

From the DEPARTMENT OF LEARNING, INFORMATICS,
MANAGEMENT AND ETHICS
Karolinska Institutet, Stockholm, Sweden
and
Sophiahemmet University, Stockholm, Sweden

Eleni Siouta



**Karolinska
Institutet**

Stockholm 2016

All previously published papers were reproduced with permission from the publisher.

Published by Karolinska Institutet.

Printed by Eprint AB

© Eleni Siouta, 2016

ISBN 978-91-7676-042-0

**Communication and Patient Involvement in Decision making
– Examples from consultations on atrial fibrillation
THESIS FOR DOCTORAL DEGREE (Ph.D.)**

By

Eleni Siouta

Principal Supervisor:

Professor Björn Fossum, PhD
Sophiahemmet University, Department of
Clinical Science and Education
Södersjukhuset, Karolinska Institutet

Co-supervisor(s):

Associate Professor Ulla Hellström
Muhli, PhD
Uppsala University,
Department of Sociology

Senior Researcher, Klas Karlgren, PhD
Karolinska Institutet,
Department of Learning, Informatics,
Management and Ethics (LIME) and
Södersjukhuset, Department of Research,
Education and Development, Education Centre

Opponent:

Professor Eva Brink, PhD
University West

Examination Board:

Professor Astrid Seeberger, PhD
Karolinska Institutet

Professor Karin Enskär, PhD
Jönköping University

Associate Professor Torkel Falkenberg, PhD
Karolinska Institutet

Defence of this thesis will take place on Friday the 22th of January 2016 at 09.30 h at
Sophiahemmet University, Weitnersalen, Vallhallavägen 91, Hus R, Stockholm

I hereby dedicate my thesis to my lovely parents Dimitra and Georgios

Αφιέρωση στους αγαπημένους μου γονείς Δήμητρα και Γεωργιο

There can be no turning back on this journey, my odyssey!

Δεν μπορεί να υπάρξει καμία στροφή πίσω σε αυτό το ταξίδι, οδύσσεια μου!

ABSTRACT

Background: Further knowledge is needed regarding communication that occurs in practice between patients with atrial fibrillation (AF) and health professionals in consultations to understand the issue of patient involvement in treatment decisions.

Overall aim: The overall aim of this thesis is to contribute knowledge on communication between patients and health professionals (cardiology nurses and cardiologists), focussing on how they create involvement in decision making in consultations.

Specific aims: (1) To describe (i) the topics that patients with AF discuss with cardiology nurses and cardiologists; (ii) the use of discursive space in consultations between these participants; and (iii) the frequency at which patients, cardiology nurses, and cardiologists introduce identified topics. (2) To describe the different types of resistance by patients to treatment with warfarin and how cardiologists respond to such resistance. (3) To examine how patients describe involvement and communication in decision making regarding treatment in consultations with cardiology nurses and cardiologists. (4) To examine how cardiologists describe their views on patient involvement in AF treatment decisions, their perceptions regarding efforts to involve patients, and how they handle decisions.

Methods: A qualitative design was used. In study I, the sample consisted of 23 videotaped consultations between patients with AF and cardiology nurses and cardiologists at six nurse-led cardiology outpatient clinics. Content analysis was used to obtain a description of topics that were discussed. The patterns of dominance for the various topics and participants were examined. In study II, the sample consisted of 11 videotaped consultations between patients with AF and cardiologists. Conversation analysis was used to describe interactions concerning resistance to treatment with warfarin. In study III, 22 patients with AF were interviewed directly after their consultations with cardiology nurses and cardiologists. Content analysis was used for the resulting data. In study IV, 10 cardiologists were interviewed in cardiology clinics at four Swedish hospitals and qualitative content analysis was used.

Findings: In study I, a medically driven agenda dominated the patient-driven agenda. However, when the patients initiated conversations about their life with AF (the topic that received the least amount of space on the agenda), involvement was created. In study II, the patients' resistance could be viewed as a source of knowledge about patients' real-life situations and what motivates them. In study III, despite not being actively involved in the decision-making process, the patients experienced a sense of involvement when they felt understood and were listened to. In study IV, by taking into account the patients' feelings in the consultations, and by actively encouraging the patients to be involved, the cardiologists contributed to patient involvement.

Conclusions: Patients, cardiology nurses, and cardiologists create involvement in decision making in consultations as communicative projects. Patients strive for space and create involvement by showing resistance to the decisions suggested by health professionals. However, involvement is not only an issue about obtaining space in the consultations, but is also associated with obtaining clarification, building confidence, feeling understood, trusting cardiology nurses and cardiologists, and having confidence in receiving consistent care within an established relationship. On a theoretical level, this thesis sheds light on the interaction between the concepts of communication, involvement, and decision making.

Keywords: Communication, patient involvement, shared decision making, atrial fibrillation, interaction, patient participation, person-centred care, resistance, discursive space, consultation

LIST OF SCIENTIFIC PAPERS

This thesis is based upon the following papers, which will be referred to in the text by their Roman numerals (I-IV):

- I. Siouta, E., Broström, A. and Hedberg, B. (2013). Content and distribution of discursive space in consultations between patients with atrial fibrillation and healthcare professionals. *European Journal of Cardiovascular Nursing*, 12(1):47-55.
- II. Siouta, E., Hedberg, B., Hedman, K. and Broström, A. (2012). Interactional resistance between patients with atrial fibrillation and cardiologists in consultation on treatment with warfarin: the value of shared decision making. *The International Journal of Person Centered Medicine*, 2(3):427-436.
- III. Siouta, E., Hellström Muhli, U., Hedberg, B., Broström, A., Fossum, B. and Karlgren, K. (2015). Patients' experiences of involvement and communication in decision making about atrial fibrillation treatment in consultations with nurses and physicians. *Scandinavian Journal of Caring Science*, doi: 10.1111/scs.12276.
- IV. Siouta, E., Hellström Muhli, U., Fossum, B. and Karlgren, K. (2015). Nurses' and physicians' experiences of patient involvement and communication in shared decision making about atrial fibrillation treatment in consultations with nurses and physicians. Manuscript.

CONTENTS

1	INTRODUCTION.....	1
2	BACKGROUND.....	2
	Atrial fibrillation.....	2
	Physiology, prevalence, and incidence	2
	Treatments for atrial fibrillation.....	3
	Care of patients with atrial fibrillation.....	3
	Central concepts	5
	Communication	5
	Patient involvement.....	12
	Decision making.....	16
	Summary of the conceptual bases of the thesis	20
	General theoretical perspective.....	22
	Social constructionism	22
	Rationale.....	23
3	AIMS	25
4	METHODS.....	26
	Design.....	26
	Settings	26
	Participants	28
	Participating health professionals and recruitment procedure	28
	Participating patients and recruitment procedure	28
	Data collection.....	29
	Video recordings in studies I and II.....	33
	Interviews with patients in study III	34
	Interviews with health professionals in study IV	34
	Description of methods and data analysis	35
	Analysis of dominance (study I)	35
	Conversation analysis (study II).....	37
	Qualitative content analysis (studies III and IV)	39
	Ethical considerations	40
5	FINDINGS	42
	Study I.....	42
	Study II	42
	Study III.....	44
	Study IV.....	44
6	DISCUSSION	47
	Discussion of findings.....	47
	Relationships between communication, involvement, and decision making.....	51
	Conclusions and implications	53
	Methodological considerations	54
	Future research	59

7	SVENSK SAMMANFATTNING	61
8	ACKNOWLEDGEMENTS.....	68
9	REFERENCES.....	70

LIST OF ABBREVIATIONS

AF	Atrial fibrillation
ASA	Acetylsalicylic acid
CA	Conversation analysis
HSL	Swedish Health and Medical Services Act (Hälso-och sjukvårdslagen)
NOAC	New oral anticoagulants
OPTION	Observing patient involvement in decision making
LIME	Department of Learning, Informatics, Management and Ethics
SDM	Shared decision making

PREFACE

My research focus is in the field of health and caring science and related issues of communication, with focus on patient involvement in decision making. In this thesis, my many years of work and interest are expressed, preceded by a long journey in clinical and pedagogical contexts. These have provided me with a deeper understanding of the processes of interaction and communication with patients. I hope that the findings in this thesis lead to insights on communication and involvement of patients in decision making in consultations and the need for further development of clinical and educational interventions. Such insights could result in clinical strategies that promote improvement in the use of communication aimed at increasing patient involvement and supporting the use of shared decision making in consultations.

In 2013, I was teaching communication for graduate nursing students at Karolinska Institutet in Stockholm, Sweden, and I had nearly finished my licentiate thesis (Siouta, 2012). This led to my interest in further research and resulted in continuation of my doctoral education.

Eleni Siouta

THESIS STRUCTURE, DEMARCATION, AND READER'S GUIDE

The context for the studies in this thesis is that of consultations between patients with AF and nurses and physicians. The term 'cardiologists' was used for physicians to reflect their specialty. Nurses and cardiologists were experienced in cardiology (also called 'health professionals' when referring to both). This study does not aim to compare between the two professional groups included in this thesis. To understand the issue of patient involvement in treatment decisions, more knowledge is required on communication that occurs in consultations in both groups. This thesis is a meta-analysis of findings as a whole. The background includes a description of AF as a disease, and treatment and care of patients with AF, as well as definitions and explanations of the central concepts that are relevant to this thesis, namely *communication*, *patient involvement*, and *decision making*. The background also includes the aims of the actual research, a description of the methodological bases, and the process of the actual research and ethical standpoints. Component studies are summarised and presented. The discussion relates to the findings as a whole and conclusions are summarised. Some implications are also outlined for clinical development.

One final consideration is that consultation is a social situation. Consultation is viewed as a social meeting where power structures and sociocultural aspects, such as class, ethnicity, sex, and age in an intersectional manner and are interwoven on different levels. However, a detailed description of these aspects and how they affect consultation, and a description of personality-related styles of conversation have not been included in this thesis. The studies in this thesis focussed on communication that occurs in institutional conversations. The created perceptions of reality between the parties involved in consultation are crucial for understanding the relationship that exists between communication, involvement, and decision making, and are of relevance from a caring science perspective. The discussion involves general language communication skills and not the complications that arise as a result of communicative handicaps or the complications that are characteristic of multilingual environments. More focus has also been placed on verbal communication rather than non-verbal forms of communication. The conversation between patients and health professionals in consultations differs in many ways from everyday conversations. To focus on communicative dynamics occurring in practice, referring to old theoretically driven research on the nature of dialogue between patients and health professionals in the medical setting was necessary. Therefore, older references are included in this thesis.

1 INTRODUCTION

The focus of this thesis is communication between patients and health professionals (cardiology nurses and cardiologists), particularly focussing on how they create involvement in decision making in consultations. This issue is especially relevant in Sweden because there are strong recommendations for patient involvement in healthcare, including treatment decisions. The Swedish Code of Statutes (2014:821) and the Guidelines for Management of Atrial Fibrillation in Cardiology highlight the importance of patient involvement in decision making about treatment (The Swedish code of statutes, 2014:821; National Guidelines for Cardiac Care, 2015). This places increased demands on health professionals to invite patients to participate in discussions on the design and implementation of healthcare interventions.

The idea of viewing the patient as an important involved partner in the decision-making process is also supported by research. Previous studies have provided evidence of the benefits of increased patient involvement in decision making in consultations between patients and health professionals regarding care and treatment decisions (Coulter and Collins, 2011; De Haes, 2006; Deber et al., 2007; Elwyn et al., 2010; Montori et al., 2013; O'Connor et al., 2007; Politi et al., 2013; Cribb and Entwistle, 2011; Ijäs-Kallio et al., 2010; Stacey et al., 2010; Shepherd et al., 2008; Légaré et al., 2008; Moumjid et al., 2007; Tutton, 2005; Stiggelbout et al., 2012; Street et al., 2012). Patient involvement in treatment decisions as highlighted by the law and supported by previous studies above means that more knowledge is required on the interaction and communication that occur between patients and health professionals in practice. Therefore, one of the caring science problems that this thesis addresses is how patients and health professionals create patient involvement in decision making within the context of consultations in cardiology concerning treatment and care. This thesis aimed to contribute to existing knowledge on communication in consultations between patients and health professionals, and how patients and health professionals create involvement in consultations in the cardiology care setting.

A qualitative perspective was applied to determine how institutional interaction is created in the context of consultations of patient involvement between patients with atrial fibrillation (AF) and health professionals. This thesis has its theoretical roots in social constructionism, which underscores the situated nature of communication and interaction. Based on the theoretical perspective of social constructionism, communication and involvement in the decision-making process in consultations are viewed as being constructed between patients and health professionals. The intention of this thesis is to not only produce a summary of the results of the studies that are included in the thesis, but also to produce a meta-study of the relationship between communication, involvement, and decision making based on the results of these studies.

2 BACKGROUND

ATRIAL FIBRILLATION

Physiology, prevalence, and incidence

If a patient has AF, the heart rate is irregular and varies from rapid to slow with narrow QRS complexes, which are three of the graphical deflections seen on an electrocardiogram (Camm et al., 2012). The prevalence of AF is 2.3% in people aged older than 40 years, 5.9 % after 65 years, and 10% in those who are 80 years or older. AF is the most common cause of rhythm disorders (Hakim and Shen, 2014). The prevalence of AF will probably increase in the developed world as people live longer ,and thus more people reach the ages at which this condition is most common (Hakim and Shen, 2014).The rate of reoccurrence of AF in many patients is high and troublesome. Comorbidities and increasing longevity significantly accelerate progression of AF and the development of complications. The risk for AF is higher in women than in men (Lip et al., 2015). AF is classified as paroxysmal, persistent, or permanent. Paroxysmal AF is defined as episodes that usually last less than 24 hours but can continue for up to 7 days, after which they terminate spontaneously. Persistent AF is defined as episodes that last for longer than 7 days and only terminate with addition of pharmacological or electrical interventions. Permanent AF is defined as AF that is present in the patient in the long-term and the heartbeat has not reverted back to a normal rhythm (Sandberg, et al., 2015).

Before AF is diagnosed, most patients experience asymptomatic episodes of arrhythmia that are self-terminating. Therefore, a correct diagnosis can take a long time in such patients, and approximately one in five strokes are probably due to undiagnosed AF (Panisello-Tafalla et al., 2015). Symptomatic embolic events may contribute to cognitive dysfunction in patients with AF in the absence of overt strokes. Breathlessness, palpitations, syncope, dizziness, and chest discomfort are all common symptoms of AF. Patients with AF exhibit symptoms, such as fatigue and loss of physical ability due to a rapidly increased working pulse. AF results in noticeable limitations within daily life caused by reduced physical capacity and the fear of provoking an episode of dysrhythmia. High levels of anxiety are often associated with more severe symptoms, such as psychological stress and reduced physical quality of life. Patients with AF have a significantly reduced feeling of well-being (Thrall et al., 2007). One third of patients with AF experience greater than average levels of depression and anxiety, and have a lower quality of life compared with those with hypertension (Turker et al., 2015). Symptoms of depression represent the strongest independent predictor of future quality of life in these patients. The patients often describe themselves as having been active, healthy, and actively involved in family, work, and leisure activities before becoming ill (Deaton et al., 2003; Turker et al., 2015).

Treatments for atrial fibrillation

Treatments for AF can be divided into regulation of frequency, obtaining an adequate heart rate, and achieving normal sinus rhythm. The treatment of AF focusses on reducing symptoms and preventing complications. Medication, cardioversion, and ablation techniques are used to treat episodes of AF and maintain sinus rhythm, and these therapies often improve symptoms. Age-related physiological changes affect the pharmacological effects of antiarrhythmic drugs. The effect of catheter-based ablation is not well represented in clinical studies (Ramlawi and Abu Saleh, 2015). In some cases, antiarrhythmic drug therapy causes side effects or results in ineffectiveness that may involve a decision on non-pharmacological treatment options in the form of surgical ablation maze procedure (Camm et al., 2012). Because of the risk of stroke, antithrombotic therapy is an important part of pharmacological management of patients with AF (Camm et al., 2012). Several randomised, controlled studies have shown that treatment with warfarin significantly reduces the risk of stroke (Camm et al., 2012). The negative consequences of taking warfarin include the need for regular blood testing, the need to change food habits and to limit alcohol intake, and the cost of the drug if it is not covered by insurance (Man-Son-Hing et al., 2005).

The quality of life for the patient decreases because of the requirement for frequent blood tests and limitations in relation to aspects of lifestyle (e.g., physical activity and alcohol intake) (Walfridsson, 2012). AF increases the risk of blood clots, but a stroke can also be caused by a brain haemorrhage during treatment with anticoagulants (Friberg, et al., 2012). Even though side-effects are possible, antithrombotic therapy should be considered for patients with AF to reduce the risk of complications from blood clots (Camm et al., 2012). Alternatives to warfarin, which hopefully can minimise the above-mentioned complications, are under development. The Swedish National Board of Health and Welfare recently released a new preliminary version of national guidelines for the use of new oral anticoagulants (NOAC) (National guidelines for cardiac care, 2015). These guidelines state that all available new oral anticoagulants have an equivalent and better preventive effect against stroke compared with warfarin. Another alternative to warfarin is acetylsalicylic acid (ASA), which prevents blood clots, although not as effectively as warfarin. ASA is usually recommended for patients with AF with a low risk for blood clots because the risk of complications is lower than that for warfarin. Treatment using ASA is based on local, national (National guidelines for cardiac care, 2015), and international guidelines (Camm et al., 2012), but there are major differences in the treatment of patients with AF.

Care of patients with atrial fibrillation

The Swedish National Board of Health and Welfare has developed guidelines for the care of patients with AF (National guidelines for cardiac care, 2015). In Holland, a care programme for patients with AF was developed that resulted in the development of guidelines for patients

with AF throughout Europe. Various risk factors and problems for these patients were identified, as well as the need for training and education, and the need for changes to existing treatment. Management and counselling by a specially trained AF nurse may lead to improved efficiency and enhanced coordination through enhanced navigation of the patient care pathway for AF, and improved multidisciplinary collaboration between physicians, nurse specialists, and patients (Hendriks et al., 2010). Nurse-led AF clinics have also been established in Sweden. The aim of the AF clinic is to assure the quality of the investigation, treatment, and follow-up of AF cases and to ensure continuity within the care system (Al-Khalili and Lindström, 2014). The patient meets a specially trained nurse and receives comprehensive information in spoken and written form. Checklists are used by the nurse to ensure correct dosage of anticoagulation treatment for AF and to make suggestions and recommendations to the physician responsible for the patient. The anticoagulation module within the Swedish national quality register, Auricula, is used for follow-up of the patients (Sjögren et al., 2015). When patients with AF meet the AF nurse, a lot of importance is placed on information about AF.

The patient's own experience of the severity of symptoms, as well as the frequency of symptoms, are important in relation to how patients feel about their health (McCabe et al., 2011). Episodes with AF arise unpredictably and the patient's level of control over his/her daily life is reduced. This causes limitations in the patient's daily life, as well as difficulty and uncertainty in planning for the future (McCabe et al., 2011). Despite repeated hospital visits (e.g., cardioversion), the patients feel that they are in an unusual situation, and they experience feelings of insecurity and have many questions they would like answered. However, the nurse expects the patients to have knowledge of the relevant procedures, and consequently, the patients keep their questions to themselves (Høgh et al., 2010). Having AF leads to increased anxiety about when the next attack might occur. This then limits the patient's daily life, and thus leads to a reduction in the patient's health-related quality of life. Achievement of an increased sense of well-being in the patient often requires introduction of lifestyle changes. For this reason, the nurse should inform the patient about factors that can contribute to onset of episodes of AF (McCabe et al., 2008). Such factors could include untreated hypertension, the use of drugs, alcohol, and tobacco, obstructive sleep apnoea, and excess weight or an inability to manage stress in one's daily life (Camm et al., 2012). McCabe et al.'s study (2011) showed that patients who sought medical care on repeated occasions for symptoms, such as tiredness, palpitations or chest pain, but who did not receive a medical diagnosis that might offer an explanation for such symptoms, felt that they had not been taken seriously by health professionals. This study also showed that patients expressed a feeling of being troublesome because the health professionals made them feel that they were taking up valuable time that could otherwise be spent on other patients with more serious conditions. Patients with AF requested more information about the disease and how it can be treated, but more often than not they were not provided such information (ibid.). Additionally, the patients wanted information on how to control the symptoms when they occurred and how to tell these symptoms apart from serious conditions, such as a heart attack

(*ibid.*). The patients felt that the provided information was restricted in nature (*ibid.*) and that it could differ from one occasion to the next, depending on the provider (Høgh et al., 2010). When the patients did not receive the relevant information, they started to develop their own theories about what caused the onset of episodes of AF. Therefore, they began to avoid the items that they believed to be such causes, including physical exercise (McCabe et al., 2011). Nurse-led clinics have been created to assure the quality of monitoring and ensure the continuity of care of patients with AF (Berti et al., 2013). There are few studies regarding conversation between patients with AF and health professionals based on an analytical perspective of conversation. Similar studies of these meetings have been performed in cancer care (Öhlen, 2008), social services (Cedersund, 1993), and conversations between administrators and elderly people in need of assessment (Hellström Muhli, 2003). A national study of coronary care in Sweden showed that patients with higher self-rated involvement experienced less chest pain and showed better adherence to prescribed medication than those with lower involvement (Arnetz et al., 2008). There are no studies in the field of communication in AF care.

CENTRAL CONCEPTS

To understand the relationship between communication, patient involvement, and decision making, which are the three central concepts discussed in this thesis, these concepts are currently examined on the basis of theoretical perspectives and previous research. The following section contains a description of each of these three concepts. Findings from studies that primarily addressed all three of these concepts have been included in the research review.

Communication

The term communication is derived from the Latin word ‘communicare’, which means making something in common. However, according to Fiske (1990), Linell (2011), and Sarangi and Roberts (1999), finding a simple way to define communication as a concept is difficult. This is because communication is such an integrated part of our reality that it is taken for granted, rarely pausing to consider what it involves or how important it is. Despite this fact, researchers are in agreement that distinguishing two perspectives on communication, which are fundamentally different from one another, is possible (Linell, 2011; Sarangi and Roberts, 1999). According to the first of these perspectives (transfer of information), information is transferred from a sender to a recipient. The second perspective (creation and exchange of meaning) maintains that a common meaning and understanding are created when patients and health professionals communicate with each other, as studied in this thesis. Both perspectives are based on the assumption that a relationship is created between patients and health professionals. A relationship in the first case is based on a monologue between a sender and a recipient, and that in the second case is based on a

dialogue between the parties involved in the interaction. Hereafter, in line with Linell (2011), the concept of monologism is used to describe the perspective that is based on transfer of information, and the concept of dialogism is used to describe the perspective that is characterised by the creation and exchange of meaning.

Monologism - transfer of information

According to Linell (2011), in the monological model, communication is a case of transfer of information from the sender to the recipient, and is a linear process involving a speaker and a listener. This has led to an interpretation of information as something that the health professional can provide to the patient. Monologism is a tradition in the understanding of language, whereby words and expressions are perceived with fixed and finished messages and connotations (Sarangi and Roberts, 1999). Connotations are decontextualized and exist independently from the individual's experience of the communication taking place (Linell, 2011; Sarangi and Roberts, 1999). In the monological model, the reality is objective because one person decides to use certain words to interpret the meaning of what is being said.

According to the monological view of language, communication can be divided into two parts: instrumental and emotional (Sarangi and Roberts, 1999). Instrumental communication relating to a patient may be described. An example of this communication is information regarding a disease or treatment aimed at encouraging the patient to provide objective information about his/her condition, or perhaps with the aim of reducing the patient's anxiety or preparing the patient for an event. Emotional communication includes providing respect, comfort, and confidence to create an atmosphere of trust in which the patients are in touch with themselves, feel understood, and can talk about their experience of the disease (McCabe and Timmins, 2013). This emotional message is intended to display empathy with the patients, to show that the patients are understood, and to provide support and maximise the patients' abilities to cope with the decision-making processes (Sarangi and Roberts, 1999). There is no correspondence between form and function in the use of language according to the monological interpretation (Sarangi and Roberts, 1999). This tradition is rooted in what Sarangi calls 'the dualistic-reductionist view' of a person. For example, providing information to the patient is a common way of talking about information, whereby communication is based on the fact that both parties must have a mutual understanding of the message (coding) from the receiver to successfully understand (decode) it (Sarangi and Roberts, 1999). In the dualistic-reductionist approach of caring, there is an attempt to reduce the experience of illness or health to a system of diagnoses, rather than focussing on reciprocity and common understanding in relation to communication, interpretation, and problem-solving, as the holistic-humanistic approach of caring. This approach closely corresponds with recent developments in health research and has, in general, advanced to a holistic-humanistic approach (Sarangi and Slembrouck, 2014; Arman et al., 2015). Health professionals who want to use holistic caring adopt a dialogical view of communication, which is described in more detail in the next section.

Dialogism – creation and exchange of meaning

In the holistic-humanistic paradigm, communication is understood as a process of interpretation, and the transfer of information is no longer a goal in itself; the goal becomes an understanding of that information instead (Sarangi and Slembrouck, 2014). According to the dialogical view, messages and connotations are co-constructed and are made concrete by the participants when they change their role from listener to speaker (Linell, 2011). According to this view on communication, the reality is co-constructed and subjectively perceived, and the participants' experiences and perspectives are important. This definition of communication, according to the dialogical model, emphasises the ways in which participants in consultations create meaning and involvement in decision making. The patients' narratives, communicated from 'the voice of the lifeworld' (Mishler, 1984; Hydén and Mishler, 1999), become vital aspects in the holistic paradigm. In this paradigm, the participants gradually adapt not only their own understanding of what has been communicated, but also to the mutual understanding that develops between the patient and health professionals in the relationship that exists between them (Sarangi and Slembrouck, 2014; Arman et al., 2015).

Another aspect of this view is that the content of what is said cannot be separated from the people involved in the interaction. Therefore, the content can be viewed as being part of contextualised and communicative projects (Hellström Muhli, 2003; Linell, 2011). The notion of context includes a number of social interactional variables (e.g., roles and structure), where one must identify an interpretation from the context before interpreting it (Linell, 2011). Culture affects individuals, their perceptions and interpretation of reality, and the ways in which they create meaning. To achieve coherent development of understanding in the conversation, the participants must create a web of coherent interactional expressions (i.e., sequence organisation) (Linell, 2011). The participants involved in a conversation take turns adopting the roles of speaker and listener according to a turn-taking system (Schegloff, 2007; Linell, 2011). Sometimes problems of understanding arise, and to move on in the conversation, people use repair techniques to repair the problems of understanding that, despite everything, arise during conversation (Linell, 2011).

In summary, monologism and dialogism are two dominant views in the understanding of communication. Monologism and dialogism are considered as having opposing and complementary views (Norrby et al., 2015). Monologism is present in consultations between patients and health professionals when the aim is to inform patients about their disease and treatment. In contrast to monologism, dialogism is present in consultations between patients and health professionals when the patients' and health professionals' knowledge about the disease and treatment is constructed and exchanged between the participants. According to Travelbee (1972), this type of interaction with the patients provides professionals with an opportunity to become closer to the individuals, to get to know them better, and in this way, be better able to meet the care needs of the patients (Travelbee, 1972). This means that the communication becomes person-centred (Fossum, 2013; Epstein and Street, 2011;

McCormack et al., 2011). This occurs when patients talk from their own experience about AF in interaction with health professionals, based on a dialogical approach.

Person-centred communication

Person-centred communication has primarily been defined in terms of the behaviour of professionals aimed at achieving person-centred care (Epstein and Street, 2011; McCormack et al., 2011). Person-centred communication, shared decision making (SDM), and patient involvement in relation to treatment are all part of, and are terms that are closely related to, person-centred care (Epstein and Street, 2011; Mazzi et al., 2015). In this type of communication, health professionals examine and understand the patient holistically. Understanding the patients in a consultation involves professionals investigating the patients' primary reasons for the consultations, as well as their concerns and information needs, including emotional needs (Entwistle and Watt, 2006). Person-centred communication can thus be considered as a requirement for patient involvement in SDM. Person-centred care is often contrasted with profession-centred care, whereby communication is steered on the basis of the perspective of the professionals rather than the patients. Such a contrast is also referred to as biopsychosocial versus biomedical communication (Ishikawa et al., 2013).

According to Epstein et al. (2004) and Epstein and Street (2011), person-centred communication should contain the following components: eliciting and understanding the patient's perspective, understanding the patient in his or her unique psychosocial context, achieving a mutual common understanding of the problem about which a decision must be made, ensuring that the treatment is in keeping with the patient's values, and helping patients to share power and responsibility by involving them in decisions to the extent that they desire (ibid.). Person-centred communication can be understood in different ways depending on how one views the role and function of patients. If the patients are viewed as 'customers', adopting a person-centred approach to communication as a professional can be considered as equivalent to being 'customer-oriented' (Ishikawa et al., 2013). The information that is provided to patients in their role as consumers is viewed as a saleable commodity, and professionals are expected to deliver it according to the wishes of the patient (ibid.). If the patients are viewed as 'partners' with health professionals, adopting a person-centred approach to communication as a professional can be considered as equivalent to being 'in a value-neutral form' (Ishikawa et al., 2013). Professionals can and should provide their patients with medical facts, such as treatment alternatives, in a value-neutral form (ibid.). The patients' role is to provide the professionals with information about their personal values and preferences. Therefore, an assessment can be made that is based on the actual facts and circumstances in relation to the specific patient (Ishikawa et al., 2013; Bowling et al., 2011).

The behaviour of patients to achieve person-centred communication is discussed less often, while professionals are asked to change their behaviour more often. This could depend on the implicit assumption that patients are vulnerable in relation to professionals and must therefore

be protected (Ishikawa et al., 2013). According to Fossum, (2013), the patient defines how much person-centred circumspection the professionals must carry out when they communicate with the patient (ibid.). A study by Cousin et al. (2013) showed that highly caring-oriented participants (i.e., participants for whom caring is an important aspect of the physicians' communication style) were dissatisfied when physicians communicated in a less caring way. An explanation for this finding was that the patients felt irritated and disappointed, and distrusted their health professionals when they placed a large amount of faith in the health professionals who were responsible for their care (Cousin et al., 2013).

Person-centred communication has often been presented as a caring style of communication (Fossum, 2013; Fredriksson, 1995; Cousin et al., 2013; Brink and Skott, 2013). Health professionals could have positive attitudes to person-centred communication, but lack the resources, knowledge, or skills necessary to be able to adopt this style in their interaction with patients in consultations. Patient-centred communication has also been discussed in a study that examined communicative constructions of patients, on the basis of the native language, in consultations in cardiology (Hedegaard et al., 2014a). According to this study, non-native Swedish speaking patients presented themselves as participating, in that they expressed demands and signalled various forms of dissatisfaction. The physicians responded in two different ways by using an argumentative manner towards the non-native Swedish-speaking patients or by acknowledging the native Swedish-speaking patients. However, communication in consultations may also involve gender differences. Hedegaard et al., (2014b) showed that patients and health professionals had stereotyped expectations of the gender through their communications during consultations, with a risk of contributing to differences and substandard care.

A common definition of person-centred communication is that patients are to be considered holistically, and focus is placed on the relationship between patients and their health professionals. This focus also takes health professionals into consideration in that communication, (i.e., consultations) occurs within the framework for the institutional setting. This means that communication in consultations is characterised by asymmetry in the interaction, skills, interests, and perspectives of the participants.

Communication in consultations in an institutional setting

Communication during a consultation between patients with AF and health professionals can be described as communication in an institutional setting, which means that the consultation occurs within institutional discourse. Discourse was defined by Olsson et al., (2011) as what can be said and thought about a phenomenon and who can talk about it, as well as when and with what authority. Although institutions may use a conversational and informal style, on a deeper level, it is still institutional discourse and its rules and procedures remain central (Cedersund and Säljö, 1993). Therefore, institutional discourse follows a specific agenda, making use of established roles and routines, procedures, and knowledge, to arrive at a joint

goal. One of the individuals represents the institution and the other seeks its services (Agar, 1985).

Consequently, institutional discourse primarily involves certain continuously re-affirmed asymmetries in which patients are subordinated, or subordinate themselves, to experts. This asymmetry is often related to a pattern of dominance (e.g., knowledge or the position of the participants) (Linell and Gustavsson, 1987; Linell et al., 1988; Linell and Luckman, 1991). Therefore, compared with everyday speech, institutional discourse is rooted in a power relationship in the interaction, skills, interests, and perspectives of the participants. There are rules for drawing conclusions and for what and to whom these rules apply. An example of this situation is that professionals have the right to ask personal questions of their patients, but the same does not apply in reverse (Linell and Luckman, 1991). Agar (1985) identified three goals for institutional interlocutors when viewed from the perspective of institutional representatives, namely diagnosis, directives, and reporting. The patients' diagnoses are based on how the institution diagnoses their condition with regard to the current issue (*ibid.*). Therefore, communication in an institutional environment is influenced by its purpose, structure, typical procedures, and the roles, rights, and responsibilities of patients and health professionals, and sometimes their relatives, in the interaction (Sarangi and Roberts, 1999).

The process of consultation requires a special structure. Byrne and Long (1976) divided consultation into six phases: (1) establish a relationship with the patient; (2) discover or attempt to discover the reason for attendance; (3) conduct a verbal and/or physical examination; (4) the health professional and the patient consider the condition; (5) the health professional, and occasionally the patient, suggest further treatment or investigation; (6) the consultation is terminated, usually by the health professional. The participants in the consultation have clear roles, and the consultation occurs in a special room. Consultations between patients and health professionals are not only affected by knowledge asymmetry that has been acquired through academic education and clinical practice, but also through context-specific interpretive procedures. When a patient and a health professional communicate with one another and one of the participants has the power to control the conversation, and when it is only the health professional that has this power, the communication then becomes asymmetric (Agar, 1985). There is uncertainty in consultations for patients and health professionals alike. However, the level of uncertainty is always greater for the patient because of the difference in medical knowledge between the patient and the health professional. Consequently, professionals are always in a superior position and have control over various resources, including medical information and technology relating to treatment, and being able to prescribe medicines. Based on this perspective, the patient–professional relationship is characterised by a conflict of interests between patients and professionals (Ishikawa et al., 2013). In consultations, this conflict between two approaches was described by Mishler (1984) who discussed the voice of medicine (i.e., the voice of medical-scientific assumptions) and the lifeworld voice, which is the voice of the patient's everyday life. Based on these terms, Mishler (1984) referred to a dialogue between two alternative ways of understanding and discussing problems as follows: the 'lifeworld voice', which localises problems within

the patients' personal and sociocultural contexts; and the 'voice of medicine', which frames these problems within the technical biomedical model, and focusses on symptoms and aetiology and the treatment of specific diseases (ibid.). Mishler (1984) noted that these 'voices' are in conflict with one another and that the medicine voice tends to control and dominate the consultation by ignoring what the patient has to say and by transforming all of the consultation's content into the biomedical framework. Patients and health professionals represent different perspectives, and this can complicate their understanding of each other. Patients use their own lifeworld voice and knowledge of their own life situation, reactions, and experiences (ibid.).

In a similar way, Agar (1985) used the concept of frames to illustrate two perspectives. The institutional frame represents beliefs and ways of acting that are shaped by an institutional rationality. Professionals act within the institutional frame and patients act within the client frame (ibid.). The patient's frame represents knowledge of the individual's everyday life, including reactions and experiences (ibid.). Consideration of the dominance of the professionals' voice of medicine and patients' predispositions to place their experiences of illness into their lifeworld is important (the patients' everyday life) when studying communication between health professionals and patients. Understanding how patients manage to make their voices heard by talking about their lifeworld situations should be considered. Mishler (1984) showed how health professionals shift the focus of conversation away from the patients' lifeworld voice and back to the voice of medicine (ibid.). An institutional way of viewing the world that includes a specific way of classifying patients and their concerns informs health professionals. To carry out medical tasks in consultations, matters involving the patient's lifeworld need not be restrained by moving the discourse to biomedical matters. Health professionals can communicate competently in both worlds. They can choose to speak in either the voice of the lifeworld or the voice of medicine, whereas patients can only speak in one of these voices. Therefore, health professionals have the responsibility of translating the patients' lifeworld perspectives into medical terms and of expressing the medical perspectives of problems in terms that the patient can understand (ibid.). Communication between patients and health professionals in consultation is not solely affected by internal institutional factors, such as asymmetry between the parties. Communication is also affected by external social factors and contemporary trends.

Factors that affect consultation

Many social factors and competing trends may affect the interaction between patients and health professionals in consultations in the institutional setting. Sarangi and Slembrouck (2014) argued that consultations should be embedded in scientific expertise, although they are also routinely affected by the following current major dimensions of contemporary challenges and trends in healthcare: globalisation and mobility; bureaucratisation (a grey zone where decisions are not always considered from a healthcare ethics perspective, but rather in terms of policy and economics); digital technicalities; and market orientation and

consumerism, whereby patients are often viewed as consumers (ibid.). The above-mentioned social dimensions challenge consultation because of pressure exerted from all these directions in debate on involvement in decision making (Latimer et al., 2013). An increased level of interest of patient involvement in healthcare is also in part a result of economic considerations and limited resources. These affect the ability of healthcare organisations to deliver healthcare services of high quality and are forcing them to find a balance between declining resources and increased costs for healthcare (Engström, 2014). This fact, together with suggestions from the scientific community that highlight how the patient's satisfaction and quality outcomes are improved when patients become actively involved in their own care, lead to challenges for communication in consultations.

Patient involvement

Patient involvement is defined by the Medical Subject Headings tool as participation of patients in matters pertaining to health (United States National Library of Medicine). In addition to patient participation, other terms associated with the concept of patient involvement include 'patient engagement', 'collaboration', 'partnership', 'influence' and 'patient self-determination', and these are sometimes used in place of the term 'patient involvement'. However, this does not mean that patient involvement is an uncomplicated concept. Cahill (1996; 1998) described patient involvement, especially in relation to decision making, as a hierarchical pyramid with different degrees of participation. Patient involvement and patient collaboration form the base of the pyramid and are the precursors to patient participation, which in turn is the precursor to patient partnership. Partnership, with its high degree of involvement or collaboration, is at the top of this hierarchy (Cahill, 1996). The process of partnership underpins involvement by identifying the values and beliefs on which decisions about care and treatment are based (Tutton, 2005). Another aspect is that the term patient involvement is understood differently within different disciplines (Barello et al., 2012). These differences are examined in more detail below in relation to the disciplines that are the focus of this thesis, namely nursing research and biomedical research (ibid.).

Patient involvement in nursing research

Within nursing research, the term patient involvement is defined as patients' self-awareness and is explained as being a central part of the legitimization of patients' expressions of their physical and emotional needs. According to Barello's et al.'s review in 2012, this leads to a better orientation of professional measures. Nurses are encouraged to evaluate the patients' emotional status, perspectives, and possible choices, and to incorporate these in the planning and execution of care (ibid.). In Barello's et al.'s review, nurses play a central role in engaging patients in the healthcare process. In this context, the definition of patient involvement is related to its behavioural component in terms of the facilitation of patient-provider communications and emotional disclosure. Nurses emerged as facilitators of patient

involvement when enacting a role of emotional support. Research on patient involvement in nursing care often uses terms such as facilitate, communication, actively, recognise, and need (Barello et al., 2012).

From nurses' perspectives, patient involvement is more about providing patients with individually-tailored information (Sahlsten et al., 2008). Patient involvement is a dynamic process that changes over time and can be facilitated by professionals seeking to understand the patient as a person (Sahlsten et al., 2009). Involvement has also been studied from a patient's perspective. Larsson et al. (2011) studied patients' perceptions and barriers when they were involved in nursing care. Patient involvement from the patient's perspective implies being confident, maintaining a sense of control, and recognising one's own responsibility as a patient (Larsson et al., 2011). Patients express a need to be listened to regarding knowledge of their own bodies and to be treated as valuable co-workers (Larsson et al., 2011; Tutton, 2005). Within the area of AF consultations, there is a lack of knowledge on patients' experiences of involvement.

Factors that hinder patient involvement have also been studied. Factors that restrict patient involvement include limited communication between nurses and patients, task-oriented nursing, and a lack of the knowledge and critical-thinking skills that are necessary for deeper reflection in nurses, which only occur with time and experience (Larsson et al., 2011). Other factors that restrict patient involvement include situations in which nurses treat patients in such a way that they feel neglected and perceive themselves to be helpless objects of a nurse's actions (ibid.). Patients who do not experience an equal relationship with nurses, or who receive insufficient information and respect from nurses, feel less involved (Eldh et al., 2006). In addition, environmental factors, such as a lack of privacy, an impersonal atmosphere, or time constraints, limit opportunities to invite patients to talk about their experiences and to have conversations with them (Proot et al., 2000).

Patient involvement in biomedical research

Within biomedical research, the term 'patient involvement' is conceptualised as an effective tool for health self-management and is described as a factor for maintaining an effective and person-oriented treatment plan (Barello et al., 2012). Biomedical research has primarily focussed on cognitive processes related to a patient's experience of involvement and degree of health knowledge, and the importance of involving patients in learning processes aimed at promoting their self-care ability. Patient involvement within biomedical research is conceptualised as a 'learnable' and 'formable' attitude of the patients (ibid.). Terms such as participation, engagement, and activation have been formulated as strategies from a top-down approach to healthcare with the aim of mobilising patients to become involved in managing their own illnesses (ibid.). Patient involvement is particularly highlighted as a method for collection of information on the patient and is treated as a part of technology (Barello et al., 2012; Clinch and Benson, 2013). Contributions from research involving the medical setting also include supporting the use of tools that can facilitate patient involvement in SDM (e.g.,

option grids (Tsululidze et al., 2015) and decision aids, which are tables that summarise the pros and cons associated with different treatment options) (van der Weijden et al., 2013; Hargraves and Montori, 2014). Using decision making tools can affect patient involvement in decisions (Légaré et al., 2012; Elwyn et al., 2010).

The main focus of previous research in communication studies on patient involvement in consultations and decision-making processes, particularly in relation to medical treatment decisions, has been on how patients participate explicitly by asking questions or requesting information during consultations (Sarangi and Slembrouck, 2014). The strongest predictors of patient involvement are situation-specific, namely the clinical setting and the physician's communicative style (Street et al., 2012). Street et al. showed that female physicians were more likely to use supportive talk than their male counterparts. They also showed that physicians generally used less supportive talk with non-white patients than they do with white patients. Additionally, more active participation in patients results in more facilitative communication from physicians and they are more likely to be educated (Street et al., 2005).

A further aspect that is emphasised in the literature includes that of concordance as a particular type of patient involvement in consultations (Ijäs-Kallio et al., 2010). Concordance stresses the importance of incorporating the patient's own experiences, opinions, values, preferences, and beliefs in the evolving process of the consultation and medical decision making (ibid.). Peräkylä et al. (2007) suggested the following important components of patient involvement in the medical setting. By providing the reason for the visit and proposing explanations for aspects of the patient's illness, the patient influences the development of the consultation's agenda. Important components include how large a role a patient plays in the medical reasoning process, and how well health professionals provide a patient with information on diagnosis, prognosis, and treatment options. The patient's opportunity to express emotion, how health professionals respond to this display, and a patient's level of influence in the decision-making process are also important components of patient involvement in the medical setting (ibid.). Elwyn et al. (2014) thought that there should be collaborative deliberation with the patient.

In summary, the term 'patient involvement' in biomedical research has primarily focussed on cognitive processes related to a patient's experience of involvement and the degree of health knowledge, as well as the importance of involving patients in learning processes aimed at promoting their self-care ability. In nursing research the term 'patient involvement' is defined as patients' self-awareness (Barello et al., 2012). Nurses are encouraged to evaluate the patients' emotional status, perspectives, and possible choices, and to incorporate these in the planning and execution of care (ibid.).

Prerequisites for patient involvement

The patient's interest in being involved and decision-making roles are recognised in research (Caress et al., 2005; Florin et al., 2008; Sainio et al., 2001; Barello et al., 2012; Collins et al., 2007). Some patients exceed their preferred level of involvement, while others are passive, perhaps because of fear or a perceived lack of knowledge (Collins et al., 2007). Therefore, patients' preferences for involvement in decision making are not uniform. Preferences range from passive to more active roles, and vary according to conditions pertaining to the individual's internal and external factors, both of which are important.

An example of an internal factor is the patient's physical and psychological ability (Larsson et al., 2007). According to Barello and Graffigna (2015), a patient's involvement varies depending on the phase of the patient's illness. Patients initially fall into a state of emotional stress because of the unexpected onset of an illness that is outside of their control. In the next phase of the illness, patients are sensitive to all symptoms, such as anxiety and emotional reactions that are triggered in a patient who suffers from AF. The recovery phase occurs when patients have gained sufficient knowledge and behavioural abilities, and they feel sufficiently secure in their own emotional strength to be able to deal with their condition. In the final phase, the patients have completely come to terms with their condition and have accepted that their illness is simply one part of their possible self (Barello and Graffigna, 2015). Other internal factors include attitude towards self-care, cultural background, desire to be a 'good' patient, social status, level of medical knowledge, and previous hospital experience (Henderson, 2000). A further internal factor is age. Older patients tend to become involved in decision making less often than younger patients (Sainio and Lauri, 2003). An example of an external factor that affects a patient's desire to participate is the manner in which professionals provide information (*ibid.*). When the patient is regarded as a symptom or a problem to be solved, involvement cannot occur (Eldh et al., 2006).

A patient's interest in being involved also depends on the patient's attitude to his/her situation. Patients who want to have a more holistic view of their situation and the issue of whether health professionals are prepared to adopt a holistic view are examples of factors that affect patient involvement (Elwyn et al., 2014). With regard to involvement and decision making roles, a study showed that patients needed health professionals to help them choose what was best for them. Additionally, when patients participated in consultations, the decision-making role was outside of their area of responsibility, with decisions largely being the physician's responsibility (Elwyn, 2014).

Patients' preferences may also be affected by the type of decision they have to make. Patients prefer active roles in decisions regarding minor illnesses (Vermeire et al., 2002; Sainio and Lauri, 2003), but prefer passive roles in decisions regarding more serious illnesses (Say et al., 2006; Epstein and Street, 2011), or during severe exacerbation and intensification of a condition (Coulter and Collins, 2011). Factors that promote patient involvement in consultations include a desire for involvement, personality, ability to confront situations,

availability of a support person, adequate information, asking questions and acquiring information, courage, and self-interest. Factors that restrict patient involvement in consultations include poor physical/mental health leading to fatigue, an inability to receive information, ignorance, fear of the future, reality or authorities, increasing age, and lack of faith by patients for their own influence (Muller-Engelmann et al., 2013). Sainio et al. (2001) have produced this list of circumstances for patient involvement in consultations with patients suffering from cancer. However, within the area of AF consultations, there is a lack of knowledge on patients' circumstances for patient involvement.

Decision making

In the topic of decision making, researchers have emphasised the importance of incorporating patients' preferences and values together with clinical evidence for treatment, and how this encourages patient involvement in the decision-making process (Montori et al., 2013; Elwyn et al., 2014; O'Connor et al., 2007; Coulter and Collins, 2011; Politi et al., 2011; Cribb and Entwistle, 2011; Ijäs-Kallio et al., 2010; Stacey et al., 2010; Shepherd et al., 2008; Légaré et al., 2008; Moumjid et al., 2007; Deber et al., 2007; De Haes, 2006; Tutton, 2005; Street et al., 2005; Chewning et al., 2012).

There is a difference between the decisions that are made in nursing and medical decision making in nurse-led clinics. In AF nurse-led clinics, nurses make treatment decisions based on delegated responsibility within the medical knowledge domain. This responsibility is based on established guidelines and directives from specialists, such as cardiologists. However, examples of activities involved in the nurses' decision-making process in areas other than consultations include observations of signs that convey information on the patient's situation, confirmation of information gathered, and implementation of action strategies (Buckingham and Adams, 2000; Hedberg and Sätterlund Larsson, 2003). In nursing, the decision-making process can include a deliberation stage, which refers to the process of expressing and discussing treatment preferences (Stacey et al., 2010; O'Connor et al., 2007; Rashotte and Carnevale, 2004). More recent research has shown that the deliberation stage is becoming increasingly shared in the decision-making process within medical decision making (Elwyn et al., 2010; 2014). Communication research has attempted to assess the degree of sharing that occurs in the decision-making process between the patient and the health professional. Terms, such as informed consent, informed decisions, SDM, and patient choice, all appear in research where the patient participates in the decision making process. Researchers have proposed different models regarding decision making, three of which are discussed further in the following section.

Decision-making models

Research on decision making includes different types of decision-making models, which vary in relation to the roles that health professionals and patients play in the final selection of treatment. This thesis present three of these models as follows: the paternalistic model, the SDM model, and the informed decision-making model (Charles et al., 1999; Sandman and Munthe, 2010).

The paternalistic model

In the paternalistic model, which is the most common model, health professionals choose treatment after evaluating information regarding the patient's disease (Cribb and Entwistle, 2011). Health professionals alone assess the benefits and risks associated with each treatment option and the probabilities of various outcomes. They dominate the planning process while the patient passively listens (Charles et al., 1999). Health professionals dominate the agenda setting, identification of goals, and decision making. The patients' voices are secondary to those of the health professionals, and their medical conditions are defined in biomedical terms (Roter, 2000). The obligation of health professionals to act in a patient's best interests is based on the assumption that the patient's values and preferences are the same as those of the health professionals (Roter, 2000). The Moreau et al., (2012) study showed that elderly persons prefer the paternalistic model.

The SDM model

SDM is defined as a process in which clinicians and patients work together to select tests or treatments based on clinical evidence and the patient's informed preferences (Elwyn et al., 2014). The SDM model involves the provision of evidence-based information on options, outcomes, and uncertainties, with decision support counselling (Durand et al., 2015; Politi et al., 2013) and a system for implementing the patient's informed preferences (Coulter and Collins, 2011; Elwyn et al., 2014). SDM is an approach to care through which patients are helped to recognise that there may be more than one reasonable way of proceeding for treatment or tests, and how to choose between these reasonable alternatives (Légaré et al., 2008; 2012; Dolan, 2008; Makoul and Clayman, 2006). In SDM, health professionals and patients share their respective areas of expertise (e.g., scientific knowledge and personal preferences and experience). This is dependent on which approach is best for a particular patient in relation to the patient's specific situation and what aspects the patient values most (Elwyn et al., 2014). Negotiating and committing to a collaborative agreement regarding healthcare decisions also occur in this model (Elwyn et al., 2014). SDM also includes components, such as establishing the patient's views on treatment options and ensuring that the patient has an adequate understanding of the information provided (ibid.). The use of

SDM is promoted because of its potential to increase the use of beneficial treatments, reduce the use of treatments without clear benefits, and promote involvement of patients in their own healthcare (ibid). Research on decision making has provided evidence of the benefits of increased patient involvement and the use of SDM in consultations.

Another example of a component of SDM is discussing the degree of involvement in decision making that a patient wants (Hirsch et al., 2011). The Observing Patient Involvement (OPTION) scale, which evaluates the quality of sharing decisions, has yielded certain information regarding SDM (e.g., SDM does not often occur) (Elwyn et al., 2014; Couët et al., 2015). Research on implementation of SDM in treatment decisions and care has been carried out during the last 10 years and is still continuing (Elwyn et al., 2014). Achieving a shared decision with a patient becomes more difficult when the patient's preferences conflict with the strongest clinical evidence (McGuire et al., 2005). Therefore, the patient's preferences and values are of greater importance when there is an element of uncertainty surrounding a decision, although patients can be a vital resource in all decisions (Dolan, 2008). Development and use of decision-making aids for patients has been shown to improve the patient's knowledge, satisfaction, and involvement (Agoritsas et al., 2015; Montori et al., 2013). However, there are still a number of obstacles to be overcome when implementing SDM, such as time constraints (Légaré et al., 2008), the complexity of the matter at hand (Montori, et al., 2013), and a lack of information on standardised methods for promotion of clinical SDM (ibid.). The role of nursing in SDM has been studied (Lewis et al., 2014). Nurses are willing and prepared to share the decision-making process (ibid.). However, SDM does not function in all circumstances and SDM-based measures have not always been effective (Matthias et. al., 2013). SDM is complex, and the decision-making process stretches beyond the decision situation and involves a greater number of participants than simply the patient and the health professionals (e.g., the patient's relatives) (ibid.). Differences in patients' expectations of SMD have been found in family practices (Fullwood et al., 2013). Not all patients, such as those with a lower level of education, feel comfortable about having a choice (ibid.). However, research on this issue is conflicting, with one study showing that there is no problem with using SDM for patients with a lower level of education and/or lower social status (Montori et al., 2013). Patients with more negative prognoses or higher levels of anxiety tend to display less of a preference for involvement in SDM (De Haes, 2006; Goossensen et al., 2007).

Different instruments have been developed that are aimed at promoting patient involvement in SDM. The OPTION scale is an instrument that assesses the extent to which professionals involve patients in the SDM process (Elwyn et al., 2005). This scale includes aspects, such as whether professionals have explained the advantages and disadvantages associated with the various treatment alternatives, examined the patient's expectations and misgivings, checked the patient's level of understanding, and identified the patient's preferences regarding the decision (Elwyn et al., 2005). The OPTION instrument, which was developed by Elwyn et al. (2005; 2010), consists of 12 items that focus on methods used by the physician or nurse with the aim of including his or her patient in the decision-making process. The skills associated

with the OPTION tool have been discussed and revised (Elwyn et al., 2005; 2014) to actively facilitate communication between the clinician, the patient, and other interested parties during all parts of a decision. One criticism of the OPTION tool is that it tends to focus on the observable forms of behaviour rather than whether the patient feels involved in decision making regarding care and treatment. This instrument has been translated to Swedish by the author of this thesis and is attached as an appendix to this thesis (Appendix 1). In one of the studies in this thesis (study IV), an interview guide was developed on the basis of OPTION.

In the area of AF care, to evaluate the effects of time in the therapeutic range, educational and behavioural interventions for oral anticoagulation therapy have been used in patients with AF. For patients with AF, the decision-making conflict regarding warfarin was reduced when decision aids were used in the decision-making process (Clarkesmith, 2013). Interventions that reduce the decision-making conflict between patients with AF and professionals involved in the consultation regarding warfarin include educational measures, decision-making aids, and self-testing, as well as education of the patients (Elwyn et al., 2013; Tiedje et al., 2013; Agoritsas et al., 2015).

The informed decision-making model

In the informed decision-making model, health professionals play no role in the decision-making process beyond the provision of information on treatment and care (Ishikawa et al., 2013). The patients are treated as purchasers of services who are solely responsible for their own decisions. This type of patient–professional relationship has also been conceptualised as an ‘informed choice model’ or ‘consumerism model’ (Ishikawa et al., 2013). Information that is provided to the patients is viewed as a saleable commodity, and professionals are expected to deliver it according to the wishes of the patient. In this type of patient–professional relationship, the patient sets the goals and the agenda for the visit, and the patient takes full responsibility for the decisions made based on the information provided by the professionals. The role of the professionals in this context is limited to that of technical consultants who provide information and technical services to satisfy the needs of the patient. Providing information is viewed as the professionals’ primary responsibility (ibid.). This model presupposes that patients need to understand all of the relevant information on the evidence available regarding the benefits and risks associated with various treatment alternatives. Additionally, the patients’ primary source of information on medical/scientific aspects of their disease and treatment options is their health professionals. However, the patients alone participate in the deliberation process and ultimate decision making (Charles et al., 1999). In the informed decision-making model, the patients make the decisions after they have received all of the relevant information regarding benefits, risks, and alternative treatment options (McGuire et al., 2005).

The interpretation of information as something that health professionals can provide to the patients, as described in the informed decision-making model, means that health professionals

assume a monological approach in this model. Patients need to be in possession of the necessary information, and they also need to be able to process that information in a manner that truly reflects their preferences (Entwistle and Watt, 2006; Cribb and Entwistle, 2011). Reasoned choices that are consistent with an individual’s beliefs can be made by rational individuals using relevant information on the advantages and disadvantages associated with all possible courses of action (Wirtz et al., 2006). The three decision-making models described above are also illustrated in Figure 1 below.

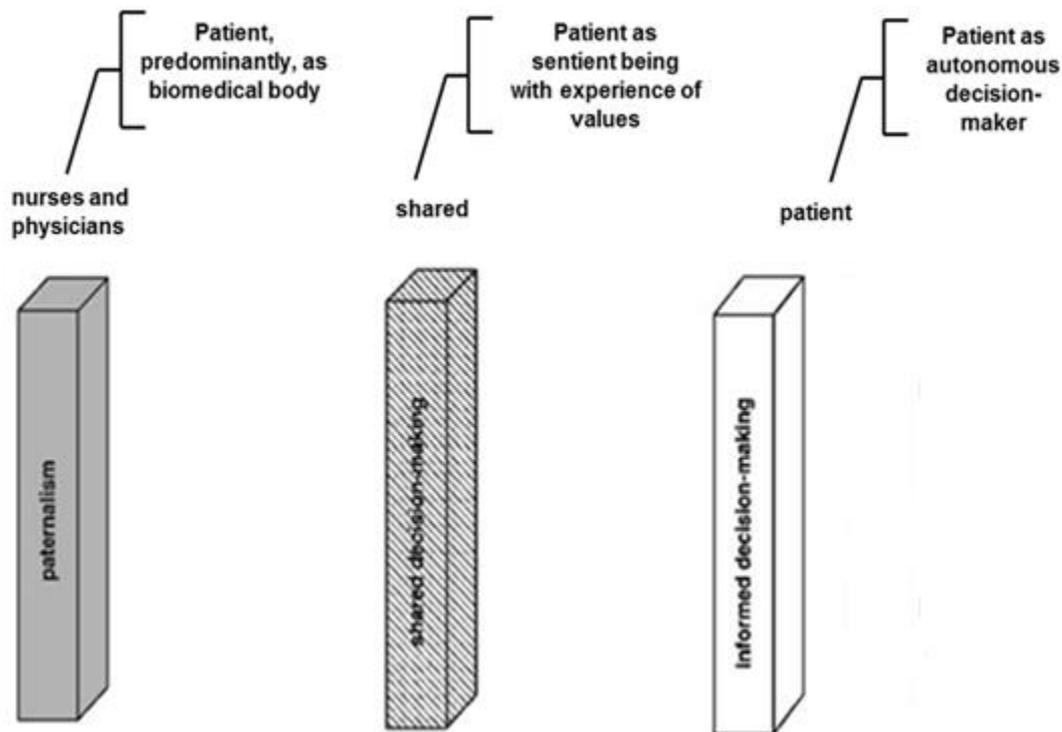


Figure 1. Decision-making models by Wirtz, Cribb, and Barber (2006), modified by the author of this thesis.

Summary of the conceptual bases of the thesis

The conceptual bases in this thesis are communication, involvement, and decision making, and the relationship that exists between these concepts. With regard to the concept of communication, this thesis highlights two different perspectives to produce a meta-analysis of the studies that are included in the thesis. According to the first perspective of monologism, communication involves the transfer of information from a sender to a recipient. In this thesis, the senders and recipients are health professionals and patients, respectively. According to the second perspective of dialogism, communication between health professionals and patients is an interaction that facilitates creation and exchange of meaning. Both perspectives are based on the assumption that a relationship is constructed between

patients and health professionals. The monological perspective on communication is based on a dualistic-reductionist paradigm that attempts to reduce the experience of illness to a system of diagnoses. However, the dialogical perspective is based on a holistic–humanistic paradigm, which more closely addresses the patient’s experiences of his/her illness, and not just the diagnosis. The aim of communication in this case is achievement of common understanding and resolution of problems.

Holistically understanding the patient in the consultation involves person-centred communication and examining the patient’s primary reason for the consultation, as well as his or her concerns and information needs, including emotional needs. Monologism exists in consultations between patients and health professionals when the aim is to inform patients about their disease and treatment. In contrast to monologism, dialogism exists in consultations between patients and health professionals when the patients’ and health professionals’ knowledge about the disease and treatment is shared between the participants.

The interaction that occurs between patients and health professionals in consultations is considered as being rooted in a power relationship. Mishler’s (1984) premise that communication through the medicine voice leads to non-involvement of patients is used to gain a better understanding of this power relationship. Mishler (1984) refers to two alternative ways of understanding and discussing problems in consultations as follows. The ‘lifeworld voice’ localises problems within the patient’s personal and sociocultural contexts. The ‘medicine voice’ frames these problems within the technical biomedical model and focusses on symptoms and aetiology, and the treatment of specific diseases. According to Mishler (1984), consideration of the dominance of professionals’ biomedical voices and patients’ predispositions to place their experiences of illness into their lifeworld is important (the patient’s everyday life). This thesis uses the concepts of communication, person-centred communication, and institutional communication to obtain a better understanding of how involvement and SDM are created and appear in consultations. Patients’ preferences for involvement in decision making are not uniform. These preferences range from passive to more active roles and vary according to conditions pertaining to the individual’s internal and external factors, both of which are important. In this thesis, the concept of decision making is viewed as a communicative process in the relationship between patients and health professionals.

Research on decision making includes different types of decision-making models, which vary in relation to the roles that health professionals and patients play in the final selection of treatment. The degree of sharing that occurs in the decision-making process is discussed in this thesis against the background of three decision-making models: the paternalistic model, the SDM model, and the informed decision-making model. The roles within the patient-professional relationship that define the nature of the communication with the patient are discussed along with the objectives of the consultation when involving patients. Neither person-centred communication nor SDM is fully integrated into the care system’s current organisational culture (McCormack et al., 2011).

GENERAL THEORETICAL PERSPECTIVE

Social constructionism

The theoretical perspective of the thesis is social constructionism (Berger and Luckmann, 1991). According to the theory of social constructionism, the behaviour of individuals is formed through social interaction with their environment, and an understanding of the social world is achieved through the perceptions of individuals when they interact with one another (ibid). This means that social construction of involvement in decision making occurs through communication. In particular, this theoretical perspective was used in the discussion of the findings in this thesis. According to Linell (2011), communication can be understood with a dialogic approach, and patients and health professionals construct the meaning of involvement in decision making through their unique experiences of interacting with each other. Patients and professionals have different points of view from which to discuss the same health problems during consultations, within which different perspectives and understanding can occur. Communicative construction of involvement in decisions occurs within the framework for institutional discourse in an organisational context (i.e., consultation). In this thesis, organisation, similar to communication, is considered to be mutually constructed by individuals and a collective (Berger and Luckmann, 1991).

The theory of social constructionism considers a medical explanation by a health professional to be just as much of a social product, rather than a value-neutral fact (Ishikawa et al., 2013). Conflict between patients and professionals arises from asymmetry in power and the inequality that exists between them. Social constructionists view such a conflict as a consequence of a fundamental gap between the patient's experience of his/her illness and the manner in which the professionals understand it in terms of disease. The conventional biomedical approach is often criticised for placing too much focus on the disease itself, while ignoring the person who has the illness (Lumpton, 2012). A consultation can be viewed as an environment in which the views and opinions of the patient and the professionals work together in an exchange of values. From a social constructionist perspective, communication and involvement in decision making must be operationalised in the interaction that occurs between patients and professionals within a specific context, rather than the independent behaviour of each party.

RATIONALE

The overall aim of this thesis is to contribute knowledge on communication between patients and nurses/physicians, focussing on how patients and professionals create involvement in decision making. These issues have not been previously studied in the specific context that is addressed in this thesis, namely consultations in cardiology between patients with AF and health professionals. In previous research, communication-related behaviour of patients and health professionals has been studied in interventions aimed at supporting SDM. Previous studies have also focussed on the perspective of risk reduction and testing the effectiveness of decision-making aids. To understand how patients and professionals create involvement in decision making in consultations, more knowledge on the following issues is required:

- Communication that occurs between patients with AF and health professionals in consultations (studies I and II).
- The manner in which communication, patient involvement, and decision making are related (studies I and II).
- Incorporation of patients' voices and perspectives into consultations (studies I, II, and III).
- The patients' perspective on patient involvement in consultations on treatment and the related decision making (study III).
- The health professionals' perspective on patient involvement in consultations on treatment and the related decision making (study IV).

3 AIMS

The overall aim of this thesis is to contribute knowledge on communication between patients and nurses/physicians, focussing on how patients and professionals create involvement in decision making in consultations. This overall aim was examined in four studies with the following specific aims and research questions:

Study I

To describe (i) the topics that participants discuss, (ii) the use of discursive space in consultations between patients with AF and their nurses and physicians, and (iii) the frequency with which patients and nurses/physicians introduce the identified topics.

- How is the consultation constructed considering its activity, structure, and function?

Study II

To describe the types of resistance when patients resist treatment with warfarin, and how cardiologists respond to such resistance.

- Which sequential variations were identified when patients resisted treatment? How did the cardiologists respond to patient resistance?

Study III

To examine how patients describe involvement and communication about decision making regarding treatment in consultations with nurses and physicians.

- How do patients describe involvement and communication about decision making?

Study IV

To examine how cardiologists describe their views on patient involvement regarding AF treatment with patients and their views on efforts to involve patients with AF in treatment decisions.

- What are cardiologists' impressions of communication and patient involvement in treatment decisions in consultations? What effort do they make to involve patients with AF in treatment decisions and how do they handle decisions?

4 METHODS

DESIGN

This thesis is based on empirical data from four studies (I, II, III, and IV), which were epistemologically based on a qualitative approach. These studies are based on a belief system that the study of human meaning involves interpretation of human experiences (Saldana, 2003). This thesis assumes a caring science perspective. The data for studies I and II were derived from video-recorded consultations between patients with AF and nurses/physicians in 2009 at nurse-led outpatient cardiology clinics at six hospitals as follows: one university hospital and five county hospitals located in different parts of southern Sweden. The data for study III were derived from interviews with patients after videotaped consultations at nurse-led outpatient cardiology clinics. The data for study IV were derived from interviews with cardiologists at four cardiology general clinics in hospitals as follows: two university hospitals and two county hospitals located in different parts of southern Sweden. An overview of the research design, aims, data resources, and data analysis in each study is shown below (Table 1).

SETTINGS

Data were collected at nurse-led outpatient clinics for studies I–III and at general cardiac care units for study IV. However, there is no statistical information on how many Swedish hospitals have such nurse-led outpatient AF clinics; an unofficial estimate of the number in Sweden is 20–25. There are no official documents describing the agenda for nurse-led outpatient AF clinics. Consequently, the respective roles and duties of nurses and cardiologists vary from clinic to clinic. One description of the functioning of a clinic in southern Sweden was as follows. The care process for nurse consultations was based on planned visits to the nurse-led clinic and occurred 3 months after the patients had been diagnosed. At the consultations, which took approximately 30–45 minutes, the nurses performed and documented electrocardiographic monitoring and the effects of cardioversion. Planned consultations with the physicians were generally shorter with an approximate duration of 10–40 minutes. Consultations that were performed by the nurse also included assessment of symptoms and signs, as well as questions related to AF treatment. When patients needed counselling and support on a level that was not within the nurses' authority, the nurses were obliged to refer them to physicians (personal communication, 23 October 2012).

Table 1. Design, aims, data resources, and data analyses of studies I–IV.

Paper	Design and aims	Data resources/sample	Data analysis
I This study is published	Explorative, descriptive Aim: To describe (i) the topics participants talk about; (ii) the use of discursive space in consultations; and (iii) the frequency with which patients and nurses/physicians introduce the identified topics.	Videotaped consultations (n=23) with patients with AF and nurses/physicians	Content analysis and dominance analysis
II This study is published	Explorative, descriptive Aim: To describe the types of resistance that patients exhibit when resisting treatment with warfarin, and how cardiologists respond to such resistance.	Videotaped consultations (n=11) with patients with AF and physicians	Conversation analysis
III This study is published	Descriptive Aim: To examine how patients describe involvement in and communication about decision making regarding treatment in consultations with nurses and physicians.	Interviews (n=23) with patients with AF	Qualitative Content analysis
IV Manuscript	Descriptive Aim: To examine how cardiologists describe their views on patient involvement in atrial fibrillation treatment decisions, their perceptions regarding efforts to involve patients and how they handle decisions.	Interviews (n=10) with cardiologists	Qualitative Content analysis

PARTICIPANTS

Participating health professionals and recruitment procedure

The participating health professionals in studies I and II were nurses and physicians at nurse-led outpatient clinics with experience in cardiology. The studies used strategic selection to ensure a broad sample with maximal variation, thus enabling description of different ways of communication and interaction (Polit and Beck, 2010). Variation in sex, age, and clinical experience of cardiology guided the selection of the participating nurses and physicians at the various hospitals. Before the study, an introduction with information on the study, including means of data collection and its purpose, was provided to potential professional participants in each clinic to motivate and instruct these professionals. Potential participants were also allowed to phone the researcher when needed. Nurses and cardiologists chose to be involved on a voluntary basis. One hospital declined because the professionals did not want to be videotaped. The participating professionals were regular staff members who were on duty as per usual at the time of data collection. The professionals gave written consent for videotaping.

The participating health professionals in study IV were physicians with experience in cardiology. Participants were recruited at four cardiology general clinics in Sweden from January to December 2014. The cardiology clinics were selected based on localisation and size, focussing particularly on university and county hospitals, thus enabling description of different views (Polit et al., 2010). Potential participants were contacted via e-mail with an explanation of the goals of the study and an information letter. If an interest in participation was expressed, a 1-hour appointment was scheduled. The participants were asked to consent to participate in the study and later received an explanation about the aim of the study in more detail, and were asked to give written consent.

Participating patients and recruitment procedure

Participating patients in studies I, II and III had AF and were selected on the basis of sex, age, education, type of AF, time since diagnosis, type of planned visit (i.e., early re-consultation or routine follow-up), treatment regime, and ability to communicate in Swedish. Three accompanying spouses were present during their partners' consultations. Data regarding the patients' characteristics in all consultations ($n = 23$) are shown in Table 3. The professionals then sent invitations to participate in the study by letter to their patients. These invitations included information on the aim and method, which involved videotaping, and described the themes of the project. The professionals repeated this information verbally during the consultations. They informed each patient about the purpose of the study and how the researchers would use the video recordings. Each patient was provided with the researcher's contact information in case they had any questions concerning the study or their participation in the study. All of the patients agreed to participate in the study and gave their written

consent. The professionals informed the patients that they had the right to cancel their consent without specifying their reasons for doing so.

DATA COLLECTION

In study I, the sample consisted of a total of 23 videotaped consultations (12 consultations between patients with AF and nurses, and 11 videotaped consultations between patients with AF and physicians). Patients were strategically selected by five nurses and five physicians who were responsible for the consultation, with the intention of achieving variation in the data (Saldana, 2003) based on sex, age, education, type of AF, time since diagnosis, type of planned consultation (early re-consultation or routine control), treatment regime, and ability to communicate in Swedish. The participants were patients with a variety of forms of AF, both men and women, from different-sized hospitals. An overview of the participants in study I is shown in Table 2. An overview of the characteristics of the patients (n = 23) who participated in consultations with nurses and physicians, and the characteristics of health professionals are shown in Table 3.

Table 2. Number of participants (patients and professionals) in study I.

Number of consultations	Number of patients	Number of professionals	Number of hospitals
23	23 10 women / 13 men	10 6 women (4 nurses / 2 physicians) 4 men (1 nurse / 3 physicians)	6 (1 university and 5 county hospitals)

Table 3. Characteristics of the patients (n = 23) who participated in nurse/physician consultations in study I.

Variables	Total sample N=23	Nurse consultations n=11	Physician consultations n=12
Sex, n (%)			
Male/Female	10 (43)/13 (57)	6 (55)/5 (45)	4 (33)/8 (67)
Age, Mean years (range)	72.6 (37-90)	70.7 (37-79)	74.4 (44-90)
Education, n (%)			
Nine-year compulsory school	7 (31)	4 (36)	3 (25)
Upper secondary school	7 (31)	4 (36)	3 (25)
University	9 (39)	3 (27)	6 (50)
Time since diagnosis of AF, n (%)			
Less than 6 months	8 (35)	6 (55)	2 (17)
1 to 2 years	5 (22)	3 (27)	2 (17)
2 to 5 years	1 (4)	0	1 (8)
More than 5 years	9 (39)	2 (18)	7 (58)
Type of AF, n (%)			
Paroxysmal	17 (74)	9 (82)	8 (67)
Persistent	3 (13)	1 (9)	2 (17)
Permanent	3 (13)	1 (9)	2 (17)
Treatment, n (%)			
Medication	16 (4)	4 (36)	12 (100)
Cardioversion	9 (36)	6 (55)	3 (25)
Pacemaker	3 (13)	2 (18)	1 (8)
Comorbidities, n (%)			
Hypertension	12 (52)	4 (36)	8 (67)
Diabetes mellitus	2 (9)	1 (9)	1 (8)
Stroke	1 (4)	1 (9)	0
Ischemic heart disease	3 (13)	2 (18)	1 (8)
Transient ischemic attack	1 (4)	1 (9)	0
Hypothyreosis	2 (9)	1 (9)	1 (8)

In study II, the sample consisted of 11 videotaped consultations between patients with AF and physicians (same as described above, see Table 3). The consultations with nurses were not included in study II. All consultations in which the conversations between patients and physicians involved warfarin were included. The term ‘cardiologists’ was used for physicians in study II as all participating physicians who had this specialty. An overview of the participants in study II is shown in Table 4. The characteristics of consultations and participating patients (n = 11) and physicians (cardiologists) in study II are shown in Table 5.

Table 4. Number of participants (patients and cardiologists) in study II.

Study	Number of consultations	Number of patients	Number of cardiologists	Number of hospitals
II	11	11 7 female / 4 male	5 2 female cardiologists 3 male cardiologists	5 (1 university and 4 county hospitals)

Table 5. Characteristics of consultations and participating patients (n = 11) and physicians (cardiologists) in study II.

Consultation number	Characteristics of the patients							Characteristics of the cardiologists	Characteristics of the consultations		
	Sex and age	Disease characteristics	Co-morbidity	Time since diagnosis	Marital status	Education	Warfarin treatment	Sex and clinical experience in cardiology	Hospital type	Consultation type	Total length of consultation
C1	Female, 80-90	Paroxysmal	HT	0,5 years	Widow	Nine-year compulsory school	Initiation of Warfarin	Male, 19 years of experience	County	Revisit	22 min 13 s
C2	Female, 70-80	Paroxysmal	_	5 years	Married	University	Initiation of Warfarin	Male, 19 years of experience	University	Revisit	25 min 45 s
C3	Male, 70-80	Paroxysmal	HT	5 years	Widower	Upper secondary school	On going	Female, 20 years of experience	University	Revisit	36 min 00 s
C4	Female, 80-90	Paroxysmal	HT	5 years	Widow	Upper secondary school	On going	Female, 20 years of experience	County	Revisit	31 min 31 s
C5	Male, 80-90	Paroxysmal	HT	5 years	Married	University	On going	Male, 30 years of experience	County	Revisit	09 min 50 s
C6	Female, 60-70	Paroxysmal	HT	5 years	Widow	Nine-year compulsory school	Initiation of Warfarin	Male, 5 years of experience	County	Revisit	20 min 42 s
C7	Female, 70-80	Paroxysmal	HT/IHD	3 years	Single	University	On going	Male, 30 years of experience	County	Revisit	10 min 39 s
C8	Male, 60-70	Permanent	HT	6 years	Married	Upper secondary school	On going	Female, 8 years of experience	County	Revisit	38 min 12 s
C9	Female, 80-90	Persistent	HTs	1 year	Widow	Nine-year compulsory school	On going	Female, 8 years of experience	County	Revisit	28 min 21 s
C10	Female, 70-80	Paroxysmal	_	5 years	Widow	University	On going	Female, 8 years of experience	County	Revisit	29 min 45 s
C11	Male, 40-50	Persistent	HT/DM	2 years	Married	University	On going	Female, 8 years of experience	County	Revisit	33 min 23 s

Abbreviations: DM = diabetes mellitus; exp = experience; HT = hypertension; IHD = ischemic heart disease.

In study III, the sample consisted of 22 interviews with patients directly after the videotaped consultations between patients with AF and nurses and physicians, see Table 3. Potential participants in the study group were identified by experienced physicians and nurses in cardiology, and were strategically selected (Polit and Beck, 2010). One of the patients in those 23 videotaped consultations refused to be interviewed without explanation.

In study IV, the sample consisted of a total of 10 cardiologists who were interviewed to examine their experiences and views of patient involvement in AF treatment decisions. The interviews were conducted at the participants' workplace, within their office. Interviews were recorded using a digital audio recorder. The interview guide (see Appendix 1) was based on topics that were relevant to patient involvement as inspired by the OPTION instrument, a shared decision-making model developed by Elwyn et al. (2005). The OPTION instrument consists of 12 items that focus on methods used by the physician or nurse to include his or her patient in the decision-making process. Respondents were asked to reflect on each item addressed, including factors influencing patient involvement in the decision for treatment of AF. The duration of the interviews was 20–40 minutes. Potential participants were contacted via e-mail with an explanation of the goals of the study and an information letter. If an interest in participation was expressed, a 1-hour appointment was scheduled. The participants were asked to consent to participate in the study and later received an explanation about the aim of the study in more detail. During the meetings, they were asked to give written consent. An overview of the characteristics of the participants in study IV is shown in Table 6.

Table 6. Characteristics of the participants in study IV (n = 10).

Characteristics	Interviews with cardiologists n=10
Sex, n	
Male/Female	7/3
Age, range years	30-57
Types of hospitals, n	
University	6
County	4
Clinical experience in cardiology	
Less than 2 years	
2 to 10 years	1
10 to 20 years	6
More than 20 years	3

Video recordings in studies I and II

The video recordings started before and ended after the actual visits. In all consultations, the researcher switched the video camera, which was already set up in the corner of the

consultation room, on and off. The researcher was not present in the consultation room, but talked with the participants before and after the consultations. The length of the consultations varied from approximately 20–90 minutes (an unusually long 90-minute consultation occurred because of complications with the patient’s pacemaker).

Interviews with patients in study III

Each patient was informed about the purpose of the study in the invitation letter to the participants. This letter was sent by the nurses and physicians organising the consultation. The interviewer explained the study in more detail and answered questions about the study, and interviewed the patient directly after the consultation. The interviews were conducted in a different room than the consultation room, where the patient and the interviewer could be alone. Interview questions were asked with a focus on how the patients viewed their involvement and communication regarding treatment decisions in their consultation. The duration of the interviews ranged from 20–40 minutes and they were audio-recorded.

Interviews with health professionals in study IV

The interview guide was based on topics that were relevant to patient involvement as inspired by the OPTION instrument (Appendix 1). Respondents were asked to reflect on each item addressed, including factors influencing patient involvement in the decision on treatment with AF. The OPTION instrument focuses on health professionals’ communication in including patients in the decision-making processes. The instrument is used in research today to assess consultations between patients and health professionals in several health care areas [28]. The OPTION instrument consists of 12 items, divided into five core dimensions: (1) Constructive interpersonal engagement, (2) recognition of alternative actions, (3) comparative learning, (4) preference construction and elicitation, and (5) preference integration. Informants were asked to reflect on each item, including factors influencing patient involvement in the decision about AF treatment. The interviews were audio-recorded, and considered important aspects of patient involvement in decision-making in AF treatment with questions such as: ‘What preconditions facilitate patient involvement in treatment decisions?’ and ‘How do you handle treatment decisions in consultations?’

DESCRIPTION OF METHODS AND DATA ANALYSIS

Analysis of dominance (study I)

Description of the method in study I

To accurately describe dominance of behaviour, understanding the power of dialogue is important (Linell, 1990). Linell defined power as a potential for exercising influence over other people's decisions, actions, and thoughts. Who has the dominant role in a dialogue varies and depends on many factors; power and dominance are not synonymous (Linell et al., 1988). Linell considered power in terms of underlying structure regulating interpersonal relations, whereas dominance is related to how the participants allocate the available space in the dialogue, its disposal space in quantitative terms. Dominating the dialogue involves dominating most of the territory, a domain, or 'the floor' (Linell et al., 1988). Asymmetric dialogues occur when interactions are dominated by one participant (Linell and Gustavsson, 1987). The patterns of dominance for each topic and participant in study I were investigated from the framework of an analysis that examined dominance in a quantitative manner (Linell and Gustavsson, 1987). In this type of analysis, researchers count all of the words of each participant for each topic that is identified in the consultations. According to quantitative dominance theory, the dominant participant is the person who talks most in terms of the number of words and turns compared with the other participant (Linell and Gustavsson, 1987). Linell and Gustavsson, (1987), distinguished four types of dominance. One of these types is quantitative dominance, in which the number of words spoken by each of the participants determines which of them is the dominant interlocutor, (i.e., the person who speaks the most). In this type of dominance, the average length of the turn also indicates who is dominant because continuing to speak restricts the other speaker's right to start talking and forces him or her to remain a listener. The number of turns of each participant is an indicator of quantitative dominance. Which participant chooses the topics characterises another type of dominance. The participant who dominates the choice of topics attempts to focus the content and to make it socially shared in discourse. Another type of dominance is strategic dominance in which the dominant interlocutor is the person who initiates the most strategically important contribution. Finally, there is interactive dominance, which involves distribution of initiatives and responses. By asking questions and taking initiatives that direct the other participant to respond in certain ways, the dominant participant controls communicative actions (Linell and Gustavsson, 1987). This restricts the other speaker's right to start talking and forces him or her to remain a listener.

Procedure of analysis in study I

A systematic description of the manifest content of the transcribed videotaped consultations was used to identify the topics that were discussed during the consultations between patients with AF and nurses/physicians (Krippendorff, 2004). First, video recordings were transcribed, checked, and compared once again with the original video recordings. Before

performing the analysis, words that had been heard inaccurately during the initial transcription and/or that compromised confidentiality of the patients were corrected or deleted. The analysis focussed on verbal activity and included verbal utterances. For the purpose of this study, non-verbal communication that accompanied the verbal utterances was not analysed. The researchers re-read the transcribed consultation texts several times to identify the topics (Krippendorff, 2004). Observational notes were made in the margins while reading the transcripts of each consultation. The continued analysis then involved re-reading the text and condensing it into meaning units. With regard to the context, the meaning units were condensed and coded into a description that was close to the text (i.e., the manifest content). The condensed text was then read and coded into sub-topics, and emergent sub-topics were continually noted. A process of reflection and discussion resulted in agreement on a set of sub-topics and identification of the final topics. Further analysis of the interpretations of the videotaped consultations did not reveal anything that contradicted the identified topics. The validation process was concluded by selecting extracts from each topic that corresponded to the description of the topic. Consistency was checked between the topics and the extracts that were selected to illustrate them.

Within the framework of analysis that treats dominance, quantitative and participatory aspects were used. The first analysis examined the dominance pattern in quantitative terms (e.g., the number of words that a certain participant used compared with another). The term 'word' means an independent orthographic unit in the written account of the consultation (Johansson-Hidén, 1998). Sounds such as 'eh' and 'er' were not counted as words, but all interrupted, incomplete words were counted. Sounds including backup 'mm hmm' were counted as words only if the participant had formulated a backup with emphasis, such as 'of course'; these were not counted as short backups (Linell and Gustavsson, 1987). The total number of words in each topic and the turns (e.g., a statement or complete thought) devoted to each topic, were calculated. The words and turns of the three accompanying spouses were included in the patients' discursive spaces.

To investigate another aspect of the dominance pattern, the second analysis examined the dominance pattern in study I focussed on distribution within each topic between the participants who were involved in the consultation. This analysis was based on the total number of turns, namely the number of statements by each participant about each topic (Linell and Gustavsson, 1987). The concepts 'turns' and 'utterances' were used synonymously and refer to the substance of what one speaker utters during the period of time that he or she directs the speech (Linell and Gustavsson, 1987). All turns for each participant for each topic in the consultations were counted. Transition between topics often occurs within the utterances before introduction of a new topic. Therefore, 10 words in the utterances immediately before and after the topic were included in the calculation of discursive space (Hedberg et al., 2007).

This analysis also included assessment of dominance in terms of who initiated each topic. This method examined another aspect of the dominance pattern. Therefore, the third analysis

examined the dominance pattern in study I was on the distribution of initiators within each topic of the statements. One way to initiate a topic is with a requesting initiative (i.e., a question). Another way is by a claiming initiative (i.e., to say something without requesting a response). A third way to initiate a topic was by a submissive initiative. This involves contributing content that is not expected by the other party, and is a more careful way of introducing new content into a conversation (Linell and Gustavsson, 1987). The distribution of initiators within each topic was calculated. The words and turns of the three accompanying spouses were included in the patients' discursive spaces. The concept of a discursive space stems from the questioning of discursive assumptions. In this thesis, the term 'discursive space' refers to the share of words and turns in the consultations.

Conversation analysis (study II)

Description of the method in study II

Conversation analysis (CA) is a method used in ethnomethodology (Heritage, 2010). The ethnomethodological view is that participants in any social situation establish social action in interactions (Sacks et al., 1995). The principles of CA concern how interactions are structurally organised and how the participants orientate to the situated context of their interactions (Heritage, 2010). The resultant detailed analysis allows a greater and more insightful understanding of how people communicate in consultations between patients and nurses/physicians (Heritage, 2010). In CA, sequence organisation is the basic method of organizing conversations. Sequences are at least two adjacent utterances that are produced interactively, and consist of at least two adjacent turns (Ten Have, 2007). Each adjacent pair of utterances has first and second pair parts. Second pair parts are projected and made relevant by first pair parts, and second pair part proposals are interpretations of first pair parts (Ten Have, 2007). During analysis, the main analytical CA question that is asked about any action produced by conversational participants is 'Why that now?' In answering this question, the conversation analyst formulates what the action does in relation to the preceding action in the conversation and what it projects about the next action (Schegloff, 2007).

CA was used to identify and describe how patients resisted treatment with warfarin and how cardiologists responded to resistance of patients. The analysis of interactional resistance in study II was related to preference organisation in conversations (i.e., preferred and dispreferred responses) (Pomerantz, 1984). Preference organisation refers to the ways in which a certain array of second pair parts becomes relevant and is oriented as expected after a first pair part is provided. A question makes an answer relevant, whereas a proposal makes its acceptance or rejection relevant. Acceptance of invitations is preferred, whereas their rejection is dispreferred. Characteristically, preferred responsive turns are produced immediately, whereas dispreferred responses are often produced with hesitations and delays (Pomerantz, 1984). The data were analysed in terms of sequence organisation, turn design, and turn taking (Schegloff, 2007) by asking questions, such as 'Which actions are performed

in this sequence?’ and ‘What action(s) are performed in the next turn?’ Actions can also include laughing, changes in body position or facial expression, eye gaze, and in some cases, pauses. The basic structure of each activity in a sequence was based on (1) an initiative, (2) a response, and (3) monitoring of the response. The minimal sequence was based on an adjacency pair (i.e., two adjacently placed turns, one after the other by different speakers) (Heritage, 2010; Schegloff, 2007). The analysis in study II was related to dispreferred responses (Pomerantz, 1984). A dispreferred action was a marked and unexpected response. Dispreferred responses characteristically occur as follows: (1) after a noteworthy delay; (2) with an explanation of why the preferred next action cannot be performed (rejection of a proposal is an example of a dispreferred next action); (3) with use of appreciation (invitations, suggestions); and (4) with apologies if considered appropriate (Pomerantz, 1984).

In the analysis in study II, distinction between passive and active resistance was performed. Stivers, (2005) distinguished two main categories of resistance: passive and active. Passive resistance includes silent gaps, nodding the head separately, and producing minimal, non-marked acknowledgements, such as ‘mm hmm’ In contrast, in active resistance, the participants implicitly or explicitly ask questions or challenge physicians’ treatment recommendations, either with counter-proposals or by expressing preferences for alternative treatments (Stivers, 2005). Only occurrences of active resistance were analysed in study II. Therefore, ‘resistance’ in study II means ‘active resistance’ according to this definition.

Procedure of analysis in study II

The procedure of analysis in study II was as follows. Initially, verbatim transcripts of all videotaped consultations between patients with AF and cardiologists were produced. All videotaped consultations together with the transcripts were reviewed and the activity sequences of interest (i.e., interactional active resistance and responses regarding warfarin treatment) were isolated. Because of the close links between active and passive resistance (Stivers, 2005), focus was placed on indications of active resistance owing to the fact that these can be clearly identified. In this analysis, interactional variations in sequences that dealt with expressions of active resistance to warfarin were identified. When occurrence of resistance was identified, each occurrence was compared with occurrences in other consultations. Each occurrence of resistance, as defined above, was counted as identified frequency of resistance. A total of 20 occurrences of resistance were identified in the other consultations (i.e., 0–4 occurrences per consultation). No resistance was identified in one of the 11 consultations. All identified occurrences of resistance in the sequences were transcribed in greater detail to examine aspects of talking for these features (i.e., overlapping talk and silence) using a simplified transcription according to Jefferson (2004).

Qualitative content analysis (studies III and IV)

Description of the method in studies III and IV

Researchers can use content analysis with either qualitative or quantitative methods, and in an inductive or deductive manner (Krippendorff, 2004; Hsieh and Shannon, 2005). Important concepts related to qualitative content analysis include manifest and latent content, unit of analysis, meaning unit, condensation, abstraction, code, category, and theme. When using qualitative content analysis, selecting the unit of analysis is a basic part of the procedure. Another basic task is deciding whether to focus the analysis on manifest (i.e., visible, obvious components) or latent content (i.e., underlying meaning of the text) (ibid). Manifest and latent content deal with interpretation. However, these interpretations vary in depth and level of abstraction. Creating categories or themes is characteristic of qualitative content analysis. A category is a group of content that shares a commonality; a category answers the question ‘What?’ and can be identified as a line throughout the codes (Krippendorff, 2004). A theme answers the question ‘How?’ and can be considered as an expression of latent content of the text because all data have multiple meanings (ibid).

Procedure of analysis in study III

For the analysis, verbatim transcripts of all 22 interviews were produced. They resulted in 235 A4 pages of singlespaced Times 12 text. The analysis was performed according to the qualitative content analysis procedure (Krippendorff, 2004). First, the transcribed interviews were read and checked regarding exactness by the first author (ES). Second, the transcripts were read multiple times, searching for statements describing experiences related to the aim. The sentences from the transcripts that shared the same meaning were condensed and coded. The codes were then transferred to a coding page, where similar codes were grouped together and, by comparing differences and similarities, subcategories and main categories were created. The categories were carefully reflected in order to detect new, more abstract dimensions to describe involvement and communication.

Procedure of analysis in study IV

Transcripts of all 10 interviews were analyzed according to qualitative content analysis (Krippendorff, 2004). The analysis focused on the respondents’ perceptions of patient involvement, as well their perceptions of their own efforts to involve the patients in AF treatment decisions during consultations, and how the cardiologists handled treatment decisions. Categorization constitutes a key element in this analysis. First, the transcribed interviews were read and checked. Subsequently, the transcripts were read multiple times, searching for statements describing experiences related to the aim. Sentences that shared the

same meaning were condensed and coded. The codes were then transferred to a coding page, where similar codes were grouped together. By comparing content differences and similarities between the codes, subcategories and main categories were created. Cardiologists' perceptions of patient involvement in shared decision-making can be described as frames or interpretation schemes, which people use when they interpret and understand situations (Hellström Muhli, 2003).

ETHICAL CONSIDERATIONS

The regional Medical Ethics Committee at Linköping University in Sweden gave permission to carry out studies I–III (Dnr. M8-09; Dnr. 2014/146-32). Ethical approval for study IV was obtained from the Regional Ethics Committee in Linköping, Sweden (Dnr. 2014/146-32). Ethical dimensions were considered according to the ethical guidelines for studies involving human subjects. Protecting the confidentiality, well-being, privacy, dignity, and self-determination of each individual is important (Williams, 2008). Consideration was also given to ethical dimensions in relation to ethical principles associated with videotaping of consultations (Beauchamp and Childress, 2001; Themessl-Huber et al., 2008). The first ethical principle is autonomy. The informed consent process allows patients to weigh up the risks and benefits of a procedure and determine whether they want to participate (Butler, 2002). All of the participants participated voluntarily and were told that they could withdraw from the study at any time without providing any explanation. Confidentiality was assured by written acceptance of the patients' voluntary, informed consent. Beneficence is the second principle. Patients wished to receive information on the project because they believed that this was for the greatest good. Nonmaleficence, the third principle, is that participants should not be harmed. In clinical research, this principle is addressed by disclosing the risks associated with being a participant in a research project, and explaining that care and treatment do not depend on participation in the study. The videotaped consultations were kept in a secure location. The final principle is justice. The principle of justice addresses respect for people's rights and for morally acceptable laws (Beauchamp and Childress, 2001). Participants should experience well-being, privacy, and dignity. Additionally, ensuring the anonymity of participating patients and health professionals is important (Priest and Roberts, 2010). One of the strategies used to achieve anonymity was to protect all identities by not using names in the transcriptions, in accordance with Swedish Research Council guidelines. All names of participants, places, and other details were removed when reporting research results for publication. Some extracts from consultations between patients and professionals (study II) have been published, but only after ensuring that the anonymity of the participants was protected in these extracts. An example of an ethical dilemma during the data collection phase is that the participants may feel pressured to communicate in a manner that supports the research goal. In this thesis, the dilemma was promotion of patient involvement and participation in treatment decisions. Based on an ethical perspective, the researcher and the participant feel a sense of duty to the research project. Consequently, the researcher must be

clear in providing information to the participants regarding how and why the data will be used. Additionally, the well-being of the persons involved is more important than anything else. Such protection was provided throughout these studies, not only during the data collection phase, but also during data processing, analysis, and publication. Based on a utilitarian perspective, a project can be of benefit to the well-being of many patients. The code of ethics regarding evaluation and research includes avoiding conflicts of interest and dual relationships with participants (Polit and Beck, 2010).

5 FINDINGS

STUDY I

The research question in study I was ‘How is the consultation constructed considering its activity, structure, and function?’ Study I primarily dealt with the topics that were discussed in consultations, and the distribution of the discursive space between them. The medical-driven agenda was dominant over the patient-driven agenda in the consultations between health professionals and patients with AF.

Four topics were discussed by nurses and physicians during the consultations as follows: ‘pathophysiology’, ‘treatment’, ‘diagnostic procedures’, and ‘activity’. In the nurse–patient consultations, an additional topic, ‘routines related to the physician’s responsibilities’, also emerged. The topics that were discussed in the consultations showed that patients and health professionals appeared to follow an implied agenda, a medically-driven agenda with communication that was largely monological in nature.

With regard to the number of words used and turns taken by the various participants, distribution of the discursive space was almost equal between nurses and patients, but it was unequal between physicians and patients. Nurses used 52% of the discursive space (14,294/27,581 words), while patients used 48% (13,287/27,581 words). In the consultations between patients and physicians, the physicians used 70% of the discursive space (32,737/46,989 words), while patients only used 30% (14,252/46,989 words). Study I showed that the patients appeared to be more active and talkative, and they took a more active role more often during consultations with nurses compared with physicians.

Patients were the dominant initiators of the topic ‘activity’, which was related to adaptation of activities in daily life in relation to AF. Even though health professionals initiated most of the topics that were discussed during the consultations, the patients were the initiators of the topic ‘activity’ in consultations with physicians and nurses. Patients in these situations appeared to want to discuss topics that were connected to their everyday knowledge.

STUDY II

The research questions in study II were (1) ‘Which sequential variations were identified when patients resisted treatment?’ and (2) ‘How did the cardiologists respond to resistance of patients?’ The types of patient resistance to accepting treatment with warfarin that were identified were divided into four categories: ‘giving reasons for their resistance’, ‘suggesting other treatment options’, ‘stating treatment preferences’ and ‘questioning or challenging the cardiologist’s treatment recommendations’. Table 7 shows an overview of the types of patient resistance that were identified in the consultations and the cardiologists’ responses, which were not subdivided according to the specific type of resistance.

Table 7. Types of patient resistance and the cardiologists' responses to them.

Patient's resistance to treatment	Cardiologist's response to resistance
Giving reasons for their resistance	Repeating the treatment recommendation
Suggesting other treatment options	Negotiation with the patient
Stating treatment preferences	Providing additional information about the proposed treatment
Questioning or challenging the cardiologist's treatment recommendations	Extending the explanation about the purpose of taking the medication

When the patients displayed resistance, they were thought to be displaying a desire to participate in their treatment decisions. Awareness of patients' resistance to treatment enables cardiologists to address the patients' experience-based views on their treatment and their individual concerns as part of clinical strategies that aim to increase a person-centred approach to medical intervention. Expression of desiring alternative treatment can be considered that the patient wants to be involved. The analysis showed that patients actively resisted the physicians' recommendations because of a feeling of insecurity. The patients were unsure of what the proposed treatment might entail. They withheld their approval as a means of gaining a better understanding of the potential risks associated with the treatment, although this withholding of approval could also have been an expression of the patients' desire to be involved. The patients' resistance did not alter the cardiologists' recommendations regarding warfarin treatment. Resistance can be considered as an expression of patients' anxiety or fear and a way for patients to display a desire to be involved.

Study II also examined how the cardiologists responded to patient resistance and how their response was expressed in communication. The cardiologists' responses to the patients' resistance included 'repeating the treatment recommendation', 'negotiation with the patient', 'providing additional information about the recommended treatment', and 'expanding their explanation of the purpose of the treatment'. The cardiologists' efforts were primarily focussed on convincing the patients to accept the proposed treatment. The cardiologists negotiated with their patients by recommending treatment. An example of this situation is that cardiologists recommended that patients should continue with their warfarin treatment because it provides good protection against stroke, and they told the patients that they did not need to have as many blood tests as they previously did. Another possibility that was

discussed was that of the patients being able to have their blood tests nearer to home and thus not need to travel to the hospital as often. The cardiologists reiterated the treatment recommendation by expressly formulating the risk factors that exist because of AF. The cardiologists also explained how it is possible to prevent new episodes of AF that could lead to more serious consequences, such as stroke. The cardiologists continued the discussion on treatment recommendations until their patients finally accepted them.

STUDY III

The research question in study III was ‘How do patients describe involvement and communication about decision making?’ In study III, patients with AF stated that they would need to acquire knowledge and build up their confidence and ability to become effectively involved in the decision-making process regarding treatment. Despite not being actively involved in decision making, the patients felt involved through experiencing supportive communication. In consultations with nurses, the patients felt involved when they received clarification and when preparing for and building up confidence in decision making. In consultations with physicians, the patients felt involved when they could cooperate in decision making, when acquiring knowledge, and when they felt that they were being understood. One common category was found in consultations with nurses and physicians where the patients felt involved when they had a sense of trust and felt secure during and between consultations. Study III showed that involvement for patients in consultations with nurses was related to gaining an understanding that the nurses contributed to understanding of the patients’ symptoms and how facts about the illness were connected to the patients’ life. This suggests the importance of inter-professional collaboration between nurses and physicians and how it can contribute to patient involvement during and in between consultations. Study III showed that being understood by the physician is a fundamental desire in relation to a patient’s feeling of security and that this is associated with power. This finding could be related to the physician being perceived as the person who is at the top of the hierarchy. Patients’ experiences and descriptions of involvement in study III were characterised by their feeling of being understood by the physicians and being trusted in terms of the experience they have with AF. The involvement of patients in physicians’ consultations meant being able to discuss the treatment, even when there was no question of the patient playing an active part in the making of decisions. Discussions in consultations helped the patients feel that they were cooperating with the physicians. This then contributed to a sense of involvement.

STUDY IV

The research questions in study IV were as follows: (1) ‘How do cardiologists describe patient involvement and communication related to SDM regarding AF treatment?’; (2) ‘What are their perceptions on efforts to involve patients in the treatment decisions?’; and (3) ‘How

do they handle treatment decisions?'. The cardiologists described how they viewed the matter of patient involvement in treatment decisions as frames of (i) ideology, (ii) experience, and (iii) responsibility. According to the cardiologists, the patient's involvement was affected by the cardiologist's experience and whether he or she as a cardiologist had a desire to involve the patient (i.e., whether the cardiologist believed the ideology of promoting patient involvement). The cardiologists reported feeling positive about the idea of patient involvement, but they also said that sharing the responsibility for decision making is difficult in practice. They expressed the belief that the patient being involved in the decision-making process is good, but they also confirmed that it is most often the cardiologist who makes the decision. They also considered that the manner in which cardiologists make decisions and how they document the treatment decision will change in the future. They believed that a shift in power towards the patient will occur and that they will meet better prepared and more well-informed patients in the future. They also predicted an increase in incorporation of preferences of the patients into treatment decisions. They believed that patients will explicitly demand increased involvement in decision making in the future, and they also referred to the fact that the new healthcare legislation requires patient involvement. For cardiologists, involvement was fact-based and involvement also meant obtaining factual knowledge from the patient. Therefore, involvement is an ability that is based on facts (e.g., facts about the patient and test results) and skill (examination methods, a pre-determined treatment goal). Study IV showed that cardiologists' contributions and efforts to involve the patients in AF treatment decisions could be described as features that are characteristic of professional assessment of patients' cognitive resources, their knowledge about AF and its treatment, and abilities and desires to be involved in making decisions on treatment for AF. Cardiologists stated that, by taking into account patients' feelings in the consultation and actively encouraging the patients to be involved, the cardiologists contributed to patient involvement.

In study IV, cardiologists stated that making treatment decisions is considered as a professional responsibility and treatment alternatives should be presented to the patient persuasively and in a protective manner. Cardiologists based their treatment decisions on clinical findings and guidelines for dealing with AF, with emphasis on the importance of warfarin treatment for preventing stroke. Health professionals take responsibility for their treatment decisions based on their medical world. The cardiologists did not always describe all treatment options for their patients, and they did not describe treatment options in a completely neutral manner. According to the cardiologists, the decisions that were made were based on evidence, and on local, national, and international guidelines. Evidence for some treatment options was described for the patient, but not in relation to all options. The pros and cons associated with all alternative treatment options were often not described for the patient. The cardiologists did not always share information about all treatment options because they felt that such information may be of limited value to some patients. All of the side effects of all medications were not described for the patients because some patients may have been frightened to hear about too many side effects. According to the cardiologists, they felt that it was risky to place patients, who were perhaps feeling vulnerable because of their illness, in

situations that involved making a decision. Asking the patient to make the decision was perceived as closing the door to conversations. The cardiologists felt that they could not let the patients make decisions about which they might not feel prepared or informed. The cardiologists were afraid of doing something wrong as a physician, and they did not want to risk exposing the patients to various risks.

6 DISCUSSION

DISCUSSION OF FINDINGS

A crucial issue in this thesis is how patients and professionals use communication to create involvement in decision making. In studies I–IV, on which this thesis is based, involvement could not be automatically created in consultations. In contrast, the opposite appears to have been the case in studies in this thesis in that the professional groups dominated the institutional conversations. In Mishler’s (1984) choice of language, the voice of medicine dominated the conversations, while the patients’ voice, (i.e., the voice of the lifeworld) was not listened to or even ignored. As a result, the possibilities for SDM were hindered rather than promoted. This finding is supported by Barry et al. (2001) who showed that the voice of medicine obstructed the patients’ voices and even interrupted them. Increased use of the lifeworld voice affects the quality of patient care and a more humane treatment of patients (Schoenthaler et al., 2015).

However, the patients’ lifeworld voices were not completely silenced. In two of the studies, there was a clear effort by the patients to become involved. In study I, the patients desired space, and in study II, there was resistance to the lack of answers from the dominant voice in relation to what the patient had to say. Furthermore, in study III, the voice of the lifeworld appeared in the form of a sense of satisfaction at understanding and being understood. However, the most common response was that health professionals attempted to transform the patients’ voices into the biomedical framework (Figure 2). This occurred by the cardiologists adopting a dominant position, by claiming that the patients were vulnerable and talking about their professional responsibility. This meant that the consultations were primarily shaped on the basis of a monological perspective, despite invitations to dialogue that were offered by the patients, and the professionals often said that they wanted more dialogue. Therefore, the consultations and the institutional conversations tended to be profession-centred rather than person-centred.

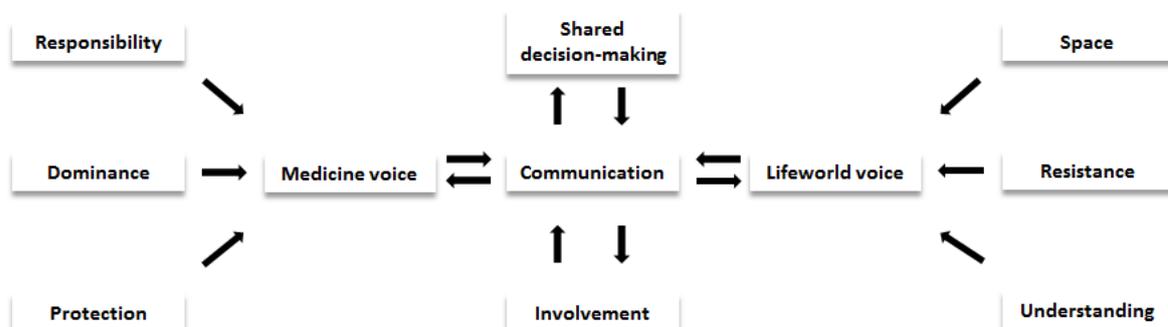


Figure 2. Institutional communication.

However, despite the dominance of the medicine voice, the voices of the medical world and lifeworld were sometimes able to become closer to one another in actual communication, both in the form of an endeavour to achieve involvement and in the form of actual creation of involvement. One interesting finding that supports this result was, as mentioned above, by wanting space in the consultation, patients showed that they wanted to be involved. Therefore, involvement, in line with social constructionism, cannot be defined as dualistic (i.e., something that either is or is not present). The desire for space by the patients, from a non-dualistic perspective, can be viewed as not only an endeavour to be involved, but also as a creation of involvement itself. Therefore, patients became involved through an actual demand to be involved. In studies I and II, involvement was created in the process of requesting space. This did not mean that the degree of involvement was complete from the beginning of the request. The degree of involvement continued to increase through further communication, which is in line with a study by Cahill (1996). This finding became particularly clear when the patients in study I became the dominant initiators of the topic 'activity', which is related to the difficulties and possibilities associated with adapting one's daily life to living with AF. Patients in this situation appeared to want to relate to topics that were connected to their everyday knowledge. The patients wanted to share these life changes with the health professionals, and they wanted to have space in the consultation so that their lifeworld voice could be heard. Therefore, incorporation of patients' voices and perspectives into consultations (studies I and II) created not only conditions for involvement, but also involvement itself.

Involvement means that attention can be paid to the patients' views, in relation to what it means to them to be sick (i.e., effects of illness on patients' everyday lives and their expectations regarding what should be done). Most couples for example, experienced a change in terms of roles and responsibilities within their relationships as a result of one person's heart disease (Dalteg et al., 2011). Experienced lack of communication, sexual problems, and feelings of overprotection; adaptation to the illness that was necessary on their part led to arguments or conflicts within their relationships (ibid.). If professionals had an opportunity to realize the importance of patients with AF dealing with lifeworld concerns, in terms of the patients' physical condition and mental state, this could lead to an increased sense of involvement in patients.

Creating of not only conditions for involvement, but also involvement itself, applies to another interesting finding that patients requested space by displaying resistance. Consequently, resistance can be viewed as not only an expression of patients' anxiety or fear, but also a way for patients to display a desire to be involved. In study II, the patients' resistance did not alter the cardiologists' recommendations regarding warfarin treatment. Resistance, as shown in the above model (see Figure 2), can be viewed as an expression of the patient's lifeworld. Therefore, awareness of patient resistance to treatment can enable cardiologists to address patients' experience-based views and the lifeworld as part of the clinical strategies that aim to increase a person-centred approach and involvement in medical intervention. Patients and health professionals can thus create involvement together through dialogue. The patients can express resistance and the health professionals can respond to such

resistance in a manner that creates dialogue between the medical world and the lifeworld. However, in study II, this situation did not occur because the cardiologists' efforts were primarily focused on convincing the patients to accept the proposed treatment. With regard to listening, in study IV, the cardiologists stressed the importance of repeating what the patients had said to them, thus helping the patients to understand that they had been listened to. This finding is in line with findings regarding the importance of listening (see below).

Health professionals did not always recognise resistance as a way for patients to conceal their concerns or their preferences regarding treatment objectives. Health professionals expanded their explanations of the purpose of medication in an attempt to convince the patients to accept it instead. Authors from previous studies have referred to this situation as a corrective reflex, which is often an expression of care (Miller et al., 2012; Street et al., 2009). Therefore, because professionals used this corrective reflex, they lost the opportunity to start a cooperative process. Elwyn et al. (2014) found that a good understanding of patients was based on collaboration between patients and healthcare personnel. For the difference between 'listening' and 'considering', they emphasised that repeating what a patient had said would help patients to understand that the professionals had listened to them (ibid.). Conversely, health professionals create openness on the part of the other person and create an opportunity to become aware of and identify a patient's resistance as ambivalence to his/her treatment. This then generates an opportunity for reflection when they meet the patient with an open and listening approach to the dialogue that occurs between them. McCormack et al. (2011) considered that using a person-centred approach in communication means finding a way of reaching decisions that are one's own and that express everything that one believes about oneself, one's values, and the world as a whole. Not considering resistance might create consequences. Lip et al. (2015) showed that under-prescription, low compliance with guidelines, and poor patient adherence to treatment have all been reported, and the perceived advantages and disadvantages associated with treatment alternatives affect the decision-making process when determining antithrombotic treatment. The background to resistance for patients with AF is often negative consequences of taking warfarin, including the requirement for regular blood tests, the need for changing food habits and limiting alcohol intake, and the cost of the drug if it is not covered by insurance. Other barriers also exist in the form of tension between primary and hospital care, logistical problems, personal and professional experiences, and the patient-professional relationship. By contributing their own values, patients can influence the decision-making process in relation to treatment with warfarin.

A third interesting finding, which is in line with a non-dualistic perspective on how involvement can be created, was that the patients in study III felt involved through experiencing supportive and confirming communication, despite not being actively involved in decision making. The patients felt involved when they had a sense of trust and felt secure during and between consultations. This was the case even though the patients' way of creating involvement was not in accordance with how the term is usually defined in the literature (Barello et al., 2012). For the patients, this was largely related to a sense of involvement that was created if they felt understood by the physician and felt that they were cooperating with the physician. Similar feelings appeared with nurses if they were achieving clarification when preparing for and building up confidence in decision making. This finding can be considered as a way to build up a patient's confidence and ability to become

effectively involved in decision making. A knowledge-sharing type of collaboration process created space to learn and promoted new understanding, and alternatives for action (Ström and Fagermoen, 2014). Consequently, according to the patients, involvement is created in terms of being understood, acquiring knowledge, cooperation, and discussion, even when there is no opportunity for the patient to play an active part in the making of decisions. Furthermore, for the patients involvement also appears to be created in terms of the importance of inter-professional collaboration between nurses and physicians during and in between consultations. Edwards and Elwyn (2006) and Butterworth and Campbell (2014) found that decisional responsibility did not align with patient preferences at that stage of a consultation. In contrast, patients with cancer show increased interested in SDM (Ernst et al., 2013). In patient groups (Briel et al., 2007) other than those with AF, taking an active part in clinical decision making in healthcare consultations is associated with sex, age, level of education, living conditions, and employment status.

A fourth interesting finding was that the professionals (i.e., cardiologists), referred to creation of involvement as some type of dilemma (study IV). They discussed their professional responsibility and the importance of protecting what they considered to be vulnerable patients as opposed to their reported positive feelings about the idea of patient involvement. They expressed the belief that involvement of patients in the decision-making process is good, but they also said that sharing the responsibility for decision making is difficult in practice. They also confirmed that the cardiologist is the person who makes the decision most often. This finding is supported by a study by Zeuner et al. (2014), who found that participants expressed general support for incorporating SDM into practice, but the participants had inconsistent beliefs about doing this. Health professionals also believed that a shift of power towards the patient will occur and that they will meet better prepared and more well-informed patients in the future. In this context, they also referred to the fact that the new healthcare legislation requires patient involvement. Health professionals' perspective on patient involvement has been studied in general practice (Wetzels et al., 2004) and in chronic heart failure in the German healthcare setting. Only a few potential strategies for improving the process of patient involvement have been mentioned (Pohontsch et al., 2015; Korteland et al., 2014). In study IV, the cardiologists viewed creation of involvement in a similar manner to the patients, in terms of taking into account the patient's feelings, actively encouraging the patient to be involved, and obtaining factual knowledge from the patient. However, the cardiologists' and the patients' views on creation of involvement were also different in one major point. The professionals emphasised involvement as a matter of SDM, while the patients emphasised the need to be involved in the communication process as such instead. The cardiologists described different methods of handling situations that they considered to be dilemmas in this context. One method was to view the patients as vulnerable because of their illness, and thus in need of protection. They did not always describe all available treatment options and they did not describe treatment options in a completely neutral manner. According to the cardiologists, placing patients in situations that involved making a decision was risky. The cardiologists felt that they could not allow the patients to make decisions on matters that they might not feel prepared for or informed. Therefore, the cardiologists problematized what is often understood as a dilemma. However, at the same time, they appeared to get caught in some form of inner monologue when they sought solutions to a dilemma that they perceived to exist, rather than communicating through dialogue to involve the patients in some form of

SDM. This finding is supported by Frongillo et al. (2013) who found that the type of recommendation was associated with involvement. Health professionals were less likely to present a view of the options when they provided a recommendation (ibid.). Information on risk is difficult to understand, and there are also psychological limits to the amount of information that patients are able to process, as well as practical limits in terms of the time and resources available to facilitate this processing (Llewellyn-Thomas and Trafford Crump, 2013). In light of all these limitations, communicating uncertainty may simply confuse patients and lead them to defer decision making to the clinician. This paradoxically diminishes, rather than enhances, patient autonomy (Han, 2013; Fraenkel, 2013; Robertson et al., 2011).

Communication may be strongly directed by a medically-driven agenda, but it also depends on the patient and what type of person he/she is. A study by Cousin et al. (2013) showed that the more sharing-oriented the patient is, the more satisfied he/she is with a physician who adopts a sharing-oriented style of communication. Heggland and Hausken, (2013) found that attitudes appear to explain why certain patients prefer a physician who uses a type of communication that is based on high levels of sharing, while other patients prefer a more directive-oriented style of communication (Heggland and Hausken, 2013). Communication between patients with AF and their healthcare professionals is also related to the connection between how other people are viewed and how language and actions are viewed. Elwyn (2014) showed that, in patients, a gain of information was more related to compiling data and treatment plans than with creating a dialogue, while a good understanding of the patients was more related to collaboration between patients and health professionals. Therefore, the studies by Cousin et al. (2013) and Elwyn (2014) support the cardiologists' views that involvement in SDM is a communication challenge.

RELATIONSHIPS BETWEEN COMMUNICATION, INVOLVEMENT, AND DECISION MAKING

The relationships between the concepts of communication, involvement, and decision making in this thesis are discussed below. This discussion is based on social constructionism, the holistic-humanistic paradigm, which is viewed as a non-dualistic perspective, and the institutional consultations that were studied. According to the theoretical perspective of social constructionism, concepts and meaning are socially constructed in communication. Reflection is created in the dialogue between the patient and the professionals, and it occurs when the patient articulates and reflects on his/her experiences of AF as an illness. New meaning is created out of the patient's narratives and reflections. In a similar manner, Hydén et al. (2012) stated that we give meaning to our own actions and the actions of others through these language-based interactions. Sarangi and Slembrouck, (2014) stated that a person's communication is created by his/her constant interactions with others, as well as by the surrounding context. Consequently, a person cannot be defined as an isolated entity. The creation of meaning is something that occurs mutually in the meeting between the parties in the consultations, regarding the relationship between the central concepts in this thesis (Figure 3). Figure 3 shows how the form used by institutional communication in the consultations affects opportunities for involvement and the degree of involvement. When

patients in study II suggested other treatment options, the cardiologists started to negotiate with the patients, thus creating a conflict between the world of medicine and the lifeworld. Hypothetically, the next sequence is that the sense of involvement would be reduced, which creates a context for enhanced monologism from the patient and the physician. Monologue in turn creates a new context, which may further reduce the sense of involvement. This example illustrates how a downward spiral can be created as a way to communicate, and the feeling of a lack of involvement is mutually reinforcing. If cardiologists are interested in what patients think about their proposals instead, the patients' sense of involvement would be strengthened, creating a context that can lead to communication built on dialogue. This would create opportunities for an upward spiral where communication and involvement gradually mutual reinforce each other.

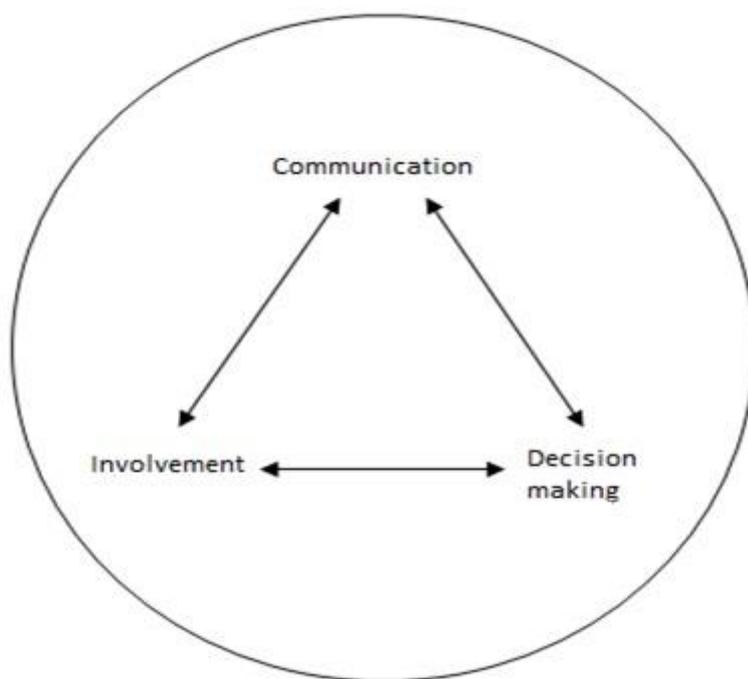


Figure 3. Relationships between the central concepts. The bi-directional arrows show that the form used by institutional communication in the consultations affects opportunities for involvement and the degree of involvement.

As shown in Figure 3, the concepts of communication, involvement, and decision making are subject to mutual interaction. Opportunities for involvement or the degree of involvement that are created by communication lead in turn to new conditions of how the continued communication is formulated. If communication is monological in nature, the opportunities for involvement tend to be reduced, which in turn leads to a risk of reduced opportunities for a dialogue. However, if communication is dialogical, the opportunities for involvement

increase, which in turn can have a positive effect on continued communication. Dialogue leads to involvement, while at the same time, involvement leads to better conditions for dialogue. The same principle also applies to the other two relationships that are represented in Figure 3. At the same time, the degree of SDM that communication leads to affects the course that communication takes. Similarly, the degree of involvement affects the conditions for SDM, which in turn affects the degree of involvement. The fact that these three concepts do not exclude one another, but rather create conditions for one another, is also apparent from the definition of the concepts. The term communication is derived from the Latin word ‘communicare’, which means making something in common. Because the term ‘common’ is included in the actual definition of communication, some form of involvement and participation exists in the concept of communication. The same applies to the term ‘SDM’, which is included in the concept of involvement, while the term ‘involvement’ forms part of the concept of SDM. Therefore, these concepts are not independent of one another. In contrast, they define or give each other meaning. These concepts are socially constructed in communication and their meanings mutually change depending on how the communication process evolves.

CONCLUSIONS AND IMPLICATIONS

Conclusions

The overall question of how patients and professionals create involvement in decision making in consultations was found to be a communicative project. The findings from the four studies represent intertwined dimensions of patients’ perspectives of communication that occurs in consultations. Patients strive for space and create involvement by showing resistance to the decisions suggested by health professionals. Therefore, resistance is a way to create involvement itself. Patient resistance can also be viewed as a resource and a source of information. When health professionals adopt this view, their patients can provide subjective accounts of their concerns. Resistance indicates a dissonance between the patient and the health professional. Resistance serves as a signal for the need to alter the communication strategies that are being used. Involvement is not only an issue of sharing of space in the consultations. Involvement is also associated with a feeling of clarity, confidence related to decision making, a feeling of being understood, trust toward physicians and/or nurses, and confidence in receiving consistent care within an established relationship.

Implications

- The main recommendations of this thesis include the idea that professionals should assume a dialogical approach and SDM.
- A dialogical approach might decrease the dominance of health professionals (i.e., in terms of initiation of certain topics during the consultation) and ‘the medical agenda’,

and at the same time, increase patients' involvement and their possibilities to initiate different topics of their own choosing.

- Communication on patients' perceptions of their experiences of illness could be increased in relation to all of the discussed topics in the consultations, which might also decrease the patients' anxiety and stress.
- Cardiologists could use patient resistance to encourage their patients to formulate their thoughts regarding treatment and to engage them in a collaborative process in which there is a shared responsibility for treatment goals.
- Cardiologists can remain in the role of the information receiver when their patients exhibit resistance.
- By observing consultations and giving voice to the participants' perspectives, findings regarding communication and involvement in decision making can lead to important educational and clinical changes.

METHODOLOGICAL CONSIDERATIONS

Design

The strength of qualitative studies is the ability to present research that creates insights and highlights the multifaceted nature of concepts, such as communication and patient involvement in decision making (Saldana, 2003). Qualitative research attempts to highlight, critically examine, and conceptualize qualities of human experience and social life (ibid.). This thesis is based on the social constructionism tradition (Berger and Luckman, 1991) by using data sources for which the author has partly been a co-constructer.

One concern regarding the methodology of the studies in this thesis was the characteristics of the samples. The samples were from large and small hospitals, and in all four studies, the data were collected in the ordinary clinical practice setting. The reason why only 23 patients were studied is as follows. According to published data analysis methods (Polit and Beck, 2010), the sample size was appropriate for the studies in question (studies I–III). Importantly, the total number of 23 consultations (i.e., 23 patients) is not a small sample in this research context. In contrast, this is in fact a rather large sample. Furthermore, the 23 consultations produced varied material. The sample, (23) patients compared with the number of physicians and nurses (10), equating to a ratio of just over 2:1. The choice of the number of consultations and participants (23 patients / 5 nurses / 5 physicians) was based on the assumption that such a sample size would allow for substantial and meaningful insight into the central issues of the study. A higher proportion of patients compared with nurses/physicians were undesirable. A

sample based on consultations that were performed by fewer nurses/physicians might have decreased variation in communicative aspects. Furthermore, having variation regarding the background variables of the professionals was important. The five nurses who were recruited were aged 30–65 years, and the five physicians included two female and three male physicians aged 35–65 years. However, out of respect for the integrity of the participants, the variables for the professionals are not described in detail in the manuscripts.

‘Strategic patient selection’ could have been clarified a bit more in the published studies. The profile of the 23 patients is shown in Table 3. The text in the *Methods* section in this thesis clearly informs the reader that strategic selection was applied to ensure a broad sample with maximal variation, as well as to enable description of different ways of communication and interaction. However, the patients had a wide range of experiences across variations in age, sex, and educational level. The differences regarding educational level are not discussed in any more detail, although they could be explored in a quantitative study with a larger sample size.

Participants

Participating patients

All of the patients who participated in studies I–III were receiving healthcare and required professional interventions. Strengths of studies I–III is that the participants in these studies were patients with a variety of forms of AF, there were men and women, and they were from different-sized hospitals.

Participating nurses and physicians

The participating nurses and physicians were experienced in cardiology and were aware of the purpose of the studies. Therefore, there is the assumption that they were experienced in communicating in consultations, which constitutes an unavoidable selection bias. A more varied group of professionals may have been preferable, and it would have been interesting to include some relatively unexperienced cardiologists. In all of the studies, the participating professionals were normal staff at the institutional settings at the time of data collection. The fact that regular staff participated in the studies may have negatively affected the data, as well as positively affected the data. Before each study, information regarding the study was provided to the professionals by making several phone calls to each clinic, with the aim of motivating and informing the professionals. There were some difficulties in choosing the professionals. One hospital declined to participate because of the fact that the professionals did not want to be videotaped.

Data collection

The participants had a variety of forms of AF, were men and women, and had varying backgrounds, educational levels, and working conditions, all of which can be viewed as strengths of this study. The fact that participants were from different hospitals and with different family situations and different types of AF (i.e., seriously ill as a result of their AF with/or comorbidities) contributed to the credibility of the research (Polit and Beck, 2010). Therefore, the value of the information in the findings is high.

The discussion in study I describes how physicians work on a tight time schedule, which is not in keeping with the range of 20–90 minutes in the videotaped consultations. The ‘normal’ time for a consultation at the hospital that was studied is short (i.e., 20–30 minutes). However, there are exceptions of this time, and the range of 20–90 minutes is evidence of variation. A complex patient can make the situation stressful for nurses and physicians, all of whom work on a tight time schedule.

Video observations

A further concern of the studies is the videotaping. The use of videotaping during the consultations may have influenced the participants’ behaviour. Because the participants may have behaved and communicated in an atypical manner, the use of videotaping may have compromised the internal validity of the study. However, people who are being videotaped tend to return to their natural behaviour fairly quickly (Heath et al., 2010). Videotaping is considered to be a valid and reliable method that causes limited disturbance to the consultation process (ibid.). However, the fact that video recording is taking place is obvious to the participants. One advantage of videotaping is that it allows the researchers to review the material whenever they want (ibid.). The data used from the studies in this thesis consisted of transcriptions of the spoken word, as well as assessments of verbal and non-verbal forms of communication. The videotapes allowed assessment of many aspects of the consultations, and these studies enabled the researchers to highlight specific dimensions of interactions between patients and health professionals. This contributed to further understanding of communication and involvement in decision making in clinical consultations.

Interviews

Studies III and IV involved participants who were interviewed and their experience and views on involvement and communication in consultations were evaluated. In study III, ensuring that the interviews with patients were performed directly after the consultation was essential to capture urgent experiences and avoid loss of data validity related to memory lapses. However, this could also be considered as a limitation of the study because it may have influenced the participants’ awareness and engagement in the involvement and

communication processes. Repeated meetings with the participants in interviews after the consultation could also have facilitated the interview. This could have achieved a level of trust that could be crucial for willingness of participants to talk about communication in the consultations. In the studies, effort was made to be open and to ask follow-up questions, and be aware of the fact that the interviewer is also a co-creator of the participant's narratives through formulation of questions, behaviour, and the ability to listen.

In study III, data were collected from 10 interviews with cardiologists. A descriptive qualitative design was used, and this may not be a representative sample. An attempt was made to strategically select cardiologists in the sample (Polit and Beck, 2010) who were men and women, and had varying working experiences, which can be viewed as strengths of this study.

Analysis

Another concern of the studies was the methods that were used. Although the videotapes of the consultations (studies I and II) enabled analysis of many aspects of the interactions, only spoken communication was analysed in study I, whereas verbal and non-verbal levels of communication were analysed in study II. CA was used in study II. Mishler (1984) criticised CA on the basis that analytical studies of conversations normalise the voice of medicine, while suppressing the voice of the lifeworld. This results in the loss of much of that which constitutes the experience of illness from the patient's point of view.

In study I, each speaker's contribution to the conversation was assessed by counting the number of words that they spoke to achieve quantitative evaluation of dominance. However, no attempt was made in these studies to analyse dominance in terms of interactional structure because of the risk of losing the detailed evaluation that is possible with frameworks that are more complex (Itakura, 2001). Itakura (2001) suggested that quantitative data regarding conversational dominance in the institutional setting need to be interpreted qualitatively by paying attention to the speakers' conversational styles, goals, and strategies, as well as the social and cultural aspects of the mutual construction of meanings (Itakura, 2001).

The content analysis that was used in study I did not allow for evaluation of the sequence of the topics. Therefore, the analysis failed to provide information on interactional sequences in conversations in which some topics were discussed and others were not. Linell (1998) stated that topics are difficult to define clearly because different topics often cannot be adequately separated from each other by defining them only in terms of their sets of referents.. An inductive approach was used, meaning that no attempts were made by the researchers to use known categories, as is the case with a deductive approach (Krippendorff, 2004).

Trustworthiness

In qualitative research, the quality of an inquiry can be assessed by using the following criteria for trustworthiness: credibility, dependability, transferability, and confirmability (Polit and Beck, 2010).

Credibility

The credibility criterion refers to confidence in the truth of the data. To enhance credibility, conversations were held with the patients and health professionals before and after the consultations. The consultations were videotaped and verbatim transcriptions were made of them, and the co-authors participated in the analysis. The findings represent information drawn from the participants' original data and an interpretation of the participants' original views was considered (Graneheim and Lundman, 2004).

In qualitative research, researchers have to be conscious of their own role in the research process (i.e., taking this into account and acknowledging their own perspective and voice) (Polit and Beck, 2010). My background and preconceptions are derived from the nursing field and education in the context of care, which provides me with insider and outsider perspectives. I am familiar with the clinical context and the professions in this context. I am also an outsider, and not a physician, but a nurse. I could have influenced communication during the interviews with cardiologists in another way if I was a physician. Interpretation during analysis of the data, and analysis of the data as a process could have been affected by my previous knowledge in the field, even though I reflected on my own preconceptions. Additionally, reflections with the research group forced me to explicitly express my interpretations and what I based my interpretations on.

Dependability

The procedures and the selections that were made in the research process are described and included in this thesis summary. Stepwise replication is a qualitative research data evaluation procedure for when any inconsistencies that arise from compared data analyses need to be addressed for achieved dependability. The code–recode strategy was used in the analysis process in studies I–IV. The code–recode strategy involves the researcher coding the same data twice, with a 1 or 2 weeks' development period between each coding. The code–recode strategy helped me to gain a good understanding of data patterns. Dependability involves evaluating the findings and interpretation to ensure stability of the data over time and over conditions of the informants of the study (Polit and Beck, 2010).

Transferability

Transferability of the data that are presented in actual studies is dependent in part on the context from which the data are collected (Saldana, 2003). Researchers in other areas and those who have good insight into other contexts may be able to derive benefit from general characteristics that are described in this thesis and transfer them to other specific contexts that are relevant to them (Polit and Beck, 2010). To allow for assessment of transferability, detailed descriptions of the analysis and participants were provided, and this will facilitate transferability. Involvement in communication in practice can be viewed as an innovation, by providing patients the space and opportunity for patients' narratives. This entails a shift of perspective in relation to the paradigms where holistic communication represents the core. Transferability of the results might be considered as placing emphasis on the concept of involvement, and not as being representative of all patient groups.

Confirmability

The confirmability criterion in qualitative studies refers to the neutrality of the data and interpretations, and ensures that the data represent those provided by the informants and that explanations are not subject to researcher bias. The findings have to reflect the participants' voices (Polit and Beck, 2010). Additionally, to strengthen confirmability, descriptions of the research process have been presented and include some of the original data in the form of citations from studies I, II, III, and IV.

FUTURE RESEARCH

For follow-up studies, data for forthcoming studies have been collected and analysed, and manuscripts are under preparation. Findings from studies (I–IV) indicate the need to conduct more research on communication patterns in consultations, with a focus on the patient's participation in decision making. These studies suggested that further investigation of communication aspects of participation in decision making in consultations could include the following:

- Investigation of how information exchange in consultations affects patient involvement by conducting further qualitative analysis of the interactions in consultations.
- Investigation of how nurses describe their views on patient involvement in treatment decisions for AF, and their perceptions regarding efforts to involve patients.
- Investigation of how nurses and physicians encourage patients to express their preferences, and thereby facilitate the incorporation of patients' perspectives into decision making. This can be achieved by examining how nurses and physicians present information during consultations with patients with AF.

- Validation of the quality of the OPTION instrument in a Swedish population. The question of ‘Is the Swedish version of OPTION a valid tool for measuring the level at which patients are involved in treatment decisions in consultations?’ needs to be answered.
- Investigation of the components of SDM by using the Swedish version of the OPTION (observing patient involvement) rating scale when assessing consultations between patients with AF and cardiologists (<http://www.optioninstrument.com/translations.php>), details are given in Appendix 1.
- Investigation of how many Swedish hospitals have nurse-led AF clinics, and whether these clinics have structured follow-up routines based on guidelines that impose constraints or provide opportunities for more effective sharing of decision making with patients.

7 SVENSK SAMMANFATTNING

INLEDNING

Det övergripande syftet med denna avhandling var att bidra med kunskap om kommunikation mellan patienter och vårdpersonal, sjuksköterskor och läkare, med fokus på hur de tillsammans skapar/konstruerar involvering i beslutsfattande. Centrala begrepp i avhandlingen är därmed kommunikation, involvering och beslutsfattande. Studiens kontext är konsultationer mellan patienter med förmaksflimmer (FF) och sjuksköterskor och kardiologer. Avhandlingen bygger på empiriska data från fyra olika kvalitativa studier.

BAKGRUND

Förmaksflimmer är ett vanligt förekommande tillstånd som innebär oregelbunden hjärtrytm och drabbar ungefär 5 % av befolkningen med ökad förekomst hos personer som är över 65 år. Förmaksflimmer kan ha en negativ effekt på fysiska, mentala och sociala aspekter av patientens vardag. Patientens preferenser, behov och önskemål är viktiga frågeställningar att beakta när behandlingen diskuteras. Enligt nationella riktlinjer för kardiologi är patient involvering och påverkan under beslutsfattandet en viktig fråga. Patienternas preferenser, behov och önskemål är viktiga frågeställningar att beakta när behandlingen diskuteras. Kunskap, förståelse och insikt om kommunikationsmönster vid konsultationer med patienter med FF är mycket viktigt för att stärka patientens involvering i behandlingen och behandlingens beslutsfattande process. Det finns en växande samsyn om att patienterna måste vara mer involverade i sin egen medicinska behandling. Den medicinska etiken understryker patienternas rätt till heltäckande information och att vara involverade i beslutsfattandet om behandlingen.

Institutionella diskurser rör primärt asymmetrier där patienten är underordnad, eller själv underordnar sig, experterna. Asymmetrin relaterar till ett mönster av dominans, t.ex. kunskap eller den andra partens position. Även om en konsultation inkluderar institutionell asymmetri mellan parterna är det fortfarande ett möte mellan två jämbördiga människor. De etiska riktlinjerna främjar en jämbördig relation mellan patient och vårdpersonal samt respekt för patientens självbestämmanderätt. Det sker en förändring av trenden i patienternas och vårdgivarnas attityder och behov inom hälsovården. Idag har patienterna större kunskap och kan ofta själva välja vårdgivare, vilket har stärkt patientens position inom hälso-och sjukvården. Patientens involvering i beslutsfattandet är inte bara en politisk och ekonomisk fråga, utan också medicinsk. Patienter som är involverade i beslutsfattandet är bättre på att följa den överenskomna behandlingsplanen och att ta de ordinerade läkemedlen. Att studera kommunikationen mellan patienter och vårdpersonal kan användas för att t.ex. utveckla aspekter av patienternas involvering och beslutsfattandet som rör behandlingen. Skillnaden mellan parterna under konsultationen har beskrivits som ett möte mellan skilda världar där

patientens värld konfronteras med institutionens värld. Vårdpersonalen styr ofta samtalen och förväntas ha övertaget när det gäller den nödvändiga expertisen. För att kunna göra en korrekt bedömning bör vårdpersonalen ha en insikt i patientens egna erfarenheter. En policy mot ökad patientinvolvering och patientcentrerad kommunikation ger patienten bättre möjlighet att vara involverad i konsultationsprocessen inklusive behandlingsbesluten.

STUDIE I

TITEL: Innehåll och fördelning av det diskursiva utrymmet vid konsultationer mellan patienter med förmaksflimmer (FF) och professionella

BAKGRUND: Ur ett kommunikativt perspektiv äger konsultationsmötet mellan patienter med FF och vårdpersonal rum inom ramarna för en institutionell diskurs. Diskursen definierar vad som kan sägas och tänkas om en företeelse, vem som kan prata om den samt när och med vilken auktoritet (Olsson et al., 2011). Det finns få studier om kommunikation inom kardiologiområdet och dessa fokuserar främst på patienter inom kardiologin i allmänhet. Läkares och patienters beteende vid kommunikation har studerats, interventioner har gjorts med syfte att stödja den gemensamma beslutsfattande processen (Elwyn et al., 2010). Studier som fokuserar på dominans inom kardiologin har undersökt relationer för kön, dominans i relation till kardiiovaskulär reaktivitet som bedöms vid dyadiska sociala interaktioner. Kunskap, förståelse och insikt är mycket viktigt för att stärka patientens engagemang i behandlingens beslutsfattande process. Andra patientgrupper, som tar aktiv del i det kliniska beslutsfattandet vid vårdkonsultationer, har associerats med kön, ålder, utbildningsnivå, levnadsförhållanden och anställning.

SYFTE: Att beskriva (i) de ämnen som deltagarna talar om, (ii) användningen av diskursivt utrymme vid konsultationer mellan patienter med FF samt deras sjuksköterskor och läkare inklusive (iii) frekvensen för de olika sätt som patienter, sjuksköterskor och läkare introducerar ämnena.

METOD: Data samlades in från 23 videofilmade konsultationer med patienter med FF (12 med läkare och 11 med sjuksköterskor). För att kunna beskriva de ämnen som diskuterades analyserades utskriften med hjälp av innehållsanalys. De dominerande mönstren för respektive ämne och deltagare undersöktes genom ett analysramverk som behandlar dominans.

RESULTAT: Fyra ämnen användes av både sjuksköterskor och läkare vid konsultationerna. Dessa var "patofysiologi", "diagnostiska procedurer", "behandling" och "aktivitet". Vid konsultationerna mellan sjuksköterska och patient togs också ämnet "rutiner som rör läkarens ansvarsområden" upp. När det gäller antalet ord och turtagning var fördelningen av diskursutrymmet nästan jämnt fördelat mellan sjuksköterskorna och patienterna och ojämnt fördelat mellan läkare och patienter. Vårdpersonalen förde oftare ämnena på tal jämfört med patienterna och därmed kändes det medicinska tillvägagångssätt som rekommenderas i

riktlinjerna för FF igen. Det var patienterna som oftast tog upp ämnet "aktivitet," vilket rör anpassningen av aktiviteter i vardagen med hänsyn till FF.

SLUSATS: Den medicinskt drivna dagordningen dominerar över den patientdrivna dagordningen vid konsultationer mellan vårdpersonal och patienter med FF. Patienterna tog initiativet i samtalen när det talades om att leva med FF och var mer talföra under samtalen vid konsultationer med sjuksköterskor.

KLINISK INNEBÖRD: Vid konsultationer, som leddes av såväl sköterskor som läkare, med patienter med AF dominerar den medicinskt drivna dagordningen över den patientdrivna dagordningen. Patientens inställning till att fördjupa sig i den egna erfarenheten av sjukdomen skulle kunna förbättras på alla de områden som diskuteras under konsultationen. Det är viktigt att vårdpersonalen utökar sin roll som aktiv lyssnare under en större del av konversationen under konsultationen. Det kan bidra till att minska vårdpersonalens dominans (d.v.s. att de tar upp vissa ämnen under konsultationerna) och användningen av en medicinskt driven dagordning och därmed öka patientens deltagande och möjlighet att på egen hand ta upp andra samtalsämnen. Ökad kommunikation som rör patientens inställning till sin sjukdomsupplevelse kan minska dennas oro och stress. När patienten beskriver sina problem och symptom för vårdpersonalen har han eller hon ofta en egen förklaring till sjukdomen. I det avseendet kan kommunikationen under konsultationen uppfattas som kompletterande istället för asymmetrisk.

STUDIE II

TITEL: Motstånd i interaktionen mellan patienter med förmaksflimmer (FF) och kardiologer vid konsultation om behandling med warfarin: Värdet av gemensamt beslutsfattande

BAKGRUND: FF ökar risken för stroke, vilken kan minskas genom behandling med warfarin. En del patienter betraktar behandlingen som påfrestande med oönskade bieffekter och därmed en ovilja att ta läkemedlet. Kunskap om hur patienter uttrycker motstånd om warfarinbehandling är användbar för att hantera det potentiella hotet mot ett gemensamt beslutsfattande vid konsultationen som en central princip för den personcentrerade medicinen.

SYFTE: Att identifiera på vilket sätt patienter motsätter sig behandling med warfarin och hur kardiologer bemöter patienternas motstånd. Avhandlingens co-konstruktiva perspektiv analyserar konsultationerna genom att understryka de kliniska kommunikationsstrategierna för både patienter och kardiologer.

METOD: Elva videoinspelade konsultationer på fyra olika sjukhus valdes ut för analys. Interaktionen mellan patienter med förmaksflimmer och kardiologer rörande behandling med warfarin analyserades med hjälp av konversationsanalys (CA).

RESULTAT: Bland patienterna förekom fyra olika typer av motstånd mot att acceptera behandling med warfarin. De inkluderar "Patienten ger skäl för sitt motstånd mot behandlingen", "Patienten föreslår ett annat behandlingsalternativ," "Patienten anger en behandlingspreferens" samt "Ifrågasättande av eller invändningar mot kardiologens behandlingsrekommendation". Kardiologens bemötande av patientens motstånd inkluderar "Upprepning av behandlingsrekommendationen," "Förhandling med patienten," "Att ge ytterligare information om den rekommenderade behandlingen" och "En mer utförlig förklaring av syftet med behandlingen".

SLUTSATS: Genom att uppvisa motstånd mot behandlingen tros patienten uttrycka sin önskan att vara involverad i behandlingsbesluten och genom att vara medveten om patientens motstånd mot behandlingen kan kardiologen bemöta patientens personliga oro och erfarenhetsbaserade syn på behandlingen som en del av de kliniska strategierna för att öka den medicinska behandlingens fokus på personen.

KLINISK INNEBÖRD: Fynden som rör ett motstånd mot behandlingen under konsultationen ger stöd för kardiologens möjlighet att betrakta motståndet som ett uttryck för patientens oro eller rädsla. Det är viktigt att patientens motstånd betraktas som en källa till kunskap. Genom att förlita sig på dessa källor kan patienten bidra med en subjektiv bild av sin oro. Det är viktigt att kardiologen, även sedan patienten har uppvisat ett motstånd mot att interagera, fortfarande behåller sin position som mottagare av information och inte tvärt om. Genom att använda en motiverande samtalsteknik kan kardiologen skapa en dialog och ta upp förändringstankar med hänsyn till patientens tankar och önskemål om behandlingen. Fynden ger stöd för kardiologens möjlighet att ytterligare utgå från patientens perspektiv genom att förstå och känna igen de olika sätten som motståndet uppvisas på. Kardiologen bör förmedla till patienten att rekommendationerna är preliminära tills mer information kan samlas in och ta reda på vad orsaken till patientens motstånd kan vara. Motståndet representerar en direkt återkoppling av oenighet från patientens sida och fungerar som en signal att ändra samtalsstrategierna. Fynden kan tillämpas inom vård- och medicinsk utbildning.

STUDIE III

TITEL: Patienters upplevelser kring kommunikation och deltagande i beslutsfattande rörande behandling av förmaksflimmer under konsultationer med sjuksköterskor och läkare

BAKGRUND: Att få mer inblick i konsultationer i olika patientinteraktioner med läkare och sjuksköterskor är mycket viktigt för att stärka patienternas involvering i den beslutsprocess som gäller behandlingen. Hur patienter upplever involvering och kommunikation i beslutsfattande har hittills inte studerats i särskilt stor omfattning inom kardiologi.

SYFTE: Att undersöka hur patienter beskriver involvering och kommunikation vad gäller beslutsfattande rörande behandling i konsultationer med sjuksköterskor och läkare.

METOD: Tjugotvå patienter med förmaksflimmer (FF) i åldern 37–90 år intervjuades direkt efter deras konsultationer med sjuksköterskor och läkare i öppenvårdskliniker för FF i sex svenska sjukhus.

RESULTAT: I konsultationer med sjuksköterskor kände sig patienterna involverade när det handlade om att få klargöranden om FF som sjukdom och hur detta behandlas, samt när det handlade att förbereda sig för beslutsfattande och bygga upp självförtroende vad gäller detta. I konsultationer med läkare kände sig patienterna involverade när de kunde samarbeta kring beslutsfattande, när de fick ny kunskap och när de kände att de kunde göra sig förstådda. En gemensam kategori hittades i konsultationer med både sjuksköterskor och läkare, och patienterna kände sig involverade när de hade en känsla av förtroende och kände sig trygga under och mellan konsultationer.

SLUTSATS: Patienter med FF uppgav att de skulle behöva ta till sig ny kunskap samt bygga upp självförtroende och förmåga för att effektivt kunna delta i beslutsfattande gällande behandling. Även om de inte deltog aktivt i beslutsfattandet, kände sig patienterna involverade då de upplevde en stödjande och bekräftande kommunikation.

KLINISK INNEBÖRD: Det är viktigt att uppmärksamma relationen med patienten för att kunna skapa förutsättningar för patienten att delta i konsultationen. Detta kan uppnås genom att skapa en känsla av klarhet samt bygga upp förtroende med hjälp av stödjande samtal. Detta kommer att underlätta deltagande i beslutsfattande gällande behandling av FF och även skapa en känsla av att bli förstådd samt tillit till läkare och/eller sjuksköterskor.

STUDIE IV

TITEL: Kardiologers erfarenheter och uppfattningar om patientinvolvering och kommunikation i samband med delad beslutsfattande om förmaksflimmer behandling.

BAKGRUND: För att känna sig involverade i beslut rörande behandling av förmaksflimmer (FF) behöver patienterna stödjande kommunikation från kardiologer. Det är viktigt att studera kardiologers uppfattningar kring patientinvolvering i vården av FF.

SYFTE: Att undersöka (i) hur kardiologer beskriver patientinvolvering och kommunikation i relation till gemensamt beslutsfattande rörande behandling av FF, (ii) hur de uppfattar försök att involvera patienter i beslut rörande behandling, samt (iii) hur kardiologer hanterar beslut rörande behandling.

METOD: Tio kardiologer intervjuades i fyra svenska sjukhus. En kvalitativ innehållsanalys utfördes på den intervjudata som samlades in.

RESULTAT: Kardiologers uppfattningar kring patientinvolvering i beslut rörande behandling skapas utifrån (i) ideologi, (ii) erfarenhet och (iii) ansvar. Att fatta beslut rörande

behandling ses som ett professionellt ansvar, och behandlingsalternativ presenteras för patienten på ett övertygande och beskyddande vis.

SLUTSATS: Kardiologer bidrog till patientinvolvering genom att ta hänsyn till patienternas känslor och aktivt uppmuntra patientinvolvering. Kardiologer prioriterar dock det professionella ansvaret att fatta beslut rörande behandling framför patientinvolvering.

KLINISK INNEBÖRD: En viktig aspekt när det gäller bättre efterlevnad av lagstiftning som syftar till att öka patientinvolvering i beslut rörande behandling skulle kunna vara att uppmärksamma läkare-patientkommunikation och förutsättningarna för patientinvolvering i beslut rörande behandling.

SAMMANFATTNING AV SLUTSATSER OCH INNEBÖRD

SLUTSATSER

Den övergripande frågan hur patienter och vårdpersonal skapar deltagande i beslutsprocessen i konsultationer visar sig vara ett kommunikativt projekt. Resultaten från de fyra studierna kan ses som uttryck för sammanflätade dimensioner vad gäller patienternas perspektiv på den kommunikation som äger rum i konsultationer. Patienter eftersträvar ett personligt utrymme och skapar involvering genom motsätta sig de beslut som föreslås av vårdpersonalen. Motstånd är därmed ett sätt i sig att skapa involvering. Motstånd från patienten kan även ses som en resurs och en informationskälla. När vårdpersonal anammar detta synsätt kan deras patienter dela med sig av subjektiva redogörelser kring sin oro. Motstånd visar på en dissonans mellan patienten och vårdpersonalen. Det fungerar som en signal som visar att de kommunikationsstrategier som används måste förändras. Patient involvering handlar inte enbart om att ta lika mycket plats i konsultationerna. Det handlar även om en känsla av klarhet, förtroende vad gäller beslutsfattande, en känsla av att bli förstådd, tillit till läkare och/eller sjuksköterskor och förtroende att man kommer att få konsekvent vård i en etablerad relation. På ett teoretisk plan belyser denna avhandling samspelet mellan begreppen kommunikation, deltagande och beslutsfattande.

INNEBÖRD

- De viktigaste rekommendationerna i denna avhandling innefattar tanken att vårdpersonal bör utgå från ett delat beslutsfattande och ett dialogbaserat tillvägagångssätt.
- En dialogbaserad strategi kan minska "den medicinska agendans" och sjukvårdspersonalens dominans (d.v.s. när det gäller att ta upp vissa ämnen under konsultationen), samt samtidigt öka patienternas involvering och deras möjligheter att ta upp olika ämnen som de vill diskutera.

- Graden av kommunikation rörande patienternas upplevelser kring sin sjukdom skulle kunna ökas i förhållande till alla frågor som diskuteras i konsultationer, vilket också skulle kunna minska patienternas oro och stress.
- Kardiologer skulle kunna använda patienters motstånd för att uppmuntra sina patienter att formulera sina tankar rörande behandling samt för att engagera dem i en samverkande process där det finns ett delat ansvar för behandlingsmålen.
- Kardiologer kan stanna kvar i rollen som informationsmottagare när deras patienter uttrycker motstånd.
- Genom att observera konsultationerna och låta deltagarnas perspektiv komma till tals kan resultaten vad gäller deltagarnas kommunikation och deltagande i beslutsfattandet leda till viktiga förändringar inom utbildning och klinisk verksamhet.

8 ACKNOWLEDGEMENTS

First, I want to thank all of the patients, nurses, and physicians who participated in the studies. The present thesis would not have been possible without the videotaped consultations and interviews.

With regard to financial support in my PhD thesis, I would like to thank Sophiahemmet University; Department of Neurobiology, Care Sciences and Society, Karolinska Institutet; the National Society for Research on Ageing; FORTE, Sweden; Vinnvård; FORSS and Futurum; the Order of Saint John (St. John) in Stockholm; and Bridging the Gaps II, the Academy of Health and Sciences, Jönköping.

I would like to especially express my warmest gratitude to my supervisors; it has been truly an honor and a privilege knowing you all.

I thank my main supervisor, Professor Bjöörn Fossum, who helped me through the PhD process, and I appreciate his support, friendliness, and faith in me. His leadership and supervision has formed a research group that feels friendly and enjoyable.

I thank my co-supervisor, Associate Professor Ulla Hellstrom Muhli, for her support and guidance. I appreciate all of the discussions on the subject of communication. She is always available to provide support, guidance and suggestions to help. I am excited about the next steps for the directions that my research is taking.

I thank my co- supervisor Klas Karlgren for supporting me and for working with me on my incomplete manuscripts. Thank you for being there to help, guide, and support me. I find him as a hardworking, and supportive supervisor.

During this thesis journey I have met people that have inspired, helped, and supported me. Many thanks to Associate Professor Berith Hedberg for the commitment and knowledge that were applied my first article, which was to become the start of this thesis. I am deeply grateful to Professor Anders Broström who supported me through my Licentiate process. I thank Elisabeth Dahlborg Lyckhage, my mentor. I thank Professor Barry Saferstein, Professor Gunilla Jansson and Professor Yvonne Wengström for their helpful comments. I am sincerely grateful to Associate Professor Ulf Olsson for his helpful comments and continued support.

My warmest thanks to Ann-Margret Olsson-Wester and Danny Watkins for support with the English Language. My warmest thanks to Per Reinholdsson, Anna Booberg, David Brodin, Lars Andersson, Håkan Montelius, Klas Moberg, Anders Wändahl, Birgitta Wannberg, Anna Fred, Thommy Andersson, Aida Huskovic and David Finer.

Thanks to all of my colleagues, present and past, at NVS and LIME, Karolinska Institutet, Sophiahemmet University, and Jönköping University, for many interesting conversations. In

particular, I would like to thank Maria Jirwe and Marie Iwarzon for allowing me to ask questions; you were always on standby for me. I thank the head of division of nursing in Karolinska institutet, Professor Ann Langius-Eklöf and my chief Eva Doukkali, for understanding and support. I would like to thank the head of research at Sophiahemmet University, Associate Professor Pernilla Hillerås, for her support. I thank Professor Gert Helgesson at LIME, the department in Karolinska Institutet at which I am registered, and Ingrid Smedberg, who is a research administrator at LIME, for guidance and assistance with all of the administrative chores.

I would like to thank those who reminded me that there are other things in life besides working. These people include all my friends, especially Vasoula Kazana for letting me rest at your wonderful home after long days at work and for the lovely dinners; and Mimika Kirgios for reminding me that there are other issues in life worth focussing on (e.g., politics). Additionally, I thank Ann Mannerheim and her husband Gunnar and especially Ulf Olsson for the generous dinners and all of the fun we have together.

Finally, I thank my family, especially my son Michael. I am so proud of him and what he has accomplished, not least of which was giving me a grandchild! Thanks also to my daughter-in-law Fredrika for enriching my child's and grandchild's. Nora, my grandchild, can hopefully get more of my attention and time now. I thank my brothers, Mpampis and Makis as well as their families. Last, but not least, thanks to my lovely parents that this thesis is dedicated to.

9 REFERENCES

- Agar, M., 1985. Institutional discourse. *Text*, 5(3), pp. 147-68.
- Agoritsas, T., Heen, A.F., Brandt, L., Alonso-Coello, P., Kristiansen, A., Akl, E.A., Neumann, I., Tikkinen, K.A., Weijden, T.V., Elwyn, G., Montori, V.M., Guyatt, G.H. and Vandvik, P.O. 2015. Decision aids that really promote shared decision making: the pace quickens. *BMJ*, 350, doi: 10.1136/bmj.g7624.
- Al-Khalili, F. and Lindström, C., 2014. Structured care for patients with new oral anticoagulants. Nursing based care of adults with atrial fibrillation. *Lakartidningen*, 111(40), pp.1720-22.
- Arman, M., Ranheim, A., Rydenlund, H., Rytterström, P. and Rehnsfeldt, A., 2015. The Nordic tradition of caring science: the works of three theorists. *Nursing Science Quarterly*, 28(4), pp.288-96.
- Arnetz JE, Höglund AT, Arnetz BB, Winblad U. 2008. Development and evaluation of a questionnaire formeasuring patient views of involvement in myocardial infarction care. *Eur J Cardiovasc Nurs* (7): pp. 229–38.
- Barello, S., & Graffigna, G. 2015. Engaging patients to recover life projectuality: An Italian cross-disease framework. *Quality of Life Research*, 24(5), pp. 1087-1096.
- Barello, S., Graffigna, G., & Vegni, E. 2012. Patient Engagement as an Emerging Challenge for Healthcare Services: Mapping the Literature. *Nursing Research and Practice*, Vol.2012, pp.1-7 .
- Barry, C.A., Stevenson, F.A., Britten, N., Barber, N. and Bradley, C.P., 2001. Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor-patient communication in general practice. *Social Science & Medicine*, 53(4), pp.487-505.
- Beauchamp, T.L. and Childress, J.F., 2001. *Principles of biomedical ethics*. 5th ed. New York: Oxford University Press.
- Berger, P.L. and Luckmann, T., 1991. *The social construction of reality: a treatise in the sociology of knowledge*. London: Penguin.
- Berti, D., Hendriks, J., Brandes, A., Deaton, C., Crijns, H., Camm, A., . . . Heidbuchel, H. (n.d.). 2013.A proposal for interdisciplinary, nurse-coordinated atrial fibrillation expert programmes as a way to structure daily practice. *European Heart Journal*, 34(35), pp.2725-2730.
- Bowling, A., Reeves, B.C. and Rowe, G., 2011. Do treatment preferences for patients with angina change? An 18-month follow-up study. *Health Expectations: an international journal of public participation in health care and health policy*, 15(4), pp.351-9.
- Briel, M., Young, J., Tschudi, P., Hugenschmidt, C., Bucher, H.C. and Langewitz, W., 2007. Shared-decision making in general practice: do patients with respiratory tract infections actually want it? *Swiss Medical Weekly*, 137(33-34), pp.483-5.
- Brink, E. and Skott, C., 2013. Caring about symptoms in person-centred care. *Open Journal of Nursing*, 3, pp.563-7.

- Buckingham, C.D. and Adams, A., 2000. Classifying clinical decision making: interpreting nursing intuition, heuristics and medical diagnosis. *Journal of Advanced Nursing*, 32(4), pp.990-8.
- Burton, D., Blundell, N., Jones, M., Fraser, A. and Elwyn, G., 2010. Shared decision-making in cardiology: do patients want it and do doctors provide it? *Patient Education and Counseling*, 80(2), pp.173-9.
- Butler, D.J., 2002. Informed consent and patient videotaping. *Academic Medicine*, 77(2), pp.181-4.
- Butterworth, J.E. and Campbell, J.L., 2014. Older patients and their GPs: shared decision making in enhancing trust. *British Journal of General Practice*, 64(628), pp.709-18.
- Byrne, P.S., Long, B.E. and Britain, G., 1976. *Doctors talking to patients: a study of the verbal behaviour of general practitioners consulting in their surgeries*. London: Her Majesty's Stationery Office (HMSO). pp.1-194.
- Cahill, J., 1996. Patient participation: a concept analysis. *Journal of Advanced Nursing*, 24, (3) pp.561-71.
- Cahill, J., 1998. Patient participation—a review of the literature. *Journal of Clinical Nursing*, 7(2), pp.119-28.
- Camm, A.J., Lip, G.Y., De Caterina, R., Savelieva, I., Atar, D., Hohnloser, S.H., Hindricks, G. and Kirchhof, P., 2012. 2012 focused update of the ESC Guidelines for the management of atrial fibrillation: an update of the 2010 ESC Guidelines for the management of atrial fibrillation--developed with the special contribution of the European Heart Rhythm Association. *Europace*, 14(10), pp.1385-413.
- Caress, A., Beaver, K., Luker, K., Campbell, M. and Woodcock, A., 2005. Involvement in treatment decisions: what do adults with asthma want and what do they get? Results of a cross sectional survey. *Thorax*, 60(3), pp.199-205.
- Cedersund, E. and Säljö, R., 1993. Bureaucratic discourse, conversational space, and the concept of voice. *Semiotica*, 97, pp. 79-102.
- Charles, C., Gafni, A. and Whelan, T., 1999. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine*, 49(5), pp.651-61.
- Chewing, B., Bylund, L.C., Bupendra, S., Neeraj, A.K., Gueguen, J.A. and Makoul, G., 2012. Patient preferences for shared decisions: a systematic review. *Patient Education and Counseling*, 8(1), pp.9-18.
- Clarkesmith, D., Pattison, H., Lip, G., & Lane, D. 2013. Educational intervention improves anticoagulation control in atrial fibrillation patients: The TREAT randomised trial. *PloS One*, 8(9), e74037, doi: 10.1371/journal.pone.0074037.
- Clinch, M. and Benson, J., 2013. Making information 'relevant': general practitioner judgments and the production of patient involvement. *Social Science & Medicine*, 96, pp.104-11.
- Collins, S., Britten, N. and Ruusuvoori, J., 2007. *Patient participation in health care consultations: qualitative perspectives*. Maidenhead: Open University Press.

- Couët, N., Desroches, S., Robitaille, H., Vaillancourt, H., Leblanc, A., Turcotte, S., Elwyn, G. and Légaré, F., 2015. Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. *Health Expectations*, 18(4), pp.542-61.
- Coulter, A. and Collins, A., 2011. *Making shared decision-making a reality: no decision about me, without me*. London: King's Fund.
- Cousin, G., Schmid Mast, M. and Jaunin-Stalder, N., 2013. Finding the right interactional temperature: do colder patients need more warmth in physician communication style? *Social Science & Medicine*, 98, pp.18-23.
- Cribb, A. and Entwistle, V.A., 2011. Shared decision making: trade-offs between narrower and broader conceptions. *Health Expectations*, 14(2), pp.210-9.
- Dalteg, T., Benzein, E., Fridlund, B. and Malm, D., 2011. Cardiac disease and its consequences on the partner relationship: a systematic review. *European Journal of Cardiovascular Nursing*, 10(3), pp.140-9.
- Davis, R.E., Dolan, G., Thomas, S., Atwell, C., Mead, D., Nehammer, S., Moseley, L., Edwards, A. and Elwyn, G., 2003. Exploring doctor and patient views about risk communication and shared decision-making in the consultation. *Health Expectations: an international journal of public participation in health care and health policy*, 6(3), pp.198-207.
- De Haes, H., 2006. Dilemmas in patient centeredness and shared decision making: a case for vulnerability. *Patient Education and Counseling*, 62(3), pp.291-8.
- Deaton, C., Dunbar, S.B., Moloney, M., Sears, S.F. and Ujhelyi, M.R., 2003. Patient experiences with atrial fibrillation and treatment with implantable atrial defibrillation therapy. *Heart Lung*, 32(5), pp.291-9.
- Deber, R.B., Kraetschmer, N., Urowitz, S. and Sharpe, N., 2007. Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations. *Health Expectations: an international journal of public participation in health care and health policy*, 10(3), pp.248-58.
- Dolan, J.G., 2008. Shared decision-making- transferring research into practice: the Analytic Hierarchy Process (AHP). *Patient Education and Counseling*, 73(3), pp.418-25.
- Durand, A.M., Witt, J., Joseph-Williams, N., Newcombe, R.G., Politi, C.M., Sivell, S. and Elwyn, G., 2015. Minimum standards for the certification of patient decision support interventions: feasibility and application. *Patient Education and Counseling*, 98(4), pp. 462-8.
- Edwards, A. and Elwyn, G., 2006. Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. *Health Expectations: an international journal of public participation in health care and health policy*, 9(4), pp.307-20.
- Eldh, A.C., Ehnfors, M. and Ekman, I., 2006. The meaning of patient participation for patients and nurses at a nurse-led clinic for chronic heart failure. *European Journal of Cardiovascular Nursing: Journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology*, 5(1), pp. 45-53.

- Eldh, A.C., Ekman, I. and Ehnfors, M., 2006. Conditions for patient participation and non-participation in health care. *Nursing Ethics*, 13(5), pp. 503-14.
- Elwyn, G., Hutchings, H., Edwards, A., Rapport, F., Wensing, M., Cheung, W.Y. and Grol, R., 2005. The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. *Health Expectations*, 8(1), pp.34-42.
- Elwyn, G., Lloyd, A., Joseph-Williams, N., Cording, E., Thomson, R., Durand, A-M. and Edwards, A., 2013. Option grids: shared decision making made easier. *Patient Education and Counseling*, 90(2), pp.207-12.
- Elwyn, G., Lloyd, A., May, C., Van Der Weijden, T., Stiggelbout, A., Edwards, A., Frosch, D.L., Rapley, T., Barr, P., Walsh, T., Grande, S.W., Montori, V. and Epstein, R., 2014. Collaborative deliberation: a model for patient care. *Patient Education and Counseling*, 97(2), pp.158-64.
- Elwyn, G., Stiel, M., Durand, M.A. and Boivin, J., 2010. The design of patient decision support interventions: addressing the theory–practice gap. *Journal of Evaluation in Clinical Practice*, 17(4), pp. 565-74.
- Engström, A., 2014. *Språkets betydelse för skapandet av kunskap och verklighet. The importance of language for the creation of knowledge and reality*. In: H. Eriksson, ed. *Vårdvetenskap och postmodernitet*. Lund: Studentlitteratur. pp. 49-80.
- Entwistle, V.A. and Watt, I.S., 2006. Patient involvement in treatment decision-making: the case for a broader conceptual framework. *Patient Education and Counseling*, 63(3), pp. 268-78.
- Epstein, R.M. and Street, R.L., 2011. Shared mind: communication, decision making, and autonomy in serious illness. *Annals of Family Medicine*, 9(5), pp. 454-61.
- Epstein, R.M., Alper, B.S. and Quill, T.E., 2004. Communicating evidence for participatory decision making. *JAMA: the Journal of the American Medical Association*, 291(19), pp. 2359-66.
- Eriksson, H., 2014. *Vårdvetenskap och postmodernitet: en introduktion*. Health Sciences and postmodernity: an introduction. Lund: Studentlitteratur.
- Ernst, J., Berger, S., Weißflog, G., Schröder, C., Körner, A., Niederwieser, D., Brähler, E. and Singer, S., 2013. Patient participation in the medical decision-making process in haemato-oncology – a qualitative study. *European Journal of Cancer Care*, 22(5), pp. 684-90.
- Fiske, J., 1990. *Kommunikationsteorier – en introduktion*. Communication Theories - An Introduction. Stockholm: Wahlström och Widstrand.
- Florin, J., Ehrenberg, A. and Ehnfors, M., 2008. Clinical decision-making: predictors of patient participation in nursing care. *Journal of Clinical Nursing*, 17(21), pp. 2935-944.
- Fossum, B., 2013. *Kommunikation: samtal och bemötande i vården. Communication: conversations and response in care*. Lund: Stockholm.
- Fraenkel, L., 2013. Incorporating patients' preferences into medical decision making. *Medical Care Research and Review*, 70(1), pp. 80-93.

Fredriksson, L., 1995. *Det vårdande samtalet: att samtala om lidande : en hermeneutisk-fenomenologisk undersökning av det vårdande samtalets väsen i psykiatrisk vårdkontext. The caring conversation: to talk about suffering: a hermeneutisk-phenomenological investigation of the caring conversation beings in psychiatric care context.* Master's Thesis. Pro gradu-avhandling: Åbo Akademi. Åbo.

Friberg, L., Rosenqvist, M. and Lip, G.Y., 2012. Evaluation of risk stratification schemes for ischaemic stroke and bleeding in 182 678 patients with atrial fibrillation: the Swedish Atrial Fibrillation cohort study. *European Heart Journal*, 33(12), pp.1500-10.

Frongillo, M., Feibelmann, S., Belkora, J., Lee, C. and Sepucha, K., 2013. Is there shared decision making when the provider makes a recommendation. *Patient Education and Counseling*, 90(1), pp. 69-73.

Fullwood, C., Kennedy, A., Rogers, A., Eden, M., Gardner, C., Protheroe, J. and Reeves, D., 2013. Patients' experiences of shared decision making in primary care practices in the United Kingdom. *Medical Decision Making: an international journal of the Society for Medical Decision Making*, 33(1), pp. 26-36.

Goossensen, A., Zijlstra, P. and Koopmanschap, M., 2007. Measuring shared decision making processes in psychiatry: skills versus patient satisfaction. *Patient Education and Counseling*, 67(1), pp. 50-6.

Graneheim, U.H. and Lundman, B., 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), pp. 105-12.

Hakim, F.A. and Shen, W.K., 2014. Atrial fibrillation in the elderly: a review. *Future Cardiology*, 10(6), pp.745-58.

Han, P.K., 2013. Conceptual, methodological, and ethical in communicating uncertainty in clinical evidence. *Medical Care Research and Review*, 70(1), pp.12-36.

Hargraves, I. and Montori, V.M., 2014. Decision aids, empowerment, and shared decision making. *British Medical Journal* , 349, doi: 10.1136/bmj.g5811.

Have, P.T., 2007. *Doing conversation analysis.* 2nd ed. London: SAGE.

Heath, C., Hindmarsh, J. and Luff, P., 2010. *Video in qualitative research: analysing social interaction in everyday life.* Los Angeles: SAGE.

Hedberg, B. and Sätterlund Larsson, U., 2003. Observations, confirmations and strategies—useful tools in decision-making process for nurses in practice? *Journal of Nursing Management*, 12(2), pp. 215-22.

Hedberg, B., Cederborg, A. and Johanson, M., 2007. Care-planning meetings with stroke survivors: nurses as moderators of the communication. *Journal of Nursing Management*, 15(2), pp. 214-21.

Hedegaard, J., Ahl, H., Rovio-Johansson, A. and Siouta, E., 2014b. Gendered communicative construction of patients in consultation settings. *Women & Health*, 54(6), pp. 513-29.

Hedegaard, J., Rovio-Johansson, A. and Siouta, E., 2014a. Communicative construction of native versus non-native Swedish speaking patients in consultation settings. *Scandinavian Journal of Public Administration*, 17(4), pp. 21-47.

- Hegglund, L-H. and Hausken, K., 2013. Patient participation, decision-makers and information flow in surgical treatment. *Journal of Clinical Nursing*, 23(9-10), pp.1430-44.
- Hellström Muhli, U., 2003. *Att överbrygga perspektiv: en studie av behovsbedömningsamtal inom äldreinriktat socialt arbete. Bridging perspective: a study of the needs assessment calls within the elderly-oriented social work*. Diss. Göteborg. University of Göteborg.
- Henderson, S., 2000. Patient participation determined by nurses' attitudes toward caring. *International Journal of Human Caring*, 4, pp. 30-35.
- Hendriks, J.M., de Wit, R., Vrijhoef, H.J., Tieleman, R.G. and Crijns, H.J., 2010. An integrated chronic care program for patients with atrial fibrillation: study protocol and methodology for an ongoing prospective randomised controlled trial. *International Journal of Nursing Studies*, 47(10), pp. 1310-6.
- Heritage, J., 2010. Conversation analysis: practices and methods. In: D. Silverman, ed. *Qualitative research: theory, method and practice*. Los Angeles: SAGE. pp. 208-30.
- Hirsch, O., Keller, H., Krones, T. and Donner-Banzhoff, N., 2011. Acceptance of shared decision making with reference to an electronic library of decision aids (arriba-lib) and its association to decision making in patients: an evaluation study. *Implementation Science* 6, p.70, doi:10.1186/1748-5908-6-70.
- Høgh V, Lauberg A, Højbjerg T, Holm Hansen M, Schantz Laursen B. 2010. "Nu må de da kende mig!"-en kvalitativ fokusgruppeinterviewundersøgelse af patienters oplevelser af og forventninger til genindlæggelse med recidiverende atrieflimren. *Klinisk Sygepleje*, 24(4), pp.10-20.
- Hsieh, H.F. and Shannon, S.E., 2005. Three approaches to qualitative content analysis. *Qualitative Health Research*, 5(9), pp.1277-88.
- Hydén, L. C. and Mishler, E. G., 1999. Medicine and language. *Annual Review of Applied Linguistics*, 19, pp.174-92.
- Hydén, L.C., Plejert, C., Samuelsson, C. and Örulv, L., 2012. Feedback and common ground in conversational storytelling involving people with Alzheimer's disease. *Journal of Interactional Research in Communication Disorders/Equinox*, 4(2), pp.211-24.
- Ijäs-Kallio, T., Ruusuvauro, J. and Peräkylä, A., 2010. Patient resistance towards diagnosis in primary care: implications for concordance. *Health*, 14(5), pp. 505-522.
- Ishikawa, H., Hashimoto, H. and Kiuchi, T., 2013. The evolving concept of "patient-centeredness" in patient-physician communication research. *Social Science & Medicine*, 96, pp.147-53.
- Itakura, H., 2001. Describing conversational dominance. *Journal of Pragmatics*, 33(12), pp.1859-80.
- Jefferson, G., 2004. Glossary of transcript symbols with an introduction. In: G. Lerner, ed. *Conversation analysis: studies from the first generation*. Amsterdam/Philadelphia: John Benjamins.
- Johansson-Hidén, B., 1998. *Analyzing talk in the workplace group: dynamics, dominance and coherence*. Diss. Göteborg. University of Göteborg.

Korteland, N.M., Kluin, J., Klautz, R.J., Roos-Hesselink, J.W., Versteegh, M.I., Bogers, A.J. and Takkenberg, J.J., 2014. Cardiologist and cardiac surgeon view on decision-making in prosthetic aortic valve selection: does profession matter? *Netherlands Heart Journal*, 22(7-8), pp. 336-43.

Krippendorff, K., 2004. *Content analysis: an introduction to its methodology*. 2nd ed. Thousand Oaks: SAGE.

Langseth, M.S., Shepherd, E., Thomson, R. and Lord, S., 2012. Quality of decision making is related to decision outcome for patients with cardiac arrhythmia. *Patient Education and Counseling*, 87(1), pp.49-53.

Larsson, I.E., Sahlsten, M.J., Segesten, K. and Plos, K.A., 2011. Patients' perceptions of nurses' behaviour that influence patient participation in nursing care: a critical incident study. *Nursing Research and Practice*, p.8, doi.org/10.1155/2011/534060.

Larsson, I.E., Sahlsten, M.J., Sjöström, B., Lindencrona, C.S. and Plos, K.A., 2007. Patient participation in nursing care from a patient perspective: a grounded theory study. *Scandinavian Journal Caring Sciences*, 21(3), pp.313-20.

Latimer, S., Chaboyer, W. and Gillespie, B., 2013. Patient participation in pressure injury prevention: giving patient's a voice. *Scandinavian Journal of Caring Sciences*, 28(4), pp. 648-56.

Légaré, F., Elwyn, G., Fishbein, M., Frémont, P., Frosch, D. and Gagnon, M.P., 2008. Translating shared decision-making into health care clinical practices: Proof of concepts. *Implementation Science*, 3(2), p. 6, doi:10.1186/1748-5908-3-2.

Légaré, F., Turcotte, S., Stacey, D., Ratté, S., Kryworuchko, J. and Graham, I.D., 2012. Patients' perceptions of sharing in decisions. *The Patient*, 5(1), pp.1-19.

Lewis, B.K., Starzomski, R. and Young, L., 2014. A relational approach to implantable cardioverter-defibrillator generator replacement: an integrative review of the role of nursing in shared decision-making. *Canadian Journal of Cardiovascular Nursing*, 24(3), pp. 6-14.

Linell, P. and Gustavsson, L., 1987. *Initiative and response: the dialogue dynamics, dominance and coherence*. Linköping: University of Linköping.

Linell, P. and Luckmann, T., 1991. Asymmetries in dialogue: Some conceptual preliminaries. In: I. Markova and K. Foppa, eds. *Asymmetries in dialogue*. Hemel Hempstead: Harvester Wheatsheaf. pp. 1-20.

Linell, P., 1990. The power of dialogue dynamics. In: I. Markova and K. Foppa, eds. *The dynamics of dialogue*. Hemel Hempstead: Harvester Wheatsheaf. pp. 147-77.

Linell, P., 1998. Interaktionen i samtal : en teoretisk bakgrund. Interaction in conversations : a theoretical background. In: P-A. Forstorp and P. Linell, eds., *Samtal pågår: dialogiska perspektiv på svenska mediedebatter*. Stockholm: Carlsson.

Linell, P., 2011. *Samtalskulturer: kommunikativa verksamhetstyper i samhället. Conversation cultures: communicative activity types in the community*. Vol. 1. Linköping: Institutionen för kultur och kommunikation, Linköpings Universitet.

Linell, P., Gustavsson, L. and Juvonen, P., 1988. Interactional dominance in dyadic communication: a presentation of initiative-response analysis. *Linguistics*, 26(3), pp. 415-42.

- Lip, G.Y., Skjøth, F., Rasmussen, L.H. and Larsen, T.B., 2015. Oral anticoagulation, aspirin, or no therapy in patients with nonvalvular AF with 0 or 1 stroke risk factor based on the CHA2DS2-VASc Score. *Journal of the American College of Cardiology*, 65(14), pp. 1385-94.
- Llewellyn-Thomas, H.A. and Crump, R.T., 2013. Decision support for patients: values clarification and preference elicitation. *Medical Care and Research Review*, 70(1), pp. 50-79.
- Lupton, D. 2012. *Medicine as culture : Illness, disease and the body* (3rd ed.). Los Angeles, [Calif.] ; London: SAGE.
- Makoul, G. and Clayman, M.L., 2006. An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*, 60(3), pp. 301-12.
- Man-Son-Hing, M., Gage, B.F., Montgomery, A.A., Howitt, A., Thomson, R., Devereaux P., Protheroe, J., Fahley, T., Armstrong, D. and Laupacis, A., 2005. Preference-based antithrombotic therapy in atrial fibrillation: Implications for clinical decision making. *Medical Decision Making*, 25(5), pp. 548-59.
- Matthias, M.S., Salyers, M.P. and Frankel, R.M., 2013. Re-thinking shared decision-making: context matters. *Patient Education and Counseling*, 91(2), pp. 176-9.
- Mazzi, M., Rimondini, M., Deveugele, M., Zimmermann, C., Moretti, F., Van Vliet, L., . . . Bensing, J. 2015. What do people appreciate in physicians' communication? An international study with focus groups using videotaped medical consultations. *Health Expectations*, 18(5), pp. 1215-1226.
- McCabe, C. and Timmins, F. *Communication skills for nursing practice*. 2013. 2nd ed. New York: Palgrave Macmillan.
- McCabe, P.J., Schad, S., Hampton, A. and Holland, D.E., 2008. Knowledge and self-management behaviors of patients with recently detected atrial fibrillation. *Heart & Lung: The Journal of Acute and Critical Care*, 37(2), pp.79-90.
- McCabe, P.J., Schumacher, K. and Barnason, S.A., 2011. Living with atrial fibrillation: a qualitative study. *Journal of Cardiovascular Nursing*, 26(4), pp.336-344.
- McCormack, B., Dewing, J. and McCance, T., 2011. Developing person-centred care: addressing contextual challenges through practice development. *Online Journal of Issues in Nursing*, 16(2), doi: 10.3912/OJIN.Vol16No02Man03.
- McGuire, A.L., McCullough, L.B., Weller, S.C. and Whitney, S.N., 2005. Missed expectations?: physicians' views of patients' participation in medical decision-making. *Medical Care*, 43(5), pp. 466-70.
- Miller, W.R., Rollnick, S., Deci, E. and Ryan, R., 2012. Meeting in the middle: motivational interviewing and self-determination theory. *The International Journal of Behavioral and Nutrition Physical Activity*, 9 (1), doi:10.1186/1479-5868-9-25.
- Mishler, E.G., 1984. *The discourse of medicine: dialectics of medical interviews*. Norwood: Ablex.
- Montori, V.M., Brito, J.P. and Murad, M.H., 2013. The optimal practice of evidence-based medicine: incorporating patient preferences in practice guidelines. *JAMA*, 310(23), pp. 2503-4.

- Moreau, A., Carol, L., Dedianne, M.C., Dupraz, C., Perdrix, C., Lainé, X. and Souweine, G., 2012. What perceptions do patients have of decision making (DM)? Toward an integrative patient-centered care model. A qualitative study using focus-group interviews. *Patient Education and Counseling*, 87(2), pp. 206-11.
- Moumjid, N., Gafni, A., Bremond, A. and Carrere, M.O., 2007. Shared decision making in the medical encounter: are we all talking about the same thing? *Medical Decision Making*, 27(5), pp. 539-46.
- Müller-Engelmann, M., Donner-Banzhoff, N., Keller, H., Rosinger, L., Sauer, C., Rehfeldt, K. and Kronen, T., 2013. When decisions should be shared: A study of social norms in medical decision making using a factorial survey approach. *Medical Decision Making*, 33(1), pp. 37-47.
- National guidelines for cardiac care 2015. Stockholm: Swedish National Board of Health and Welfare. *Hjärtsjukvård: målnivåer för indikatorer : nationella riktlinjer - målnivåer.* (2015). Stockholm: Socialstyrelsen.
- O'Connor, A.M., Wennberg, J.E., Légaré, F., Llewellyn-Thomas, H.A., Moulton, B.W., Sepucha, K.R., Sodano, A.G. and King, J.S., 2007. Toward the 'tipping point': decision aids and informed patient choice. *Health Affairs*, 26(3), pp. 716-25.
- Olsson, U., Petersson, K. and Krejsler J.B., 2011. Youth' making us fit: on Europe as operator of political technologies. *European Educational Research Journal*, 10(1), pp. 1-10.
- Panisello-Tafalla, A., Clua-Espuny, J.L., Gil-Guillen, V.F., González-Henares, A., Queralt-Tomas, M.L., López-Pablo, C., Lucas-Noll, J., Lechuga-Duran, I., Ripolles-Vicente, R., Carot-Domenech, J. and López, M.G., 2015. Results from the registry of atrial fibrillation (AFABE): gap between undiagnosed and registered atrial fibrillation in adults--ineffectiveness of oral anticoagulation treatment with VKA. *BioMed Research International*, p 11, doi:org/10.1155/2015/134756.
- Peräkylä, A., Ruusuvoori, J. and Lindfors, P., 2007. What is patient participation: reflections arising from the study of general practice, homoeopathy and psychoanalysis. In: S. Collins, N. Britten, J. Ruusuvoori and A. Thompson, eds. *Patient participation in health care consultations*. Maidenhead: Open University Press, pp.121-42.
- Pohontsch, N.J., Herzberg, H., Joos, S., Welti, F., Scherer, M. and Blozik, E., 2015. The professional perspective on patient involvement in the development of quality indicators: a qualitative analysis using the example of chronic heart failure in the German health care setting. *Patient Preference and Adherence*, 9, pp.151-9.
- Polit, D.F. and Beck, C.T., 2010. *Essentials of nursing research: appraising evidence for nursing practice*. 7th ed. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Politi, M.C., Carmen, L.L. and Frosch, D.L., 2013. Supporting shared decisions when clinical evidence is low. *Medical Care and Research Review*, 70(1), pp.113-28.
- Pomerantz, A.M., 1984. Giving a source or basis: the practice in conversation of telling 'how I know'. *Journal of Pragmatics*, 8(5-6), pp. 607-25.
- Priest, H. and Roberts, P., 2010. Conducting ethical research in healthcare. In: H. Priest and P. Roberts, eds. *Healthcare research: a handbook for students and practitioners*. Chichester;Hoboken: J. Wiley, pp.111-29.

- Proot, I.M., Abu-Saad, H.H., de Esch-Janssen, W.P., Crebolder, H.F. and ter Meulen, R.H., 2000. Patient autonomy during rehabilitation: the experiences of stroke patients in nursing homes. *International Journal of Nursing Studies*, 37(3), pp. 267-76.
- Ramlawi, B. and Abu Saleh, W.K., 2015. Surgical ablation of atrial fibrillation. *Methodist Debakey Cardiovascular Journal*, 11(2), pp. 104-8.
- Rashotte, J. and Carnevale, F.A., 2004. Medical and nursing clinical decision making: a comparative epistemological analysis. *Nursing Philosophy*, 5(2), pp. 160-73.
- Robertson, M., Moir, J., Skelton, J., Dowell, J. and Cowan, S., 2011. When the business of sharing treatment decisions is not the same as shared decision making: a discourse analysis of decision sharing in general practice. *Health*, 15(1), pp.78-95.
- Roter, D., 2000. The enduring and evolving nature of the patient-physician relationship. *Patient Education and Counseling*, 39(1), pp. 5-15.
- Sacks, H., 1995. *Lectures on conversation: volumes I & II*. Oxford: Blackwell Publishers.
- Sahlsten, M.J., Larsson, I.E., Sjöström, B. and Plos, K.A., 2008. An analysis of the concept of patient participation. *Nursing Forum*, 43(1), pp. 2-11.
- Sahlsten, M.J., Larsson, I.E., Sjöström, B. and Plos, K.A., 2009. Nurse strategies for optimising patient participation in nursing care. *Scandinavian Journal of Caring Science*, 23(3), pp.490-7.
- Sainio, C. and Lauri, S., 2003. Cancer patients' decision-making regarding treatment and nursing care. *Journal of Advanced Nursing*, 41(3), pp.250-60.
- Sainio, C., Eriksson, E. and Lauri, S., 2001. Patient participation in decision making about care: The cancer patient's point of view. *Cancer Nursing*, 24(3), pp.172-9.
- Saldaña, J., 2003. *Longitudinal qualitative research: analyzing change through time*. Walnut Creek: AltaMira Press.
- Sandberg, F., Corino, V., Mainardi, L., Ulmoen, S., Enger, S., Tveit, A., Platonov, P.G. and Sörnmo, L., 2015. Non-invasive assessment of the effect of beta blockers and calcium channel blockers on the AV node during permanent atrial fibrillation. *Journal of Electrocardiology*, 48(5), pp. 861-6.
- Sandman, L. and Munthe, C., 2010. Shared decision making, paternalism and patient choice. *Health Care Anal*, 18(1), pp. 60-84.
- Sarangi, S. and Roberts, C.1999. *Talk, work and institutional order: discourse in medical, mediation and management settings*. Berlin and New York: Mouton de Gruyter.
- Sarangi, S. and Slembrouck, S., 2014. *Language, bureaucracy and social control*: Routledge. New York.
- Say, R., Murtagh, M. and Thomson, R., 2006. Patients' preference for involvement in medical decision making: a narrative review. *Patient Education and Counseling*, 60(2), pp. 102-14.
- Schegloff, E.A., 2007. *Sequence organization in interaction: a primer in conversation analysis volume 1*. Cambridge: Cambridge University Press.

Schoenthaler, A., Kalet, A., Nicholson, J. and Lipkin, M., Jr., 2015. Does improving patient-practitioner communication improve clinical outcomes in patients with cardiovascular diseases? A systematic review of the evidence. *Patient Education and Counseling*, 96(1), pp. 3-12.

Shepherd, H.L., Tattersall, M.H. and Butow, P.N., 2008. Physician-identified factors affecting patient participation in reaching treatment decisions. *Journal of Clinical Oncology*, 26(10), pp. 1724-31.

Sjögren, V., Grzymala-Lubanski, B., Renlubb, G.H., Friberg, L., Lip, G.Y., Svensson, P.J. and Själander, A., 2015. Safety and efficacy of well managed warfarin. *Thrombosis and Haemostasis*, 13(6), pp. 1370-7.

Siouta, E., 2012. *Communication patterns in consultations between patients with atrial fibrillation and health professionals*. Licentiatavhandling (sammanfattning) Jönköping: Jönköping University.

Stacey, D., Légaré, F., Pouliot, S., Kryworuchko, J. and Dunn, S., 2010. Shared decision making models to inform an interprofessional perspective on decision making: a theory analysis. *Patient Education and Counseling*, 80(2), pp. 164-72.

Stiggelbout, A.M., Van der Weijden, T., De Wit, M.P.T., Frosch, D., Légaré, F., Montori, V.M., Lyndal, T. and Elwyn, G. 2012. Shared decision making: really putting patients at the centre of healthcare. *BMJ*, 344:e256, doi: <http://dx.doi.org/10.1136/bmj.e256>.

Stivers, T., 2005. Parent resistance to physicians' treatment recommendations: one resource for initiating a negotiation of the treatment decision. *Health Communication*, 18(1), pp. 41-74.

Street Jr, R.L., Makoul, G., Arora, N.K. and Epstein, R.M., 2009. How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counseling*, 74(3), pp. 295-301.

Street, R.L. Jr., Gordon, H.S., Ward, M.M., Krupat, E. and Kravitz, R.L., 2005. Patient participation in medical consultations: why some patients are more involved than others. *Medical Care*, 43(10), pp. 960-9.

Street, R.L., Elwyn, G. and Epstein, R.M., 2012. Patient preferences and healthcare outcomes: an ecological perspective. *Expert Review of Pharmacoeconomics & Outcomes Research*, 12(2), pp. 167-80.

Swedish Code of Statutes. [Svensk författningssamling (SFS)] (2014:821). *Patientlag*. Stockholm: Riksdagen.

Themessl-Huber, Markus, Humphris, Gerry, Dowell, Jon, Macgillivray, Steve, Rushmer, Rosemary, & Williams, Brian. (2008). Audio-visual recording of patient-GP consultations for research purposes: A literature review on recruiting rates and strategies. *Patient Education and Counseling*, 71(2), pp. 157-168.

Thrall, G., Lip, G.Y., Carroll, D. and Lane, D., 2007. Depression, anxiety, and quality of life in patients with atrial fibrillation. *Chest*, 132(4), pp. 1259-64.

Tiedje, K., Shippee, N.D., Johnson, A.M., Flynn, P.M., Finnie, D.M., Liesinger, J.T., May, C.R., Olson, M.E., Ridgeway, J.L., Shah, N.D., Yawn, B.P. and Montori, V.M., 2013. 'They leave at least believing they had a part in the discussion': understanding decision aid use and

patient-clinician decision-making through qualitative research. *Patient Education and Counseling*, 93(1), pp. 86-94.

Travelbee, J., 1972. *Interpersonal aspects of nursing*. 2nd ed. Philadelphia: Davis.

Tsulukidze, M., Grande, S.W. and Gionfriddo, M.R., 2015. Assessing Option Grid® practicability and feasibility for facilitating shared decision making: an exploratory study. *Patient Education and Counseling*, 98(7), pp. 871-7.

Turker, Y., Ekinozu, I., AYTEKIN, S., Turker, Y., Basar, C., Baltaci, D. and Kaya, E., 2015. Comparison of changes in anxiety and depression level between dabigatran and warfarin use in patients with atrial fibrillation. *Clinical and Applied Thrombosis/Hemostasis*, 5(1), pp 1-4.

Tutton, E.M., 2005. Patient participation on a ward for frail older people. *Journal of Advanced Nursing*, 50(2), pp. 143-52.

van der Weijden, T., Pieterse, A.H., Koelewijn-van Loon, M.S., Knaapen, L., Légaré, F., Boivin, A., Burgers, J.S., Stiggelbout, A.M., Faber, M. and Elwyn, G., 2013. How can clinical practice guidelines be adapted to facilitate shared decision making? A qualitative key-informant study. *BMJ Quality & Safety*, 22(10), pp. 855-63.

Vermeire, E., Hearnshaw, H., Van Royen, P. and Denekens, J., 2002. Patient adherence to treatment: three decades of research. A comprehensive review. *Journal of Clinical Pharmacy and Therapeutics*, 26(5), pp. 331-42.

Walfridsson, U., Arestedt, K. and Stromberg, A., 2012. Development and validation of a new arrhythmia-specific questionnaire in tachycardia and arrhythmia (ASTA) with focus on symptom burden. *Health and Quality of Life Outcomes*, 10 (1), p 44. doi: 10.1186/1477-7525-10-44.

Wetzels, R., Geest, T.A., Wensing, M., Ferreira, P.L., Grol, R. and Baker, R., 2004. GPs' views on involvement of older patients: an European qualitative study. *Patient Education and Counseling*, 53(2), pp. 183-8.

Williams, J.R., 2008. The Declaration of Helsinki and public health. *Bulletin of the World Health Organization* 86(8), pp. 650-2.

Wirtz, V., Cribb, A. and Barber, N., 2006. Patient-doctor decision-making about treatment within the consultation--a critical analysis of models. *Social Science & Medicine*, 62(1), pp.116-24.