misconceptions and thus hamper mutual understanding. Contronyms in the language or arising when words were interpreted from different dialectal perspectives also made a shared understanding difficult. Communication, as an interpersonal process of developing shared understanding (Manojlovich et al., 2015), was mostly handled by physicians taking advantage of the synchronous communication during a consultation and made great efforts to reach understanding. In asynchronous communication, such as, written information in discharge letters, patients do not have the possibility to ask questions if they perceive the information as unclear, and physicians are unable to ask questions to ensure that the patient has understood the information.

Even when discharge information is verbal, understanding in previous studies have been poor (Karliner et al., 2012; Sheikh et al., 2018). In other studies, patients claiming to have a good comprehension of given instructions did not have a better understanding than patients who did not plea that they understood (Engel et al., 2009; Lin et al., 2015). In the consultations (Study I), physicians made great efforts to reach understanding and avoided medical or technical terms. However, medication names, especially generic names, posed problems in the communication (Study I). Patients having difficulties recalling the names of their medications is consistent with previous research (Jones et al., 2015). A previous study of medication names in relation to WHO naming guidelines showed a range of discrepancies from the guidelines (Bryan et al., 2015).

Medication names not only posed problems for patients; even physicians occasionally mentioned a similar medication name instead of the one under discussion (Study I). Whether medication names were intelligible or not when patients read their discharge letter was not studied (Study II).

In Study I, several patients were found to be using a different dose than prescribed according to the medication list, referring to a recommendation from another physician (usually at a specialist clinic), without this being documented. Discrepancies in medication lists have been studied previously, and inaccuracies have been shown to be common (Hammar et al., 2022). Patients becoming messengers between specialist physicians in hospitals and general practitioners has been identified as a part of medication communication (Manias, 2010). A national medication list has been decided by the Swedish government (Socialdepartementet, 2018), but has been delayed and has, to date, not yet come into use (implementation planned to December 2025). However, if physicians do not always document verbal medication changes and recommendations, it is not very likely that a new, national medication list will solve the problem of discrepancies in medication lists.

The quality of care transitions, including comprehensive information transfer, is especially important for older patients, who have a high prevalence of comorbidity (Jacobs et al., 2018; Wideqvist et al., 2021) to prevent adverse events and readmissions (Oksholm et al., 2023). In Study II, the content in discharge letters were not correlated with readmission rate or associated with time to readmission. Patients self-rated quality of care transition were negatively correlated to discharge letter content (Study II), indicating that a higher discharge letter score was associated with a lower perception of the quality of care transition. This counterintuitive result might indicate that discharge letters are neither the only nor the most important aspect of perceived quality in transitional care. More than four fifths of patients in a recent study in Norway reported not needing more information about their medications. Most patients were provided information about their medications by their primary care physician and, to a lesser extent, by pharmacists (Walquist et al., 2022). Since primary care physicians are regarded as the most important source of information about medications, early follow-up in primary care after discharge from inpatient hospital care might have the potential to improve readmission rates (Saxena et al., 2022).

Previous studies on discharge letter contents and readmission rates have shown ambiguous results. Rodwin et al. (2021) found that redesigned letter

templates, with guiding headings like 'documentation of the correct discharge diagnosis', 'information about the admission and treatment', 'disease-specific warning signs' and 'issues that require follow-up', improved the quality of discharge letters more effectively than educational outreach programmes for physicians. Still, the improved quality of discharge letters did not result in a statistically significant change in readmission rates. Even if all key elements were included in a discharge letter, patients might still feel unprepared to manage their medications and symptoms at home.

Conversations with healthcare professionals, during the period of inpatient hospital care, not only with physicians, but also physiotherapists, occupational therapists, pharmacists and social workers, might have been of greater importance for the patients self-management capacity than the written discharge letter. In a recent Swedish study, discharge encounters lasted for on average 4 minutes and 46 seconds (Flink & Ekstedt, 2017), indicating that time for questions or patient education was sparse. Information given during the hospital admission, e.g., by nurses during their regular work with patients, might have been an important source of information regarding self-management. More spontaneous conversations during regular work have the potential to reduce the knowledge imbalance between patients and healthcare professionals. According to Berlo (1960), the prerequisite for effective communication is that the sender and the receiver are on the same level of communication. Information in the discharge letters (Study II) focused on medications and the past time, rather than on knowledge and abilities to perform self-management, or symptoms to be aware of and what measures to take in case they would appear. Information about lifestyle factors and how lifestyle changes could improve well-being and health and reduce the need of medications was frequently disclosed.

Patients might also need individual self-management support during the first period at home. Self-management is gradually changing as the time goes from hospital discharge (Brandberg et al., 2021). Therefore, repeated contact with healthcare professionals might be implicated after discharge. A primary care visit within seven days of discharge was associated to reduced 90-day readmission rate in a study by Saxena et al. (2022). Medication changes and other changes that might have been done during the hospital stay might need follow-up. In a study on patients with heart failure, patients thought that symptoms of worsening heart failure were an effect of their

medication, which could have delayed both self-management efforts and possible efforts from primary healthcare system (Reeder et al., 2015). Some of the patients discharged from hospital in Study II did not have any more follow-up planned. Since all patients had at least CHF or COPD, annual follow-up in primary care might be their next encounter with the primary care or at hospitals. All patients had, to some extent, a medication treatment and are therefore likely to see a pharmacist more often than healthcare professionals in primary care or hospitals. This resource, which may be largely untapped, even though patients may have many contacts with pharmacies staffed by well-trained staff.

As most of the healthcare for patients with chronic illness is performed at home, self-management and information on how self-management should be carried out is of outmost importance (Freilich et al., 2020; Hibbard & Greene, 2013). Both Study I and Study II showed that information was primarily focused on medications, rather than, for example, discussing the possibilities of reducing the need for medication through lifestyle changes. Other information that was often omitted were symptoms to be aware of and what measures to take in case of deterioration.

Furthermore, in both studies, information about lifestyle and self-management, symptoms to be aware of and measures to take in case they would appear, seemed to be the most commonly parts omitted from annual consultations (Study I) and discharge letters (Study II), despite those parts have been considered particularly important for patients' self-management in previous studies (Doos et al., 2015; Shoeb et al., 2012). In Study I, dialectal disparity illustrates that words can be used and understood differently, even in a national language. Language proficiency was not investigated in Study II, however, birth outside the Nordic countries was significantly associated to an increased risk for readmission.

In a recent study, patients wanted a plan for follow-up, dialogue with healthcare professionals at the ward and to be involved in decisions during admission to feel prepared for discharge (Lindblom et al., 2020). In Study II, a previous unplanned admission as a predictor of time to readmission may indicate that these patients were fragile and required recurrent acute hospital care. This highlights that patients with chronic illness need not only a discharge letter, but also individual self-management support during care transitions and the first period at home (Brandberg et al., 2021; Ljungholm et al., 2022).

Methodological considerations

The methods used in the two studies in this thesis were carefully chosen to explore verbal communication about medications during consultations in primary care and to determine the impact of written information in discharge letters.

To explore communication, taking into account that communication entails several aspects other than the spoken language (Jacobi, 2011; Manojlovich et al., 2015), a qualitative approach with passive participant observations was chosen (Spradley, 1980). Passive participant observation was a strength as it enables observations of both verbal and non-verbal communication. The observations revealed what was actually said or otherwise communicated. The use of an observation protocol strengthened consistency in data collection. It is, however, possible that the presence of an observer might have influenced what and how freely patients and physicians were discussing during the consultations. The observers did not get the impression that this had a major impact on the collected data, reluctant patients refrained from participation in the study, which might have limited the range of data available. Furthermore, it is possible that dropout from this study was to some extent systematic, i.e., that patients with certain diagnoses or certain issues to discuss were more prone to refrain from participation.

Terms abound in the qualitative literature that address validity, are trustworthiness, authenticity and credibility (Creswell & Miller, 2000). To increase credibility, analyses and interpretation of data was performed by all authors, using the different professional background and preunderstanding of the authors. Although the team of authors consisted of nurses with experience from different areas, a sociologist and a pharmacist, no physician or patient representative participated in the analysis.

At the time when the studies were planned, the intention was to interview the patients who participated in the observations approximately one week after the consultation. In such interviews, there would be opportunities to investigate, for example, patients' understanding of the information in the consultation. However, most patients declined participation in a follow-up interview. There was also no possibility to assess the accuracy of the information provided during consultations. This was never the intention of either of the studies.

Study I was performed in two primary care settings in the South of Sweden, including 18 consultations, which might limit transferability to some extent. However, patients with chronic illness and polypharmacy occur widely in Sweden, as well as in other comparable countries, highlighting the need for further exploring and improving communication about medications.

To determine the impact of the content in discharge letters, mixed methods were used (Creswell & Creswell, 2018). To be able to assess the discharge letters quantitatively, an assessment matrix was systematically constructed, based on the results of an initial literature review. The relative importance of the different key elements was not feasible to rank, and consequently, all key elements were assigned the same importance, i.e., the same value in the analyses. Assigning the same value to each of the key elements is consistent with previous research (Regalbuto et al., 2014; Rodwin et al., 2021). To be able to assess the discharge letters in a comparable way, minimum required content for each key element was defined in the assessment matrix (Appendix 2).

In quantitative studies, validity and reliability are the extent to which a research instrument accurately measures the concept studied and to which the instrument consistently yields the same result when used repeatedly in similar situations, respectively (Heale & Twycross, 2015). Two measures, *Care Transition Measure* and *Patient Activation Measure* (Hellström et al., 2019; Hibbard et al., 2005; Hibbard et al., 2004) were used in the study. Both measures have been psychometrically validated and found to be sufficiently dependable.

The *validity* of key elements and discharge letter score in Study II has not been analysed for this particular population. However, the key elements were selected as a result of a literature review and are thus based on previous research on discharge letters. The fact that certain information is in a discharge letter does not necessarily imply that the patient has understood the information (Horwitz et al., 2013), or that the letter has even been read, could impose difficulties in interpretation of discharge letters. It has not been examined whether the patients understood their discharge letters, or if they read the discharge letters at all. Other information, such as, discharge encounters or conversations with nurses during the admission, has not been studied. This would pose a risk of impaired validity, as measuring a discharge letter is not a consistent value of patient understanding. However,

discharge letters could still be an adequate measure of the *written* information given at discharge.

In the multivariable time-to-event analysis, multiple imputation was used in order to avoid listwise deletion (Newman, 2014). There are several ways to manage missing data, but just ignore them is not an option (Newman, 2014). A model without imputed data was also performed, to verify the imputation model. This model yielded a similar result, however with an additional step in the stepwise Cox proportional hazards model, yielding only one variable significantly associated with time to readmission: a previous unplanned hospital admission the past 180 days.

Conclusion

Physicians informed patients about tests and examinations performed in the past time, and comprehensive information was provided about medications, both during consultations and in discharge letters. However, information about symptoms to be aware of and measures to take in case they would appear was scarce in consultations and discharge letters. In conversations where lifestyle changes were raised, the topic was quickly dropped without recommendations or offering support if the patient showed unconcern. Lifestyle changes in relation to chronic illness and medications were rarely discussed. Improved lifestyle as a means of reducing the need for medications was not discussed or informed about in discharge letters. Discharge letter content did not have any impact on readmissions.

Implications

Among other transitional care interventions, planning of discharge in advance, during the admission, is present in previous intervention protocols. Such an intervention would have a disadvantage as many patients are discharged the same day as the discission is made (Flink & Ekstedt, 2017).

Human communication considered as more than language (Jacobi, 2011; Manojlovich et al., 2015) highlights the need for taking more than just language in account in communication about medications and self-management.

Readmissions were considered to be related to patient factors, such as poor understanding and lack of ability to self-manage their illnesses, by both hospital and primary care physicians (Herzig et al., 2016). This is supported by patients who report not feeling ready for discharge, often because patients felt that their symptoms had been adequately resolved (Howard-Anderson et al., 2016). However, patients also identified a mismatch between the patient's needs of healthcare and the available healthcare services and poor communication between healthcare professionals and healthcare facilities as contributing factors to their readmission (LeClair et al., 2019). Improved communication between healthcare providers (e.g., hospital physicians and primary care physicians) might thus have similar or even greater potential in reducing readmissions than discharge letters alone.

This can reduce the possibility for staff to prepare the discharge and follow-up care properly.

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