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Doctoral thesis

Elise Kvalsund Bårdsgjerde

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NTNU
Norwegian University of Science and Technology
Thesis for the Degree of
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Pasienter og helsepersonell sine erfaringer med pasientmedvirkning i pasientforløpet ved hjerteinfarkt

Pasientmedvirkning ved hjerteinfarkt

Hensikten med studien var å belyse pasienter, sykepleiere og leger sine erfaringer med pasientmedvirkning ved hjerteinfarkt. Årlig rammes over 12 000 nordmenn av hjerteinfarkt. Hjerteinfarkt inntreffer akutt og må behandles raskt med medikamentell behandling og utblokking. Utblokking blir utført ved ni sykehus og 50% av pasientene opplever å bli overflyttet mellom sykehus. Pasientmedvirkning kan føre til bedre pasienttilfredshet, økt samarbeid mellom pasient og helsepersonell og bedre mestring av sykdom. I denne studien deltok 10 pasienter, 22 sykepleiere og 9 leger.

Intervjustudiene med pasienter, sykepleiere og leger viste at pasientmedvirkning var utfordrende i akuttfasen, men at pasientene hadde behov for kortfattet og tydelig informasjon. Informantene fortalte at under behandling med utblokking fikk pasienten individuell informasjon om diagnose og behandling.

Funnene viste at mangel på kontinuitet og koordinering i pasientforløpet vanskeliggjorde pasientmedvirkning. Pasientene opplevde mangelfull informasjon om livsstilsendringer, medisiner og rehabilitering. Helsepersonellet ønsket sjekklister for pasientinformasjon, og de gav innsikt i hvordan rammefaktorer hindret de i å tilrettelegge for pasientmedvirkning. Informantene understreket betydningen av deltakelse i hjerterehabilitering etter utskrivelse. Pasientmedvirkning og samvalg i hjerterehabiliteringen var viktige forutsetninger for at pasientene skulle lykkes med livsstilsendringer og medisinetterlevelse.

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Contents

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As a PhD candidate I have been part of the research group *Helsetjenester i reformtid* (Healthcare in times of reform). In this group I have been involved in various research activities, of the greatest importance to me has been working on the book *Brukermedvirkning i helsetjenestene – realitet eller retorikk?* (User participation in healthcare services – reality or rhetoric?). Many thanks to all my good colleagues and fellow PhD candidates at the Department of Health Sciences in Ålesund. I am grateful for all the interest and support you have shown in the PhD project.

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List of included papers

Paper I*

Bårdsgjerde EK, Kvangarsnes M, Landstad B, Nylenna M, Hole T. Patients' narratives of their patient participation in the myocardial infarction pathway. *J Adv Nurs.* 2019;75:1063-1073. https://doi.org/10.1111/jan.13931

Paper II

Bårdsgjerde EK, Landstad BJ, Hole T, Nylenna M, Gjeilo KH, Kvangarsnes M. Nurses' perceptions of patient participation in the myocardial infarction pathway. *Nursing Open.* 2020;00:1-10. https://doi.org/10.1002/nop2.544

Paper III

Bårdsgjerde EK, Kvangarsnes M, Hole T, Nylenna M, Landstad BJ. Physicians' perceptions of patient participation in the myocardial infarction pathway. Submitted

*Reprint was made with permission, see Appendix 1.

ABBREVIATIONS

CABG – Coronary artery bypass grafting

CVD – Cardiovascular disease

EHII - European Health Information Initiative

ESC – European Society for Cardiology

GP – General practitioner

MI – Myocardial infarction

M-POHL – Measuring Population and Organisational Health Literacy

NSTEMI – Non-ST-elevation myocardial infarction

PCI – Percutaneous coronary intervention

NSD – The Norwegian Centre for Research Data

REK – Regional Committee for Medical and Health Research Ethics

STEMI – ST-elevation myocardial infarction

WHO – World Health Organisation

SAMMENDRAG

Bakgrunn

Akutt hjerteinfarkt er en av de vanligste og alvorligste sykdommene globalt. Sykdommen har ofte en akutt debut, men er forårsaket av kronisk underliggende aterosklerose som medfører forkalkninger og innsnevringer i hjertets kransårer. Behandlingen består derfor av både akutt livreddende behandling, etterfulgt av langsiktig behandling av den underliggende årsaken for å hindre videreutvikling av aterosklerose og tilbakefall. Hjerteinfarkt er en skremmende og livstruende situasjon for pasientene som rammes og deres pårørende. Pasientmedvirkning er utfordrende i akuttsituasjoner, likevel trenger pasienten tydelig informasjon om sykdommen og behandlingsforløpet.

Tidligere forskning har vist at pasienter og helsepersonell kan ha ulike oppfatninger av helsetjenestene og pasientmedvirkning. Derfor er det viktig å studere helsetjenestene fra ulike perspektiv for å kunne møte pasientenes behov for medvirkning i ulike faser av pasientforløpet. Forskning har funnet at pasientmedvirkning fører til bedre pasienttilfredshet, økt samarbeid med helsepersonell og bedre mestring av sykdom. Hensikten med denne avhandlingen er å studere pasientmedvirkning i ulike faser av hjerteinfarktforløpet fra et pasient-, sykepleie- og legeperspektivet. Avhandlingen er en syntese av tre vitenskapelige artikler.

Metode

Avhandlingen har et kvalitativt design. En kvalitativ tilnærming er verdifull når en ønsker å få en helhetlig forståelse av fenomenet en studerer. Artikkel I omhandler hvordan pasienter erfarte å medvirke i pasientforløpet ved hjerteinfarkt. En narrativ tilnærming ble valgt. Individuelle intervju ble gjennomført med ti pasienter to til fem måneder etter sykehusinnleggelsen. Datainnsamling ble foretatt på to sykehus uten koronar angiografi i januar og februar 2016. Artikkel II og III belyser sykepleiere og leger sine oppfatninger av pasientmedvirkning i hjerteinfarktforløpet. I artikkel II ble

det gjennomført 5 fokusgrupper med 22 sykepleiere som arbeidet i ulike faser av hjerteinfarktforløpet. I artikkel III ble ni erfarne leger individuelt intervjuet. Datainnsamling til artikkel II og III ble gjennomført fra februar til november i 2018 på to sykehus, ett med koronar angiografi og ett uten. En hermeneutisk tilnærming ble valgt.

Funn

Pasientene, sykepleierne og legene erfarte at graden av pasientmedvirkning varierte i pasientforløpet og at de ulike fasene gav ulike behov og muligheter for pasientmedvirkning.

I akuttfasen vurderte sykepleierne og legene at pasientmedvirkning var vanskelig å oppnå, og de prioriterte å diagnostisere og initiere riktig behandlingen innenfor behandlingstidsfristene. Pasientenes fortellinger løftet frem betydningen av tydelig informasjon i akuttfasen.

Under behandlingen med perkutan koronar intervensjon fikk pasienten individuelt tilpasset informasjon. Ved slutten av behandlingen fikk de oppsummerende informasjon om diagnose og hvilken behandling de hadde fått.

Pasienter, sykepleiere og leger erfarte at mangel på kontinuitet og koordinering hindret pasientmedvirkning under sykehusoppholdet og frem til utskrivelse. Legene og sykepleierne etterlyste sjekklister for pasientinformasjon. Pasientene erfarte mangel på informasjon om livsstilsendringer, medisiner og rehabilitering. Sykepleierne og legene erfarte at systemet begrenset mulighetene deres for å tilrettelegge for pasientmedvirkning. Måten arbeidet deres var organisert på, gav begrensede muligheter for kontinuitet i behandling og pleie. I tillegg manglet sykehusene rom hvor private samtaler mellom pasient og helsepersonell kunne foregå.

Sykepleierne og legene anbefalte pasientene å delta i hjerterehabiliteringsprogram etter utskrivelse. De fortalte at pasientmedvirkning var en viktig forutsetning for å oppnå livsstilsendringer og medikamentell etterlevelse. Pasientenes fortellinger understøttet betydningen av pasientmedvirkning og samvalg i hjerterehabiliteringsprogrammene.

Konklusjon

Denne avhandlingen har gitt innsikt i pasientmedvirkning i ulike faser i pasientforløpet ved hjerteinfarkt fra et pasient- og helsepersonellperspektiv. Pasientmedvirkning er kontekstuelt, og de ulike fasene i pasientforløpet gav ulike muligheter og utfordringer for pasientmedvirkning.

Pasientene og helsepersonellet synes å ha en felles forståelse av at pasientmedvirkning er vanskelig å oppnå i akuttfasen av et hjerteinfarkt. Helsepersonell må være spesielt oppmerksomme på pasientenes behov for tydelig informasjon i denne fasen.

Pasienter, sykepleiere og leger opplevde at mangel på kontinuitet og koordinering hindret pasientmedvirkning under sykehusoppholdet. Funnene i denne avhandlingen viser at det er nødvendig med en omstrukturering av hjerteinfarktforløpet. Standardiserte sjekklister for pasientinformasjon kan sikre at alle pasienter får en viss mengde med informasjon om sykdommen, behandlingen og sekundær forebygging som kan øke pasientens helsekompetanse. Det er behov for å styrke samarbeidet mellom helsepersonell og mellom sykehusene i pasientforløpet for å øke kontinuiteten og bedre koordinering av pasientforløpet.

Denne avhandlingen fremhever den viktige rollen til hjerterehabiliteringsprogrammene i hjerteinfarktforløpet. Pasientene, sykepleierne og legene understreket at pasientmedvirkning og samvalg var et sentralt fokus i hjerterehabiliteringsprogrammene for å øke pasientens muligheter til å oppnå sekundærprofylaktiske behandlingsmål.

SUMMARY

Background

Acute myocardial infarction is one of the most common serious illnesses; its acute onset is caused by an underlying cardiovascular disease. Life-saving treatment is implemented in the acute phase, followed by long-term treatment to prevent its recurrence. Myocardial infarction is a frightening and life-threatening condition for affected patients and their relatives. Patient participation is challenging in acute situations; however, patients need clear information about the disease and the clinical pathway.

Previous research has shown that patients and healthcare professionals have different perceptions of healthcare services and patient participation. Therefore, it is important to examine healthcare services from different perspectives to meet the patients' demands for participation in the different phases of the pathway. Studies have found that patient participation leads to improved patient satisfaction, co-operation with healthcare professionals, and enhanced management of the disease. Thus, this thesis aims to explore patient participation in the different phases of the myocardial infarction pathway from the perspectives of patients, nurses, and physicians. It is a synthesis of three scientific papers.

Methods

This thesis has a qualitative design that is valuable for gaining a complex and detailed understanding of the phenomenon under investigation. Paper I explored how patients experienced their participation in the myocardial infarction pathway. A narrative approach was applied. Individual interviews were conducted with ten patients two to five months after their hospital admission. The data were collected from two hospitals without percutaneous coronary intervention facilities in January and February 2016. Papers II and III explored nurses' and physicians' perceptions of patient participation in the myocardial infarction pathway. In the former, 5 focus groups were conducted with 22 nurses working in different phases of the myocardial infarction pathway. In Paper III, nine experienced physicians were interviewed individually. The data collection for

Papers II and III was carried out from February to November 2018 at two hospitals, one with percutaneous coronary intervention facilities and one without them. A hermeneutic approach was used in these studies.

Findings

The patients, nurses, and physicians experienced that the level of patient participation varied during the pathway and that the different phases led to diverse needs and opportunities for patient participation.

In the acute phase, the nurses and physicians did not consider patient participation as achievable, as they prioritised diagnosing correctly and initiating treatment within the time limits. The patients' narratives highlighted the importance of clear information in this phase.

Patient involvement during treatment was achieved through individualised patient information throughout the percutaneous coronary intervention. A summary of the diagnosis and treatment was provided at the end of the intervention.

The patients, nurses, and physicians perceived that lack of continuity and coordination challenged patient participation during hospitalisation and at the point of discharge. The nurses and physicians called for checklists of patient information. The patients experienced lack of information about lifestyle changes, medications, and rehabilitation. The nurses and physicians expressed that the system limited their opportunities to facilitate patient participation. The way their work was organised provided scarce opportunities for continuity in treatment and care. In addition, the hospitals lacked facilities where private conversations between patients and healthcare professionals could occur.

The nurses and physicians recommended that the patients attend cardiac rehabilitation programmes after discharge. They considered patient participation as an important precondition to achieve adherence to lifestyle changes and medications. The patients' narratives acknowledged the importance of patient participation and shared decision-making in cardiac rehabilitation programmes.

Conclusion

This thesis provides new insights into patient participation in the different phases of the myocardial infarction pathway from the perspectives of patients and healthcare professionals. Patient participation is contextual, and the various phases of the pathway provide different opportunities for it.

Patients and healthcare professionals seemed to have a shared understanding that patient participation was difficult to achieve in the acute phase of myocardial infarction. The healthcare professionals must be aware of the former’s need for clear information.

Patients, nurses, and physicians perceived that a lack of continuity and coordination challenged patient participation during hospitalisation. The findings of this thesis show the need for a restructuring of the myocardial infarction pathway. Standardised checklists for patient information might provide basic knowledge about the disease, acute treatment, and secondary prevention that might increase patients’ health literacy. It is necessary to strengthen the collaboration between healthcare professionals and between transferring hospitals to reinforce continuity, which might lead to better coordination of the pathway.

This thesis highlighted the important role of cardiac rehabilitation programmes in the myocardial infarction pathway. The patients, nurses, and physicians emphasised that these programmes focused on patient participation and shared decision-making to increase the possibility of patients achieving secondary prevention treatment goals.

1 INTRODUCTION

Myocardial infarction (MI) is a frightening and life-threatening condition for patients and their relatives (Dullaghan et al., 2014; Fors, Dudas, & Ekman, 2014). Patient participation is challenging in acute situations (Kvangarsnes, Hole, Bårdsgjerde, & Landstad, 2020; Thompson, 2007). Previous research from patients' perspective has shown that those with MI need clear information about the disease and the clinical pathway (Decker et al., 2007; Höglund, Winblad, Arnetz, & Arnetz, 2010).

Patient participation leads to improved patient satisfaction and safety (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016; Collins, Britten, Ruusuvuori, & Thompson, 2007; Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014), efficient co-operation between patients and healthcare professionals, and enhanced management of the disease (Collins et al., 2007; Vahdat et al., 2014). Previous research has reported that patients and healthcare professionals have different perceptions of healthcare services and patient participation (Florin, Ehrenberg, & Ehnfors, 2006; Höglund et al., 2010; Landstad, Bårdsgjerde, & Kvangarsnes, 2020). Therefore, it is important to examine the phenomenon from different perspectives to meet the patients' demands for participation. Thus, this thesis aimed to explore patient participation in the different phases of the MI pathway from the perspectives of patients, nurses, and physicians.

1.1 Myocardial infarction

Acute MI is one of the most common serious diseases globally (WHO, 2017); its acute onset is caused by underlying cardiovascular disease (CVD), which is a chronic illness causing calcifications and narrowing of the blood vessels (Grovatsmark et al., 2020; WHO, 2017). Approximately 17.9 million people have died from CVD in 2016 (WHO, 2017); furthermore, in Norway, approximately 12,000 people are affected by MI annually (Grovatsmark et al., 2020). The treatment consists of acute and life-saving treatment, followed by long-term treatment to prevent its recurrence (Grovatsmark et al., 2020).

1.1.1 Acute treatment

Acute MI treatment follows European Society of Cardiology (ESC) Guidelines (Neumann et al., 2018) and depends on the diagnosis of whether it is an ST-elevation MI (STEMI) or a non-ST-elevation MI (NSTEMI). In Norway, about a quarter of the MIs are STEMIs (Grovatsmark et al., 2020).

Acute treatment of STEMI depends on the distance to the nearest hospital with percutaneous coronary intervention (PCI) facilities. The preferred treatment involves the patient being treated with primary PCI within 120 minutes of the first medical contact. In cases where this is unfeasible, treatment with fibrinolysis followed by PCI is recommended (Ibanez et al., 2017; Neumann et al., 2018).

Acute treatment of NSTEMI is based on risk calculations. Very high-risk conditions, such as hemodynamic instability or cardiogenic shock, require immediate PCI treatment within 120 minutes, analogous to the treatment of STEMI. In 2020, new guidelines recommend that patients at a high risk of an established NSTEMI diagnosis demand PCI treatment within 24 hours (Collet et al., 2020); however, previous guidelines have suggested PCI for stable patients with NSTEMI within 72 hours (Roffi et al., 2016).

PCI must be performed by trained operators preferably with annual volumes of ≥ 75 procedures at institutions performing ≥ 400 PCIs each year (Neumann et al., 2018, p. 150). Therefore, it is often centralised to high-volume centres, resulting in long geographical distances to hospitals with PCI facilities in sparsely populated countries. In Norway, nine hospitals have such facilities; thus, 50% of patients are transferred between hospitals to receive invasive treatment (Grovatsmark et al., 2020). Figure 1 provides an overview of the four potential MI pathways with and without transfer(s) between hospitals. In addition to invasive treatments, both STEMI and NSTEMI patients are treated with blood-thinning medications, morphine, and eventually oxygen in the acute phase (Collet et al., 2020; Ibanez et al., 2017). In cases with severe multivessel diseases, surgery with coronary artery bypass grafting (CABG) is considered (Ibanez et al., 2017; Neumann et al., 2018). The acute treatment is effective, and Norway has a survival rate of 92% after 30 days (Grovatsmark et al., 2020).

Figure 1 Potential MI pathways

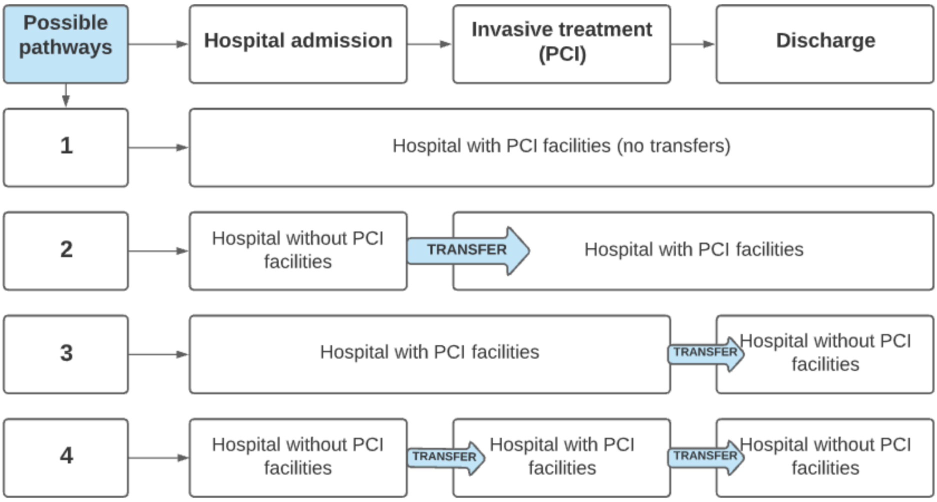


Figure 1 is inspired by Grovatsmark et al.'s (2020) Figure 47 on page 84 in the annual report of the Norwegian MI Register. Permission to use the figure was obtained from the licensees, see Appendix 2.

1.1.2 Long-term treatment and lifestyle changes

Patients with MI commonly have CVD with several associated risk factors, such as hypertension, diabetes, and hyperlipidaemia (Grovatsmark et al., 2020; WHO, 2017). Therefore, secondary prevention consisting of long-term treatment with medications and lifestyle changes, such as smoking cessation, physical activity, and diet, is necessary to reduce its progression and the risk of recurrent MI (Kotseva et al., 2019; Kotseva et al., 2016). Secondary prevention should be initiated during hospitalisation and before discharge (Piepoli et al., 2010; Piepoli et al., 2017; Piepoli et al., 2016).

Patient participation is essential to motivate patients to adhere to medications and lifestyle changes (Piepoli et al., 2016). The short hospital stay (Piepoli et al., 2017) and fragmented pathways with hospital transfers provide limited time to offer them patient information and education. Patient-reported data from the Norwegian MI Register show that 28% of the patients receive insufficient information, and over 50% lack knowledge about what they themselves can do after discharge and in the case of new events (Grovatsmark et al., 2020). The lack of information in the MI pathway is supported by international research (Mentrup, Harris, Gomersall, Köpke, & Astin, 2020).

Globally, prior research has shown that a large majority of patients with MI fail to achieve their treatment targets (Jortveit et al., 2019; Kotseva et al., 2019; Kotseva et al., 2016; Piepoli et al., 2016). In Norway, on average half of the treatment targets are attained, whereas only 1% of patients with MI achieve all of them (Jortveit et al., 2019). Cardiac rehabilitation is recommended for all patients after MI to increase adherence to medication and lifestyle changes (Piepoli et al., 2010; Piepoli et al., 2017; Piepoli et al., 2016). It is traditionally divided into three phases (Bjarnason-Wehrens et al., 2010; Piepoli et al., 2017). Phase I is initiated while the patient is still hospitalised; it consists of early mobilisation, information and counselling about the disease, treatment and risk factor management, and follow-up after discharge. Phase II comprises an outpatient programme lasting 2-16 weeks and most often contains group-based exercises and educational sessions twice a week (Bjarnason-Wehrens et al., 2010). A global concern is that the participation rate in cardiac rehabilitation programmes are low (Kotseva et al., 2016; Olsen, Schirmer, Bønaa, & Hanssen, 2018). Phase III consists of lifetime maintenance, where the goal is to continue exercise and maintain lifestyle modifications to minimise the risk factors (Bjarnason-Wehrens et al., 2010; Piepoli et al., 2017).

1.2 Structure of the thesis

The thesis is a synthesis of three papers and is divided into the following seven chapters: 1) Introduction, 2) Background, 3) Aim and research questions, 4) Methodology and methods, 5) Findings, 6) Discussion and 7) Conclusions.

2 BACKGROUND

This chapter presents the development of the patient participation phenomenon, the theoretical framework of the thesis, and previous research on patient participation.

2.1 A historical perspective

The 1960s and 1970s represented a change in the patient-professional relationship, from paternalism to an increased focus on patient involvement (Castro et al., 2016; Thompson, 2007). This transformation must be understood in light of changes in society where the medical field underwent major modifications. Severe pandemics and infectious diseases were combatted with vaccines and antibiotics, and new medications and treatment techniques were developed, making it possible to treat various illnesses such as cardiac diseases, diabetes, and cancer. A new patient group emerged with chronic diseases that required a different approach and restructuring of the healthcare system (WHO, 2005).

2.1.1 Ideological and political shifts

The changes in the healthcare system were influenced by an ideological political shift in which two different approaches reflecting dissimilar political values and trends emerged (Austvoll-Dahlgren, 2013; Thompson, 2007). One was based on individual rights to freedom, while the other on collective freedom that involved inclusion and equality. The individualistic approach was linked to the consumerist model and new public management, where the goal was to increase efficacy and quality. The patients were assigned a consumer role with rights and were perceived as co-producers of their own health and healthcare (Austvoll-Dahlgren, 2013; Thompson, 2007). In Norway, such rights included choosing one’s own general practitioner (GP), selecting hospitals for elective inquires, requesting second opinions, and complaining about incorrect or inadequate treatment and care (Kunnskapssenteret, 2013; Nylenna, 2020). The other approach was based on the democratic movement, in which human rights, respect for autonomy, inclusiveness, and equality in healthcare services were central (Austvoll-Dahlgren, 2013; Thompson, 2007). Through the Alma-Ata Declaration, the World Health Organisation (WHO) stated that: ‘people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare’ (WHO, 1978, p. 3).

Political approaches have emphasised patient empowerment (Thompson, 2007), defined as ‘a process that enables patients to exert more influence over their individual health by increasing their capacities to gain more control over issues they themselves define as important’ (Castro et al., 2016, p. 1927). An international goal within healthcare has been to empower patients to control and improve their health so that they can be co-producers of it (WHO, 1978, 1986, 2005). Hospital settings have been identified as an important arena for health-promoting interventions. Patient participation through patient education, rehabilitation, counselling, and support has been emphasised as important to enable patients to improve their health through lifestyle interventions (WHO, 2005).

From the change in the patient-professional relationship, the patient role has evolved from being a passive recipient of medical care to an active, empowered, and informed co-producer of health (WHO, 2013). This increase in patient engagement and participation has improved clinical outcomes and is, therefore, desirable (WHO, 2013). The Norwegian healthcare reforms and strategies have mainly followed international developments. For the past 20 years, emphasis has been placed on strengthening patients’ rights. In the previous decade, efforts have been directed towards efficient coordination of the health services, and quality and patient safety have been receiving increased attention simultaneously (Kunnskapssenteret, 2013). The Norwegian government has a clear vision of creating patients’ health services, depicted through the following well-known statement: ‘No decisions about me without me’ (Meld. St. 34 (2015-2016), 2016). Additionally, this has been evident in the latest National Health and Hospital Plan that aims to achieve a sustainable and patient-centred health service that facilitates patient participation and involves shared decision-making as a norm (Meld. St. 7 (2019-2020), 2019).

In recent years, there has been an increased focus on the ‘What Matters to You’ campaigns globally, aiming to increase personal engagement between healthcare professionals and patients and their relatives. The goal is to gain a deeper understanding of what truly matters to patients and to develop a partnership for co-creating health (FHI, 2019; IHI, 2021).

2.1.2 Health literacy

Another societal change that has influenced patient participation is the increased level of education in the population (Nylenna, 2020). Medical information has become more accessible through the Internet, social media, voluntary groups, and helplines (Austvoll-Dahlgren, 2013; Thompson, 2007; WHO, 2013). Readily available information can enhance medical knowledge in the population and contribute to improving health literacy. The WHO (1998, p. 10) defines health literacy as: ‘the achievement of a level of knowledge, personal skills, and confidence to take action to improve personal and community health by changing personal *lifestyles* and *living conditions*’. It indicates something beyond simply being able to read health information and implies a capacity to use it effectively. Thus, health literacy is crucial for empowerment and patient participation (WHO, 1998).

In 2019, the Norwegian government presented a strategy to increase health literacy (Helse- og omsorgsdepartementet, 2019). Sufficient health literacy is an important prerequisite for patients to actively participate in decisions regarding their health. This strategy applies to choices related to lifestyle preferences, interventions to prevent diseases, self-management of illnesses, and the use of health and care services (Helse- og omsorgsdepartementet, 2019). The Norwegian Directorate of Health conducted a national survey of health literacy of the population (Helsedirektoratet, 2020), part of a larger international collaboration initiated by the WHO European Health Information Initiative’s (EHII) network Action Network on Measuring Population and Organisational Health Literacy (M-POHL) concerning the implementation of the Health Literacy Population Survey 2019-2021. The results of the survey conducted in Norway were made available in 2020 and demonstrated that 20%, 46%, and 33% of the population had high, sufficient, and low levels of health literacy, respectively (Helsedirektoratet, 2020).

2.1.3 The legislation

The 1980s and 1990s represent a lasting shift in the patient-professional relationship (Nylenna, 2020). In most European and developed countries, patients' rights are regulated through national legislations, in which patients' rights to receive information and to participate in decisions regarding their treatment and care are central (WHO, 1994, 2013). In Norway, these rights are regulated by several laws: the Patients' Rights Act, the Health Personnel Act, and the Specialist Health Services Act (Act related to Health Personnel, 1999, last changed 2020; Act related to patients' rights, 1999, last changed 2020; The Specialist Health Services Act, 1999, last changed 2020). The Patients' Rights Act includes numerous paragraphs about the content and form of information and participation. Patients have the right to necessary information to gain insight into their state of health and the content of healthcare, including possible risks and side effects. The information must be adapted to the patient's individual preconditions, such as age, maturity, experience, culture, language, and background. It should be provided in a considerate manner, and healthcare professionals are responsible for ensuring that the information provided is understood by the patient. Patients have the right to participate in the implementation of health and care services and to choose between available and justifiable forms of services, examinations, and treatment methods. The form of participation must be adapted to each patient's ability to provide and receive information (Act related to patients' rights, 1999, last changed 2020).

2.2 Theoretical perspectives

Etymologically, the word ‘participation’ stems from the Latin verb *participare*, which means ‘to share in’ (Oxford English Dictionary, 2021). Participation refers to being actively involved in an event or a matter of importance for those partaking (Oxford English Dictionary, 2021). ‘Patient participation’ and ‘patient involvement’ are often used synonymously (Cahill, 1996; Thompson, 2007). Other related terms are ‘patient collaboration’, ‘patient partnership’, ‘user involvement’, ‘user participation’, and ‘consumer involvement’ (Cahill, 1996; Castro et al., 2016; Longtin et al., 2010; Thompson, 2007; Vahdat et al., 2014). ‘Decision-making’ and ‘shared decision-making’ are other terms closely associated with patient participation (Arnstein, 1969; Brownlea, 1987; Thompson, 2007). In this thesis, the term ‘patient participation’ was chosen. It has also been used in the Patient Rights Act, referring to a person who needs healthcare, defined in the legislation as a ‘patient’ (Act related to patients' rights, 1999, last changed 2020).

Patient participation became a mesh term in PubMed in 1978, and several researchers contributed to the clarification of its meaning and content. The theory of patient participation is often linked to either the micro, meso, and/or macro levels (Castro et al., 2016; Halabi et al., 2020). At the micro level, patient participation deals with individual treatment; at the meso level, it involves health services at an organisational level, while at the macro level, it deals with health policy (Castro et al., 2016). Different types and activities of participation can be connected to these levels (Castro et al., 2016). Tritter (2009) divided participation into five types: 1) individual patient participation in treatment decisions, 2) involvement in service development, 3) incorporation of the user perspective in evaluating the services, 4) participation in education and training of healthcare professionals, and 5) participation in research.

Sherry Phyllis Arnstein (1930-1997) was the first researcher to develop a framework for participation in the 1969 paper *‘A Ladder of Citizen Participation’* (Arnstein, 1969). In this paper, she discussed eight types of participation arranged in a hierarchy, wherein each type is connected to levels of power. At the bottom of the ladder is manipulation and therapy, representing non-participation, while the top constitutes higher degrees of citizen power and participation in decision-making (Arnstein, 1969). Although the ladder was developed for citizen participation, it was adapted to and used in developing frameworks for patient participation in healthcare contexts by later research.

Brownlea’s (1987, p. 605) definition of participation has been widely cited and claims that participation entails involvement in a decision-making process or in the delivery of a service or evaluation of a service, or simply being consulted on an issue or a matter. More importantly, Brownlea (1987) has indicated the key resources for participation to occur: access to appropriate information and knowledge, power, and skills.

Arnstein (1969) and Brownlea (1987) have highlighted participation at the meso and macro levels and how citizens can influence the development of society through involvement at the system level. At the beginning of the 1990s, several researchers started to explore patient participation and its meaning in a healthcare context.

Ashworth, Longmate, and Morrison (1992) claimed that patient participation is a mode of social interaction dependent on mutuality between patients and healthcare professionals. Further, they argued that participation required emotional and motivational reciprocity between patient and healthcare professionals, where both groups believed that their contributions were valuable and their identities secure. Ashworth et al. (1992) identified that this was especially challenging in the healthcare services where healthcare professionals were considered experts, the care culture was based on paternalistic values, and the healthcare professionals knew what was best for the patients.

Jo Cahill, a British nurse and researcher, conducted a concept analysis of patient participation within a nursing context (Cahill, 1996). The work of Brownlea (1987) was evident in Cahill’s concept analysis. Patient participation was compared in a hierarchical order, wherein involvement/collaboration, participation, and partnership were at the lowest, mid, and highest levels, respectively. Its five attributes were identified in the concept analysis: 1) a relationship between the patient and the nurse must exist; 2) the information, knowledge, and competence gaps between them must be reduced; 3) nurses must release some of their power to the patient; 4) the nurse and the patient must be engaged in intellectual or physical activities; and 5) a positive benefit must occur (Cahill, 1996, p. 565). Two years later, Cahill (1998) published a literature review on patient participation and concluded it to be complex and multifactorial in nature.

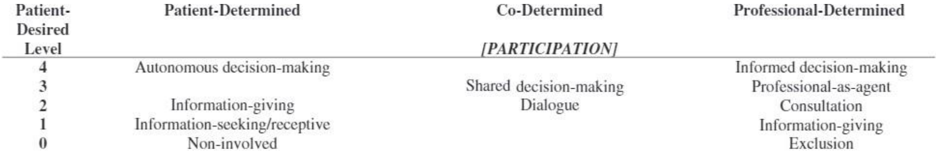
Sahlsten, Larsson, Sjöström, and Plos (2008) conducted a concept analysis of patient participation noticeably inspired by Cahill (1996). The same attributes of patient participation as found by Cahill (1996) were pursued by them; however, they were more detailed and the surrendering of power had greater prominence. Sahlsten et al. (2008, p. 2) defined patient participation as an established relationship between patient and nurse characterised by a surrendering of power and control, sharing of information and knowledge, and mutual engagement in an activity. Both Cahill (1996) and Sahlsten et al. (2008) were essential contributors to developing an understanding of patient participation in research and nursing practice. The latter emphasised the importance of a patient-centred approach with a focus on the patients' experiences and respect for patient autonomy.

2.2.1 An integrative approach to patient participation

Andrew Thompson, a researcher from Scotland, has made theoretical contributions to the understanding of patient participation by developing a taxonomy of patient involvement (Thompson, 2007) and an integrative approach to patient participation (Thompson, Ruusuvuori, Britten, & Collins, 2007). Patient involvement is identified as a complex, multifaceted, and dynamic concept occurring at different levels (Thompson, 2007; Thompson et al., 2007), whereas patient participation is a specific form of involvement that occurs only through mutual relationships, dialogue, and potentially shared decision-making (Thompson, 2007).

The taxonomy of involvement and participation (Thompson, 2007) is based on data from the perspectives of patients and representatives from health voluntary groups; it consists of five levels that are arranged as follows: 'non-involvement', 'information-seeking/receptive', 'information-giving/dialogue', 'shared decision-making', and 'autonomous decision-making'. Each level is presented in relation to patients' relative power to influence the situation and varies from non-involvement or exclusion to full autonomy. In the development of the taxonomy, Thompson (2007) contrasted the patient's desired levels of involvement with professional-determined levels identified from the literature, where Arnstein's (1969) ladder of citizen participation is central. The relationship between patient- and healthcare professional-determined involvements as well as the levels of involvement are illustrated in Figure 2.

Figure 2 Levels of patient involvement



Patient-Desired Level	Patient-Determined	Co-Determined *[PARTICIPATION]*	Professional-Determined
4	Autonomous decision-making		Informed decision-making
3		Shared decision-making	Professional-as-agent
2	Information-giving	Dialogue	Consultation
1	Information-seeking/receptive		Information-giving
0	Non-involved		Exclusion

Fig. 2. Levels of involvement.

The figure is retrieved from Thompson's (2007) Figure 2. Levels of involvement on page 1306 in the paper 'The meaning of patient involvement and participation in health care consultations: A taxonomy'. The figure is reproduced with permission from Elsevier, see Appendix 3.

Patient participation occurs at the level of 'shared decision-making' and 'dialogue', as shown in Figure 2; it can only be achieved through willingness from both patients and healthcare professionals, a two-way communication characterised by openness and mutual respect (Thompson, 2007). However, Thompson (2007) argues that patient participation does not necessarily include the sharing of decisions or consensus, as the patient can choose to allow the healthcare professional to make the final decision.

The level of involvement depends on the contextual dimensions. For example, the type of illness, whether it is acute or chronic, and the severity of the condition should be considered. Chronic conditions offer greater possibilities for higher levels of patient involvement. Additionally, the level of involvement also depends on patient characteristics and the relationship between patients and healthcare professionals. The desired level of involvement can vary according to circumstances and/or over time for the same person in the same context (Thompson, 2007).

The multifaceted nature of patient participation is evident in the integrative approach presented through three elements: components, levels, and contexts. The levels and contextual dimensions are known from the taxonomy, whereas the components consist of five key areas where the patients can participate within or across consultations (Thompson et al., 2007). These components were developed by Peräkylä and Ruusuvuori (2007) as a model for researching patient participation at the individual level; they are as follows: (1) patients' contribution to the direction of action, for example, through initiation or response; (2) patients' influence in defining the problem; (3) patients' role in the reasoning process, for example, discussing the issue and its possible solutions; (4) patients' influence in decision-making; and (5) emotional reciprocity between patients and healthcare professionals (Peräkylä & Ruusuvuori, 2007; Thompson et al., 2007). The level of involvement can vary within and across these five areas of participation based on the context (Thompson et al., 2007). For example, a patient seeking medical help for an acute condition, such as an MI, will not necessarily be able to contribute in discussions about diagnosis or treatment in the acute phase. Later in the pathway, at discharge or during rehabilitation, the patient might desire to participate in discussions about further medical treatment and secondary prevention.

2.2.2 Theoretical framework

Thompson's (2007) taxonomy of patient involvement and participation, Thompson et al.'s (2007) integrative approach to patient participation, and the four ethical principles within medicine and nursing (Beauchamp & Childress, 2019) were chosen as the theoretical framework for this thesis.

The taxonomy (Thompson, 2007) and the integrative approach (Thompson et al., 2007) shed light on interactions between patients and healthcare professionals and have been developed to understand patient participation at the individual level. Patient participation has been attached to the ethical principles of autonomy. In the case of acute illness, one may be temporarily unable to participate and exercise autonomy (Beauchamp & Childress, 2019). Respect for autonomy is one of the four ethical principles that constitute a comprehensive moral framework aimed at guiding practice within nursing and medicine; the three others are non-maleficence, beneficence, and justice. None of the principles are superior, indicating that in practice, they are weighed and balanced towards each other due to different contexts. Autonomy is dependent on the patients' competence and context (Beauchamp & Childress, 2019). For example, in acute situations, the patients' ability to participate might be reduced and the healthcare professionals may perform based on non-maleficence and beneficence rather than involving the patient in medical decisions. The four ethical principles add complementary perspectives to the moral dimensions of patient participation.

2.3 Previous research

In this section, I present systematic reviews and primary studies on patient participation from the perspectives of patients and healthcare professionals. In recent years, many studies have been carried out in relation to specific diagnoses and care contexts, such as diabetes, heart failure, chronic obstructive pulmonary disease, kidney failure, and cancer. I have selected relevant studies and review articles on patient participation within the hospital care setting.

2.3.1 Systematic reviews

Systematic reviews are characterised by a careful and transparent integration of primary studies on a specific research question. The methods used are disciplined, reproducible, and verifiable. Several types of systematic reviews that result in diverse products are described (Polit & Beck, 2020). Systematic reviews and other forms of evidence syntheses (concept analysis and comprehensive summaries based on extensive literature searches) on patient participation are included in this section.

Numerous researchers have conducted different types of systematic reviews that clarify patient participation in relation to other terms, such as patient-centred care (Castro et al., 2016; Halabi et al., 2020; Kitson, Marshall, Bassett, & Zeitz, 2013) and patient empowerment (Castro et al., 2016; Halabi et al., 2020). A narrative review based on 60 papers from health policies, medicine, and nursing literature identified that patient-centred care was dependent on three core elements: patient participation, a relationship between patients and healthcare professionals, and the context of care delivery. These represent a common understanding of patient participation; however, the review also pointed out differences, especially between nurses and physicians. Articles from nursing and physician perspectives focused on the patients' values and preferences and the informed decision-making process, respectively (Kitson et al., 2013).

In accordance with Sahlsten et al.'s (2008) concept analysis, Kitson et al. (2013) stated that there was an evident connection between the patient-centred approach and patient participation. This is supported by Castro et al. (2016), who conducted a concept analysis based on a literature review to clarify the meaning of the concepts of patient empowerment, patient participation, and patient-centredness. Several similarities were found between them; for example, a balance of power between patients and healthcare professionals was highlighted as an important precondition for all three concepts. In addition, all of them were dependent on interactions and communications between patients and healthcare professionals, where the latter were aware of the former's values and preferences. In this concept analysis, patient participation was identified as an important antecedent of patient empowerment and patient-centredness. Castro et al. (2016) concluded that patient participation was a strategy to achieve patient-centredness in healthcare, which could, in turn, promote patient empowerment.

In their scoping review of 39 articles, Halabi et al. (2020), explored patient participation and related concepts such as patient-centred care, patient empowerment, and patient partnership at the micro, meso, and macro levels. The concepts were studied transversally, and the review focused on the contents' commonalities rather than their differences. Many of their findings were in line with previous reviews, especially those at the micro level. At the micro level, the collaboration between patients and healthcare professionals based on a reciprocal relationship characterised by mutual trust, engagement, and open dialogue were mentioned as important to achieve patient participation. Patient participation was further dependent on the characteristics of healthcare professionals and patients. At the meso and macro levels, it relied on the characteristics of the healthcare organisation and system, organisational culture, training, and access to resources. However, Halabi et al. (2020) criticised Castro et al.'s (2016) portrayal of patient empowerment as a broader concept than patient-centred care and patient participation. They stated that patient empowerment was a dimension of patient participation.

In their comprehensive literature summary, Longtin et al. (2010) identified that patient participation challenged the traditional and paternalistic model that characterised the healthcare system. To achieve patient participation, healthcare professionals must be willing to surrender some of their power to their patients (Longtin et al., 2010). This is in line with the findings of two Danish researchers, Angel and Frederiksen (2015) who aimed to explore the challenges experienced in achieving patient participation in clinical nursing. In their systematic review of 33 empirical articles (32 qualitative and 1 quantitative), 5 key elements important for patient participation were identified: the patients' situation, time, exchange of information and knowledge, the relationship between patients and nurses, and nurses' attitude towards patient participation. Angel and Frederiksen (2015) concluded that patient participation is difficult to achieve in its ideal form, as there always exists an imbalance in power between patients and healthcare professionals as laypersons and experts, respectively. However, they emphasised the importance of the active engagement of the latter in promoting patient participation.

In their integrative review of three quantitative and six qualitative articles, Tobiano, Marshall, Bucknall, and Chaboyer (2015) found that patient participation was difficult to achieve in medical wards. They identified an incongruence between nurses' and patients' preferences for patient participation, where the latter experienced more or less participation than desired. Busy and task-oriented nurses hindered patient participation.

Kvangarsnes et al. (2020) and Landstad et al. (2020) conducted two qualitative metasyntheses on patients' and healthcare professionals' experiences of patient participation within acute and chronic care contexts. The first metasynthesis involved acute illnesses and was based on 12 qualitative articles; it showed that the time dimension determined whether patient participation was possible in treatment decisions in acute situations. An acute illness can lead to demanding interactions between patients and healthcare professionals, where ethical dilemmas may arise (Kvangarsnes et al., 2020). The second metasynthesis consisted of 14 qualitative articles; it indicated that patients with chronic diseases experienced that information and dialogue eventually provided good conditions for patient participation. Ambiguous roles and a lack of interprofessional collaboration could hinder patient participation; moreover, the healthcare professionals experienced that ethical dilemmas arose quickly if the patients' situation worsened and treatment plans were not discussed (Landstad et al., 2020).

The reviews show that several prerequisites must be met to achieve patient participation, and numerous obstacles that hinder it were also mentioned. First, patients must desire to participate, and this desire to participate varies according to characteristics, the type of illness, and the severity of the situation (Angel & Frederiksen, 2015; Longtin et al., 2010; Tobiano, Marshall, et al., 2015; Vahdat et al., 2014). Low health literacy was identified as a main obstacle to patient participation (Longtin et al., 2010). In addition, it is important that healthcare professionals have a positive attitude towards promoting patient participation (Angel & Frederiksen, 2015; Halabi et al., 2020; Longtin et al., 2010; Tobiano, Marshall, et al., 2015). The promotion of patient participation could also be obstructed by the characteristics of the healthcare organisation and system (Halabi et al., 2020). The organisational culture, how well healthcare professionals are trained in facilitating patient participation, and access to resources such as time and knowledge impact how it is supported within a hospital care setting (Angel & Frederiksen, 2015; Halabi et al., 2020; Longtin et al., 2010; Tobiano, Marshall, et al., 2015).

Although patient participation can be challenging and difficult to achieve, Angel and Frederiksen (2015) found that in the studies included in their review, it was described as being unquestionably beneficial to the patients. Furthermore, several reviews highlighted that it may increase patient safety and healthcare quality (Castro et al., 2016; Halabi et al., 2020; Vahdat et al., 2014).

2.3.2 Patient participation from the healthcare perspective

Sahlsten and colleagues studied nurses' understanding of patient participation and what hindered and facilitated it in a clinical nurse context (Sahlsten, Larsson, Lindencrona, & Plos, 2005; Sahlsten, Larsson, Plos, & Lindencrona, 2005; Sahlsten, Larsson, Sjöström, Lindencrona, & Plos, 2007; Sahlsten, Larsson, Sjöström, & Plos, 2009). They found that patient participation was dependent on a mutual relationship based on empathy, trust, and respect between patients and nurses, with exchange of information and knowledge serving as its basis (Sahlsten, Larsson, Lindencrona, et al., 2005; Sahlsten et al., 2007). Nurses' strategies to optimise patient participation included cooperating with the patients, having a patient-centred approach, and encouraging and motivating them to increase their self-care capacity (Sahlsten et al., 2009). Patient participation might have been hindered if the nurses had insufficient insight or knowledge on how to facilitate it or if there was a lack of continuity in the patient-nurse relationship. Lack of co-worker support and shortcomings during ward rounds, in care planning, and the physical environment were additional obstacles that were identified. Further, patient participation could be challenging if the patients and their relatives have conflicting desires (Sahlsten, Larsson, Plos, et al., 2005).

Tobiano, Bucknall et al's (2015) and Oxelmark et al's (2018) research on nurses' perceptions of patient participation, which were in accordance with the majority of studies, reported that patient participation was achieved by listening to patients, engaging patients, relinquishing of power, and partnering with patients (Oxelmark et al., 2018; Tobiano, Bucknall, et al., 2015). These findings confirm and support previous research rather than add something new to the field. The strength of the studies was the nurses' understanding of what hinders and facilitates patient participation.

Oxelmark et al. (2018) conducted a qualitative study that found that the routines of the hospitals and wards were still organised in accordance with paternalistic norms where patient participation was not central. Ward rounds were used as an example of a situation where patient participation was difficult to achieve. The medical jargon employed in the ward rounds, decisions made in advance by the physicians, and several patients who shared the same room were described as obstacles to patient participation.

Additionally, the nurses pointed out that there was a need to strengthen teamwork and inter-professional collaboration between nurses and physicians as well as to include patients in the collaborating team (Oxelmark et al., 2018).

Rules, perceptions of maintaining safety, and patient characteristics can limit nurses in their attempts to promote patient participation (Tobiano, Bucknall, et al., 2015). An interesting finding is that nurses experience a conflict between enacting the principles of autonomy and beneficence. From a nursing viewpoint, patient autonomy may be perceived as a threat to nurses’ ethical and legal responsibilities for patients’ safety and well-being (Tobiano, Bucknall, et al., 2015).

A quantitative study in a hospital setting examined nurses’ perceptions of patient participation (Kolovos et al., 2015). Nurses perceived patient participation as a process of information provision, patients communicating their symptoms, and patient compliance. The study provides insight into the complexity of patient participation in hospital settings, where patients, nurses, and the care context affect the degree of patient participation (Kolovos et al., 2015).

Patient participation in acute care settings such as intensive care units is challenging. Schandl, Falk, and Frank (2017) assessed how nurses perceived patient participation in intensive care units. They found that patient participation was dependent on patients’ condition and consciousness. If patients were unable to participate, nurses attempted to involve them indirectly through external sources of information, such as the relative knowledge of patients’ preferences (Schandl et al., 2017).

2.3.3 Participation from the patient perspective

Larsson and colleagues studied patient participation from a patient perspective. The preconditions for patient participation as described by patients were in accordance with nurses’ descriptions, such as dialogues with exchange of information where the former were involved, felt heard, and received an opportunity to participate in activities (Larsson, Sahlsten, Sjöström, Lindencrona, & Plos, 2007). Nurses’ attitudes and behaviours related to patient participation determined the extent to which patients were allowed to participate (Larsson, Sahlsten, Segesten, & Plos, 2011a). Barriers to patient participation arose when patients felt unable to participate because of an illness, a lack of medical knowledge, when experiencing a paternalistic attitude and insufficient empathy, or when structural barriers such as lack of continuity, collaboration, and resources hindered patient participation (Larsson, Sahlsten, Segesten, & Plos, 2011b).

Eldh and colleagues performed a survey to explore how patients admitted to hospital wards or visiting outpatient clinics experienced patient participation and non-participation (Eldh, Ekman, & Ehnfors, 2006, 2008, 2010). Patient participation could not be understood only in terms of decision-making (Eldh et al., 2008, 2010). It occurred when patients felt that they were treated individually and provided with information and explanations adapted to their individual needs and when their knowledge was recognised by healthcare professionals (Eldh, Ekman, et al., 2006). In 2015, Eldh, Luhr, and Ehnfors (2015) presented the Patient Preferences for Patient Participation tool. Based on Eldh's previous research, both qualitative and quantitative, it aimed to allow patients to depict, prioritise, and evaluate their participation in healthcare (Eldh et al., 2015).

Tobiano, Bucknall, Marshall, Guinane, and Chaboyer (2016) found that patients reported various personal preferences for participation. Patients were satisfied when they experienced participation at the desired level. Patient participation was dependent on information and knowledge exchange between them and the nurses. The patients reported that they participated by monitoring their care, for example, by ensuring that the nurses provided them with their correct medications. Nurses' paternalistic attitude hindered the patients from participating (Tobiano et al., 2016).

2.3.4 Similarities and differences in the perceptions of patient participation

Some studies included perspectives of healthcare professionals and patients. The similarities and differences in perceptions of patient participation were identified. Henderson (1997) conducted interviews and observations to examine patients' and nurses' perceptions of patient participation in a hospital setting. Four factors were identified as necessary to achieve patient participation: 1) mutual trust and an established relationship, 2) positive nurse-patient attitude, 3) sustained nurse-patient contact, and 4) meaningful interactions. Patients reported that personalised care and conversations increased their possibilities of participation. Patients and nurses emphasised the importance of continuity of care. Three factors were identified as inhibiting patient participation: 1) lack of time, 2) negative nurse-patient contact, and 3) task-oriented nursing. Time constraints led to nurses being task-oriented to ensure patients were provided with basic care as a minimum. This impacted their opportunities to interact with patients; moreover, the observation data showed that they often used close-ended questions in conversations with their patients. Short hospital stays prevented them from getting sufficiently acquainted with each other, which in turn hindered patient participation (Henderson, 1997).

Another study conducted by Henderson (2003) explored nurses' and patients' views of partnership in a hospital care setting. The findings showed that a power imbalance between the two might hinder patient participation. In some cases, nurses were reluctant to provide information and involve patients in the decision-making process. They expressed that they often 'knew' what was best for the latter, as patients frequently lacked medical knowledge. Patients found they needed to be fully informed before they could be involved in decisions about their care. Some of them expressed that they had inadequate information and experienced uncertainty regarding what was happening (Henderson, 2003).

Eldh, Ehnfors, and Ekman (2006) investigated how patients and nurses experienced patient participation and non-participation in a nurse-led clinic for heart failure. Data collection consisted of interviews and observations. Conflicting values were identified between patients and nurses, especially with regard to non-participation. Patient participation was understood by patients as taking responsibility and being an equal partner in the relationship, while nurses understood it in terms of providing patient information that enabled them to take actions. Non-participation was experienced by patients as a lack of equality in the relationship, where nurses overruled them and did not take their situation into consideration. However, nurses reported it to occur when patients rejected information and recommendations from them. The observations showed that nurses dominated the visits and often provided standardised information that seemed to be prepared in advance (Eldh, Ehnfors, et al., 2006).

In a quantitative study, Florin et al. (2006) explored the degree of concordance between patients' and nurses' perceptions of patient participation in decision-making in nursing care. Most patients preferred a passive role in the decision-making process. Differences related to age and social situation were identified; younger patients wanted a more active role than the older ones, and those living alone preferred a more active role than the married or cohabitant ones. Most nurses believed that patients preferred to participate to a greater extent than the patients themselves wanted. Patients reported that they experienced a more passive role in situations where they desired a more active one and vice versa. Communication, breathing, and pain problems were areas where patients preferred a more active role (Florin et al., 2006).

Tobiano, Marshall, and Chaboyer (2021) explored patients' and nurses' perceptions of non-participation in nursing care at a private and a public hospital in Australia. They found that non-participation occurred when nurses impeded two-way communication. In public hospitals, nurses reported that non-participation arose when their communication was insufficient due to perceived rules and efficiency needs. Patient participation was often limited in immediate discharges; this was also evident from the patients' perspective as they reported that they did not seek involvement because of the nurses' business. At private hospitals, patients expected high-quality care and their needs being met by nurses, thus reducing the demand for patient participation (Tobiano et al., 2021).

2.4 Previous research on patient participation in the myocardial infarction pathway

In the period from 2016 to 2021, I have performed regular literature searches in electronic databases such as PubMed, CINAHL, and Scopus. This was challenging because of the many synonyms and terms used interchangeably with patient participation. Assistance from librarians was useful on several occasions. The main terms and combinations employed in the search strategy were patient participation OR patient involvement AND myocardial infarction. Other terms used in various combinations with the aforementioned ones were patient perspective/experiences/perceptions and healthcare professional/nurse/physician perspective/experiences/perceptions. Google Scholar was utilised for free text search and to hand-search reference lists. In addition, I explored relevant journals.

Since the use of PCI as a treatment method for MI was introduced around the year 2000 in most countries, the literature presented here is limited to publications from 2005 to date. It originates from Sweden, Norway, Iceland, Finland, the United Kingdom, Germany, Spain, the United States of America, Australia, and Israel. The studies included were peer-reviewed; 19, 13, and 6 articles were quantitative, qualitative, and systematic review studies, respectively. Although several of them did not deal with patient participation directly, they addressed various aspects that are important for patient participation, such as patient information, shared decision-making, continuity in care, secondary prevention, and cardiac rehabilitation.

2.4.1 Patient participation

A Swedish research group examined patient participation in MI care. Questionnaires were developed to measure (a) nurses’ and physicians’ perceptions and behaviours regarding patient involvement in MI care (Arnetz, Höglund, Arnetz, & Winblad, 2008b) and (b) patients’ perceptions of their involvement during hospitalisation for MI (Arnetz, Höglund, Arnetz, & Winblad, 2008a). The patient and healthcare professional surveys were conducted in 2005-2006 at 11 and 12 hospitals in Sweden, respectively.

In total, 488 healthcare professionals answered the questionnaire; 53, 132, and 303 were physicians, licensed practical nurses, and nurses, respectively (Arnetz, Winblad, Arnetz, & Höglund, 2008). The results showed that healthcare professionals supported patient involvement. Overall, 97% of them reported that involving patients enriched their work; simultaneously, patient involvement was considered time consuming. Lack of time and prioritising other tasks were reported to hinder patient involvement. Information was considered an important aspect of it, and the majority of the respondents agreed that exchange of information, where the patients could ask questions and express their opinions, was important. Moreover, 64% and 50% agreed that patients should participate in discussions about treatment and care and in decision-making, respectively. Patient involvement in the acute phase was considered less important; however, respondents reported that information in this phase was important. Notably, 62%, 44%, and 9% of physicians, nurses, and licensed practical nurses discussed lifestyle changes before discharge, respectively (Arnetz, Winblad, et al., 2008). Later, in 2015, Arnetz and Zhdanova (2015) used the same data material to introduce and define patient involvement climate and measure its quality and strength among nurses. In this study, they found that although most nurses strongly believed in the importance of patient involvement, it was not necessarily reflected in their clinical behaviours. Further, correlations between nurses' views on patient involvement and their clinical behaviours were identified. For example, (a) when nurses perceived patient involvement as a hindrance in their clinical work, they were less attentive to patient needs, and (b) motivational behaviours among nurses led to improved information exchange and discussion of suitable patient activities after discharge (Arnetz & Zhdanova, 2015).

The questionnaire developed for patients was answered by 652 patients aged <75 years, of whom 77% were men (Arnetz & Arnetz, 2009). The results showed that 86% and 76% of them believed that it was important to be involved in discussions about care and treatment during hospitalisation and in decision-making about their care, respectively. In the acute phase, 64% of patients experienced security in leaving all decisions to healthcare professionals. Notably, nearly 30% and 35% of the patients reported that they would have liked more involvement during hospitalisation and in planning their follow-up at discharge, respectively. Prior to hospital discharge, nearly 15% had not discussed any lifestyle changes with their healthcare professionals; this was more prevalent among younger female patients (Arnetz & Arnetz, 2009). In Arnetz et al. (2010) the questionnaire data of patients' ratings of their involvement were compared with medical outcome data 6-10 weeks after hospital discharge. The results did not indicate any significant association between experienced involvement and in-hospital and treatment outcomes. However, enhanced involvement during hospitalisation was associated with fewer cardiovascular symptoms, such as chest pain and breathlessness, at the first follow-up after discharge for MI (Arnetz et al., 2010). The time, 6-10 weeks, can be considered too short for assessing whether patient involvement influences treatment outcomes.

Furthermore, the Swedish research group consisting of Höglund, Winblad, Arnetz, and Arnetz, also published a qualitative study consisting of focus groups with patients and healthcare professionals (Höglund et al., 2010). At three hospitals in Sweden, five focus groups were conducted in 2005, two with patients and three with healthcare professionals. Information from these focus groups was used as a foundation for the development of the questionnaires (Arnetz, Höglund, et al., 2008a, 2008b). The findings showed that patients and healthcare professionals expressed that patient participation was both valuable and desirable for patients with MI. How patient participation was understood varied among the participants. Nurses encouraged patients to participate in decision-making, while physicians equalised patient participation by obtaining informed consent based on good patient information. Nevertheless, patients found that information was the most important part of the process of participation. Although patient participation was difficult to achieve in the acute phase, both patients and healthcare professionals emphasised the importance of information in this phase. Insufficient time and resources, patient characteristics, and lack of medical knowledge were mentioned as hindrances to patient participation. Some of the patients were unaware that they had the right to participate, and thus healthcare professionals would frequently have to initiate patient participation (Höglund et al., 2010).

An American qualitative study explored 19 patients' preferences for involvement in decision-making in the MI pathway (Decker et al., 2007). They found that the immediate treatment an MI required led to limited possibilities for patient participation in decisions regarding treatment in the acute phase. During hospitalisation, patients' desires for involvement varied; thus, for most, the desire seemed to increase throughout the pathway. They needed individualised and precise information in plain language that was easy to understand. Simultaneously, they realised that grasping information during hospitalisation was challenging. After discharge, patients' information needs increased, and they experienced a more active role (Decker et al., 2007).

A quantitative study, examined anxiety, depression, coping, and the desire of patient involvement in care in 128 patients and their partners after an MI (Nilsson, Ivarsson, Alm-Roijer, & Svedberg, 2013). Their results reported that patients and partners of female gender, younger age, and higher education levels preferred a higher degree of participation in decision-making in patient care. Additionally, they emphasised the importance of including partners in patient care.

2.4.2 Patient information

Patient information is an important prerequisite for patient participation. Three Norwegian studies, one quantitative (Oterhals, Hanestad, Eide, & Hanssen, 2006) and two qualitative (Hanssen, Nordrehaug, & Hanestad, 2005; Pettersen et al., 2018), revealed that patients with MI experienced a lack of information. They were satisfied with the general information they received during hospitalisation; however, they found it difficult to adapt it to their individual needs. The patients had insufficient information about the consequences of their disease, adapting to their daily activities, secondary lifestyle changes, and medications. (Hanssen et al., 2005). Oterhals et al. (2006) found that patients lacked knowledge about medications, follow-up after discharge, and possible future problems after an MI. Further, Pettersen et al. (2018) reported that patients received limited information from physicians and nurses about the side effects of medications, the importance of taking the medications as prescribed, and the consequences of not adhering to their medical treatment (Pettersen et al., 2018).

Patients’ abilities to absorb information during hospitalisation can be reduced due to short hospital stays and the emotional shock they experience (Astin, Closs, McLenachan, Hunter, & Priestley, 2008; Svavarsdóttir, Sigurðardóttir, & Steinsbekk, 2015). The rapid resolution of symptoms during PCI treatment and their quick recovery made some of them experience uncertainty regarding their condition (Dullaghan et al., 2014), while others were unsure about the seriousness of it (Astin, Closs, McLenachan, Hunter, & Priestley, 2009) or whether it was truly a heart attack (Sampson, O'Cathain, & Goodacre, 2009). A common misunderstanding found among patients was that they believed that MI was an acute condition that could be solved by PCI treatment (Astin et al., 2009; Dullaghan et al., 2014; Sampson et al., 2009).

2.4.3 Shared decision-making

Shared decision-making is an important theoretical and clinical aspect of patient participation. Physicians are responsible for medical decisions in the MI pathway. In a study, patients' and cardiologists' perceptions of the informed consent process was investigated (Astin et al., 2020). Prior to PCI, patients were informed about the procedure, and their informed consent was obtained. Notable findings were that patients forgot considerable information that they had received in this process (Astin et al., 2020); furthermore, they seldom participated in decisions regarding their treatment and were satisfied with the physicians' treatment recommendations (Astin et al., 2020; Probyn, Greenhalgh, Holt, Conway, & Astin, 2017).

Two studies explored patients' preferences regarding treatment options: PCI, CABG, or medications for angina and NSTEMI (Bowling, Culliford, Smith, Rowe, & Reeves, 2008; Doll et al., 2019). Bowling et al. (2008) found that 49% preferred shared decision-making with cardiologists, whereas 30% wanted their physicians to make decisions. Doll et al. (2019) compared a group that used a web-based decision aid with a control group receiving standard care. They reported that web-based decision aid for making decisions increased patients' knowledge; however, it did not influence their preferences for shared decision-making. Both groups preferred PCI over CABG and medications (Doll et al., 2019).

In a Norwegian video observational study of shared decision-making in four different medical cases, one of the cases was a male patient with MI. The findings showed that medical decisions regarding follow-up appointments and medications were made in advance of the discharge conversation with the patient, who was informed about them rather than being involved in decision-making (Ofstad, Frich, Schei, Frankel, & Gulbrandsen, 2014). Another Norwegian qualitative study of 22 patients found that they experienced the encounter with the physician at discharge to be short and it was often carried out in busy corridor environments (Valaker et al., 2017).

2.4.4 Continuity in the myocardial infarction pathway

Continuity of care and patient-healthcare professional relationships have been identified as important preconditions for patient participation. The manner in which patients experience continuity of care after PCI has been studied in a Norwegian context (Valaker et al., 2020; Valaker et al., 2017). In Valaker et al.'s (2017) qualitative study, they found that patients experienced the discharge process as fragmented, with a lack of coordination across hospitals for patients transferred among them (Valaker et al., 2017). In a quantitative research, it was demonstrated that it was challenging to achieve a seamless flow of information between hospitals to ensure continuity in treatment and care. Furthermore, patients reported having insufficient information about symptoms to be expected, medications, what can be done if side effects occurred, and information related to lifestyle changes, such as diet advice and physical activity. Patients with STEMI experienced greater satisfaction with the continuity of their care pathways than those with NSTEMI (Valaker et al., 2020).

2.4.5 Secondary prevention and cardiac rehabilitation

Both international and national studies have shown that most patients with MI do not achieve treatment goals for secondary prevention (Jortveit et al., 2019; Kotseva et al., 2019; Kotseva et al., 2016). Treatment goals based on European guidelines are as follows: daily use of acetylsalicylic acid and statins, smoking cessation, blood pressure <140/90 mmHg, low density lipoprotein (LDL)-cholesterol <1.8 mmol/L, and body mass index <25 kg/m^2. Jortveit et al. (2019) found that on average, three of the six defined treatment goals were achieved, and only 1% of the patients reached all their treatment targets. The study did not provide a reason for the low risk factor control among the Norwegian MI patients; however, in the discussion, a need for specific follow-ups regarding medications after MI to titrate the correct dose of medicines to reach treatment goals was mentioned (Jortveit et al., 2019).

Previous studies have investigated the association between patient engagement, motivation, and healthy lifestyle behaviours (Kähkönen et al., 2015; Peters & Keeley, 2017). Patient motivation and responsibility were related to adherence to medication and healthy lifestyle behaviours among patients with cardiac diseases. Support of next of kin, nurses, physicians, co-operation, fear of complications, and a sense of normality were identified to have an indirect impact on adherence to treatment (Kähkönen et al., 2015). One study used a tool called the Patient Activation Measure that evaluates how engaged patients are in their own healthcare (Peters & Keeley, 2017). The results showed an association between low scores in patients' engagement and adverse clinical outcomes. Additionally, those patients with low engagement were also more likely to continue smoking, and hospital readmissions were more common among them.

A qualitative synthesis explored how patients with coronary heart disease experienced health education, particularly risk communication (Mentrup et al., 2020). The review revealed that limited studies focused directly on how patients experienced risk communication. Despite this, it was reported that tailoring information and education to each individual patient was important for their ability to engage and to adopt a healthy lifestyle. Another significant aspect indicated was that words such as 'fixed', 'your electrocardiogram is clear', or 'your heart is good' were used by the healthcare professionals; these could have impacted the patients' understanding of the situation's severity and resulted in a misunderstanding of being cured and further influenced their responses to lifestyle advice and information (Mentrup et al., 2020). A qualitative study found that both internal and external motivators were crucial for adherence to lifestyle changes and treatment among patients with MI (Hanna et al., 2020). MI was a critical point for patients, immediately after which they felt motivated to implement lifestyle changes. However, they revealed that they quickly returned to their previous habits. Adherence was easier for those who felt supported by their families in initiating lifestyle changes in their everyday lives. Patients who had a second MI realised that they needed to commit to their new habits (Hanna et al., 2020).

The ESC Guidelines clearly recommended cardiac rehabilitation for patients after MI (Ibanez et al., 2017; Neumann et al., 2018; Piepoli et al., 2017). Patients attending cardiac rehabilitation programmes experienced satisfaction with the follow-up and treatment they received through the programmes (Valaker et al., 2017). Additionally, they reported having improved control over their risk factors (Peersen et al., 2017). In addition, cardiac rehabilitation programmes were found to be associated with a reduction in mortality (Rauch et al., 2016). Previous research demonstrated low participation rates in these programmes (Kotseva et al., 2016). Furthermore, a Norwegian study indicated that 28% of patients treated with PCI for the first time attended a cardiac rehabilitation programme (Olsen et al., 2018); additionally, it found that typical cardiac rehabilitation participants were young, overweight, well-educated, and had been treated for an acute coronary event (Olsen et al., 2018). Another Norwegian study (Peersen et al., 2017) compared participation rates in two counties and found them to vary. It was exceedingly high (75%) in one county, and low (18%) in the other. This could be due to the differences in their referral systems (Peersen et al., 2017).

Previous reviews found that reasons for missing cardiac rehabilitation were multifactorial, including age, female sex, frailty, comorbidity, and travel distances to its location (Jelinek, Thompson, Ski, Bunker, & Vale, 2015; Ruano-Ravina et al., 2016; Shimada & Scirica, 2015). Additionally, socioeconomic factors such as education, employment status, and income affected attendance (Ruano-Ravina et al., 2016). Shimada and Scirica (2015) highlighted that a precondition for attending cardiac rehabilitation was physician referral. Moreover, Valaker et al. (2020) found that 49% of their study participants were not referred to a cardiac rehabilitation programme. A systematic review investigated alternative models of cardiac rehabilitation (Clark et al., 2015) and found individualised telehealth and community- or home-based cardiac rehabilitation to be effective. Furthermore, these alternative models demonstrated a similar reduction in the CVD risk factors as compared to the traditional hospital-based cardiac rehabilitation programmes (Clark et al., 2015).

2.5 Summary of previous research and the rationale of this study

In the vast research from the past decades, a common understanding of patient participation can be observed. Most recent as well as older studies are in line with Thompson (2007) who assumes that patient participation occurs only through mutual relationships characterised by a shared willingness and a two-way communication based on openness and mutual respect between patients and healthcare professionals.

In the review of systematic reviews and concept analyses exploring patient participation with respect to other related concepts, such as patient-centred care and patient empowerment, evident similarities between them were identified. The concepts are based on similar perspectives and presupposition that healthcare professionals are willing to surrender some of their power and control to their patients. The patient's values and preferences are important prerequisites for patient participation, patient-centred care, and patient empowerment.

Patient participation is dynamic and contextual (Thompson, 2007), indicating that the level of involvement can vary for patients in different healthcare contexts and pathway phases; moreover, it can change over time. Therefore, it is necessary to study patient participation in diverse healthcare contexts and diagnoses (Thompson, 2007). Patient participation in patients with MI has been studied qualitatively and quantitatively from the perspective of patients and healthcare professionals. A limitation of previous research is that it has mainly focused on patient participation during hospitalisation; additionally, none included the rehabilitation phase. In several studies, data collection was conducted in the early 2000s. Since then, the MI pathway has changed, PCI is a more commonly used treatment method, and hospital stays are considerably shorter than before, ranging from two to four days. Establishing a mutual relationship requires time and continuity in care, which has been identified as difficult to achieve in pathways that are short and fragmented, like the MI pathway.

The obstacles hindering patient participation have received considerable attention in previous research. Patient participation represents a shift in the traditional and established thinking within healthcare services. Paternalistic culture and structure continue to exist in the organisation of healthcare services and can prevent patient participation. The challenges to patient participation have been identified at the micro, meso, and macro levels. At the micro level, patient and healthcare professional characteristics, attitudes towards patient participation, and disease influence the level of patient participation. At the meso and macro levels, the culture and structure of the healthcare organisation and system as well as access to resources may impact participation possibilities.

Previous research has shown that participation can be perceived differently by patients and healthcare professionals and that it can be difficult to achieve in acute situations. MI can be a life-threatening situation requiring prompt treatment, and patients’ need for information and participation must be addressed simultaneously in the pathway. Patient participation is contextual, and insufficient research is available on participation in the different phases of the MI pathway. Thus, the purpose of this thesis was to gain insight into patient participation in the MI pathway from various perspectives. New knowledge about patient participation in the MI pathway may be applied to increase quality of healthcare services and strengthen participation in care and treatment for patients with MI.

3 AIM AND RESEARCH QUESTIONS

This thesis aimed to explore patient participation in the MI pathway from the perspectives of patients, nurses, and physicians. The research questions were as follows:

I: How do patients in areas without local PCI facilities experience patient participation in different phases of the myocardial infarction pathway?

II: What are nurses' perceptions of patient participation in different phases of the myocardial infarction pathway?

III: How do physicians perceive patient participation in different phases of the myocardial infarction pathway?

4 METHODOLOGY AND METHODS

This thesis has a qualitative design including methodology and methods (Howell, 2013; Landstad & Kvangarsnes, 2020). It encompassed the entire research process, starting with defining and conceptualising the problem, then developing the research questions that were crucial for the methods and procedures chosen for the data collection, and finally analysis and interpretation (Creswell & Poth, 2018).

4.1 Qualitative designs

A research design is connected to the philosophical and theoretical assumptions related to specific world views or paradigms and shapes the epistemological and ontological positions of a research project (Creswell & Creswell, 2018; Patton, 2015). Qualitative research involves an interpretive and naturalistic approach to the world (Denzin & Lincoln, 2018; Howell, 2013). Data are collected in natural settings, and data analysis attempts to interpret the phenomenon under investigation. The perspectives of the participants as well as the researcher's interpretations are central to establishing patterns and themes in the data analysis process (Creswell & Poth, 2018; Denzin & Lincoln, 2018).

Qualitative research is a field that moves in several directions (Denzin & Lincoln, 2018) with various philosophical and theoretical perspectives (Patton, 2015). Phenomenology, hermeneutics, narratives, ethnography, grounded theory, critical discourse analysis, social constructionism, and constructivism are examples of different designs within the qualitative paradigm (Howell, 2013; Patton, 2015). Several of these designs have been used in previous research on patient participation (Landstad & Kvangarsnes, 2020).

A qualitative research design provides a complex and detailed understanding of the phenomenon under investigation. It is useful when there is a problem within a group of people that needs to be explored. Furthermore, it provides an opportunity to understand the contexts or settings through the participants' perspectives (Creswell & Creswell, 2018). In qualitative research, individuals are encouraged to tell their stories (Creswell & Creswell, 2018); moreover, it is suitable for exploring patient participation (Bugge & Jones, 2007; Collins et al., 2007; Landstad & Kvangarsnes, 2020).

The use and combination of different qualitative designs and perspectives can provide a more complete representation and greater understanding of the phenomenon under study (Denzin & Lincoln, 2018). In this thesis, I have chosen to use various qualitative designs appropriate for the aims and research questions of the papers (Creswell & Poth, 2018; Patton, 2015). Paper I had a narrative approach, while Papers II and III had a hermeneutic one.

In qualitative research, participants are usually selected by purposive sampling (Tong, Sainsbury, & Craig, 2007). Purposive sampling "involves selecting participants who share particular characteristics and have the potential to provide rich, relevant and diverse data pertinent to the research question" (Tong et al., 2007, p. 352). In the studies, emphasis was placed on recruiting participants who had experience from the different phases of the MI pathway from either the patient, nurse, or physician's perspective. Data collection was carried out at three hospitals within The Central Norway Regional Health Authority.

Participants in Paper I were recruited from two hospitals without PCI facilities. They participated in cardiac rehabilitation programs at the hospitals when they were included in the study. It was considered appropriate to recruit participants from the cardiac rehabilitation programs because they had experience from all phases of the MI pathway. Common for these participants was that they had been treated for MI at a hospital with PCI facilities and had experience from all the different phases of the MI pathway, including the rehabilitation phase. Therefore, they had experiences that provided appropriate data to answer the research question.

In Papers II and III participants were recruited from two hospitals, one without PCI facilities and one with such facilities. These two hospitals collaborate to provide MI treatment in the different phases of the pathway. The healthcare professionals who participated in the studies worked in wards responsible for patients with MIs in different phases of the pathway. Altogether, they had experiences from all the phases of the MI pathway. Data saturation was achieved related to all the phases (Tong et al., 2007). The different designs of the three studies are summarised in Table 1.

Table 1 Study designs

Data collection method	**Participants, data collection, and study setting**	**Data analysis**
Paper I		
Individual in-depth interviews with patients	Three participants from one hospital and seven from another. Both hospitals had no PCI facilities.	Narrative analysis
Paper II		
Focus groups with nurses	Three focus groups with five nurses at a hospital with PCI facilities. Two focus groups with three and four nurses at a hospital without PCI facilities.	Hermeneutic analysis
Paper III		
Individual interviews with physicians	Three physicians from a hospital with PCI facilities and six from one without them.	Hermeneutic analysis

4.2 Paper I

The empirical data in Paper I consisted of narrative interviews (Chase, 2005; Kvale & Brinkmann, 2009). Ten patients were interviewed about their experiences with patient participation in the different phases of the MI pathway. A narrative analysis was performed.

4.2.1 Narrative approach

The term ‘narrative’ has its origin in the Latin words *narrativus* and *narrare,* which refer to the means to tell a story or to give an account of something (Oxford English Dictionary, 2021). A narrative research approach is rooted in the social sciences and is used in different fields, such as sociology, anthropology, psychology, ethnography, and auto-ethnography (Chase, 2005; Creswell & Poth, 2018), which has led to a diversity in narrative approaches and the evolution of multiple methodologies and methods (Chase, 2005, 2011, 2018).

The American sociologist and researcher Susan E. Chase contributed to the understanding of how narrative research approaches have developed over the last three decades. Her original chapter, ‘Narrative Inquiry’, in the third edition of *The Sage Handbook of Qualitative Research*, draws a picture of narrative research as a field in the making with several different approaches with few commonalities (Chase, 2005). In the fourth edition, she maintains the focus on the flourishing of diverse, complex, and multiple narrative approaches (Chase, 2011), but in the fifth and latest editions, she describes a growing maturity in the field, both theoretically and methodologically (Chase, 2018). Further, Chase (2018) dwells on what a narrative and a narrative approach or inquiry is. The latter, using personal narratives, is explained by Chase (2018, p. 549) as ‘a distinct form of communication’.

A narrative is shaped by the way we make meaning of our experiences; how we understand our own or others’ actions; the way we organise events, objects, feelings, or thoughts in relation to each other; and how we connect and perceive the consequences of actions, events, feelings, or thoughts over time. How we make meaning of our experiences can be linked to the past, present, and/or future. This last definition represents a shift in the understanding of narratives. Chase’s first definition of narratives focused on retrospective meaning-making from past experiences (Chase, 2005, 2011), whereas the latest one is extended to include how previous experiences affect our present situation and/or our future (Chase, 2018).

In Paper I, the aim was to examine patients’ experiences with patient participation in the different phases of the MI pathway. A narrative approach provides patients a clear voice, allowing them to communicate their personal experiences (Chase, 2018). The patients might be unfamiliar with the term ‘patient participation’; therefore, permitting them to freely articulate their experiences could be useful to elucidate how patient participation was expressed in their narratives. Narratives have a structure with a beginning, middle, and end (Polkinghorne, 1988; Sarbin, 1986). Narrative interviews invite patients to tell about their illness experiences (Holloway & Freshwater, 2007). The MI pathway has a time perspective and a chronology of phases suitable for a narrative approach. Its phases can be linked to the classic timeline of events in a narrative that consists of events that represent a plot (Polkinghorne, 1988), which can be understood as a recognisable pattern of events in it (Sarbin, 1986).

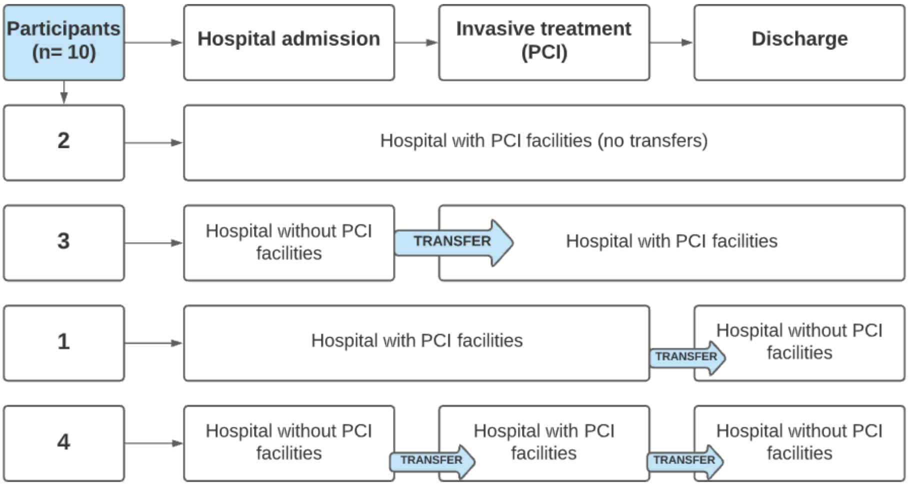
4.2.2 Participants

Participants were attending an outpatient cardiac rehabilitation programme when they were invited to participate in the study. They were recruited from two outpatient cardiac rehabilitation units that were appropriate settings for selecting participants (Polit & Beck, 2020); because the patients attending a cardiac rehabilitation programme after an MI had experiences from all phases of the MI pathway.

The participants were purposive selected based on specific criteria and a desire for maximum variation (Patton, 2015; Polit & Beck, 2020). Contact persons, nurses and physiotherapists working at the cardiac rehabilitation units, recruited participants. The contacts were instructed to invite both women and men of varying ages, backgrounds, and marital status. The inclusion criteria were as follows: (a) diagnosed with acute MI; (b) living in areas more than 300 km away from a PCI hospital; (c) transported by helicopter/air ambulance in the acute phase; (d) not suffering from other serious illness; and (e) able to give informed consent.

In all, two women and eight men aged 37-79 years participated in the study. Of them, nine were married or cohabiting, while one was a widower. Four were employed full- or part-time, and six were retired. Moreover, two participants had a history of CVD. Eight and two participants were hospitalised for four to seven days and for more than seven days, respectively. Additionally, three participants bypassed the local hospital and were not transferred among hospitals in the acute phase, while eight of them were moved once or twice. Figure 3 shows the variations in the pathways due to hospital admission, transfers, and discharge.

Figure 3 Different pathways



4.2.3 Data collection

Data were collected in January and February 2016. An interview guide (Kvale & Brinkmann, 2009), see Appendix 4, was developed based on previous research, the theoretical framework (Thompson, 2007; Thompson et al., 2007) and in accordance with the study’s aim. However, the introductory question, ‘Can you describe how you experienced being admitted to the hospital with an MI?’, seemed pivotal and invited the participants to share their stories (Chase, 2005; Kvale & Brinkmann, 2009). During the initial interviews, I found that the participants told their stories in detail from the beginning to the end of their MI pathway, integrating their experiences with patient participation. I used the interview guide and follow-up questions when necessary to extend the conversation (Kvale & Brinkmann, 2009). Typically, in qualitative methods, the interviewer asks questions of the interviewee, who then answers; however, in narrative research, the latter and the former take the role of a narrator and a listener, respectively (Chase, 2005; Kvale & Brinkmann, 2009).

4.2.4 Data analysis

Five analytic lenses, as presented by Chase (2005) influenced the structure of the data analysis. First, I read the stories searching for ‘what’ the narrative was about and ‘how’ it was told (Chase, 2005). In this process, I was attentive to the participants’ voices and how they narrated their experiences. A narrative consists of more than a sequence of events; it also contains expressions of emotions, thoughts, interpretations, and viewpoints (Chase, 2005). In the first phase of the analysis, each narrative was analysed separately. Focusing on and listening to the voices within each narrative, before moving across the narratives to identify themes, is central in narrative analysis (Polkinghorne, 1988; Riessman, 2008).

In the following step, I focused on the similarities and differences across the narratives (Chase, 2005). The participants told their stories with a narrative structure, precisely from the beginning of the MI’s initial symptoms, throughout hospitalisation and treatment for it (the middle), and towards the end, involving their hospital discharge and follow-up at a cardiac rehabilitation programme. Therefore, it was considered as a logical structure of the compiling narrative to follow the phases of the MI pathway, divided into the acute, treatment, discharge, and rehabilitation phase. The data were coded based on these phases and the participants’ experiences of patient participation.

Narrative analysis implies how narratives were shaped in context and through interactions between the participants and the interviewer (Chase, 2005), as well as how I and the other researchers interpret the data. The initial coding of themes based on the MI pathway’s phases and the study’s theoretical framework (Thompson, 2007) was central to developing themes that could reveal how the participants experienced patient participation in the different phases of the MI pathway.

The data analysis conducted was not as linear as described above, as I moved back and forth throughout the analytical process. Finally, the data were compiled into one narrative (Kvale & Brinkmann, 2009), following the phases of the MI pathway and the chronology of a narrative.

4.3 Paper II and Paper III

I chose different types of interview methods when I interviewed nurses and physicians. The former were experienced in one department or phase of the pathway. By combining focus groups with nurses who worked in different phases of the MI pathway, data on patient participation from the entire pathway were obtained. The physicians worked in departments that represented the different phases of the MI pathway; therefore, they could provide data on patient participation in the entire pathway through individual interviews. Paper II consisted of 5 focus groups with 22 nurses, and Paper III consisted of 9 individual interviews with the physicians. The studies aimed to explore the nurses' and physicians' perceptions of patient participation in different phases of the MI pathway using a hermeneutic approach.

4.3.1 Hermeneutic approach

Etymologically, the term 'hermeneutics' originates from the word *hermeneuein* (Gulddal & Møller, 1999; Landstad & Kvangarsnes, 2020; Patton, 2015). It has a threefold meaning: (1) to express through conveying or speaking, (2) to understand or interpret, and (3) to translate (Gilje, 2019; Gulddal & Møller, 1999; Landstad & Kvangarsnes, 2020). Of these, understanding and interpretation is the most recognised one in the literature on hermeneutics as a research approach (Howell, 2013; Patton, 2015).

The origins of hermeneutics can be traced back to antiquity, where it was used to interpret texts from the bible and ancient classics (Alvesson & Sköldberg, 2018;

Gulddal & Møller, 1999). The hermeneutic circle is a dialectic process, in which the meaning of the parts can only be understood in relation to the whole, and the whole, in turn, only from the parts (Alvesson & Sköldberg, 2018; Gilje, 2019). Friedrich Schleiermacher (1768-1834), a German theologian and philosopher, is considered one of the first founders of modern hermeneutics. Furthermore, he gave the hermeneutic circle a central position for the interpretation of not only written texts but also verbal dialogues (Gulddal & Møller, 1999).

At the beginning of the 19th century, Wilhelm Dilthey (1833-1911), a German philosopher and historian of ideas, who relied on Schleiermacher's contribution to the field, was essential to the establishment of an independent hermeneutic tradition with its own history. He extended the use of the hermeneutic circle, from being employed to interpret texts and dialogues to individual lives and world history (Gulddal & Møller, 1999).

In the 20th century, Martin Heidegger (1889-1976), another German philosopher and a student of Husserl, who is considered the founder of phenomenology, caused a break in hermeneutics history. This signified a shift from the linguistic, psychological, and historical directions, which characterised 19th-century hermeneutics, to the philosophical. Heidegger transferred and extended the hermeneutic circle from the interpretation of a text or a historical event to that of a human 'being' and a 'being in the world'. This Heideggerian shift is termed the ontologisation of hermeneutics. Some chose to reject this philosophy and adhere to Schleiermacher's and Dilthey's approaches, while others preferred following Heidegger's ontologising. Hans-Georg Gadamer, Heidegger's student, continued in the Heideggerian direction (Gulddal & Møller, 1999).

Hans-Georg Gadamer (1900-2002) was of great importance for the development of hermeneutics in a philosophical direction. In his work, *Truth and Method* (*Wahrheit und Methode*), he was certain that philosophical hermeneutics was neither a technique nor a method; instead, it aimed to clarify what it means to be an understanding human being in the world. Nevertheless, his philosophical hermeneutics has been important in terms of methods (Gilje, 2019).

Gadamer was concerned with prejudices and how they affect our preunderstanding and understanding. Prejudices are shaped by the context we live in and the past, such as culture, history, and traditions. They can be either positive or negative; thus, they can both promote or inhibit our understanding. We can never completely free ourselves from our prejudices, and we can never meet a text or other human being without them or established perceptions. Similarly, we may never enter the hermeneutic circle without such preconditions. In this circle, our prejudices and preunderstandings are confronted with new experiences, and thus we may gain novel insights. This process is called the fusion of horizons by Gadamer; it indicates that the horizon of our preunderstanding combines with that of the new experience and collectively creates a new understanding. Without a preunderstanding, we would be unable to be part of this process wherein our understanding is alternated and expanded when we are confronted with new experiences (Alvesson & Sköldberg, 2018; Gadamer, 2004; Gilje, 2019).

In research projects with a hermeneutic approach, one often observes elements from both philosophical hermeneutics and hermeneutic intentionalism, where hermeneutics is considered a method (Gilje, 2019). In this thesis, Gadamer's philosophy of preunderstanding and the hermeneutic circle have been central to interpreting the underlying meaning of patient participation in the MI pathway.

In a hermeneutic approach, the context is central to understanding something (Gadamer, 2004; Patton, 2015). Patient participation is contextual; therefore, a hermeneutic approach is appropriate to study participation. My prejudices have been central, and I have clarified in advance the term 'patient participation' and its content. A theoretical framework was applied to examine patient participation in the MI pathway. In a hermeneutic approach, the researcher is a participant and producer of new knowledge as the data are collected, analysed, and interpreted (Howell, 2013).

4.3.2 Participants

The participants in Papers II and III were nurses and physicians, respectively. The studies were approved by the hospital management that appointed contact persons who recruited the participants. One hospital with PCI facilities and one without were chosen because the aim of the study was to cover all phases of the MI pathway. The hospitals were part of the same hospital region and thus cooperated to provide treatment to patients diagnosed with MI.

The hospital with PCI facilities had a regional function for approximately 700,000 inhabitants; transfer of patients from hospitals without PCI facilities was common. The chosen hospital without these facilities was responsible for providing services to approximately 100,000 inhabitants.

Purposive sampling was used to select participants (Patton, 2015). We wanted to include nurses and physicians who worked in cardiac care and were responsible for the care and treatment of patients with MI. Variation in the sample was desired (Polit & Beck, 2020), and the contact persons were requested to invite both male and female nurses and physicians of different ages, educational backgrounds, and durations of professional experience (Polit & Beck, 2020). The following inclusion criteria were used: nurses and physicians who (a) worked in cardiac care and (b) had a minimum of one year of experience in cardiac care.

In Paper II, 22 nurses participated in 5 focus groups. Specifically, three and two were conducted at the hospitals with and without PCI facilities, respectively. In Paper III, nine physicians participated, of which three were recruited from the hospital with PCI facilities and six from the hospital without. The demographic data of Papers II and III are summarised in Table 2.

Table 2 Demographic data

Participants (n)	**Age (average)**	**Education**	**Experience within cardiac care in years (average)**
Paper II			
22 nurses	24-58 (37.8)	22 Bachelor in Nursing 9 specialised in cardiac care 2 specialised in intensive care nursing 1 Master’s degree	1.5-33 (12.5)
Paper III			
9 physicians	30-66 (40.8)	9 medical education 4 were specialised in cardiology/internal medicine 1 had a PhD	1-32 (11.1)

4.3.3 Data collection

Paper II

Five focus groups were conducted between February and November 2018. Focus groups are appropriate when the goal is to explore the participants’ opinions, perceptions, and experiences (Krueger & Casey, 2015), in this case, nurses’ perceptions of patient participation in the MI pathway. The main purpose of using focus groups was to utilise the group interaction to stimulate different experiences and stories (Krueger & Casey, 2015; Malterud, 2012).

The focus groups were based on homogeneity, meaning participants of the groups had something in common (Krueger & Casey, 2015); all of them were nurses working within cardiac care. Homogeneity may establish security and prevent power differentials within the group; however, sufficient variation is necessary among the participants to allow for discussions and contrasting opinions (Krueger & Casey, 2015). Therefore, we requested the contact persons to recruit nurses working in the different phases of the MI pathway and with variations in experience and competence in each of the focus groups. In focus groups 1, 2, and 3, the participating nurses worked in the MI pathway's different areas; some were employed in cardiac wards and others in a catheterisation laboratory. Focus group 4 consisted of three participants working in an emergency department and one who worked both in a cardiac ward and an outpatient cardiac rehabilitation unit. Focus group 5 consisted of three participants employed in a cardiac ward. Initially, the plan was to conduct one focus group at the hospital without PCI facilities; however, two participants could not participate due to illnesses and workload in the cardiac ward in focus group 4, therefore we decided to carry out focus group 5. After five focus groups, patterns and preliminary themes were identified across the groups, and data saturation was considered to be achieved (Krueger & Casey, 2015).

I moderated the focus groups, and my main supervisor was the assistant moderator. A questioning route (Krueger & Casey, 2015) was developed based on the study's aim, previous research, and the theoretical framework (Thompson, 2007; Thompson et al., 2007). See Appendix 5 for a complete questioning route. The questioning route was logical and sequenced, and the first questions of each sequence were broad and general; thereafter, the questions became more focused and specific (Krueger & Casey, 2015). I experienced that the participants were well-prepared in relation to the topic and that the questions encouraged discussions and exchanges of experiences among them. The group dynamics were characterised by a relaxed and confident atmosphere. Several times during the focus groups, the participants expressed that discussing the topic was relevant and beneficial to their clinical work.

Paper III

Nine individual interviews with physicians were conducted from February to June 2018. A semi-structured interview guide, see Appendix 6, was developed based on the theoretical framework, previous research, and the study's aim; it was not used rigidly (Kvale & Brinkmann, 2009). There was a difference between the participants; some were exceptionally engaged and had plenty of experience with patient participation, while others needed additional follow-up questions.

4.3.4 Data analysis

The analysis in Papers II and III had a hermeneutic approach using Gadamer’s (2004) philosophy, and the hermeneutic circle was valuable in generating new insights based on interpretation. In addition to a hermeneutic approach, the analysis was guided by the studies aims, research questions, and theoretical framework (Beauchamp & Childress, 2019; Thompson, 2007; Thompson et al., 2007).

Paper II

Analysing focus groups requires a clear purpose and systematics (Krueger & Casey, 2015). The research question: ‘What are nurses’ perceptions of patient participation in different phases of the MI pathway’ directed the analysis; further, the data were initially coded as phases of the pathway: acute, treatment, discharge, and rehabilitation. The transcripts and field notes based on the observations of interactions and group dynamics were employed to identify nurses’ experiences, meanings, and discussions of patient participation in the data.

By using the hermeneutic circle (Alvesson & Sköldberg, 2018; Gadamer, 2004), we gained new insight into patient participation and furthered our understanding. Our prejudices and preunderstandings were shaped by the study’s theoretical framework, which was valuable for identifying perceptions of patient participation in the data. Simultaneously, the data provided novel understandings of patient participation in the MI pathway, and a further new and extended understanding was possible. In the analysis, there was constant movement between the parts and the whole of the interviews, as well as across them, to elucidate similarities, patterns, and variations in the data. Our different backgrounds of clinical practice and academia were valuable for gaining a holistic understanding.

Paper III

The phases of the pathways were used to code the data. The acute phase included both hospital admission and PCI treatment, followed by hospitalisation, discharge, and rehabilitation.

The hermeneutic circle (Gadamer, 2004) was applied to alternate between the parts and the whole in the interviews and across them to identify patterns, similarities, and diversity in the data. The theoretical framework constituted our preunderstanding of patient participation. Further, it was valuable not only in obtaining access to perceptions, opinions, and experiences of patient participation in the data but also for maintaining the focus on patient participation during data analysis. Our preunderstanding might have hindered new insights (Gadamer, 2004). I was open and empathetic to the physicians' expressions, perceptions, and meanings of patient participation and focused on their perspectives on it.

4.4 Ethical considerations

Ethical considerations were important throughout the study design (Creswell & Poth, 2018). The study was conducted in concordance with the Declaration of Helsinki (World Medical Association, 2013) and the Norwegian Guidelines for Qualitative Research (Den nasjonale forskningsetiske komitè for medisin og helsefag, 2009). Paper I included patients' experiences; an application was submitted to the Regional Committee for Medical and Health Research Ethics, which concluded that the study did not require approval (REK Mid-Norway, 2015/2002, Appendix 7). This study was approved by the Norwegian Centre for Research Data (project number 56617, Appendix 8).

Informed consent based on oral and written information is necessary to ensure that ethical principles are maintained (Malterud, 2017; World Medical Association, 2013). Thus, prior to data collection, the participants received both oral and written information about the research project and its purposes; moreover, written informed consent was obtained from them. The information letters (Appendix 9,10,11) covered the study's aim, how the interviews would be conducted, and how confidentiality and anonymity would be assured. Participation in the studies was voluntary (Creswell & Poth, 2018). Participants were informed that they could withdraw from the study without providing any reason.

In Paper I, patients narrated their experiences of patient participation. During the interviews, I was aware of the possible emotional reactions that could occur when the patients discussed their experience of an acute and life-threatening event. The interviews were conducted at the hospitals; moreover, the healthcare professionals were available if medical help was needed. During the interviews, I was aware of the power imbalance that might arise between participants and the interviewer and the importance of avoiding leading questions (Creswell & Poth, 2018).

In Papers II and III, the nurses and physicians shared and discussed their perceptions and experiences in the focus groups and the individual interviews, respectively. In both studies, the participants were requested to anonymise the examples and patient histories used during the interviews. Additionally, the participants of the focus groups were asked to maintain confidentiality regarding their content (Polit & Beck, 2020).

Data collection in qualitative studies centres on dialogues between participants and researchers based on mutual trust and respect. The latter must be aware of the responsibility to reproduce what is said in a way that best matches how it was intended (Malterud, 2017). Within the hermeneutic tradition, this is referred to as interpreting with empathy and compassion (Gilje, 2019) and indicates the researcher's sincere attempts to understand the underlying meaning of what the participant has expressed. Malterud (2017) is particularly aware of how data obtained from healthcare professionals are represented. In the interviews, they provided insight into their clinical practice; additionally, it is important to be mindful of research ethics when interpreting and conveying data from colleagues (Malterud, 2017).

Qualitative data contain human life experiences and thoughts. Linguistic expressions are often sensitive and personal. Hence, the quotations, demographic data, and information were reproduced with care to prevent disclosure of individual participants (Malterud, 2017).

5 FINDINGS

The findings provide answers to the research questions about patient participation in the different phases of the MI pathway explored from the perspectives of patients, nurses, and physicians. A synthesis of the findings from the three papers is presented, followed by the findings of each paper.

5.1 Synthesis of the findings

The findings show that the level of patient participation varied throughout the pathway, from non-involvement to shared decision-making in the acute and the rehabilitation phase, respectively. The phases of the MI pathway provided different needs and opportunities for patient participation.

5.1.1 Low level of patient participation in the acute and treatment phases

The findings showed that patients and healthcare professionals experienced patient participation as healthcare professional-determined in the acute phase. The latter had a short time to complete treatment in accordance with the guidelines, indicating that there was insufficient time to involve and inform the former about it. The acute phase was characterised by paternalism, and healthcare professionals expressed that they prioritised acting beneficially in the patients' best interests; in this phase, this was considered more important than patient participation. The patients experienced safety and trust during their treatment. However, they conveyed that they were seeking and receptive to clear information about the treatment and the pathway. The healthcare professionals had experienced that the elderly and frail patients who refused invasive treatments were listened to. Ethical dilemmas may have arisen when they attempted to balance the patients' rights to make autonomous decisions against following treatment guidelines.

During PCI treatment, patients trusted the healthcare professionals. In this situation, the latter had a higher degree of power due to the former's dependence on the treatment to survive. The healthcare professionals were the experts, and the patients did not have the prerequisites to participate in decision-making. These situations were characterised by non-involvement. However, both of them highlighted the importance of information regarding the diagnosis and the treatment provided at the end of PCI treatment. In this phase, patient information could be ethically challenging for healthcare professionals. On occasion, the disease was more severe than expected, and treatment options, such as CABG surgery, had to be considered. In such circumstances, healthcare professionals found it difficult to provide information before they knew the treatment option to be recommended.

5.1.2 Lack of continuity hindered patient participation

The MI pathway was described as short and fragmented by patients and healthcare professionals, which threatened the continuity and coordination of patient information and participation. Healthcare professionals found it difficult to discuss and provide patients with sufficient information during hospitalisation. Nevertheless, the patients stated that they needed specific and clear information about lifestyle changes, medications, and rehabilitation. The system was important for healthcare professionals' opportunities to facilitate patient participation. The lack of time and room for private conversations often hindered patient information. The healthcare professionals conveyed that checklists in the patient record could strengthen patient information and enhance continuity in care.

Physicians were mainly responsible for patient information during discharge. They expressed that they attempted to increase patients' health literacy at discharge by providing them with a written and oral summary of their hospital stay, medications, and further follow-up. Nurses said that they were less involved in discharge information. However, they were often responsible for organising the journey home for the patients. Patients and nurses experienced challenges when there were long geographical distances between the hospital and the former's home.

5.1.3 Shared decision-making in rehabilitation

In the rehabilitation phase, patient involvement was co-determined by the patients and the healthcare professionals. Shared decision-making and dialogue were central to the cardiac rehabilitation programmes. Healthcare professionals expressed that patient engagement was a precondition for achieving treatment goals. They acted as professional agents to enable patients to participate in shared decision-making. Patients conveyed that their participation in the cardiac rehabilitation programmes increased their engagement in implementing lifestyle changes to prevent recurrent cardiac events. Nevertheless, healthcare professionals were concerned about high dropout rates from cardiac rehabilitation programmes.

5.2 Paper I

Bårdsgjerde EK, Kvangarsnes M, Landstad B, Nylenna M, Hole T. Patients' narratives of their patient participation in the myocardial infarction pathway. *J Adv Nurs.* 2019;75:1063-1073. https://doi.org/10.1111/jan.13931

This study aimed to explore how patients in areas without local PCI facilities experience patient participation in different phases of the MI pathway. The patients narrated how they participated at the beginning, middle, and end of the pathway. Four themes related to the phases of the pathway were identified: lack of verbal communication in the acute phase, trust in healthcare professionals and treatment, lack of participation and coordination at discharge, and shared decision-making in rehabilitation.

In the acute phase, patients struggled to understand their situation and experienced insufficient verbal communication from healthcare professionals. They observed the healthcare professionals' actions and interactions to receive information about their medical condition and treatment plan. Despite this lack of information, they trusted them as well as the treatment received. At the end of the PCI procedure, they received tailored information about treatment outcomes.

The patients experienced varying amounts of information about lifestyle changes, medications, and rehabilitation before discharge. They wanted tailored information that was concrete and detailed, practically similar to a recipe on how they should initiate lifestyle changes. Medication was highlighted as an area where additional information was preferred before discharge. At discharge, patients were concerned about their journey home from the PCI hospital as they had inadequate personal belongings that challenged their use of public transportation.

All patients attended a cardiac rehabilitation programme. They reported that a high level of patient participation increased their motivation, responsibility, knowledge, and understanding of their medical condition.

5.3 Paper II

Bårdsgjerde EK, Landstad BJ, Hole T, Nylenna M, Gjeilo KH, Kvangarsnes M. Nurses' perceptions of patient participation in the myocardial infarction pathway. *Nursing Open.* 2020;00:1-10. https://doi.org/10.1002/nop2.544

This study aimed to explore nurses' perceptions of patient participation in different phases of the MI pathway. The analysis resulted in four themes related to the phases of the pathway: variation between paternalism and autonomy in the acute phase, individualisation of dialogue and patient participation during treatment, lack of coherence in the pathway hinder patient participation at discharge, and cardiac rehabilitation promotes patients' autonomous decisions in lifestyle changes.

In the acute phase, the nurses experienced that the time limits, situation severity, and patients being less receptive to information led to a paternalistic approach. However, they described that some elderly and fragile patients were against invasive treatments and that such preferences caused a shift from the paternalistic approach to patient autonomy.

In the treatment phase, nurses individualised the amount of information based on the patient's receptivity. Providing patient information was challenging when severe multi-vessel disease was detected during angiography.

Nurses experienced the pathway as short and fragmented, which threatened continuity. Collaboration across wards and between healthcare professionals was considered important. A lack of checklists for patient information, especially about secondary prevention, was discussed during the interviews as the nurses stated that they lacked standardised routines for what information the patients should receive before discharge. They experienced that patient participation was dependent on the patients' medical knowledge. The patients' lack of medical knowledge often led the healthcare professionals to make decisions without involving them. The nurses were concerned about rarely participating in the discharge process, as physicians normally provided information to the patients. Furthermore, they stated that being responsible for planning and organising the patients' journey home was often time consuming.

The nurses expressed concern for patients after discharge. They reported that patients forgot important written information at the hospital and that some were readmitted because they had ceased their medication intake. Therefore, they attempted to encourage patients to attend cardiac rehabilitation programmes in which patient participation and patient engagement were described as essential to achieving treatment adherence. However, the nurses were concerned as they observed that the patients who most needed the programme often declined to attend.

5.4 Paper III

Bårdsgjerde EK, Kvangarsnes M, Hole T, Nylenna M, Landstad BJ. Physicians' perceptions of patient participation in the myocardial infarction pathway. Submitted.

This study aimed to explore physicians' perceptions of patient participation in different phases of the MI pathway. The findings were divided into four themes related to the different phases of the pathway: paternalism in the acute phase, lack of continuity in the physician-patient relationship, strengthening health literacy through paternalism at discharge, and shared decision-making and adherence to treatment during rehabilitation.

The physicians stated that a paternalistic approach was necessary in the acute phase, where clear guidelines for treatment were followed as patients' abilities to understand information were reduced. However, they occasionally experienced that elderly patients were sceptical of invasive treatments.

Fragmentation of the pathway, hospital transfers, and the physicians' workload led to a lack of continuity. The physicians reported not documenting patient information in the patient records; moreover, they highlighted the need for checklists for information. Insufficient time and opportunities for private conversation often restricted them from providing patient information and participation during hospitalisation.

Physicians experienced that patients often struggled to understand their medical condition and rarely asked questions or shared their opinions related to their disease. The next of kin often requested more information than they did. At discharge, physicians focused on providing patients with a summary of their hospital stay, further medication, and follow-ups. In particular, information about medication was considered important, as the physicians feared patients would quit taking some of their medications after discharge. However, they usually did not discuss medications and attempted to provide information about their side effects as clearly as possible.

The physicians described cardiac rehabilitation programmes as the key to successfully achieving treatment goals. They believed that these programmes provided patients with follow-up over time and increased their medical knowledge and health literacy for shared decision-making in treatment. However, they were concerned about mass dropout from cardiac rehabilitation programmes.

6 DISCUSSION

This thesis explored patient participation in the MI pathway from the perspectives of patients, nurses, and physicians; they experienced that the level of patient participation varied during the pathway, and that the phases provided different needs and opportunities for patient participation. The main themes of the papers are summarised in Table 3.

In the acute phase, healthcare professionals expressed that they had to act in a paternalistic manner and prioritised making an accurate diagnosis and initiating treatment within the time limits. The patients told about a lack of clear information about treatment and the clinical pathway. They trusted healthcare professionals and the treatment they received. The patients' and healthcare professionals' accounts highlighted how patient information was individualised during PCI treatment. Nurses and physicians elaborated that ethical dilemmas could occur in the first phase of the pathway. One example was when elderly and frail patients refused invasive treatment procedures, such as PCI. Another example was the detection of severe multi-vessel disease during angiography. Healthcare professionals found it difficult to provide sufficient information to patients because the different treatment options were to be discussed with the Heart Team before they could be presented to the patient.

Patients, nurses, and physicians perceived that lack of continuity and coordination challenged patient participation towards and at discharge. Patients experienced a lack of information about lifestyle changes, medications, and rehabilitation. Nurses and physicians explained that the system set limits on their opportunities to facilitate patient participation, and they required checklists to ensure it. They found that time constraints and the short and fragmented MI pathway did not provide the best frame factors for strengthening patients' health literacy.

Nurses and physicians recommended cardiac rehabilitation programmes for patients after discharge. They stated that patient participation was emphasised in these programmes and considered patient participation as an important precondition for achieving secondary prevention treatment goals. Patients acknowledged the importance of patient participation and shared decision-making in cardiac rehabilitation programmes.

Table 3 Summary of themes across the papers

Perspective	**Theme 1**	**Theme 2**	**Theme 3**	**Theme 4**
Patient	Lack of verbal communication in the acute phase	Trust in healthcare professionals and treatment	Lack of participation and coordination at discharge	Shared decision-making in rehabilitation
Nurse	Variation between paternalism and autonomy in the acute phase	Individualisation of dialogue and patient participation during treatment	Lack of coherence in the pathway hinders patient participation at discharge	Cardiac rehabilitation promotes patients' autonomous decisions in lifestyle changes
Physician	Paternalism in the acute phase	Lack of continuity in the physician-patient relationship	Strengthening health literacy through paternalism at discharge	Shared decision-making and adherence to treatment during rehabilitation

6.1 Discussion of findings

This thesis has explored patient participation in different phases of the MI pathway from the perspectives of patients, nurses, and physicians. The findings from these perspectives have shed light on the complexity of the studied phenomenon. Patterns as well as variations among the patients, nurses, and physicians were identified. Comparing the findings across the three studies have provided insight into different experiences and perceptions of patient participation in the MI pathway. Differences in the findings between nurses and physicians can be understood in terms of their different roles, areas of responsibility, functions, and contexts.

6.1.1 The acute phase

The findings showed that patients, nurses, and physicians experienced a low degree of patient participation and involvement in the acute phase. This was in accordance with previous research indicating that acute situations reduced the demand for patient participation (Arnetz & Arnetz, 2009; Arnetz, Winblad, et al., 2008; Höglund et al., 2010; Kvangarsnes et al., 2020; Thompson, 2007). However, patients needed clear information about treatment and clinical pathways. Patient narratives revealed that they had a lack of information. A notable finding of our study was how patients interpreted healthcare professionals' actions and interactions to understand what was happening. For some, it led to frightening episodes; for example, one of the patients experienced that the defibrillator was prepared without receiving information about the reason for it. In such cases, short and concise information could be reassuring.

In the acute phase, the nurses and physicians described having a common interest in quickly diagnosing and initiating the correct treatment in accordance with guidelines. This is expressed in quotes from the acute phase from the perspectives of nurses and physicians. The nurses emphasised that providing the patients with in-depth information could delay the initiation of treatment in the acute phase. The physicians expressed that the clear recommendations for treatment meant that there was less room for patient involvement in terms of information and choices. The findings from the nurses' and physicians' perspectives showed that they prioritised the diagnosis and initiation of treatment, especially in critical conditions. Life-threatening and acute situations may prevent healthcare professionals from facilitating patient participation. In the acute phases of illness, doing good for the patient is valued more than facilitating patient participation. This might be linked to the earliest forms of paternalism, where healthcare professionals' actions were based on their medical competence in the patients' best interests (Beauchamp & Childress, 2019). The MI pathway comprises evidence-based guidelines regarding which treatment is the best (Collet et al., 2020; Ibanez et al., 2017;

Neumann et al., 2018). In our study, patients trusted the healthcare professionals and the treatment they received. Trust is a key aspect of Thompson's (2007) findings and may be related to non-involvement. Trust in healthcare professionals and their expertise may be a way to cope with fear and reduce anxiety (Thompson, 2007). Grimen (2009) stated that patients are often confident that healthcare professionals act in their best interests and that trust can provide the latter the space they need to use their competence completely. This is in concordance with our study as the patients described how they experienced that the highly qualified healthcare professionals handled the situation and acted in their best interests.

Nurses have reported that ethical dilemmas may arise in acute situations where there is a need for rapid initiation of life-saving treatment (Kvangarsnes et al., 2020; Tobiano, Bucknall, et al., 2015). Our findings revealed that healthcare professionals could, for example, experience ethical dilemmas when elderly patients decline invasive treatments. The moral dilemma that may arise in this case is the conflict between beneficence and respect for autonomy (Beauchamp & Childress, 2019): Healthcare professionals recommend a treatment based on their medical knowledge that they know will benefit the patient, whereas the patients decline it. Our findings have shown that in such situations, the healthcare professionals listened to the patients, even if it meant that the treatment guidelines were not followed. Previous research on this topic has not been found, either from the patient or the healthcare professional perspective. However, a study of patients' preferences for treatment options for angina (PCI, CABG, or medications) showed that elderly patients >70 years were more positive about treating angina with medications than younger patients (Bowling et al., 2008).

The nurses emphasised ethical dilemmas that could arise in the acute phase. They told stories about elderly and frail patients who expressed that they did not want invasive treatment. The nurses and physicians have different responsibilities and roles in care and treatment. The nurses are continuously caring for the patients in the ward and therefore often have opportunities to establish a relationship with the patient. Within the nursing profession, the concept of care is central. The Norwegian nurse and professor, Kari Martinsen, has been an important contributor to philosophy of care in the nursing profession. Martinsen claims that to care is to form bonds, and to enter into relationships (Martinsen, 2005). An established relationship based on mutual respect and reciprocity are described as important prerequisites for patient participation (Thompson, 2007) and might enable the patient to convey wishes that are not in accordance with the recommended treatment. A previous study found that patients found it easier to establish a dialogue and a relationship with the nurses than the physicians after an MI (Kristofferzon, Löfmark, & Carlsson, 2007).

Patients have a reduced ability to receive information in the acute phases of illness (Astin et al., 2008; Svavarsdóttir et al., 2015). In our research, the nurses and physicians expressed how they attempted to balance, repeat, and maintain information consistency when they prepared patients with NSTEMI for angiography and PCI treatment. Previous studies have explored patients' and physicians' experiences with informed consent prior to PCI for both elective and acute patients. The findings showed that patients often forgot the information they received prior to the PCI procedure; moreover, they rarely participated in treatment decisions as they preferred to follow the physicians' treatment recommendations (Astin et al., 2020; Probyn et al., 2017). Our studies found that patients with MI had no desire to participate in the acute phase, which is in line with previous research (Arnetz & Arnetz, 2009; Decker et al., 2007; Höglund et al., 2010).

6.1.2 The PCI treatment

During PCI treatment for MI, patients must rely on healthcare professionals to act in their best interests. The relationship between patients and healthcare professionals is characterised by asymmetry in this treatment situation. The latter have knowledge and experience, whereas the former do not. Surrendering power and knowledge from healthcare professionals is essential to facilitate patient participation (Cahill, 1996; Sahlsten et al., 2008). The findings of our study showed how the patients were involved through a continuous dialogue during the PCI procedure where they were informed about it. As part of the PCI procedure, some patients were requested by physicians to provide their informed consent to have a stent inserted. It was highlighted that this is not shared decision-making because the patients were completely dependent on receiving this treatment; this is in line with Beauchamp and Childress (2019). At the end of the procedure, the patients received information about which coronary arteries were affected by the MI and were often shown pictures of the stent's placement. The patients' narratives conveyed that they received individualised and patient-centred care during their treatment. No previous research has studied this phase of the process. Furthermore, the healthcare professionals provided appropriate information to involve the patients and achieve symmetry in their relationship.

During PCI, healthcare professionals may experience ethical dilemmas. Especially, in the focus groups consisting of nurses working in the catheterisation laboratory and cardiac wards it was highlighted that patient information and involvement was difficult to achieve when angiography detected multivessel disease. The nurses experienced that while information was balanced to not overwhelm the patients during PCI, the patients were left with insufficient information about their condition afterwards. In this situation the nurses and physicians have different responsibilities and roles. The physician's role is to consult colleagues in the Heart Team and discuss treatment options, whereas the nurse is responsible for taking care of the patients. They often discover that the patients have not understood the complexity of their situation. This require an attentiveness from the nurse while encountering the patient. In light of their position, nurses have the opportunity to find time and space for an attentiveness; to listen to the patient and through dialogue gain insight into the patient perspective (Martinsen, 2006). The nurses as well as the physicians were aware of the importance of clear communication between nurse and physician about patients that needed more information. Reducing the knowledge gap between healthcare professionals and patients is a well-known prerequisite for patient participation (Angel & Frederiksen, 2015; Cahill, 1996; Sahlsten et al., 2008).

In some cases, it might be difficult to immediately observe the consequences of several treatment options. The healthcare professionals found it challenging to inform the patients in an appropriate way while simultaneously making treatment decisions, the consequences of which were unknown to them. This illustrated an ethical dilemma regarding information and patient participation in acute treatment situations. The physicians had insufficient knowledge to involve the patients in the decision-making process. This is a new finding, which I believe has been inadequately elucidated in the literature on patient participation of patients with MI thus far. Beauchamp and Childress (2019) discussed the term ‘veracity’, which implies the patients’ right to information that is timely, accurate, objective, and comprehensive. In some contexts, such as the situation described here, it is necessary to delay or spread information over time. Communication can be complex, and healthcare professionals must consider how much information the patient is able to receive at the time (Beauchamp & Childress, 2019). In such situations, emotional reciprocity might be important for a patient’s well-being (Beauchamp & Childress, 2019; Martinsen, 2006; Thompson et al., 2007).

6.1.3 The hospital stay

The length of hospital stay for patients with MI varied depending on the type of MI and the treatment outcome. Most patients were discharged within four to seven days. In line with the treatment guidelines, several medications were prescribed to prevent progression of CVD (Kotseva et al., 2019; Kotseva et al., 2016). In addition, these guidelines recommend that lifestyle changes, such as smoking cessation, diet, and physical activity, should be initiated before discharge (Piepoli et al., 2010; Piepoli et al., 2017; Piepoli et al., 2016). Data from the patients, nurses, and physicians showed challenges in patient information and involvement during hospitalisation. The participants across the various studies expressed deficiencies in information. A comparison nevertheless shows nuances in how they experienced the lack of information, both across and within the various data sets. The patients experienced the information they received differently; some had their needs met, while others found it to be insufficient. This is in accordance with previous research that reported a lack of information about the consequences of living with CVD, medications, lifestyle changes, and follow-up after discharge (Hanssen et al., 2005; Oterhals et al., 2006; Pettersen et al., 2018; Valaker et al., 2020).

The nurses and physicians explained that lack of information often occurred due to lack of resources and continuity in the pathway. In the studies, the physicians communicated more clearly how they perceived that the context and frame factors prevented them from involving the patients. Lack of available room for private conversation and lack of time were frame factors that could prevent the physicians from fulfilling their responsibility to provide patient information and involve the patients in their treatment and care. The nurses have more time with the patient and might more easily have a dialogue with the patient when there is time and space for this. The nurses can create frameworks to establish relationships and dialogue (Martinsen, 2006). Physicians and nurses work is differently organised. The time physicians have for each patient is often limited to ward rounds and discharge conversation. These differences in organisational structure of the professionals' work might provide an understanding into why physicians and nurses perceived the significance of the frame factors differently.

In Thompson's (2007) theoretical framework, participation is described as contextual. He describes a clinical context dependent on the type of illness, whether it is acute or chronic, the severity, the patient's knowledge and experiences and the relationship between healthcare professionals and patients. Frame factors are not included in Thompson's (2007) theoretical framework. This has inspired me to develop a new model for understanding patient participation that will be presented later.

Other challenges to patient information and involvement indicated by the healthcare professionals included the short and fragmented pathway. This led to a lack of continuity; however, this was experienced differently among nurses and physicians. The nurses considered the short time with transfers between the various wards that were involved in the pathway as challenging in relation to continuity. The physicians emphasised that the way their work was organised meant that they rarely met the patient more than once during the pathway. In the interviews with nurses and physicians, these challenges were discussed. They suggested introducing checklists. They thought that checklists in the patient record could ensure that the patients received sufficient information and might improve involvement. Advantages and disadvantages were discussed with great commitment in the focus groups with the nurses. Different views of the use of checklists were conveyed. Some of the nurses were sceptical of introducing more checklists and feared increased bureaucracy. Other nurses argued for the benefit of checklists in ensuring quality and patient safety. The physicians expressed confidence in the usefulness of checklists. Previous research have shown that standardisation may be useful for quality assurance and continuity. Although it can be difficult for patients to adapt standardised information and involvement to their own situations (Decker et al., 2007; Hanssen et al., 2005). Kari Martinsen (2005, 2006) is critical to the modernisation of the health care system, where care and treatment are standardised to meet demands for productivity and efficiency. When quality is measured based on productivity and efficiency, we get an instrumental use of time that may not promote patient participation in care. Martinsen (2005) claims that the momentary space becomes smaller, and that this might threaten the conversation and dialogue. In the light of this criticism, a challenge for healthcare professionals may be to adjust standardised checklists to the individual patients needs and health literacy. The patients in our study preferred information that was tailored and concrete, preferably in a recipe-like form. This requires healthcare professionals who have time for conversations and dialogue despite working in a time structure that promotes task orientation. A task-oriented attitude among healthcare professionals may lead to paternalistic approaches where the patients are not listened to, and a lack of dialogue and trust may arise (Martinsen, 2005).

In our research, nurses and physicians were concerned about patients' understanding of the disease, treatment, and secondary prevention. Some patients strived to understand that an MI was caused by an underlying CVD and might have believed that PCI treatment was curative (Astin et al., 2009; Dullaghan et al., 2014; Mentrup et al., 2020; Sampson et al., 2009). Thus, some patients might not have understood the secondary prevention's purpose. A notable finding of our study was that patients seemed to be aware of their own responsibility in preventing new cardiac events. They were attending cardiac rehabilitation programmes that could have increased their knowledge about the association between the progression of CVD and secondary prevention. Previous studies have revealed that patients achieve treatment goals for secondary prevention after an MI to a lesser extent (Jortveit et al., 2019; Kotseva et al., 2019; Kotseva et al., 2016). In this study, the physicians provided patients with information that could increase their health literacy as well as enable them to manage their medications and recommended lifestyle changes after discharge.

Health literacy is associated with lifestyle and living habits (WHO, 1998). Patient health literacy is important for patient choices in relation to health, disease prevention, and self-management of disease (Helse- og omsorgsdepartementet, 2019; WHO, 1998, 2016). A Norwegian survey found that the level of health literacy varied in the population and that 33% of the population had low health literacy (Helsedirektoratet, 2020). An acute illness can cause changes in patients’ health literacy (Beauchamp & Childress, 2019) and reduce the possibility of patient participation. In our research, nurses and physicians perceived that some patients had an insufficient level of health literacy. They stated that patients seldom asked questions about their care and treatment. The healthcare professionals were aware that the timing might not be the best for comprehensive information. Thompson (2007) argues that patient involvement and participation may be dependent on the patients’ experiences and knowledge. Based on his findings he suggests that patients with chronic diseases have greater possibilities for involvement than patients with acute diseases. Patients with chronic conditions have prolonged experience and therefore might have achieved increased health literacy (Thompson, 2007).

In our study, medications were a recurring issue. Patients had many questions related to medication effects, side effects, and administration. Additionally, nurses and physicians were concerned about patients’ adherence to medications. Although physicians provided information about new medications at discharge, they were reluctant to do so about their side effects for fear of causing unnecessary concerns for the patients. Furthermore, patients reported that inadequate information could lead to less adherence to medications after MI (Pettersen et al., 2018). The importance of sufficient information about medications has been supported by ESC Guidelines (Ibanez et al., 2017). Providing information about several new medications at discharge could be time consuming and overwhelming. This could be solved by including pharmacists to share the responsibility of providing information about medications. ESC Guidelines have recommended multidisciplinary care for patients with MI, where pharmacists have been mentioned among other professionals (Ibanez et al., 2017).

6.1.4 The discharge

At discharge, the physicians and nurses have different responsibility. In the discharge conversation the physician and patient were usually present. Due to time restraints, the physicians prepared written information in advance of the discharge conversation, where they focused on summarising the hospital stay, further medication, and follow-up after discharge. A Norwegian observation case study reported similar findings; the patient was involved by being informed and did not participate in decision-making at discharge (Ofstad et al., 2014).

This study's patients and nurses described that travelling home over large geographical distances was challenging. On one hand, the former lacked personal belongings, making it difficult for them to use public transport. On the other hand, the nurses reported spending a substantial amount of time organising these journeys for the patients. Health services have strict financial budgets, and patient transport is expensive; however, the travel distance should be considered when planning the mode of transport for these patients. In this study, the patients that were transported by air ambulance to their local hospital were satisfied. Previous research has similar findings regarding this issue (Valaker et al., 2017).

6.1.5 The rehabilitation phase

Patients, nurses, and physicians agreed on the importance of attending outpatient cardiac rehabilitation programmes. In the interviews several physicians expressed that in the cardiac rehabilitation program they offered the patient what the hospital pathway lacked: continuity and time for each patient. A challenge with standardised pathways, such as the MI pathway, is that it provides less time and space for individual care for patients (Martinsen, 2006). The nurses and physicians expressed that they experienced a shortfall in relation to involving the patients during the hospitalisation. Getting as many patients as possible to participate in cardiac rehabilitation programmes might be important to ensure that the patients were involved in their own treatment and increase patients' health literacy.

The patients expressed that they in the rehabilitation phase were ready to seek and receive information and be actively involved. According to Thompson (2007) being receptive to information is an elementary stage of involvement. Further, that the patients receives sufficient information to understand their illness and condition is a core requirement. Based on this, information may be understood as the basic building block for involvement and shared decision-making (Thompson, 2007). This is supported by data from the nurses and physicians, as they experienced that patient involvement required a certain level of health literacy. Often, they experienced that the patients struggled with health information and therefore found it difficult to involve the patients during hospitalisation.

The content and duration of cardiac rehabilitation programmes varies (Peersen et al., 2017; Rauch et al., 2016). In our study, the patients attended multi-disciplinary programmes that lasted for 12 weeks and consisted of individual counselling, group-based lectures, and training twice a week. These programmes were consistent with the ESC guidelines for cardiac rehabilitation programmes (Bjarnason-Wehrens et al., 2010; Ibanez et al., 2017). Our findings indicated that attending cardiac rehabilitation programmes was important for increasing patients' health literacy. Patient engagement and participation seemed to be a precondition for achieving lifestyle changes and adherence to medications. Furthermore, national and international studies demonstrated that cardiac rehabilitation was effective for achieving treatment goals (Peersen et al., 2017); additionally, it was associated with reduced mortality (Rauch et al., 2016).

Internationally, fewer than half of eligible patients participate in cardiac rehabilitation programmes (Kotseva et al., 2016). In Norway, participation rates vary, ranging from 20% to 31% (Olsen et al., 2018). Peersen et al. (2017) compared two Norwegian counties and found that the participation rates varied, the participation rate was 18% in one county and 75% in the other. The reasons for this variation could be that one of the counties systematically referred all eligible patients to the cardiac rehabilitation programme, whereas the other lacked such a referral system (Peersen et al., 2017). Insufficient referral to cardiac rehabilitation programmes was found by other studies as well (Shimada & Scirica, 2015; Valaker et al., 2020). Other reasons for not participating in such programmes were multifactorial and depended on patients' characteristics, including socioeconomic factors, frailty, comorbidity, and travel distance (Jelinek et al., 2015; Ruano-Ravina et al., 2016; Shimada & Scirica, 2015). In our research, healthcare professionals were concerned about dropout rates in cardiac rehabilitation programmes and motivated most patients to attend them. However, they mentioned it was difficult to persuade patients who needed cardiac rehabilitation. Researchers have expressed the need to increase referral rates for cardiac rehabilitation programmes and to develop national standards to standardise programme content (Olsen et al., 2018; Peersen et al., 2017). It might be necessary to consider the introduction of alternative and effective models for cardiac rehabilitation (Clark et al., 2015) if one is unsuccessful in increasing the number of patients who participate in traditional hospital-based cardiac rehabilitation programmes.

6.1.6 Suggesting a new model incorporating frame factors

The findings revealed that patient participation may be difficult to achieve during hospitalisation for an acute MI, yet patient information was much emphasised. This is in line with Thompson's (2007) identification of information as a building block for involvement and decision making. Thompsons' theoretical framework was developed to provide a comprehensive and nuanced understanding of patient participation. The framework is suitable for studying patient participation in clinical contexts at the micro level. Patient participation comprises three elements: components, levels, and context (Thompson, 2007; Thompson et al., 2007).

In this thesis patients and healthcare professionals pinpointed that there were several hinders to patient information and involvement during hospitalisation. Findings from the healthcare professionals revealed new and interesting findings, showing that frame factors at the system level are crucial for understanding patient participation. The healthcare professionals clearly expressed that a connection exists between the frame factors for facilitating patient participation at the system level and what is possible to achieve in practice at the individual level. This coincides with a narrative review conducted by Crawford, Brown, Kvangarsnes, and Gilbert (2014), which points out that there is a connection between the system's way of thinking and the culture that unfolds at the individual level in clinical contexts. For example, Crawford et al. (2014) point out that the system level's emphasis on productivity and efficiency with the lowest possible resources and time use, affects healthcare professionals at the individual level in their ability to meet the patients with compassionate care. There are commonalities between compassionate care and patient participation. A relationship based on trust and reciprocity between patient and healthcare professional is the basis for both approaches in care (Crawford et al., 2014; Martinsen, 2005, 2006; Thompson, 2007).

The findings in this thesis have inspired me in the development of a new model, which integrates the system level, to understand patient participation. The new model builds on Thompson et al.'s (2007) three elements in addition to comprising a fourth element: components, levels, context, and frame factors. The findings in this thesis showed that frame factors as *legislation, clinical guidelines, checklists, time, resources, health literacy, and organisational structure and culture*, are of great importance for patient participation in practice. The new model is presented in detail in the conclusion in the chapter implications for research.

6.2 Discussion of methodology and methods

The interviews provided rich data for answering the research questions of this thesis. The participants shared their experiences and expressed that participating in these studies was a positive experience for them. Using a qualitative approach provides complementary understanding and new insights into the phenomenon being studied (Denzin & Lincoln, 2018). Various qualitative designs were chosen to gain a comprehensive understanding of patients' and healthcare professionals' perceptions of patient participation in the MI pathway.

6.2.1 Design

Narrative interviews were chosen because I wanted to emphasise the patients' viewpoints (Chase, 2018; Holloway & Freshwater, 2007). The narratives started with patients sharing their lived stories about having an MI. A narrative is well-suited for elucidating clinical pathways. The MI pathway with acute onset and treatment suits the narrative structure, having a beginning, middle, and end (Holloway & Freshwater, 2007). In previous literature, narratives have often been applied to understand past events; however, recently, they have also been conducted to elucidate the present and future (Chase, 2018). In our study, they conveyed patients' past experiences from their hospital stay, including their present time and how they could prevent recurrent cardiac events in the future.

A hermeneutic approach was chosen for the studies involving nurses and physicians. This was because it provides an understanding based on interpretation of the meaning of what is being said. In a hermeneutic interpretation, the historical and cultural context is an important dimension (Patton, 2015). In our studies, nurses' and physicians' perceptions of patient participation in the MI pathway were examined. Patient participation is contextual, and a hermeneutic approach was appropriate for interpreting the underlying meaning of the interviews. The researcher's preunderstanding of the context and the phenomenon being studied was important for the interpretation of what was conveyed by healthcare professionals. My background as a nurse and the theoretical framework were part of my preunderstanding.

6.2.2 Participants

Purposive sampling (Patton, 2015; Polit & Beck, 2020) was appropriate to provide essential data covering the dimensions we explored. The participants who had experiences from the different phases of the MI pathway were included. Although the sample size was small, it provided rich and complementary data for all phases of the MI pathway. In qualitative studies, it is important to assess the sample size to obtain an appropriate sample to shed light on the research questions thoroughly. An excess of participants may lead to confusing data material and superficial analysis (Malterud, 2017).

6.2.3 Data collection and analysis

A narrative is a methodology that gives the patient a clear voice in interactions with the researcher (Chase, 2018; Malterud, 2017). Narrative interviews were conducted, and I invited participants to share their stories about patient participation in the MI pathway (Chase, 2005, 2018; Kvale & Brinkmann, 2009). The narrative structure, with its flow consisting of a beginning, middle, and end (Malterud, 2017; Patton, 2015), was appropriate to highlight patient participation in the MI pathway. The narratives were created through interaction between the researcher and the participant characterised by time, place, and mood (Malterud, 2017). The interviews were conducted in meeting rooms at the hospital two to five months after the treatment. The time and choice of place for the interview provided a safe environment for patients to share their experiences.

Focus groups were applied to collect data in Paper II. Focus groups are ‘carefully planned discussions that take advantage of group dynamics and synergies for accessing rich information’ (Polit & Beck, 2020, p. 515). In this study, they were conducted to collect data on nurses’ perceptions of patient participation, as they had different experiences and competencies. This facilitated an effective dynamic in the groups wherein they shared opinions, experiences, thoughts, and perceptions of patient participation in the MI pathway.

Individual semi-structured interviews were conducted to examine and gain insight into physicians’ perceptions and perspectives of patient participation in the MI pathway (Kvale & Brinkmann, 2009). The physicians were responsible for patients in different phases of the pathway.

I was responsible for the studies’ data collection and interview transcriptions. During the transcription of the interviews, oral narratives were translated to written language; I paid attention to what was said to avoid losing meaning in this process (Gilje, 2019).

Taking notes of pauses, body language, tone of voice, and actions performed while the persons talked provided valuable information in the analysis where the texts were interpreted (Gilje, 2019).

The data material in the studies was coded systematically. The analysis was described accurately to enable readers to follow the choices I made, understand the systematic organisation of the data, and comprehend the interpretations and how I reached conclusions (Malterud, 2017). An advantage was that the analyses were carried out by more than one researcher (Malterud, 2017). In the analyses, I benefited greatly from collaborating with my supervisors and co-authors. The interprofessional research group consisted of researchers with various experiences that provided appropriate conditions for strengthening the communicative validity of the studies (Kvale & Brinkmann, 2009).

The results of the analysis were presented through main themes anchored in the empirical data material (Malterud, 2017). In this thesis, the findings of the papers were synthesised into three themes: low level of patient participation in the acute and treatment phases, lack of continuity hindered patient participation, and shared decision-making in rehabilitation.

6.2.4 Limitations and strengths

Rigour and trustworthiness are important aspects for ensuring research integrity and quality. The terms, ‘rigour’ and ‘validity’ are often associated with positivism, whereas trustworthiness is often applied within the qualitative paradigm (Polit & Beck, 2020). Lincoln and Guba have proposed five criteria for enhancing trustworthiness: credibility, dependability, confirmability, transferability, and authenticity (Lincoln & Guba, 1985; Polit & Beck, 2020). Several checklists have been developed to ensure trustworthiness in qualitative research; in this section, I have used two different checklists to reflect on trustworthiness: 1) the consolidated criteria for reporting qualitative research checklist developed by Tong et al. (2007) and 2) Malterud’s (2001) ‘Qualitative research:

standards, challenges, and guidelines'. I have used the second checklist to structure the rest of this section (Malterud, 2001).

Reflexivity

In qualitative research, the research process should be characterised by reflexivity. My own and my supervisors' backgrounds affected all steps of the research process, including the methodological choices made in advance and along the research process. Qualitative researchers should identify and communicate their positions, preconceptions, assumptions, and interests within the research topic (Malterud, 2001; Tong et al., 2007). I have previously worked as a nurse and intensive care nurse in a ward for children and youths. In my clinical work, patient involvement and participation was central when encountering the individual patient and their relatives. My interest in the topic of patient participation has always been strong. When I entered academia and at the same time completed my master's degree, I was invited to take a closer look at patient information in the MI pathway, which later led on to this PhD project. Thus, I had knowledge from clinical and academic fields that was valuable in the research process.

The fact that I have not, during this PhD project nor before, worked directly with patients with MIs may have been both an advantage and a disadvantage (Alvesson, 2003). The advantage is that I could meet the data material with an open mind, at the same time as having less knowledge of the clinical context of the study may have been a disadvantage (Alvesson, 2003). However, my clinical experience as an intensive care nurse was important when I interviewed patients, nurses, and physicians. I was familiar with the MI pathway and the medical terms.

In the research project, I participated in a research group consisting of two nurses specialised in intensive care and cardiological nursing, a cardiologist, a community physician, and a social scientist. The members of the research group have extensive experience in qualitative and quantitative research. The interdisciplinary research group was a strength as we could contest and supplement each other's statements during all steps of the research process (Malterud, 2001).

Methods and design

The design of the studies were chosen to fit the aims and research questions. The methodology and methods were justified and explained in the papers and the thesis. A narrative approach was appropriate for highlighting the patients' experiences with patient participation in the MI pathway (Chase, 2018; Holloway & Freshwater, 2007). The patients willingly shared their experiences in conversations with the researcher. A hermeneutic approach was suitable because the aim was to interpret the underlying opinions about the phenomenon under investigation. Patient participation is closely linked to context, and a hermeneutic approach involves contextual interpretation (Gadamer, 2004; Patton, 2015).

In research there should be a consistency between methodology and method choices, and research questions (Creswell, 2014). The purpose of my thesis was to study patient participation from the patients, nurses, and physicians' perspective. Qualitative research interviews became an appropriate choice of method. Nevertheless, I am aware that interviews represent the informants' voices of their experiences and perceptions (Alvesson, 2003).

Participants and data collection

The participants were purposively sampled (Patton, 2015; Polit & Beck, 2020; Tong et al., 2007), either as patients or healthcare professionals, based on their experiences with patient participation in the MI pathway. The aim was to select those cases that provided wide variations in the experiences of the MI pathway (Patton, 2015; Polit & Beck, 2020). The demographic data were collected to describe the sample and to ensure and clarify the variations in it. This information was necessary for the readers to consider situations in which the findings could be applied (Malterud, 2001; Tong et al., 2007). Data saturation was considered to be achieved when the data in the studies were rich and diverse and when repetition and redundancy could be identified through patterns across the interviews (Polit & Beck, 2020).

The sample in Paper I consisted of two women and eight men aged 37-80 years. Data regarding whether the 10 patients in Paper I had STEMI or NSTEMI were not collected, which might be a limitation in the description of the study sample. Previous research stated that participation rates in cardiac rehabilitation programmes were low (Kotseva et al., 2016; Olsen et al., 2018). The participants in our study were recruited from outpatient cardiac rehabilitation units. Those who did not attend a programme were excluded.

In Paper II, focus groups were used to collect data. Ideally, they should consist of five to eight participants (Krueger & Casey, 2015). The literature recommends recruiting one or two additional participants because of high probability of dropouts. In our study, the size of the focus groups ranged from three to five participants. In focus groups 1, 2, and 3, two nurses from a cardiac recovery unit, where the patients were monitored during the initial hours after PCI, were restricted from participating. The remaining participants of the focus groups were knowledgeable of this specific ward's responsibility in the pathway; we considered the data to be saturated after five focus groups (Krueger & Casey, 2015). Focus groups with limited participants can be valuable when the participants are considered information-rich and have in-depth knowledge and experience about the subject under examination (Krueger & Casey, 2015; Patton, 2015).

In Paper III, nine physicians were interviewed. Of them, three and six worked at the hospitals with and without PCI facilities, respectively. This unequal distribution in the number of participants from each hospital was considered irrelevant as the physicians were knowledgeable about the functions and responsibilities of the different hospitals. We did not plan to include physicians working as GPs in primary healthcare services. During the interviews, we were made aware that the GPs had a special responsibility in the follow-up of patients after MI, especially for those patients who did not attend cardiac rehabilitation programmes. In future research, it is relevant to include the perspective of GPs.

Interview guides were developed based on earlier research, the theoretical framework and the research questions (Thompson, 2007; Thompson et al., 2007). In the interview guide applied for the patient perspective, emphasis has been placed on patient information, which might be considered a limitation. However, previous research has shown that the term patient participation might be difficult for patients to relate to (Landstad & Kvangarsnes, 2020). In addition, as showed in the interview guide, the questions were open ended and formulated to provide insight into how the informants experienced being involved in patient information and participation during the different phases of the pathway. Acute treatment reduces the need for participation, and it was therefore natural to ask questions about information rather than shared decision-making, which is a higher level of participation (Thompson, 2007).

The interview guides developed for healthcare professionals were twofold, where the first part focused on patient information and the second part focused on patient participation. These interview guides were similar in content, but adapted to the perspective of nurses and physicians, and whether it was focus groups or individual interviews. Patient information and participation are part of the professional area of responsibility of healthcare professionals (Act related to Health Personnel, 1999, last changed 2020; Act related to patients' rights, 1999, last changed 2020). Therefore, it was natural to use the term patient participation in these guides.

In the interviews, it is the informants’ experiences and perceptions that is created in a social context. Interviews do not provide a picture of what is happening in practice. Collecting data using observation could have provided insight into what happens in practice (Alvesson, 2003; Cahill, 1996).

Observations in addition to interviews could have been applied to collect data for the study. Method triangulation may be valuable to develop an even more comprehensive, consistent, and coherent understanding of patient participation as a phenomenon (Polit & Beck, 2020). Collecting data using observations is challenging in the MI pathway. An MI occurs acute, which can present ethical and methodological challenges related to informed consent and in gaining access to the field. In addition, 50% of the patients are transferred between hospitals, often over large geographical distances, which pose challenges in observing the different phases of the MI pathway. In my studies, I considered that interviews were appropriate to answer the research questions.

Theoretical framework

The theoretical framework provided a lens for what was looked at in the study, and inspired the research questions, how data were collected and analysed, and the presentation and discussion of the findings (Creswell, 2014).The theoretical framework chosen for this study represented patient participation as a complex, dynamic, and contextual concept (Thompson, 2007; Thompson et al., 2007). Patient participation can be experienced differently from patient and healthcare perspectives (Eldh, Ehnfors, et al., 2006; Florin et al., 2006; Höglund et al., 2010).

Autonomy is the highest level of patient involvement in Thompsons' taxonomy. The theoretical framework of the thesis was extended by including theory about ethical principles (Beauchamp & Childress, 2019). The ethical theory was particularly useful in the discussion of the findings related to the acute and treatment phase of the MI pathway. The healthcare professionals said that they experienced ethical dilemmas in the intersections between involving patients and acting out of beneficence for the patients. The theoretical framework shed light on the phenomenon I wanted to study and provided good opportunities to interpret the different forms and levels of patient participation from the perspectives of patients, nurses, and physicians (Creswell & Creswell, 2018; Tong et al., 2007).

The chosen theoretical framework was well-suited to assess patient participation in the MI pathway. The integrative approach to patient participation influenced the research questions and interview guides; moreover, it revealed that patient participation varied in the different phases of the MI pathway. A weakness of the framework was that the frame factors for patient participation were unelaborated in the integrative approach (Thompson et al., 2007). Therefore, in the conclusion of this thesis, I presented a new model wherein the frame factors were one of the four elements that were important to examine in order to understand patient participation in practice.

In the discussion of the findings, I have used other theoretical perspectives, for example Grimen (2009), Martinsen (2005, 2006) and Crawford et al. (2014). This provided a complementary understanding of the findings. I might have chosen studying other phenomena related to the MI pathway, for example patient-centred care. However, that would have required another theoretical framework, research questions, and study design.

Data analysis

The data analyses were explained in detail in the papers and thesis. An important requirement in qualitative studies is that the analysis is described systematically (Malterud, 2001; Tong et al., 2007).

A narrative data analysis may be conducted in multiple ways (Holloway & Freshwater, 2007; Riessman, 2008). The five lenses presented by Chase (2005) were not a procedure or guideline on how to perform a narrative data analysis; rather, they directed me on how to treat the narratives told by the participants in the analytical process. However, the five lenses (Chase, 2005) had several commonalities with thematic and structural analyses, as described by Riessman (2008). I found that by using them, I was able to listen to the narratives, grasp how each of the participants narrated their experiences, and create a single compiled narrative through data interpretation (Kvale & Brinkmann, 2009).

Gadamer (2004) did not develop research techniques, his stance was rather philosophical (Gilje, 2019; Kvale & Brinkmann, 2009). His philosophical approach was valuable for understanding how we developed and expanded our understanding of the phenomenon we were investigating. In addition, the hermeneutic circle was applied to uncover the underlying meaning in the data and discover new perspectives and insights into patient participation.

Malterud (2001) noted that knowledge emerges from the relationship between empirical data and theory. The theoretical framework worked as a lens for interpreting the data in our studies. Clarifying and declaring the use of theory in data analysis enhanced the intersubjectivity of the study (Malterud, 2001). The analysis process started inductively, where the patterns, subthemes, and themes were built on the data in an iterative process; I moved back and forth between them and datasets. At the end of the process, I worked deductively and reflected on the data from the themes to determine if they supported the abstractions made (Creswell, 2014; Creswell & Creswell, 2018). The theoretical framework was valuable in this process, focusing on patient participation.

Findings

The findings provided knowledge about how patients and healthcare professionals perceive patient participation in the different phases of the MI pathway. The major themes and subthemes were clearly presented in the tables that illustrated their development: quotations, subthemes, and main themes. The quotations were carefully selected to substantiate the findings and demonstrate the link between the data and findings (Tong et al., 2007). Examining patient participation from the perspectives of the patients, nurses, and physicians provided an opportunity to create a holistic understanding of patient participation in the MI pathway. The findings shed light on the contextual nature of patient participation and that the need and opportunities for participation may change during a pathway. They substantiated each other; simultaneously, there were nuances and variations in the perceptions of patient participation from different perspectives.

A notable finding was that healthcare professionals expressed that older and more fragile patients desired to be involved in decisions regarding invasive treatments. They conveyed that they respected the patients' autonomy regarding the wish for non-invasive treatments. These situations could be experienced as ethical dilemmas for healthcare professionals, as they had to choose between the best treatment for the patient and the patient's autonomy (Beauchamp & Childress, 2019). These findings, to a small extent, were highlighted in previous research. It is important that the community of practitioners involved in treatment decisions discuss this ethical dilemma and the consequences of different treatment choices. This may provide a deeper understanding of the complexity of patient participation.

An interesting finding was healthcare professionals' consideration of frame factors' importance for patient participation. Legislation, clinical guidelines and checklists, time and resources, patients' health literacy, and the organisational structure and culture were examples of such frame factors that hindered patient participation. These frame factors were not highlighted in the integrative approach of Thompson et al. (2007).

I aimed to present the findings through abundant descriptions that showed the patterns and different cases in the data material (Lincoln & Guba, 1985; Tong et al., 2007). This provides readers with an opportunity to consider whether the findings may be transferable to other settings with similar healthcare services (Lincoln & Guba, 1985; Malterud, 2001).

In this study, patient participation in the MI pathway was studied in a Norwegian context. The study context will have an impact on the transferability of the findings (Polit & Beck, 2020; Tong et al., 2007).

In Norway, patient participation is enshrined in the legislation for patients and users of health and care services (Act related to patients' rights, 1999, last changed 2020). Several other countries have similar legislation, which may increase the transferability (WHO, 1994, 2013). PCI treatment for MI is centralised in Norway due to a scattered population with large geographical distances, this may limit the transferability of parts of the findings to countries not affected by similar challenges. In principle, the phases of the MI pathway are the same regardless of transfers between hospitals, which strengthens the transferability of the study findings.

I argue that some of the findings may be important for understanding patient participation generally in health services, not just in the MI pathway. For example, the study has highlighted the frame factors importance for healthcare professionals' opportunities to facilitate patient participation in a clinical context, which will probably be transferable to other pathways as well.

Discussion

The papers and this thesis provided answers to the research questions, which were related to the internal validity of the study (Malterud, 2001). External validity was assessed when the findings were discussed with respect to previous research (Malterud, 2001). These findings were discussed in relation to international and Norwegian studies.

The theoretical framework was applied in the discussion section to underpin our findings and explain the variations in patient participation in the MI pathway.

Presentation

The research process and findings were thoroughly disseminated to increase validity (Kvale & Brinkmann, 2009; Malterud, 2017). The IMRAD structure was used in the papers and thesis. The findings conveyed that the participants' voices and quotations were used to underpin the analytical text (Malterud, 2001).

References

I have become well-acquainted with the literature and previous research on patient participation. In the three papers, it was necessary to limit the amount of theory and previous research presented. This thesis provided an opportunity for a more comprehensive presentation of the relevant research and the background of patient participation. I regularly conducted literature searches in relevant databases. The subchapter on previous research on patient participation in the MI pathway provides an updated research review.

7 CONCLUSIONS

This thesis provides new insights into patient participation in the MI pathway from the perspectives of patients, nurses, and physicians. The patients and healthcare professionals seemed to have a shared understanding that patient participation is difficult to achieve in the acute phase of MI. The former need clear information during the acute phase. Individualised information and trust characterise the patients' experiences of PCI treatment. Healthcare professionals must be aware that elderly and frail patients may have increased demands regarding patient participation in their treatment choices.

Patients, nurses, and physicians perceived that continuity and coordination challenge patient participation. Patients experienced a lack of information about lifestyle changes, medications, and rehabilitation. Nurses and physicians emphasised how the system sets limits on their opportunities to facilitate patient participation. Short hospital stays and the fragmented pathway do not provide the best conditions for strengthening patients' health literacy. The new guidelines that require invasive treatments for patients with NSTEMI within 24 hours (Collet et al., 2020) actualise the issues raised in this thesis. The results of faster invasive treatment for all patients with MI might lead to shorter hospital stays and increased pressure on hospitals with PCI facilities to meet the demand for earlier revascularisation.

This thesis also highlights the important role of cardiac rehabilitation programmes in the MI pathway. Patients, nurses, and physicians conveyed that these programmes focused on patient participation and shared decision-making to increase patients' health literacy and their possibility of achieving secondary prevention treatment goals. Nurses and physicians strongly recommended that patients attend cardiac rehabilitation programmes and were concerned about high dropout rates.

7.1 Implications for practice

The findings of this thesis emphasise a need to restructure the MI pathway, with a focus on strengthening continuity and collaboration. In Paper I, the requirement for an individual plan for patient information was suggested as an implication for practice. This was further emphasised by the findings in Papers II and III, where the nurses and physicians required common checklists. However, I believe that implementing standardised checklists for patient information in the patient medical record may ensure basic levels of information about disease, acute treatment, and secondary prevention; moreover, they might strengthen patients' health literacy. The findings identified the need to strengthen collaboration between healthcare professionals and transfer hospitals. The checklist in the patients' medical record should follow them across departments, healthcare professionals, and between different hospitals.

Healthcare professionals indicated several limitations of the system, such as lack of time, continuity, and available rooms for private conversations at hospitals. Increased collaboration and division of responsibilities through standardised checklists between nurses and physicians might lead to an improved and seamless information flow that could save time. Long travel times for patients should be discussed at the organisational level. User representatives should be invited to participate in the discussion.

Nurses and physicians were concerned about high dropout rates in cardiac rehabilitation programmes. The reasons for patients avoiding such programmes were appropriately highlighted in several primary studies and reviews. Although the findings of this thesis do not provide solutions to this problem, they indicate the importance of cardiac rehabilitation programmes. In other studies, patients have reported lacking information about offerings and referrals to cardiac rehabilitation programmes. One solution could be to refer them to a follow-up consultation after discharge, where they could be invited to partake in a cardiac rehabilitation programme.

7.2 Implications for research

In this thesis, Thompson et al.’s (2007) integrative approach was applied to examine patient participation in the MI pathway. The findings can be synthesised as follows: 1) low level of patient participation in the acute and treatment phases; 2) lack of continuity hindered patient participation during hospitalisation; 3) shared decision-making in the rehabilitation phase. The integrative approach was valuable for identifying and highlighting patterns in patient participation in the MI pathway. However, in the last study, we discovered that Thompson et al.’s (2007) framework inadequately highlighted the important aspects of patient participation.

Our findings showed that the frame factors played an important role in the implementation of patient participation. Additionally, we found that legislation and clinical guidelines had a great impact on it. The Health Personnel Act stipulates that healthcare professionals must provide professionally sound and immediate healthcare when required (Act related to Health Personnel, 1999, last changed 2020). The treatment of MI follows evidence-based clinical guidelines, where rapid treatment with thrombolysis or PCI is recommended. Legislation and clear clinical guidelines have prioritised treatment instead of patient participation in the acute phase. For secondary prevention, the clinical guidelines clearly state recommendations for medications that the patients should be prescribed, which might lead to less patient involvement in decisions regarding medications (Collet et al., 2020; Ibanez et al., 2017; Neumann et al., 2018). Simultaneously, patient participation has been promoted as a legal right enshrined in the Patients’ Rights Act (Act related to patients' rights, 1999, last changed 2020). Furthermore, the clinical guidelines indicate the importance of patient information and involvement, especially due to secondary prevention (Collet et al., 2020; Ibanez et al., 2017; Neumann et al., 2018).

Lack of time and resources, such as rooms available for private conversations at hospitals, hinder healthcare professionals’ facilitation of patient participation. Another obstacle is the lack of continuity due to how healthcare professionals’ workloads are organised. They believed that introducing checklists for patient information could enhance continuity and strengthen patient participation. Furthermore, they were concerned about patients' health literacy and attempted to increase their knowledge during hospitalisation. Previous research supports the importance of these frame factors (Angel & Frederiksen, 2015; Arnetz, Winblad, et al., 2008; Arnetz & Zhdanova, 2015; Halabi et al., 2020; Longtin et al., 2010; Oxelmark et al., 2018; Sahlsten, Larsson, Plos, et al., 2005; Tobiano, Marshall, et al., 2015).

Frame factors are not explicitly formulated in Thompson et al.'s (2007) approach. Therefore, I developed an integrative model to include them as a fourth element. This addition was inspired by the frame factor theory developed in pedagogy by educational researchers Urban Dahllöf and Ulf Lundgren; it focuses on organisational conditions that could hinder and facilitate learning processes (Dahllöf, 1967, 1998; Lundgren, 1972). Examples of frame factors within pedagogy include physical and administrative frames, legislation, and curriculum design. Frame factors are governed by external conditions that are difficult to control (Vaage, 1998). They are linked to the system level at the meso and macro levels. Recently, a multilevel approach to enhance shared decision-making was published (Thomas, Bass, & Siminoff, 2021). This model is divided into three levels: patient, clinician, and system. The system level pinpoints similar frame factors as those identified in our empirical data. Thomas et al.'s (2021) model is limited to shared decision-making and does not address other aspects of patient participation; it intends to strengthen shared decision-making. The model I present uses a holistic approach to study patient participation.

7.2.1 An integrative model to patient participation in care and treatment

Figure 4 presents an integrative model consisting of four elements that comprise patient participation: frame factors, interaction, levels of involvement, and clinical context. The three elements—components, levels of involvement, and context—in Thompson et al.'s (2007) integrative approach have been slightly modified. In the model, I replaced components with interaction because the former describe different areas of interaction where the patient can participate in their care and treatment. To distinguish context and frame factors, I use the term 'clinical context'. The clinical context should be related to the specific healthcare setting where the clinical pathway, type of illness, and severity of the conditions are important.

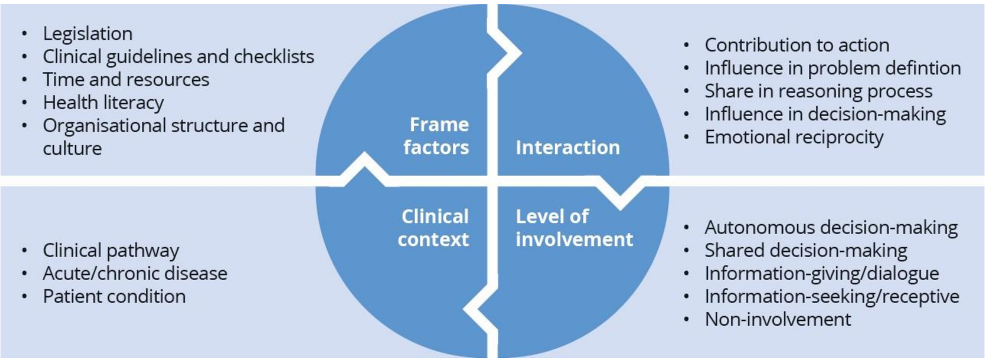
Frame factors in a care and treatment process constitute legislation, clinical guidelines and checklists, time and resources, health literacy, and the structure and culture of the organisation. The frame factors provide conditions that may be achievable, while simultaneously offering insights into why things do not work.

Interaction is divided into five areas of collaboration in which the patient can participate: 1) contribution to action, 2) influence in problem definition, 3) contribution in the reasoning process, 4) influence in decision-making, and 5) emotional reciprocity (Thompson et al., 2007). These areas may be helpful in identifying patient participation in empirical data. In the clinical pathway, patients may have different wishes for the level of participation in these five areas.

Levels of involvement range from non-involvement to autonomous decision-making on a scale from zero to four. According to Thompson (2007) patient participation is placed at levels two and three and is represented through dialogue and shared decision-making; the level of involvement is related to that of power, where a low level of the latter is associated with reduced levels of the former and vice versa.

The clinical context is dependent on the clinical pathway, type of disease, whether acute or chronic, and severity of the patient's condition (Thompson et al., 2007). For example, a hospitalisation that is elective and planned in advance will provide other opportunities for patient participation than an acute and life-threatening disease requiring immediate hospital admission and rapid initiation of treatment.

Figure 4 An integrative model to patient participation in care and treatment



In this thesis, the three elements of Thompson et al.'s (2007) approach were applied to identify patient participation in the empirical data. Three of the elements in Figure 4, namely, interaction, level of involvement, and clinical context, coincide with those of the integrative approach. The fourth element, frame factors, contribute a new dimension to Thompson et al.'s (2007) integrative approach. The clinical context may be considered to overlap with the frame factors. However, the frame factors provide a comprehensive understanding of their significance and must be applied in an open manner; moreover, the four elements in the model are interrelated. The frame factors affect the interaction and level of involvement during the pathway. Simultaneously, the clinical context, type of illness, and severity constitute the conditions and possibilities for patient participation.

The integrative model for patient participation in care and treatment should not be applied in a deterministic way. It is an open model and interpretive framework for understanding the complexity of patient participation. The contents of the four elements may vary in different healthcare settings. A key element of the frame factor is that it provides insight into the factors that might hinder practice while simultaneously opening for what is achievable (Kvalsund, 1998).

This approach is intended to be an analytical model for understanding patient participation. Its aim is to provide a systematic and integrative approach that might offer concrete input to planning, data collection, and data analysis in research. The model can be applied to study patient participation from the perspectives of patients and healthcare professionals. Previous research has highlighted the importance of studying participation from the next of kin perspective (Lamore, Montalescot, & Untas, 2017; Landstad et al., 2020; Landstad & Kvangarsnes, 2020). Gaps exists in the understanding of involvement of next of kin (Lamore et al., 2017). The integrative model to patient participation may with small adjustments also be appropriate to study the involvement of this group.

The model may be valuable for future research on patient participation in different clinical settings. It can be applied to qualitative, quantitative, and mixed-method studies. Obstacles and opportunities for patient participation that have been unknown thus far may be identified, as the frame factors have not been emphasised in previous theoretical models.

REFERENCES

Act related to Health Personnel. (1999, last changed 2020). *Lov om helsepersonell m.v. [The Health Personnel Act]*. Helse- og omsorgsdepartementet [Ministry of Health and Care Services] Retrieved from https://lovdata.no/dokument/NL/lov/1999-07-02-64

Act related to patients' rights. (1999, last changed 2020). *Lov om pasient- og brukerrettigheter [Act related to patiens' rights]*. Helse- og omsorgsdepartementet [Ministry of Health and Care Services] Retrieved from https://lovdata.no/dokument/NL/lov/1999-07-02-63

Alvesson, M. (2003). Methodology for close up studies–struggling with closeness and closure. *Higher education, 46*(2), 167-193.

Alvesson, M., & Sköldberg, K. (2018). *Reflexive methodology: new vistas for qualitative research* (3 ed.). Los Angeles, California: SAGE.

Angel, S., & Frederiksen, K. N. (2015). Challenges in achieving patient participation: a review of how patient participation is addressed in empirical studies. *International Journal of Nursing Studies, 52*(9), 1525-1538. doi:10.1016/j.ijnurstu.2015.04.008

Arnetz, J. E., & Arnetz, B. B. (2009). Gender differences in patient perceptions of involvement in myocardial infarction care. *European Journal of Cardiovascular Nursing, 8*(3), 174-181. doi:10.1016/j.ejcnurse.2008.11.002

Arnetz, J. E., Höglund, A. T., Arnetz, B. B., & Winblad, U. (2008a). Development and evaluation of a questionnaire for measuring patient views of involvement in myocardial infarction care. *European Journal of Cardiovascular Nursing, 7*(3), 229-238. doi:10.1016/j.ejcnurse.2007.11.003

Arnetz, J. E., Höglund, A. T., Arnetz, B. B., & Winblad, U. (2008b). Staff views and behaviour regarding patient involvement in myocardial infarction care: development and evaluation of a questionnaire. *European Journal of Cardiovascular Nursing, 7*(1), 27-35. doi:10.1016/j.ejcnurse.2007.05.006

Arnetz, J. E., Winblad, U., Arnetz, B. B., & Höglund, A. T. (2008). Physicians' and nurses' perceptions of patient involvement in myocardial infarction care. *European Journal of Cardiovascular Nursing, 7*(2), 113-120. doi:10.1016/j.ejcnurse.2007.05.005

Arnetz, J. E., Winblad, U., Höglund, A. T., Lindahl, B., Spångberg, K., Wallentin, L., . . . Arnetz, B. B. (2010). Is patient involvement during hospitalization for acute myocardial infarction associated with post-discharge treatment outcome? An exploratory study. *Health Expectations, 13*(3), 298-311. doi:10.1111/j.1369-7625.2009.00588.x

Arnetz, J. E., & Zhdanova, L. (2015). Patient involvement climate: views and behaviours among registered nurses in myocardial infarction care. *Journal of Clinical Nursing, 24*(3-4), 475-485. doi:10.1111/jocn.12629

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners, 35*(4), 216-224. doi:10.1080/01944366908977225

Ashworth, P. D., Longmate, A. M., & Morrison, P. (1992). Patient participation: its meaning and significance in the context of caring. *Journal of Advanced Nursing, 17*(12), 1430-1439. doi:10.1111/j.1365-2648.1992.tb02814.x

Astin, F., Closs, S. J., McLenachan, J., Hunter, S., & Priestley, C. (2008). The information needs of patients treated with primary angioplasty for heart attack: an exploratory study. *Patient Education and Counseling, 73*(2), 325-332. doi:10.1016/j.pec.2008.06.013

Astin, F., Closs, S. J., McLenachan, J., Hunter, S., & Priestley, C. (2009). Primary angioplasty for heart attack: mismatch between expectations and reality? *Journal of Advanced Nursing, 65*(1), 72-83. doi:10.1111/j.1365-2648.2008.04836.x

Astin, F., Stephenson, J., Probyn, J., Holt, J., Marshall, K., & Conway, D. (2020). Cardiologists' and patients' views about the informed consent process and their understanding of the anticipated treatment benefits of coronary angioplasty: a survey study. *European Journal of Cardiovascular Nursing, 19*(3), 260-268. doi:10.1177/1474515119879050

Austvoll-Dahlgren, A. (2013). Pasient og kliniker representerer kilder til ulike typer kunnskap. *Tidsskrift for den Norske legeforening, 16*(133), 1726-1728. Retrieved from https://tidsskriftet.no/sites/default/files/pdf2013--1726-8.pdf

Beauchamp, T. L., & Childress, J. F. (2019). *Principles of biomedical ethics* (8 ed.). New York: Oxford University Press.

Bjarnason-Wehrens, B., McGee, H., Zwisler, A.-D., Piepoli, M. F., Benzer, W., Schmid, J.-P., . . . Niebauer, J. (2010). Cardiac rehabilitation in Europe: results from the European cardiac rehabilitation inventory survey. *European Journal of Preventive Cardiology, 17*(4), 410-418. doi:10.1097/HJR.0b013e328334f42d

Bowling, A., Culliford, L., Smith, D., Rowe, G., & Reeves, B. C. (2008). What do patients really want? Patients' preferences for treatment for angina. *Health Expectations, 11*(2), 137-147. doi:10.1111/j.1369-7625.2007.00482.x

Brownlea, A. (1987). Participation: myths, realities and prognosis. *Social Science & Medicine, 25*(6), 605-614. doi:10.1016/0277-9536(87)90085-2

Bugge, C., & Jones, A. (2007). Methods for studying patient participation. In S. Collins, N. Britten, J. Ruusuvuori, & A. Thompson (Eds.), *Patient participation in health care consultations qualitative perspectives* (pp. 22-40). Maidenhead: Open University Press.

Cahill, J. (1996). Patient participation: a concept analysis. *Journal of Advanced Nursing, 24*(3), 561-571. doi:10.1046/j.1365-2648.1996.22517.x

Cahill, J. (1998). Patient participation—a review of the literature. *Journal of Clinical Nursing, 7*(2), 119-128. doi:10.1046/j.1365-2702.1998.00132.x

Castro, E. M., Van Regenmortel, T., Vanhaecht, K., Sermeus, W., & Van Hecke, A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: a concept analysis based on a literature review. *Patient Education and Counseling, 99*(12), 1923-1939. doi:10.1016/j.pec.2016.07.026

Chase, S. E. (2005). Narrative Inquiry Mutliple lenses, Approaches, Voices In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3 ed., pp. 651-679). Thousand Oaks, California: SAGE.

Chase, S. E. (2011). Narrative inquiry Still a field in the making. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (4 ed., pp. 421-434). Los Angeles, California: SAGE.

Chase, S. E. (2018). Narrative inquiry toward theoretical and methodological maturity. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (5 ed., pp. 546-560). Los Angeles, California: SAGE.

Clark, R. A., Conway, A., Poulsen, V., Keech, W., Tirimacco, R., & Tideman, P. (2015). Alternative models of cardiac rehabilitation: a systematic review. *European Journal of Preventive Cardiology, 22*(1), 35-74. doi:doi.org/10.1177/2047487313501093

Collet, J.-P., Thiele, H., Barbato, E., Barthélémy, O., Bauersachs, J., Bhatt, D. L., . . . Folliguet, T. (2020). 2020 ESC Guidelines for the management of acute coronary syndromes in patients presenting without persistent ST-segment elevation. The Task Force for the management of acute coronary syndromes in patients presenting without persistent ST-segment elevation of the European Society of Cardiology (ESC). *European Heart Journal, 42*(14), 1289-1367. doi:10.1093/eurheartj/ehaa575

Collins, S., Britten, N., Ruusuvuori, J., & Thompson, A. (2007). Understanding the process of patient participation. In S. Collins, N. Britten, J. Ruusuvuori, & A. Thompson (Eds.), *Patient participation in health care consultations qualitative perspectives* (pp. 3-21). Maidenhead: Open University Press.

Crawford, P., Brown, B., Kvangarsnes, M., & Gilbert, P. (2014). The design of compassionate care. *Journal of clinical nursing, 23*(23-24), 3589-3599. doi:10.1111/jocn.12632

Creswell, J. W. (2014). *Research design qualitative, quantitative and mixed methods approaches* (4 ed.). Los Angeles, California: SAGE.

Creswell, J. W., & Creswell, J. D. (2018). *Research design: qualitative, quantitative & mixed methods approaches* (5 ed.). Los Angeles, California: SAGE.

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design. Choosing among five approaches* (4 ed.). Thousand Oaks, California: SAGE.

Dahllöf, U. (1967). *Skoldifferentiering och undervisningsførlopp : komparativa mål- och processanalyser av skolsystem I* (Vol. 2). Stockholm: Almqvist & Wiksell.

Dahllöf, U. (1998). En återblick på det tidiga ramfaktorteoretiska tänkandet och några av dess senare utlöpare. In R. Kvalsund, L. Bøe, K. Heggen, K.-A. Madssen, & S. Vaage (Eds.), *I lærande fellesskap*. Volda: Høgsulen i Volda og Møreforskning Volda.

Decker, C., Garavalia, L., Chen, C., Buchanan, D. M., Nugent, K., Shipman, A., & Spertus, J. A. (2007). Acute myocardial infarction patients' information needs over the course of treatment and recovery. *Journal of Cardiovascular Nursing, 22*(6), 459-465. doi:10.1097/01.JCN.0000297391.11324.0f

Den nasjonale forskningsetiske komitè for medisin og helsefag. (2009). *Veiledning for forskningsetisk og vitenskapelig vurdering av kvalitative forskningsprosjekt innen medisin og helsefag*. Retrieved from https://www.forskningsetikk.no/globalassets/dokumenter/4-publikasjoner-som-pdf/kvalitative-forskningsprosjekt-i-medisin-og-helsefag-2010.pdf

Denzin, N. K., & Lincoln, Y. S. (2018). Introduction the discipline and practice of qualiative research In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE Handbook of Qualitative Research* (5 ed., pp. 1-35). Los Angeles, California: SAGE.

Doll, J. A., Jones, W. S., Lokhnygina, Y., Culpepper, S., Parks, R. L., Calhoun, C., . . . Patel, M. R. (2019). PREPARED study: a study of shared decision-making for coronary artery disease. *Circulation: Cardiovascular Quality and Outcomes, 12*(2). doi:10.1161/circoutcomes.118.005244

Dullaghan, L., Lusk, L., McGeough, M., Donnelly, P., Herity, N., & Fitzsimons, D. (2014). 'I am still a bit unsure how much of a heart attack it really was!' Patients presenting with non ST elevation myocardial infarction lack understanding about their illness and have less motivation for secondary prevention. *European Journal of Cardiovascular Nursing, 13*(3), 270-276. doi:10.1177/1474515113491649

Eldh, A. C., Ehnfors, M., & 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, 5*(1), 45-53. doi:10.1016/j.ejcnurse.2005.06.002

Eldh, A. C., Ekman, I., & Ehnfors, M. (2006). Conditions for patient participation and non-participation in health care. *Nursing Ethics, 13*(5), 503-514. doi:10.1191/0969733006nej898oa

Eldh, A. C., Ekman, I., & Ehnfors, M. (2008). Considering patient non-participation in health care. *Health Expectations, 11*(3), 263-271. doi:10.1111/j.1369-7625.2008.00488.x

Eldh, A. C., Ekman, I., & Ehnfors, M. (2010). A comparison of the concept of patient participation and patients' descriptions as related to healthcare definitions.

International Journal of Nursing Terminologies and Classifications, 21(1), 21-32. doi:10.1111/j.1744-618X.2009.01141.x

Eldh, A. C., Luhr, K., & Ehnfors, M. (2015). The development and initial validation of a clinical tool for patients' preferences on patient participation–The 4Ps. *Health Expectations, 18*(6), 2522-2535. doi:10.1111/hex.12221

FHI. (2019). Hva er viktig for deg? En retningsendring Retrieved from https://www.fhi.no/kk/forbedringsarbeid/pasientforlop/hva-er-viktig-for-deg-en-retningsendring/

Florin, J., Ehrenberg, A., & Ehnfors, M. (2006). Patient participation in clinical decision-making in nursing: a comparative study of nurses’ and patients’ perceptions. *Journal of Clinical Nursing, 15*(12), 1498-1508. doi:10.1111/j.1365-2702.2005.01464.x

Fors, A., Dudas, K., & Ekman, I. (2014). Life is lived forwards and understood backwards–Experiences of being affected by acute coronary syndrome: A narrative analysis. *International Journal of Nursing Studies, 51*(3), 430-437. doi:10.1016/j.ijnurstu.2013.06.012

Gadamer, H.-G. (2004). *Truth and method* (2nd, rev. ed. translation revised by Joel Weinsheimer and Donald G. Marshall. ed.). London: Continuum.

Gilje, N. (2019). *Hermeneutikk som metode : ein historisk introduksjon*. Oslo: Samlaget.

Grimen, H. (2009). *Hva er tillit* (Vol. 30). Oslo: Universitetsforlaget.

Grovatsmark, R. E. S., Halle, K. K., Berge, V. B., Sneeggen, S., & Bønaa, K. H. (2020). Norsk hjerteinfarktregister Årsrapport 2019 [The Norwegian Myocardial Infarction Register Annual Report 2019]. Retrieved from https://stolav.no/seksjon/Hjerteinfarktregisteret/Documents/%C3%85rsrapporter/%C3%85rsrapport%202019/2020-10-01%20Norsk%20hjerteinfarktregister%20-%20%C3%85rsrapport%202019_%20Innlevert_2.pdf

Gulddal, J., & Møller, M. (1999). *Hermeneutik : en antologi om forståelse*. København: Gyldendal.

Halabi, I. O., Scholtes, B., Voz, B., Gillain, N., Durieux, N., Odero, A., . . . Guillaume, M. (2020). 'Patient participation' and related concepts: A scoping review on their dimensional composition. *Patient Education and Counseling, 103*(1), 5-14. doi:10.1016/j.pec.2019.08.001

Hanna, A., Yael, E.-M., Hadassa, L., Iris, E., Eugenia, N., Lior, G., . . . Liora, O. (2020). ``It's up to me with a little support''–Adherence after myocardial infarction: A qualitative study. *International Journal of Nursing Studies, 101*, 103416. doi:10.1016/j.ijnurstu.2019.103416

Hanssen, T. A., Nordrehaug, J. E., & Hanestad, B. R. (2005). A qualitative study of the information needs of acute myocardial infarction patients, and their preferences for follow-up contact after discharge. *European Journal of Cardiovascular Nursing, 4*(1), 37-44. doi:10.1016/j.ejcnurse.2004.11.001

Helse- og omsorgsdepartementet. (2019). *Strategi for å øke helsekompetansen i befolkningen 2019-2023*. Retrieved from https://www.regjeringen.no/contentassets/97bb7d5c2dbf46be91c9df38a4c94183/strategi-helsekompetanse-uu.pdf

Helsedirektoratet. (2020). *Befolkningens helsekompetanse, del 1* Retrieved from https://www.helsedirektoratet.no/rapporter/befolkningens-helsekompetanse/Befolkningens%20helsekompetanse%20-%20del%20I.pdf/_/attachment/inline/e256f137-3799-446d-afef-

24e57de16f2d:646b6f5ddafac96eef5f5ad602aeb1bc518eabc3/Befolkningens%20helsekompetanse%20-%20del%20I.pdf

Henderson, S. (1997). Knowing the patient and the impact on patient participation: a grounded theory study. *International Journal of Nursing Practice, 3*(2), 111-118. doi:10.1111/j.1440-172X.1997.tb00083.x

Henderson, S. (2003). Power imbalance between nurses and patients: a potential inhibitor of partnership in care. *Journal of Clinical Nursing, 12*(4), 501-508. doi:10.1046/j.1365-2702.2003.00757.x

Holloway, I., & Freshwater, H. (2007). *Narrative research in nursing*. Oxford, UK: Blackwell.

Howell, K. E. (2013). *An introduction to the philosophy of methodology*. Los Angeles, California: SAGE.

Höglund, A. T., Winblad, U., Arnetz, B. B., & Arnetz, J. E. (2010). Patient participation during hospitalization for myocardial infarction: perceptions among patients and personnel. *Scandinavian Journal of Caring Sciences, 24*(3), 482-489. doi:10.1111/j.1471-6712.2009.00738.x

Ibanez, B., James, S., Agewall, S., Antunes, M. J., Bucciarelli-Ducci, C., Bueno, H., . . . Group, E. S. D. (2017). 2017 ESC Guidelines for the management of acute myocardial infarction in patients presenting with ST-segment elevation: the Task Force for the management of acute myocardial infarction in patients presenting with ST-segment elevation of the European Society of Cardiology (ESC). *European Heart Journal, 39*(2), 119-177. doi:10.1093/eurheartj/ehx393

IHI. (2021). "What matters" Retrieved from http://www.ihi.org/Topics/WhatMatters/Pages/default.aspx

Jelinek, M. V., Thompson, D. R., Ski, C., Bunker, S., & Vale, M. J. (2015). 40 years of cardiac rehabilitation and secondary prevention in post-cardiac ischaemic patients. Are we still in the wilderness? *International Journal of Cardiology, 179*, 153-159. doi:10.1016/j.ijcard.2014.10.154

Jortveit, J., Halvorsen, S., Kaldal, A., Pripp, A. H., Govatsmark, R. E. S., & Langørgen, J. (2019). Unsatisfactory risk factor control and high rate of new cardiovascular events in patients with myocardial infarction and prior coronary artery disease. *BMC Cardiovascular Disorders, 19*(1), 71. doi:10.1186/s12872-019-1062-y

Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing, 69*(1), 4-15. doi:10.1111/j.1365-2648.2012.06064.x

Kolovos, P., Kaitelidou, D., Lemonidou, C., Sachlas, A., Zyga, S., & Sourtzi, P. (2015). Patient participation in hospital care: nursing staffs' point of view. *International Journal of Nursing Practice, 21*(3), 258-268. doi:10.1111/ijn.12242

Kotseva, K., De Backer, G., De Bacquer, D., Rydén, L., Hoes, A., Grobbee, D., . . . Abreu, A. (2019). Lifestyle and impact on cardiovascular risk factor control in coronary patients across 27 countries: Results from the European Society of Cardiology ESC-EORP EUROASPIRE V registry. *European Journal of Preventive Cardiology, 26*(8), 824-835. doi:10.1177/2047487318825350

Kotseva, K., Wood, D., De Bacquer, D., De Backer, G., Rydén, L., Jennings, C., . . . Castro Conde, A. (2016). EUROASPIRE IV: A European Society of Cardiology survey on the lifestyle, risk factor and therapeutic management of coronary patients from 24 European countries. *European Journal of Preventive Cardiology, 23*(6), 636-648. doi:10.1177/2047487315569401

Kristofferzon, M. L., Löfmark, R., & Carlsson, M. (2007). Striving for balance in daily life: experiences of Swedish women and men shortly after a myocardial infarction. *Journal of Clinical Nursing, 16*(2), 391-401. doi:10.1111/j.1365-2702.2005.01518.x

Krueger, R. A., & Casey, M. A. (2015). *Focus groups : a practical guide for applied research* (5 ed.). Los Angeles, California: SAGE.

Kunnskapssenteret. (2013). *Det norske helsesystemet [Health Systems in Transition Vol. 15 No. 8 2013]*. Kunnskapssenteret Retrieved from https://www.fhi.no/globalassets/dokumenterfiler/rapporter/2014/hit-det-norske-helsesystemet-2013

Kvale, S., & Brinkmann, S. (2009). *Det kvalitative forskningsintervju [InterView: Learning the Craft of Qualitative Research Interviewing]* (T. M. Anderssen & J. Rygge, Trans. 2 ed.). Oslo: Gyldendal akademisk.

Kvalsund, R. (1998). Om det konstruerande i utdanningsforskinga. In R. Kvalsund, L. Bøe, K. Heggen, K.-A. Madssen, & S. Vaage (Eds.), *I lærande fellesskap*. Volda: Høgskulen i Volda og Møreforskning Volda.

Kvangarsnes, M., Hole, T., Bårdsgjerde, E. K., & Landstad, B. J. (2020). Patient participation in acute illness - a metasynthesis of the experiences of patients and health professionals. *Michael, 17*(24), 77-93. Retrieved from https://www.michaeljournal.no/i/2020/08/Pasientmedverknad-ved-akutt-sjukdom-%E2%80%93-ein-metasyntese-av-pasient--og-helsepersonell%C2%ADerfaringar-

Kähkönen, O., Kankkunen, P., Saaranen, T., Miettinen, H., Kyngäs, H., & Lamidi, M. L. (2015). Motivation is a crucial factor for adherence to a healthy lifestyle among people with coronary heart disease after percutaneous coronary intervention. *Journal of Advanced Nursing, 71*(10), 2364-2373. doi:10.1111/jan.12708

Lamore, K., Montalescot, L., & Untas, A. (2017). Treatment decision-making in chronic diseases: what are the family members' roles, needs and attitudes? A systematic review. *Patient Education and Counseling, 100*(12), 2172-2181. doi:10.1016/j.pec.2017.08.003

Landstad, B. J., Bårdsgjerde, E. K., & Kvangarsnes, M. (2020). Patient participation in chronic disease - a metasynthesis. *Michael, 17*(24), 95-109. Retrieved from https://www.michaeljournal.no/asset/pdf/1000/supplements/michaelsupplement-24/095-110.pdf

Landstad, B. J., & Kvangarsnes, M. (2020). Theoretical perspectives and qualitative designs in research on patient participation. *Michael, 17*(24), 181-197. Retrieved from https://www.michaeljournal.no/i/1000/24?xp=michael-1000-24.xml

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

Larsson, I. E., Sahlsten, M. J., Segesten, K., & Plos, K. A. (2011b). Patients' perceptions of barriers for participation in nursing care. *Scandinavian Journal of Caring Sciences, 25*(3), 575-582. doi:10.1111/j.1471-6712.2010.00866.x

Larsson, I. E., Sahlsten, M. J., Sjöström, B., Lindencrona, C. S., & Plos, K. A. (2007). Patient participation in nursing care from a patient perspective: a Grounded Theory study. *Scandinavian Journal of Caring Sciences, 21*(3), 313-320. doi:10.1111/j.1471-6712.2007.00471.x

Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. In Y. S. Lincoln & E. G. Guba (Eds.), *Naturalistic inquiry* (pp. 289-331). Beverly Hills, California: SAGE.

Longtin, Y., Sax, H., Leape, L. L., Sheridan, S. E., Donaldson, L., & Pittet, D. (2010). Patient participation: current knowledge and applicability to patient safety. *Mayo Clinic Proceedings, 85*(1), 53-62. doi:10.4065/mcp.2009.0248

Lundgren, U. P. (1972). *Frame factors and the teaching process : a contribution to curriculum theory and theory of teaching* (Vol. 8). Stockholm: Almqvist & Wiksell.

Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *The Lancet, 358*(9280), 483-488. doi:10.1016/S0140-6736(01)05627-6

Malterud, K. (2012). *Fokusgrupper som forskningsmetode for medisin og helsefag*. Oslo: Universitetsforlaget.

Malterud, K. (2017). *Kvalitative forskningsmetoder for medisin og helsefag* (4. ed.). Oslo: Universitetsforlaget.

Martinsen, K. (2005). *Samtalen, skjønnet og evidensen [Dialogue, judgement and evidence]*. Oslo: Akribe.

Martinsen, K. (2006). *Care and vulnerability* (L. E. Kjerland, Trans.). Oslo: Akribe.

Meld. St. 7 (2019-2020). (2019). *Nasjonal helse- og sykehusplan [National health and hospital plan]*. Helse- og omsorgsdepartementet Retrieved from https://www.regjeringen.no/contentassets/95eec808f0434acf942fca449ca35386/no/pdfs/stm201920200007000dddpdfs.pdf

Meld. St. 34 (2015-2016). (2016). *Verdier i pasientens helsetjeneste. Melding om prioriteringer*. Retrieved from https://www.regjeringen.no/contentassets/439a420e01914a18b21f351143ccc6af/no/pdfs/stm201520160034000dddpdfs.pdf

Mentrup, S., Harris, E., Gomersall, T., Köpke, S., & Astin, F. (2020). Patients' experiences of cardiovascular health education and risk communication: a qualitative synthesis. *Qualitative Health Research, 30*(1), 88-104. doi:10.1177/1049732319887949

Neumann, F.-J., Sousa-Uva, M., Ahlsson, A., Alfonso, F., Banning, A. P., Benedetto, U., . . . Head, S. J. (2018). 2018 ESC/EACTS guidelines on myocardial revascularization. *European Heart Journal, 40*(2), 87-165. doi:10.1093/eurheartj/ehy394

Nilsson, U. G., Ivarsson, B., Alm-Roijer, C., & Svedberg, P. (2013). The desire for involvement in healthcare, anxiety and coping in patients and their partners after a myocardial infarction. *European Journal of Cardiovascular Nursing, 12*(5), 461-467. doi:10.1177/1474515112472269

Nylenna, M. (2020). Fra lydighet til likeverd. Pasientmedvirkning i et historisk og helsepolitisk perspektiv. *Michael, 17*(24), 15-42. Retrieved from https://www.michaeljournal.no/asset/pdf/1000/supplements/michaelsupplement-24/015-044.pdf

Ofstad, E. H., Frich, J. C., Schei, E., Frankel, R. M., & Gulbrandsen, P. (2014). Temporal characteristics of decisions in hospital encounters: a threshold for shared decision making? A qualitative study. *Patient Education and Counseling, 97*(2), 216-222. doi:10.1016/j.pec.2014.08.005

Olsen, S. J., Schirmer, H., Bønaa, K. H., & Hanssen, T. A. (2018). Cardiac rehabilitation after percutaneous coronary intervention: results from a nationwide survey. *European Journal of Cardiovascular Nursing, 17*(3), 273-279. doi:10.1177/1474515117737766

Oterhals, K., Hanestad, B. R., Eide, G. E., & Hanssen, T. A. (2006). The relationship between in-hospital information and patient satisfaction after acute myocardial infarction. *European Journal of Cardiovascular Nursing, 5*(4), 303-310. doi:10.1016/j.ejcnurse.2006.01.004

Oxelmark, L., Ulin, K., Chaboyer, W., Bucknall, T., & Ringdal, M. (2018). Registered Nurses' experiences of patient participation in hospital care: supporting and hindering factors patient participation in care. *Scandinavian Journal of Caring Sciences, 32*(2), 612-621. doi:10.1111/scs.12486

Oxford English Dictionary. (2021). *Oxford English Dictionary The definitive record of the English language* Retrieved from https://www.oed.com/

Patton, M. Q. (2015). *Qualitative research & evaluation methods: integrating theory and practice* (4. ed.). Los Angeles, California: SAGE.

Peersen, K., Munkhaugen, J., Gullestad, L., Liodden, T., Moum, T., Dammen, T., . . . Otterstad, J. E. (2017). The role of cardiac rehabilitation in secondary prevention after coronary events. *European Journal of Preventive Cardiology, 24*(13), 1360-1368. doi:10.1177/2047487317719355

Peräkylä, A., & Ruusuvuori, J. (2007). Components of participation in health care consultations In S. Collins, N. Britten, J. Ruusuvuori, & A. Thompson (Eds.), *Patient participation in health care consultations qualitative perspectives* (pp. 167-175). Maidenhead: Oxford University Press.

Peters, A. E., & Keeley, E. C. (2017). Patient engagement following acute myocardial infarction and its influence on outcomes. *American Journal of Cardiology, 120*(9), 1467-1471. doi:10.1016/j.amjcard.2017.07.037

Pettersen, T. R., Fridlund, B., Bendz, B., Nordrehaug, J. E., Rotevatn, S., Schjøtt, J., & Norekvål, T. M. (2018). Challenges adhering to a medication regimen following first-time percutaneous coronary intervention: A patient perspective. *International Journal of Nursing Studies, 88*, 16-24. doi:10.1016/j.ijnurstu.2018.07.013

Piepoli, M. F., Corra, U., Benzer, W., Bjarnason-Wehrens, B., Dendale, P., Gaita, D., . . . Schmid, J. P. (2010). Secondary prevention through cardiac rehabilitation: from knowledge to implementation. A position paper from the Cardiac Rehabilitation Section of the European Association of Cardiovascular Prevention and Rehabilitation. *European Journal of Cardiovascular Prevention & Rehabilitation, 17*(1), 1-17. doi:10.1097/HJR.0b013e3283313592

Piepoli, M. F., Corrà, U., Dendale, P., Frederix, I., Prescott, E., Schmid, J. P., . . . Pelliccia, A. (2017). Challenges in secondary prevention after acute myocardial infarction: a call for action. *European Journal of Cardiovascular Nursing, 16*(5), 369-380. doi:10.1097/HJR.0b013e3283313592

Piepoli, M. F., Hoes, A. W., Agewall, S., Albus, C., Brotons, C., Catapano, A. L., . . . Binno, S. (2016). 2016 European Guidelines on cardiovascular disease prevention in clinical practice: The Sixth Joint Task Force of the European Society of Cardiology and Other Societies on Cardiovascular Disease Prevention in Clinical Practice (constituted by representatives of 10 societies and by invited experts) Developed with the special contribution of the European Association for Cardiovascular Prevention & Rehabilitation (EACPR). *European Journal of Preventive Cardiology, 23*(11), NP1-NP96. doi:10.1177/2047487316653709

Polit, D. F., & Beck, C. T. (2020). *Nursing research: generating and assessing evidence for nursing practice* (11 ed.). Philadelphia: Lippincott Williams & Wilkins.

Polkinghorne, D. (1988). *Narrative knowing and the human sciences*. Albany: State University of New York Press.

Probyn, J., Greenhalgh, J., Holt, J., Conway, D., & Astin, F. (2017). Percutaneous coronary intervention patients' and cardiologists' experiences of the informed consent process in Northern England: a qualitative study. *BMJ Open, 7*(6). doi:10.1136/bmjopen-2016-015127

Rauch, B., Davos, C. H., Doherty, P., Saure, D., Metzendorf, M.-I., Salzwedel, A., . . . Schmid, J.-P. (2016). The prognostic effect of cardiac rehabilitation in the era of acute revascularisation and statin therapy: A systematic review and meta-analysis of randomized and non-randomized studies–The Cardiac Rehabilitation Outcome Study (CROS). *European Journal of Preventive Cardiology, 23*(18), 1914-1939. doi:10.1177/2047487316671181

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Los Angeles, California: SAGE.

Roffi, M., Patrono, C., Collet, J.-P., Mueller, C., Valgimigli, M., Andreotti, F., . . . Chew, D. P. (2016). 2015 ESC Guidelines for the management of acute coronary syndromes in patients presenting without persistent ST-segment elevation: Task Force for the Management of Acute Coronary Syndromes in Patients Presenting without Persistent ST-Segment Elevation of the European Society of Cardiology (ESC). *European Heart Journal, 37*(3), 267-315. doi:10.1093/eurheartj/ehv320

Ruano-Ravina, A., Pena-Gil, C., Abu-Assi, E., Raposeiras, S., van't Hof, A., Meindersma, E., . . . González-Juanatey, J. R. (2016). Participation and adherence to cardiac rehabilitation programs. A systematic review. *International Journal of Cardiology, 223*, 436-443. doi:10.1016/j.ijcard.2016.08.120

Sahlsten, M. J., Larsson, I. E., Lindencrona, C. S., & Plos, K. A. (2005). Patient participation in nursing care: an interpretation by Swedish registered nurses. *Journal of Clinical Nursing, 14*(1), 35-42. doi:10.1111/j.1365-2702.2004.00957.x

Sahlsten, M. J., Larsson, I. E., Plos, K. A., & Lindencrona, C. S. (2005). Hindrance for patient participation in nursing care. *Scandinavian Journal of Caring Sciences, 19*(3), 223-229. doi:10.1111/j.1471-6712.2005.00336.x

Sahlsten, M. J., Larsson, I. E., Sjöström, B., Lindencrona, C. S., & Plos, K. A. (2007). Patient participation in nursing care: towards a concept clarification from a nurse perspective. *Journal of Clinical Nursing, 16*(4), 630-637. doi:10.1111/j.1365-2702.2006.01660.x

Sahlsten, M. J., Larsson, I. E., Sjöström, B., & Plos, K. A. (2008). An analysis of the concept of patient participation. *Nursing Forum, 43*(1), 2-11. doi:10.1111/j.1744-6198.2008.00090.x

Sahlsten, M. J., Larsson, I. E., Sjöström, B., & Plos, K. A. (2009). Nurse strategies for optimising patient participation in nursing care. *Scandinavian Journal of Caring Sciences, 23*(3), 490-497. doi:10.1111/j.1471-6712.2008.00649.x

Sampson, F., O'Cathain, A., & Goodacre, S. (2009). Feeling fixed and its contribution to patient satisfaction with primary angioplasty: a qualitative study. *European Journal of Cardiovascular Nursing, 8*(2), 85-90. doi:10.1016/j.ejcnurse.2008.07.003

Sarbin, T. R. (1986). The narrative as a root metaphor for psychology. In T. R. Sarbin (Ed.), *Narrative Psychology The storied nature of human conduct*. New York: Praeger.

Schandl, A., Falk, A.-C., & Frank, C. (2017). Patient participation in the intensive care unit. *Intensive & Critical Care Nursing, 42*, 105-109. doi:10.1016/j.iccn.2017.04.006

Shimada, Y. J., & Scirica, B. M. (2015). Long-term management and unmet needs after an acute coronary syndrome event. *American Journal of Cardiology, 115*(5), 29A-35A. doi:10.1016/j.amjcard.2015.01.005

Svavarsdóttir, M. H., Sigurðardóttir, Á. K., & Steinsbekk, A. (2015). What is a good educator? A qualitative study on the perspective of individuals with coronary heart disease.

European Journal of Cardiovascular Nursing, 15(7), 513-521. doi:10.1177/1474515115618569

The Specialist Health Services Act. (1999, last changed 2020). *Lov om spesialisthelsetjenesten m.m. [Act related to Specialist Health Services]*. Helse- og omsorgsdepartementet [Ministry of Healt and Care Services] Retrieved from https://lovdata.no/dokument/NL/lov/1999-07-02-61?q=spesialisthelsetjenesteloven

Thomas, E. C., Bass, S. B., & Siminoff, L. A. (2021). Beyond rationality: expanding the practice of shared decision making in modern medicine. *Social Science & Medicine, 277*, 113900. doi:10.1016/j.socscimed.2021.113900

Thompson, A. (2007). The meaning of patient involvement and participation in health care consultations: a taxonomy. *Social Science & Medicine, 64*(6), 1297-1310. doi:10.1016/j.socscimed.2006.11.002

Thompson, A., Ruusuvuori, J., Britten, N., & Collins, S. (2007). An integrative approach to patient participation in consultations In S. Collins, N. Britten, J. Ruusuvuori, & A. Thompson (Eds.), *Patient participation in health care consultations qualitative perspectives* (pp. 176-193). Maidenhead: Open University Press.

Tobiano, G., Bucknall, T., Marshall, A., Guinane, J., & Chaboyer, W. (2015). Nurses' views of patient participation in nursing care. *Journal of Advanced Nursing, 71*(12), 2741-2752. doi:10.1111/jan.12740

Tobiano, G., Bucknall, T., Marshall, A., Guinane, J., & Chaboyer, W. (2016). Patients' perceptions of participation in nursing care on medical wards. *Scandinavian Journal of Caring Sciences, 30*(2), 260-270. doi:10.1111/scs.12237

Tobiano, G., Marshall, A., Bucknall, T., & Chaboyer, W. (2015). Patient participation in nursing care on medical wards: an integrative review. *International Journal of Nursing Studies, 52*(6), 1107-1120. doi:10.1016/j.ijnurstu.2015.02.010

Tobiano, G., Marshall, A. P., & Chaboyer, W. (2021). Comparing perceptions of patient nonparticipation in nursing Care: A secondary analysis. *Journal of Nursing Scholarship*. doi:10.1111/jnu.12643

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357. doi:10.1093/intqhc/mzm042

Tritter, J. Q. (2009). Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world. *Health Expectations, 12*(3), 275-287. doi:10.1111/j.1369-7625.2009.00564.x

Vahdat, S., Hamzehgardeshi, L., Hessam, S., & Hamzehgardeshi, Z. (2014). Patient involvement in health care decision making: a review. *Iranian Red Crescent Society, 16*(1). doi:10.5812/ircmj.12454

Valaker, I., Fridlund, B., Wentzel-Larsen, T., Nordrehaug, J. E., Rotevatn, S., Råholm, M.-B., & Norekvål, T. M. (2020). Continuity of care and its associations with self-reported health, clinical characteristics and follow-up services after percutaneous coronary intervention. *BMC Health Services Research, 20*(1), 71. doi:10.1186/s12913-020-4908-1

Valaker, I., Norekvål, T. M., Råholm, M.-B., Nordrehaug, J. E., Rotevatn, S., & Fridlund, B. (2017). Continuity of care after percutaneous coronary intervention: The patient's perspective across secondary and primary care settings. *European Journal of Cardiovascular Nursing, 16*(5), 444-452. doi:doi.org/10.1177/1474515117690298

Vaage, S. (1998). Perspektivtaking og rammefaktorar. In R. Kvalsund, L. Bøe, K. Heggen, K.-A. Madssen, & S. Vaage (Eds.), *I lærande fellesskap*. Volda: Høgskulen i Volda og Møreforskning Volda.

WHO. (1978). *Primary health care, Alma Ata*. Geneva: World Health Organization Retrieved from https://www.who.int/docs/default-source/documents/almaata-declaration-en.pdf?sfvrsn=7b3c2167_2

WHO. (1986). *Ottawa Charter for Health Promotion*. World Health Organization Retrieved from https://www.euro.who.int/__data/assets/pdf_file/0004/129532/Ottawa_Charter.pdf

WHO. (1994). *A DECLARATION ON THE PROMOTION OF PATIENTS' RIGHT IN EUROPE.* . Amsterdam: World Health Organization Retrieved from https://www.who.int/genomics/public/eu_declaration1994.pdf

WHO. (1998). *Health Promotion Glossary*. Geneva: World Health Organization Retrieved from https://www.who.int/healthpromotion/about/HPR%20Glossary%201998.pdf?ua=1

WHO. (2005). *Health promotion in hospitals: Evidence and quality management*. World Health Organization Retrieved from https://www.euro.who.int/__data/assets/pdf_file/0008/99827/E86220.pdf

WHO. (2013). *Exploring patient participation in reducing health-care-related safety risks*. Retrieved from http://www.euro.who.int/_data/assets/pdf_file/0010/185779/e96814.pdf?ua=1

WHO. (2016). Health literacy. Retrieved from https://www.who.int/healthpromotion/health-literacy/en/

WHO. (2017). Cardiovascular diseases (CVDs). Retrieved from https://www.who.int/news-room/fact-sheets/detail/cardiovascular-diseases-(cvds)

World Medical Association. (2013). World Medical Association Declaration of Helsinki ethical principles for medical research involving human subjects Retrieved from https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

Paper I

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ORIGINAL RESEARCH:
EMPIRICAL RESEARCH – QUALITATIVE

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Patients' narratives of their patient participation in the myocardial infarction pathway

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Abstract

Aim: To explore how patients in areas without local percutaneous coronary intervention (PCI) facilities experience patient participation in different phases of the myocardial infarction pathway.

Background: Acute treatment of myocardial infarction often involves PCI. In Norway, this treatment is centralized at certain hospitals; thus, patients often require long-distance transportation and experience frequent hospital transfers. Short hospital stays, transfers between hospitals and the patient's emotional state pose challenges to promoting patient participation.

Design: A qualitative design with a narrative approach.

Methods: Participants were recruited through purposive sampling. Eight men and two women were interviewed in 2016.

Findings: Four themes related to the patients' experiences at the beginning, middle and end of the pathway were identified: (a) Lack of verbal communication in the acute phase; (b) trust in healthcare professionals and treatment; (c) lack of participation and coordination at discharge; and (d) shared decision-making in rehabilitation. The findings showed how the patients moved from a low level of patient participation in the acute phase to a high level of patient participation in the rehabilitation phase.

Conclusion: This is the first study to explore patient participation in different phases of the myocardial infarction pathway. We argue that individual plans for information and patient participation are important to improve patient involvement in an earlier stage of the pathway. Further research from a healthcare professional perspective can be valuable to understand this topic.

Impact: This study gives new insight that can be valuable for healthcare professionals in implementing patient participation throughout the pathway.

KEYWORDS
interview, myocardial infarction, myocardial infarction care, narratives, nursing, patient involvement, patient participation, patient pathway, patient perspective, qualitative

1 | INTRODUCTION

Cardiovascular disease (CVD) remains the leading cause of death worldwide; causing 7.4 million deaths yearly (World Health Organization 2017). Over 12,000 people were diagnosed with myocardial infarction in Norway in 2016 (Grovatsmark, Digre, Sneeggen, Karlsaune, & Bønaa, 2017). The European Society of Cardiology guidelines for the treatment of acute myocardial infarction (AMI) include thrombolysis and percutaneous coronary intervention (PCI), in addition to standard medical treatment. The pathway consists of different phases. The acute phase starts with the onset of symptoms and until PCI treatment is received. This phase often last only a few hours for patients with ST-segment elevation acute myocardial infarction (STEMI) and up to 72 hr for those diagnosed with non-ST-segment elevation (nSTEMI). The acute phase is followed by the discharge phase and the rehabilitation phase, which often last for several months. According to the ESC guidelines PCI facilities are centralized in many countries with sparse population (Roffi et al., 2016; Task Force on the management of ST segment elevation acute myocardial infarction of the European Society of Cardiology, Steg et al. 2012) and patients from sparsely populated areas are often transferred between hospitals (Chew et al., 2013; Clune, Blackford, & Murphy, 2014; Hagen, Häkkinen, Belicza, Fatore, & Goude, 2015; Tanguay, Dallaire, Hébert, Bégin, & Fleet, 2015). Eight hospitals have PCI facilities in Norway. Because of this centralization of treatment in Norway a significant proportion of the population lives more than 300 km away from the nearest PCI hospital and are dependent on helicopter or air ambulance to receive treatment in the acute phase. The AMI pathway has four possible options: (a) admitted to and discharged from a PCI hospital; (b) admitted to a PCI hospital and then transferred to and discharged from a local hospital; (c) admitted to a local hospital and then transferred to and discharged from a PCI hospital; and (d) admitted to a local hospital, transferred to a PCI hospital and then transferred back to and discharged from a local hospital (Grovatsmark et al., 2017).

Secondary prevention with lifelong medication and lifestyle changes is crucial to prevent new cardiac events (Piepoli et al., 2016). In most western countries, cardiac rehabilitation programmes are available after discharge, but participation in those programmes is low (Grovatsmark et al., 2017; Kotseva et al., 2016). Guidelines recommend that secondary prevention should be initiated before discharge (Piepoli et al., 2010; Task Force on the management of ST segment elevation acute myocardial infarction of the European Society of Cardiology, Steg et al. 2012). Short hospital stays (Piepoli et al., 2016; Townsend, Nichols, Scarborough, & Rayner, 2015) and transfers between hospitals can reduce the opportunity for patient participation.

According to Norwegian legislation (Ministry of Health and Care Services 1999), patients have a right to information and participation in all health and care services. Information and information-sharing between healthcare professionals and patients is a key requirement for participation (Angel & Frederiksen, 2015; Brownlea, 1987; Tobiano, Marshall, Bucknall, & Chaboyer, 2015). Patient participation is a complex phenomenon and no clear definitions exist (Cahill, 1996; Collins, Britten, Ruusuvuori, & Thompson, 2007; Thompson, 2007). Despite the lack of a clear definition, patient participation is characterized by the following attributes; a relationship must exist between patient and healthcare professionals; there must be a narrowing of the gap in information, knowledge and competence among the parts; a degree of power and control must be handed over from the healthcare professional to the patient; and patient and healthcare professionals must collaborate in activities (Cahill, 1996; Sahlsten, Larsson, Sjöström, & Plos, 2008). Thompson (2007) emphasized that participation is dependent on context, the patients' desire to participate and reciprocity between patient and healthcare professionals.

In Norway, much attention has recently been placed on the Coordination reform (Report No. 47 (2008-2009) 2008), which focuses on coordination between primary health care and hospitals, with cohesive patient pathways and increased patient involvement as targets. There has been a sparse focus on the coordination between hospitals in regard to cohesive pathways and patient

Why is this research needed?

- Patient participation in the myocardial infarction pathway is challenging because of acute and often dramatic onset of symptoms, centralized treatment, transfers between hospitals and short hospital stays.
- The perceptions and experiences of patients are important for improving cohesive patient pathways and increasing the quality of health care.

What are the key findings?

- The patients perceived lack of verbal information and experienced low level of involvement and participation in the acute phase.
- The acute phase is perceived as dramatic because of the transfers between hospitals and the centralized treatment.
- The patients perceived low level of participation in planning the discharge and lack of initiatives about secondary prevention.

How should the findings be used to influence policy/practice/research/education?

- An individual plan for information would improve patient participation and shared decision-making for patients transferred between different hospitals in the myocardial infarction pathway.
- Before discharge, patients need specific guidance about secondary prevention, which should be standardized and implemented in clinical and educational guidelines.

participation. This study explores patient participation in the myocardial infarction pathway.

1.1 | Background

Patient participation can improve patient safety and quality in health care (Delnoji & Hafner, 2013). Patient participation through person- and family-centred care is highlighted internationally and the campaign "what matters to you?" is implemented in many countries (IHI 2018a,b).

Myocardial infarction is often experienced as an unexpected and life-threatening event (Dullaghan et al., 2014; Fors, Dudas, & Ekman, 2014; Sampson, O'Cathain, & Goodacre, 2009). Rapid diagnosis and initiation of treatment is prioritized in the acute phase and this often pose challenges to information and patient participation. Studies have shown that patients with myocardial infarction do not wish to participate in the acute phase (Arnetz & Arnetz, 2009; Decker et al., 2007; Höglund, Winblad, Arnetz, & Arnetz, 2010; Radcliffe, Harding, Rothman, & Feder, 2009). Despite this lack of desire to participate, Decker et al. (2007) and Höglund et al. (2010) found that patient appreciated short and clear information in the acute phase.

Studies have explored patient's experiences with information. Astin, Closs, McLenachan, Hunter, and Priestley (2008) found that most patients were satisfied with the general information but missed tailored and individualized information. Oterhals, Hanestad, Eide, and Hanssen (2006) found that patients received information about smoking habits and the nature and causes of myocardial infarction. Patients have reported to receive less information about medication, lifestyle changes, risks of recurrence and future problems, sexual activity and heart muscle damage (Astin et al., 2008; Oterhals et al., 2006). Several studies have found that a face-to-face dialogue was important for the patients (Astin et al., 2008; Decker et al., 2007; Svavarsdóttir, Sigurdardottir, & Steinsbekk, 2016). In addition, the information should be honest, consistent and easy to understand (Astin et al., 2008) and the presence and time of the healthcare professionals were valued (Svavarsdóttir et al., 2016). At discharge and early recovery, many patients experienced fear and anxiety (Astin et al., 2008; Fålun, Fridlund, Schaufel, Schei, & Norekvål, 2016; Junehag, Asplund, & Svedlund, 2014). Oterhals et al. (2006) and Decker et al. (2007) found that information was especially lacking at this point. Short hospital stays, rapid throughput of patients and the patient's emotional state have been found to be barriers to the patient's ability to absorb information (Astin et al., 2008; Salminen-Tuomaala, Åstedt-Kurki, Rekiaro, & Paavilainen, 2012; Svavarsdóttir et al., 2016).

Arnetz and Arnetz (2009) and Decker et al. (2007) found that the patients expressed an increased desire for participation during hospitalization, especially at discharge (Arnetz & Arnetz, 2009). Barriers to participation often include patient's characteristics and lack of time and resources (Arnetz, Winblad, Arnetz, & Höglund, 2008; Eldh, Ehnfors, & Ekman, 2004; Höglund et al., 2010; Larsson, Sahlsten, Sjöström, Lindencrona, & Plos, 2007; Sahlsten, Larsson, Plos, & Lindencrona, 2005). Another obstacle for patient participation could be lack of patient—nurse continuity (Eldh et al., 2004; Larsson et al., 2007; Sahlsten et al., 2005).

Studies have explored how patients experience PCI treatment and patients have reported being satisfied with PCI treatment and outcomes (Dullaghan et al., 2014; Radcliffe et al., 2009; Sampson et al., 2009). Patient misunderstanding about the PCI treatment as curative (Astin, Closs, McLenachan, Hunter, & Priestley, 2009; Sampson et al., 2009) and the condition as acute rather than chronic (Alsén, Brink, & Persson, 2008; Astin et al., 2009) have been documented. Dullaghan et al. (2014) found that the patients expressed an understanding of the condition as chronic and were therefore motivated to make lifestyle changes. Kähkönen et al. (2015) found that motivation was a key factor for adherence to secondary prevention. These findings highlight the need for patient participation during treatment to enhance the understanding of their condition and their motivation to initiate lifestyle changes. As far as we know, no previous research has systematically explored how patient participation is experienced in different phases of the myocardial infarction pathway. We have not found studies exploring how patients experience long travel distances to receive treatment. This study contributes to new knowledge that can improve patient participation in the clinical pathway. The study can give insight from a patient perspective that can be used in education and in further research about patient participation.

We have chosen to use Thompson's (2007) taxonomy as a theoretical framework. Thompson (2007) found that patient involvement and participation occurred at different levels. These levels are as follows: (0) "non-involvement"; (1) "information-seeking/receptive"; (2) "information giving/dialogue"; (3) "shared decision-making"; and (4) "autonomous decision-making". Each of the levels are related to levels of power, where patient power is increasing from no power at level 0 to having full autonomy at level 4. A high level of involvement and patient power also includes more responsibility for the patients. Participation is based on expectations of reciprocal open and honest relationships, mutual respect and a sharing of information through two-way communication that leads to dialogue. This dialogue underpins the possibility of shared decision-making Thompson (2007).

2 | THE STUDY

2.1 | Aim

To explore patient participation in the myocardial infarction pathway. The research question was: How do patients in areas without local PCI facilities experience patient participation in different phases of the myocardial infarction pathway?

2.2 | Design

A qualitative design using a narrative approach was chosen to investigate the patients' experiences of participation. A personal narrative is a distinct form of communication (Chase, 2018) and is a suitable approach when the goal is to explore the experiences of people during certain life situations (Chase, 2005), for example, a heart attack.

Narrative is coterminous with story and has a beginning, a middle and an ending. The narrative has a temporal dimension and is held together by a recognizable pattern of events that represent the plots (Sarbin, 1986).

2.3 | Sample

The participants were recruited through purposive sampling (Polit & Beck, 2012). Men and women from different ages and backgrounds were included to increase diversity. The inclusion criteria were patients who were: (a) diagnosed with AMI; (b) living in areas more than 300 km away from a PCI hospital; (c) transported by helicopter/air ambulance in the acute phase; (d) not suffering from other serious illnesses; and (e) able to give informed consent. Healthcare professionals working at two different cardiac rehabilitation units invited patients, that met the inclusion criteria, face-to-face to attend in the study. Sixteen patients were invited, six did not wish to attend and no reason for not attending was given. Two women and eight men between 37–79 years participated in the study. Demographic data are listed in Table 1.

2.4 | Data collection

An interview guide (Kvale & Brinkmann, 2009) was developed based on the aim of the study, previous research, the theory of narrative inquiry (Chase, 2005) and participation (Thompson, 2007). Open-ended questions (Table 2) were used and the participants told their stories mostly uninterrupted (Chase, 2005). The guide was not used in a rigid way and follow-up questions were asked when needed. Ten interviews were conducted in January and February of 2016. The interviews were carried out 2–5 months after the myocardial infarction event in an office at the cardiac rehabilitation unit at two local hospitals. Only the participant and the interviewer (the first author) were present during the interview. The interviews lasted between 38 and 128 min. The interviews were audio recorded and transcribed verbatim by the first author. Data saturation was discussed throughout the process of interviewing and in the first phase of analysis. After 10 interviews, the data were rich and diverse (Chase, 2005; Grbich, 2012) and became repetitive and redundant (Polit & Beck, 2012); therefore, the data were considered to be saturated.

2.5 | Ethical considerations

An application was submitted to the Regional Committee for Medical and Health Research Ethics (REK Mid-Norway 2015/2002), which concluded that the study did not need their approval. The Norwegian Centre for Research Data approved the study (project number 56617). During the interviews, the interviewer was aware of the participants' possible emotional reactions to an acute and life-

TABLE 1 Demographic data and pathways

	Participants
Demographic data	
Gender	
Men	8
Women	2
Age	
<40	1
41–50	0
51–60	1
61–70	4
71–80	4
Employment	
Employed	2
Part-time employed	2
Retired	6
Civil status	
Married/cohabiting	9
Living alone	1
Previous CVD	
Yes	2
No	8
Differences in pathway	
Length of hospital stay	
4–7 days	8
>7 days	2
Treatment	
PCI	10
CABG	1
Pathways	
Admitted to and discharged from a PCI hospital[a]	2
Admitted to a PCI hospital and then transferred to and discharged from a local hospital	1
Admitted to a local hospital and then transferred to and discharged from a PCI hospital	3
Admitted to a local hospital, transferred to a PCI hospital and then transferred back and discharged from a local hospital	4
Regional health trusts	
Treated in the regional health trust they geographically belonged to	7
Treated in another geographical regional health trust than the one they belonged to	3

Note. PCI, percutaneous coronary intervention; CABG, coronary artery bypass grafting.

[a] Hospital with percutaneous coronary intervention facilities.

TABLE 2 Interview guide

Can you tell me how you experienced having a myocardial infarction?
How did you experience the information you received in different phases of the pathway (e.g. acute phase, discharge phase, rehabilitation phase)?
How did you experience participating in the different phases of the pathway (e.g. acute phase, discharge phase, rehabilitation phase)?

threatening event. Healthcare professionals were available if medical help was needed. Informed consent based on oral and written information was obtained prior to data collection. The participants were informed that they could withdraw from the study at any point.

2.6 | Data analysis

In the analysis, the five analytic lenses described by Chase (2005) were used. First, each narrative was read focusing on what the story was about and how it was told (lense 1 and 2). Then, we looked for diversity and similar patterns among the narratives (lense 3). The participants' experiences were related to the different phases in the pathway, the acute phase, the discharge phase and the rehabilitation phase. The data were coded based on the described phases (lense 4 and 5) and in the process of coding we used Thompson's (2007) levels of involvement and participation. Furthermore, the codes were used to construct the plot consisting of recognizable patterns of events in the narratives (Sarbin, 1986). Finally, the 10 interviews were compiled and reconstructed into one story (Kvale & Brinkmann, 2009) consisting of four themes following the beginning, the middle and the end of the narratives. Table 3 shows how one of the themes was developed.

2.7 | Rigour

Credibility was enhanced through explicit description of the study and being as transparent as possible. A member check at the end of each interview was performed and quotations are used to increase credibility (Lincoln & Guba, 1985). The first author, under the guidance of the second author, performed the analysis. To achieve confirmability (Lincoln & Guba, 1985), two of the other authors also read the transcripts and all four discussed the findings. The last author had specific clinical experience with the myocardial infarction pathway. To increase transferability, the findings are presented through rich descriptions (Lincoln & Guba, 1985).

3 | FINDINGS

The findings showed how 10 patients, age 37–79 years old, experienced participation in the myocardial infarction pathway. Four themes related to the phases in the pathway were constructed: (a) lack of verbal communication in the acute phase; (b) trust in healthcare professionals and treatment; (c) lack of participation and coordination at discharge; and (d) shared decision-making in rehabilitation.

3.1 | Lack of verbal communication in the acute phase

In the acute phase, the patients explained how they tried to understand the situation. Most of the patients experienced a sudden onset of symptoms. A repeated phrase in the data was "I did not get any warning". In addition, the symptoms could be diffuse. Except the two patients who had previous CVDs, few of the patients understood that their symptoms were caused by a myocardial infarction. One patient said, "I did not believe it was a myocardial infarction, because I did not have so much pain" (*Informant J, male*). One patient with a previous CVD said, "If I had not had it before, maybe I would have thought I was tired and gone to rest" (*Informant F, male*).

Some of the patients received information that included their diagnosis and a brief treatment plan. One patient described it as

TABLE 3 Development from quotes to theme

Quotes	Patterns	Theme
"I did not get any warning" "I did not believe it was a myocardial infarction, because I did not have so much pain" "If I had not had it before, maybe I would have thought I was tired and gone to rest"	Sudden onset and diffuse symptoms	
"They told me that it was a myocardial infarction and they gave me some medicine directly in my blood vessels. If the medication did not work, I would be transferred" "They did not say anything. Except the chief physician saying you will be transferred immediately" "No one said anything before we were at the heliport, waiting for the elevator. Then, the physician from the helicopter touched my shoulder and said; 'now you are safe'"	Lack of information	Lack of verbal communication in the acute phase
"The physician put on the ECG electrodes and probably he saw that I had an ongoing myocardial infarction. Then, he called for an ambulance, and I heard them discussing back and forth" "I did understand that it was critical when they needed our defibrillator [from his workplace]. They were relieved that we had one nearby, so they did not have to go back to the ambulance to pick up their own"	Getting information through interpretation of healthcare professionals' actions and interactions	

follows: “They told me that it was a myocardial infarction and they gave me some medicine directly in my blood vessels. If the medication did not work, I would be transferred” (*Informant G, male*). Most of the patients received little verbal information, as stated by one patient: “They did not say anything. Except the chief physician saying; you will be transferred immediately” (*Informant D, male*). Another patient said, “No one said anything before we were at the heliport, waiting for the elevator. Then, the physician from the helicopter touched my shoulder and said; ‘now you are safe’” (*Informant H, male*).

The patients reported how they interpreted the healthcare professional's actions and interactions due to the shortage of information. One patient described it as follows: “The physician put on the ECG electrodes and probably he saw that I had an ongoing myocardial infarction. Then, he called for an ambulance and I heard them discussing back and forth” (*Informant B, female*). Another patient had a traumatic experience when a defibrillator was prepared and described it as follows: “I did understand that it was critical when they needed our defibrillator [from his workplace]. They were relieved that we had one nearby, so they did not have to go back to the ambulance to pick up their own” (*Informant H, male*).

3.2 | Trust in healthcare professionals and treatment

In the treatment phase, the patients revealed that they trusted the healthcare professionals and were confident with the treatment they received. Several of the patients used the phrase “to be in safe hands” to describe their experiences. They described the healthcare professionals as highly qualified, calm and knowledgeable about what to do in the situation and reported that medical decisions were made quickly. The following quote illustrates one patient's experience: “Even if it was intense situations in the beginning, the people were calm and said what was necessary to say. I think that the way you are met is important in these situations, that they are calm and show that they have control” (*Informant G, male*). In the acute phase, the patients appreciated having their next of kin with them. However, after the PCI treatment, they did not think that it was necessary.

Some of the patients reported that their impression of the PCI procedure was that it was something ordinary. One patient described it as follows: “It seemed like it was something that they had done several times before and that it actually was not a severe intervention” (*Informant G, male*). Another patient said, “A treatment like this, if it works, is simple” (*Informant E, male*).

The patients reported that they received tailored information about the treatment and outcome during or immediately after the PCI procedure. One patient described it as follows: “I did not feel anything during the procedure. At 03.20 in the night the cardiologist was done and said; ‘this went well, now you can go home’” (*Informant I, male*). Some of the patients also watched the screen during the procedure and spoke vividly about it: “I saw the little thing [wire] and felt how it tickled upwards my arm. They told me; ‘look at the screen, there he [the wire] is coming out and there it is, your myocardial infarction’. Next to the myocardial infarction, you could see the normal heart beating” (*Informant D, male*).

3.3 | Lack of participation and coordination at discharge

The patients reported receiving a varying amount of information about lifestyle changes, further medical treatment and rehabilitation. Some of the patients were satisfied and had received both oral and written information. One patient described the written information as an instruction book: “If I wonder about something I just look in the folder. It is written in simple sentences that are easy to understand” (*Informant A, male*).

Others would have preferred tailored and concrete information on how to initiate lifestyle changes in their everyday life. One patient described it as follows: “If you could receive simple diet advices at the hospital, for example, reduce the use of milk products and choose oils instead of butter, then you could start make changes already at discharge” (*Informant B, female*). Medication was another topic where the patients reported receiving poor information, especially about effects and side effects. Some also repeatedly talked about their medication and wondered how long they needed them for and if they could reduce some of the medications after a while. About physical activity, the patients wanted the information to be as specific as possible. One patient reported that he received a recipe: “Tomorrow you can start walking 500 m on flat road and then you can gradually increase the distance and accelerate” (*Informant E, male*).

Several of the patients stated that they worried about discharge, especially the journey home from the PCI hospital. All of the patients were treated at hospitals more than 300 km away from where they lived, and their journey home could include several bus lines, planes and ferries. The patients lacked personal belongings; that is, clothes, money, credit cards and mobile charger. As described by one patient, “I only had a sweat suit and my mobile” (*Informant D, male*).

Patients treated at a regional health trust other than the one they geographically belonged to became responsible for both the arrangement and cost of their journey home. One of these patients used the metaphor “being promised the moon” when the healthcare professionals first promised him that he would be transferred home by air ambulance. Then, the next day, he was told that it was too expensive and not the hospital's responsibility because of the geographical borders.

The patients who were transferred back to the local hospital by air ambulance described relief: “I was a bit worried about how I should return home. I was relieved when they told me that I would be transported by air ambulance” (*Informant C, female*).

3.4 | Shared decision-making in rehabilitation

All of the patients participated in an outpatient cardiac rehabilitation programme lasting 3–4 months at their local hospital. Those who were transferred back to their local hospital initiated contact with the staff from the rehabilitation programme before discharge through a ward visit.

All the patients described the cardiac rehabilitation programme with positive phrases; one patient expressed, “To start here is the best thing ever happened to me” (*Informant I, male*). Through the programme, they not only received information but also increased their knowledge and understanding of the coherence between disease and lifestyle. One patient described it as follows: “I have received most information through this course, they have told us about the heart's physiology and its function, diets and exercise” (*Informant C, female*).

The patients reported that the follow-up from the staff was good and appreciated the opportunity to test themselves physically in a safe environment. One patient said the following: “After I started the training I knew that I [my body] tolerate a lot” (*Informant B, female*). Through the programme, they also met other patients and they described this interaction to be motivating. One statement was as follows: “Among fellows you can talk about problems and discuss challenges together” (*Informant F, male*). They stated how both their motivation and responsibility for their own health were increased throughout the programme. One patient described it as follows: “I will never have another myocardial infarction. I know you cannot choose that, but I will do my very best to prevent another one” (*Informant H, male*).

Some of the patients reflected on the time aspect, stating that it was easier to gain new information during the rehabilitation programme rather than at the hospital. One patient reflected on this as follows: “One of the good things at the cardiac rehabilitation is the distance to the acute event. If they had told me much more at the hospital I do not know if I could have grasped it” (*Informant C, female*).

4 | DISCUSSION

In this qualitative study, we aimed to explore how patients living in areas without local PCI facilities experience patient participation in the myocardial infarction pathway. We identified that participants moved from a low level of patient participation in the acute phase to a high level of patient participation in the rehabilitation phase.

In our study, the participants had a passive role in the acute phase and there was a lack of verbal communication between the participants and healthcare professionals. Passive patient participation in the acute phase of a myocardial infarction has also been identified by other researchers (Arnetz & Arnetz, 2009; Decker et al., 2007; Höglund et al., 2010; Radcliffe et al., 2009) and Thompson (2007) also claims that patient participation is less important in acute phases of illness. A notable finding in our study was the way the participants were able to accurately recall what had happened to them during the acute phase of their myocardial infarction and discussed in detail the healthcare professionals’ actions and conversations. In the most dramatic situations, this could be frightening for some of them, for example, the participant who experienced the defibrillator being prepared without receiving any verbal information. Previous studies have found that clear information is important in this phase (Decker et al., 2007; Höglund et al., 2010).

We identified that participants trusted the healthcare professionals and the treatment they received. Trust can be a coping strategy to situations with high levels of fear and anxiety (Thompson, 2007). Trust can also be connected to a lack of understanding of the severe situation, as described by other researchers (Alsén et al., 2008; Astin et al., 2009; Sampson et al., 2009). Some of the participants in our study reported that the procedure was described as a routine intervention, which might have an impact on how they understand the severity of their situation. The participants reported that information about treatment and outcome was given during or immediately after the procedure. Through their stories, it seemed like this was a one-way communication from the cardiologist to the participant, without dialogue between the parts. This is described by Thompson (2007) as level 1 of involvement, where the patient is information-seeking. An explanation could be that the participants’ abilities to advance to a dialogue may be reduced right after the acute event.

The narratives revealed a difference among the participants about secondary prevention and some participants described a lack of guidance on how they should initiate lifestyle changes in their everyday life. This lack of specific and tailored information has also been reported in other studies (Arnetz & Arnetz, 2009; Astin et al., 2008; Oterhals et al., 2006). It is of concern that despite international guidelines (Task Force on the management of ST segment elevation acute myocardial infarction of the European Society of Cardiology, Steg et al. 2012) highlighting the importance of initiating lifestyle changes before discharge, patients still lack information and guidance. Some of the participants were transferred between different hospitals, which may have affected the continuity in care, as other studies have found that nurse–patient continuity is an important precondition for patient participation (Eldh et al., 2004; Larsson et al., 2007; Sahlsten et al., 2005). Another explanation for the variation in the amount of information could be due to differences between the hospitals. Some of the participants were treated only at hospitals with PCI facilities and not at their local hospital. PCI hospitals may have a focus on giving highly technical treatment and may have a higher turnover rate with a rapid throughput of patients. Meanwhile, local hospitals may focus more on rehabilitation through follow-up treatment and secondary prevention. Another explanation could be the participant's ability to absorb both the severe situation and information. These challenges have been described in previous research (Astin et al., 2008; Salminen-Tuomaala et al., 2012; Svavarsdóttir et al., 2016). Lack of time and resources have also been found in previous studies to be barriers to patient participation (Arnetz et al., 2008; Eldh et al., 2004; Höglund et al., 2010; Larsson et al., 2007; Sahlsten et al., 2005). Previous research indicate that the patients’ understanding of the condition, as acute or chronic, might have an impact on patient motivation (Alsén et al., 2008; Astin et al., 2009; Dullaghan et al., 2014; Sampson et al., 2009). Thompson

(2007) also emphasize that patient participation is easier to achieve in chronic conditions.

Some of the participants described a vulnerable situation in the discharge process, especially discharge from the PCI hospital. The participants lacked personal belongings, such as clothes, money and credit cards, which are needed to travel by public transportation. This finding is also supported by Valaker et al. (2017), who also found that transportation was inadequately planned for patients who had to travel long distances.

In the present study, all of the participants attended an outpatient cardiac rehabilitation programme and they highlighted how valuable the programme had been to them. The participants spoke of the rehabilitation programme as a turning point at which they started to take an active role in their treatment and became motivated to initiate lifestyle changes. The setting at the rehabilitation programme, with continuity over time, seems to improve the preconditions for increasing knowledge and understanding. This finding is in accordance with Thompson's (2007) theory that a reciprocal and mutual relationship must be established between the patient and the healthcare professionals as a precondition for patient participation. It is of concern how important the rehabilitation programme was for the participants when previous studies have found that participation in outpatient cardiac rehabilitation programmes is low (Grovatsmark et al., 2017; Kotseva et al., 2016). The reasons for not attending outpatient cardiac rehabilitation programmes appear to be multifactorial, including age, female sex and travel distance to the outpatient cardiac rehabilitation centre (Jelinek, Thompson, Ski, Bunker, & Vale, 2015; Ruano-Ravina et al., 2016; Shimada & Scirica, 2015). In our study, healthcare professionals from the cardiac rehabilitation programme visited some of the participants at the ward, which might have a positive impact on their motivation and may increase participation in the rehabilitation programmes.

Our study findings suggest that patients progressed from passive to active participants, following a continuum of levels of patient participation as explained by Thompson (2007). This finding is also supported by Eldh et al. (2004), who found that patients did not expect to participate in the acute care setting but wanted to participate later during the treatment.

4.1 | Limitations

Thompson's taxonomy was published in 2007. We are aware of that research on patient participation at both individual and system levels have developed the last 10 years (Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014). Therefore, Thompson's (2007) taxonomy can be considered as outdated. However, the taxonomy contributes to an understanding of patient participation as dynamic and contextual, which makes it appropriate to study patient participation in the clinical pathway.

At the time of the study, 2–5 months had passed since the participants were discharged from the hospital. This can be a long time regarding memory, but the elapsed time could also be a benefit emotionally by giving some distance from the AMI event. Only two women participated, but the aim was not to explore different perceptions between women and men.

5 | CONCLUSION

This is the first study to explore patient participation in different phases of the myocardial infarction pathway. We have identified that participants progressed from a low level of involvement in the acute phase to shared decision-making in the rehabilitation phase. We argue that individual plans for information and patient participation are important to improve patient involvement in an earlier stage of the pathway. Further research from a healthcare professional perspective can be valuable to understand this topic.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE [http://www.icmje.org/recommendations/]):

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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CONFLICTS OF INTEREST

No conflict of interest has been declared by the authors.

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REFERENCES

Alsén, P., Brink, E., & Persson, L. O. (2008). Patients' illness perception four months after a myocardial infarction. *Journal of Clinical Nursing*, *17*(5a), 25–33. https://doi.org/10.1111/j.1365-2702.2007.02136.x

Angel, S., & Frederiksen, K. N. (2015). Challenges in achieving patient participation: A review of how patient participation is addressed in empirical studies. *International Journal of Nursing Studies*, *52*(9), 1525–1538. https://doi.org/10.1016/j.ijnurstu.2015.04.008

Arnetz, J. E., & Arnetz, B. B. (2009). Gender differences in patient perceptions of involvement in myocardial infarction care. *European*

Journal of Cardiovascular Nursing, *8*(3), 174–181. https://doi.org/10.1016/j.ejcnurse.2008.11.002

Arnetz, J. E., Winblad, U., Arnetz, B. B., & Höglund, A. T. (2008). Physicians' and nurses' perceptions of patient involvement in myocardial infarction care. *European Journal of Cardiovascular Nursing*, *7*(2), 113–120. https://doi.org/10.1016/j.ejcnurse.2007.05.005

Astin, F., Closs, S. J., McLenachan, J., Hunter, S., & Priestley, C. (2008). The information needs of patients treated with primary angioplasty for heart attack: An exploratory study. *Patient Education and Counseling*, *73*(2), 325–332. https://doi.org/10.1016/j.pec.2008.06.013

Astin, F., Closs, S. J., McLenachan, J., Hunter, S., & Priestley, C. (2009). Primary angioplasty for heart attack: Mismatch between expectations and reality? *Journal of Advanced Nursing*, *65*(1), 72–83. https://doi.org/10.1111/j.1365-2648.2008.04836.x

Brownlea, A. (1987). Participation: Myths, realities and prognosis. *Social Science & Medicine*, *25*(6), 605–614. https://doi.org/10.1016/0277-9536(87)90085-2

Cahill, J. (1996). Patient participation: A concept analysis. *Journal of Advanced Nursing*, *24*(3), 561–571. https://doi.org/10.1046/j.1365-2648.1996.22517.x

Chase, S. E. (2005). Narrative inquiry multiple lenses, approaches, voices. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (pp. 651–679). Thousand Oaks, CA: Sage.

Chase, S. E. (2018). Narrative inquiry toward theoretical and methodological maturity. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research*. Los Angeles, CA: Sage.

Chew, D. P., French, J., Briffa, T. G., Hammett, C. J., Ellis, C. J., Ranasinghe, I., … Lefkovits, J. (2013). Acute coronary syndrome care across Australia and New Zealand: The SNAPSHOT ACS study. *The Medical Journal of Australia*, *199*(3), 185–191. https://doi.org/10.5694/mja12.11854

Clune, S. J., Blackford, J., & Murphy, M. (2014). Management of the acute cardiac patient in the Australian rural setting: A 12 month retrospective study. *Australian Critical Care*, *27*(1), 11–16. https://doi.org/10.1016/j.aucc.2013.03.002

Collins, S., Britten, N., Ruusuvuori, J., & Thompson, A. (2007). Understanding the process of patient participation. In S. Collins, N. Britten, J. Ruusuvuori, & A. Thompson (Eds.), *Patient participation in health care consultations qualitative perspectives* (pp. 3–21). Maidenhead, UK: Open University Press.

Decker, C., Garavalia, L., Chen, C., Buchanan, D. M., Nugent, K., Shipman, A., & Spertus, J. A. (2007). Acute myocardial infarction patients' information needs over the course of treatment and recovery. *Journal of Cardiovascular Nursing*, *22*(6), 459–465. https://doi.org/10.1097/01.JCN.0000297391.11324.0f

Delnoji, D., & Hafner, V. (Eds.) (2013). *Exploring patient participation in reducing health-care-related safety risks*. Europe: World Health Organization. Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0010/185779/e96814.pdf?ua=1

Dullaghan, L., Lusk, L., McGeough, M., Donnelly, P., Herity, N., & Fitzsimons, D. (2014). 'I am still a bit unsure how much of a heart attack it really was!'Patients presenting with non ST elevation myocardial infarction lack understanding about their illness and have less motivation for secondary prevention. *European Journal of Cardiovascular Nursing*, *13*(3), 270–276. https://doi.org/10.1177/1474515113491649

Eldh, A. C., Ehnfors, M., & Ekman, I. (2004). The phenomena of participation and non-participation in health care-experiences of patients attending a nurse-led clinic for chronic heart failure. *European Journal of Cardiovascular Nursing*, *3*(3), 239–246. https://doi.org/10.1016/j.ejcnurse.2004.05.001

Fålun, N., Fridlund, B., Schaufel, M. A., Schei, E., & Norekvål, T. M. (2016). Patients' goals, resources and barriers to future change: A qualitative study of patient reflections at hospital discharge after myocardial infarction. *European Journal of Cardiovascular Nursing*, *15*(7), 495–503. https://doi.org/10.1177/1474515115614712

Fors, A., Dudas, K., & Ekman, I. (2014). Life is lived forwards and understood backwards–Experiences of being affected by acute coronary syndrome: A narrative analysis. *International Journal of Nursing Studies*, *51*(3), 430–437. https://doi.org/10.1016/j.ijnurstu.2013.06.012

Grbich, C. (2012). *Qualitative data analysis: An introduction*. London: Sage.

Grovatsmark, R. E. S., Digre, T., Sneeggen, S., Karlsaune, H., & Bønaa, K. H. (2017). *Norsk hjerteinfarktregister Årsrapport 2016 [The Norwegian Myocardial Infarction Register (NORMI) annual report 2016]*. Trondheim, Norway: St. Olavs Hospital.

Hagen, T. P., Häkkinen, U., Belicza, E., Fatore, G., & Goude, F. (2015). Acute myocardial infarction, use of percutaneous coronary intervention and mortality: A comparative effectiveness analysis covering seven European countries. *Health Economics*, *24*(S2), 88–101. https://doi.org/10.1002/hec.3263

Höglund, A. T., Winblad, U., Arnetz, B., & Arnetz, J. E. (2010). Patient participation during hospitalization for myocardial infarction: Perceptions among patients and personnel. *Scandinavian Journal of Caring Sciences*, *24*(3), 482–489. https://doi.org/10.1111/j.1471-6712.2009.00738.x

IHI. (2018a). *Person- and family-centered care institute for healthcare improvement*. IHI. Retrieved from http://www.ihi.org/Topics/PFCC/Pages/Overview.aspx

IHI. (2018b). *"What matters"*. Institute for Healthcare Improvement. Retrieved from http://www.ihi.org/Topics/WhatMatters/Pages/default.aspx

Jelinek, M. V., Thompson, D. R., Ski, C., Bunker, S., & Vale, M. J. (2015). 40 years of cardiac rehabilitation and secondary prevention in post-cardiac ischaemic patients. Are we still in the wilderness? *International Journal of Cardiology*, *179*, 153–159. https://doi.org/10.1016/j.ijcard.2014.10.154

Junehag, L., Asplund, K., & Svedlund, M. (2014). A qualitative study: Perceptions of the psychosocial consequences and access to support after an acute myocardial infarction. *Intensive and Critical Care Nursing*, *30*(1), 22–30. https://doi.org/10.1016/j.iccn.2013.07.002

Kähkönen, O., Kankkunen, P., Saaranen, T., Miettinen, H., Kyngäs, H., & Lamidi, M. L. (2015). Motivation is a crucial factor for adherence to a healthy lifestyle among people with coronary heart disease after percutaneous coronary intervention. *Journal of Advanced Nursing*, *71*(10), 2364–2373. https://doi.org/10.1111/jan.12708

Kotseva, K., Wood, D., De Bacquer, D., De Backer, G., Rydén, L., Jennings, C., … Castro Conde, A. (2016). EUROASPIRE IV: A European Society of Cardiology survey on the lifestyle, risk factor and therapeutic management of coronary patients from 24 European countries. *European Journal of Preventive Cardiology*, *23*(6), 636–648. https://doi.org/10.1177/2047487315569401

Kvale, S., & Brinkmann, S. (2009). *Det kvalitative forskningsintervju [Inter-View: Learning the Craft of Qualitative Research Interviewing]*. Oslo: Gyldendal akademisk.

Larsson, I. E., Sahlsten, M. J., Sjöström, B., Lindencrona, C. S., & Plos, K. A. (2007). Patient participation in nursing care from a patient perspective: A Grounded Theory study. *Scandinavian Journal of Caring Sciences*, *21*(3), 313–320. https://doi.org/10.1111/j.1471-6712.2007.00471.x

Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. In Y. Lincoln & E. Guba (Eds.), *Naturalistic inquiry* (pp. 289–330). Beverly Hills, CA: Sage.

Ministry of Health and Care Services. (1999). *Lov om pasient- og brukerrettigheter [Act related to patient`s rights]*. Oslo: Helse- og omsorgsdepartementet [Ministry of Health and Care Services (HOD)].

Oterhals, K., Hanestad, B. R., Eide, G. E., & Hanssen, T. A. (2006). The relationship between in-hospital information and patient satisfaction after acute myocardial infarction. *European Journal of Cardiovascular Nursing*, *5*(4), 303–310. https://doi.org/10.1016/j.ejcnurse.2006.01.004

Piepoli, M. F., Corra, U., Benzer, W., Bjarnason-Wehrens, B., Dendale, P., Gaita, D., … Zwisler, A.-D. O. (2010). Secondary prevention through cardiac rehabilitation: From knowledge to implementation. A position paper from the Cardiac Rehabilitation Section of the European Association of Cardiovascular Prevention and Rehabilitation. *European Journal of Cardiovascular Prevention & Rehabilitation*, *17*(1), 1–17. https://doi.org/10.1097/HJR.0b013e3283313592

Piepoli, M. F., Corrà, U., Dendale, P., Frederix, I., Prescott, E., Schmid, J. P., … Giannuzzi, P. (2016). Challenges in secondary prevention after acute myocardial infarction: A call for action. *European Journal of Preventive Cardiology*, *23*(18), 1994–2006. https://doi.org/10.1177/2047487316663873

Polit, D. F., & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice*. Philadelphia, PA: Wolters Kluwer Health.

Radcliffe, E. L., Harding, G., Rothman, M. T., & Feder, G. S. (2009). 'It got right to the spot'The patient experience of primary angioplasty: A qualitative study. *European Journal of Cardiovascular Nursing*, *8*(3), 216–222. https://doi.org/10.1016/j.ejcnurse.2009.02.001

Report No. 47 (2008-2009) (2008). *The coordination reform proper treatment - at the right place and right time*. Oslo: Norwegian Ministry of Health and Care Services.

Roffi, M., Patrono, C., Collet, J. P., Mueller, C., Valgimigli, M., Andreotti, F., … European Society of Cardiology Scientific Document Group. (2016). 2015 ESC Guidelines for the management of acute coronary syndromes in patients presenting without persistent ST-segment elevation: Task Force for the Management of Acute Coronary Syndromes in Patients Presenting without Persistent ST-Segment Elevation of the European Society of Cardiology (ESC). *European Heart Journal*, *37*(3), 267–315. https://doi.org/10.1093/eurheartj/ehv320

Ruano-Ravina, A., Pena-Gil, C., Abu-Assi, E., Raposeiras, S., van't Hof, A., Meindersma, E., … González-Juanatey, J. R. (2016). Participation and adherence to cardiac rehabilitation programs. A systematic review. *International Journal of Cardiology*, *223*, 436–443. https://doi.org/10.1016/j.ijcard.2016.08.120

Sahlsten, M. J. M., Larsson, I. E., Plos, K. A. E., & Lindencrona, C. S. C. (2005). Hindrance for patient participation in nursing care. *Scandinavian Journal of Caring Sciences*, *19*(3), 223–229. https://doi.org/10.1111/j.1471-6712.2005.00336.x

Sahlsten, M. J., Larsson, I. E., Sjöström, B., & Plos, K. A. (2008) An analysis of the concept of patient participation. *Nursing Forum*, *43*, 2–11, Wiley Online Library. https://doi.org/10.1111/j.1744-6198.2008.00090.x

Salminen-Tuomaala, M., Åstedt-Kurki, P., Rekiaro, M., & Paavilainen, E. (2012). Coping experiences: A pathway towards different coping orientations four and twelve months after myocardial infarction—a grounded theory approach. *Nursing Research and Practice*, *2012*, 674783.

Sampson, F., O'Cathain, A., & Goodacre, S. (2009). Feeling fixed and its contribution to patient satisfaction with primary angioplasty: A qualitative study. *European Journal of Cardiovascular Nursing*, *8*(2), 85–90. https://doi.org/10.1016/j.ejcnurse.2008.07.003

Sarbin, T. R. (1986). The narrative as a root metaphor for psychology. In T. R. Sarbin (Ed.), *Narrative psychology: The storied nature of human conduct* (pp. 3–21). New York: Praeger.

Shimada, Y. J., & Scirica, B. M. (2015). Long-term management and unmet needs after an acute coronary syndrome event. *American Journal of Cardiology*, *115*(5), 29A–35A. https://doi.org/10.1016/j.amjcard.2015.01.005

Svavarsdóttir, M. H., Sigurdardottir, A. K., & Steinsbekk, A. (2016). What is a good educator? A qualitative study on the perspective of individuals with coronary heart disease. *European Journal of Cardiovascular Nursing*, *15*(7), 513–521. https://doi.org/10.1177/1474515115618569

Tanguay, A., Dallaire, R., Hébert, D., Bégin, F., & Fleet, R. (2015). Rural patient access to primary percutaneous coronary intervention centers is improved by a novel integrated telemedicine prehospital system. *The Journal of emergency medicine*, *49*(5), 657–664. https://doi.org/10.1016/j.jemermed.2015.05.009

Task Force on the management of ST segment elevation acute myocardial infarction of the European Society of Cardiology; Steg, P. G., James, S. K., Atar, D., Badano, L. P., Blomstrom-Lundqvist, C., … Zahger, D. (2012). ESC guidelines for the management of acute myocardial infarction in patients presenting with ST-segment elevation. *European Heart Journal*, *33*(20), 2569–2619.

Thompson, A. G. H. (2007). The meaning of patient involvement and participation in health care consultations: A taxonomy. *Social Science & Medicine*, *64*(6), 1297–1310. https://doi.org/10.1016/j.socscimed.2006.11.002

Tobiano, G., Marshall, A., Bucknall, T., & Chaboyer, W. (2015). Patient participation in nursing care on medical wards: An integrative review. *International Journal of Nursing Studies*, *52*(6), 1107–1120. https://doi.org/10.1016/j.ijnurstu.2015.02.010

Townsend, N., Nichols, M., Scarborough, P., & Rayner, M. (2015). Cardiovascular disease in Europe—epidemiological update 2015. *European Heart Journal*, *36*(40), 2696–2705. https://doi.org/10.1093/eurheartj/ehv428

Vahdat, S., Hamzehgardeshi, L., Hessam, S., & Hamzehgardeshi, Z. (2014). Patient involvement in health care decision making: A review. *Iranian Red Crescent Medical Journal*, *16*(1), e12454.

Valaker, I., Norekvål, T. M., Råholm, M.-B., Nordrehaug, J. E., Rotevatn, S., & Fridlund, B. (2017). Continuity of care after percutaneous coronary intervention: The patient's perspective across secondary and primary care settings. *European Journal of Cardiovascular Nursing*, *16*(5), 444–452. https://doi.org/10.1177/1474515117690298

World Health Organization. (2017). *Cardiovascular diseases (CVDs)* Fact sheet. WHO. Retrieved from http://www.who.int/news-room/fact-sheets/detail/cardiovascular-diseases-(cvds)

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RESEARCH ARTICLE

Nurses' perceptions of patient participation in the myocardial infarction pathway

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Abstract

Aim: To explore nurses' perceptions of patient participation in different phases of the myocardial infarction pathway.

Design: Qualitative design with a hermeneutical approach.

Methods: Five focus groups were conducted at two hospitals, one with and one without percutaneous coronary intervention facilities, between February–November 2018. Participants were recruited through purposive sampling. Twenty-two nurses experienced in cardiac care participated. The analysis had a hermeneutical approach.

Results: The findings revealed nurses' perceptions of patient participation in different phases of the myocardial infarction pathway. Four themes were identified: (a) variation between paternalism and autonomy in the acute phase; (b) individualization of dialogue and patient participation during treatment; (c) lack of coherence in the pathway hinders patient participation at discharge; and (d) cardiac rehabilitation promotes patients' autonomous decisions in lifestyle changes.

KEYWORDS

focus group, myocardial infarction, myocardial infarction care, nurse perception, nurse perspective, nurses, nursing, patient involvement, patient participation, qualitative research

1 | INTRODUCTION

Patient participation is a core element in patient-centred care (Kitson, Marshall, Bassett, & Zeitz, 2013) and can improve patient safety and quality in health care (Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014; WHO, 2013). In most developed countries, patient participation is considered a legal right and a healthcare standard. Nurses have a key role in promoting patient participation (Angel & Frederiksen, 2015; Tobiano, Bucknall, Marshall, Guinane, & Chaboyer, 2015).

Treatment of myocardial infarction (MI) follows a standardized pathway which is divided into four phases: acute phase; treatment phase; discharge phase; and rehabilitation phase. An MI requires urgent treatment with antithrombotic medications and percutaneous coronary intervention (PCI). The urgency of PCI is dependent on the type of MI. For non-ST-elevation myocardial infarction (nSTEMI), the European Society of Cardiology (ESC) guidelines recommend PCI within 2–72 hr, dependent on the ischaemic risk, while for ST-elevation myocardial infarction (STEMI), the recommendation is within 120 min (Ibanez et al., 2017; Roffi et al., 2015). PCI facilities are generally centralized to high-volume centres for invasive treatment (Neumann et al., 2018). Norway has eight hospitals with PCI facilities. Therefore, patients often are transferred between hospitals to receive treatment (Hagen, Häkkinen, Belicza, Fatore, & Goude, 2015). Patients with MI being transferred between different hospitals have experienced the pathway as unplanned where the various hospitals were perceived as uncoordinated (Valaker et al., 2017).

Even if an MI is characterized as an acute event, it is caused by coronary artery disease (CAD), which is a chronic condition related to several risk factors, such as high blood pressure, high cholesterol levels, overweight and tobacco use. Therefore, secondary prevention with medication and lifestyle changes to reduce risk factors is necessary to prevent new cardiac events (Piepoli et al., 2016). Short hospital stays allow limited time for the initiation of secondary prevention (Ibanez et al., 2017; Roffi et al., 2015).

Patients are recommended to attend cardiac rehabilitation after discharge (Ibanez et al., 2017). Yet, participation rates in cardiac rehabilitation are low (Kotseva et al., 2016; Olsen, Schirmer, Bønaa, & Hanssen, 2018). Jortveit et al. (2019) found that risk factor control after MI was low; on average, three of six defined treatment targets for secondary prevention were achieved. Patient participation can increase patient motivation and responsibility for adhering to secondary prevention (Kähkönen et al., 2015; Thompson, 2007).

1.1 | Background

Patient involvement and participation are often used synonymously. Thompson (2007) distinguished the two terms, defining involvement as a precondition for participation. Participation means that patients are engaged in discussions, provided with relevant information, asked about their opinions and participating in decision-making processes (Thompson, 2007). Patient participation is attached to the ethical principle of autonomy. Autonomy is dependent on both the patient's competence and the context (Beauchamp & Childress, 2013).

Thompson, Ruusuvuori, Britten, and Collins (2007) provided an approach to understand patient participation based on three elements: components, levels and contexts. The components are divided into five different areas where the patient can participate: (a) contribution to action by initiation or responding in consultations; (b) defining the problem; (c) participation in the reasoning process; (d) participation in decision-making; and (e) emotional reciprocity in encounters with healthcare professionals. These components are related to levels of involvement defined in Thompson's (2007) taxonomy. The levels follow a continuum from no involvement, to information-seeking/reception, to information-giving and dialogue, to shared decision-making, to autonomous decision-making (Thompson, 2007). In this study, we have used Thompson et al.'s (2007) integrative and dynamic approach to patient participation as a theoretical framework.

Previous research has found that patients with MI did not wish to participate in treatment decisions during the acute phase (Arnetz & Arnetz, 2009; Decker et al., 2007; Höglund, Winblad, Arnetz, & Arnetz, 2010; Radcliffe, Harding, Rothman, & Feder, 2009; Sampson, O'Cathain, & Goodacre, 2009). Later, when situations were stabilized and until discharge, patients' desires to participate increased (Arnetz & Arnetz, 2009; Decker et al., 2007).

Patients have reported a lack of information about secondary prevention (Astin, Closs, McLenachan, Hunter, & Priestley, 2008; Oterhals, Hanestad, Eide, & Hanssen, 2006; Valaker et al., 2017). Pettersen et al. (2018) found that patients perceived information about medications as insufficient.

The first period after discharge has been reported by patients as difficult (Astin et al., 2008; Junehag, Asplund, & Svedlund, 2014). Patients have reported that participating in cardiac rehabilitation enhanced their knowledge about their medical condition and increased their motivation to secondary prevention (Bårdsgjerde, Kvangarsnes, Landstad, Nylenna, & Hole, 2019; Valaker et al., 2017).

Previous research from a healthcare professional perspective has found that nurses considered patient information and participation as important in the MI pathway (Arnetz, Winblad, Arnetz, & Höglund, 2008; Arnetz & Zhdanova, 2015; Höglund et al., 2010). Arnetz and Zhdanova (2015) found that although patient participation was considered important, it did not necessarily result in a behaviour that facilitated participation. Furthermore, Arnetz et al. (2008) found that only 44% of the nurses and 62% of the physicians in their sample discussed lifestyle changes with patients before discharge.

An acute setting, short and fragmented hospital stay can hinder patient participation (Eldh, Ehnfors, & Ekman, 2004; Thompson, 2007; Valaker et al., 2017), and it has been identified that patients and healthcare professionals often have different perceptions of patient participation (Eldh, 2019; Höglund et al., 2010). Patients have reported lack of information and participation in different phases of the MI pathway (Bårdsgjerde et al., 2019). By exploring nurses' perceptions of patient participation in the MI pathway, we can gain new knowledge that can improve patient participation in clinical care. Therefore, the aim of the study was to explore nurses' perceptions of patient participation in the MI pathway. The research question was: What are nurses' perceptions of patient participation in different phases of the MI pathway?

2 | THE STUDY

2.1 | Design

This study had a qualitative design with a hermeneutical approach (Alvesson & Sköldberg, 2018; Gadamer, 2004; Howell, 2013). A hermeneutical approach is useful when the purpose is to seek, understand and interpret the underlying meaning of a concept in reference to a specific context (Alvesson & Sköldberg, 2018; Patton, 2015).

A hermeneutical inquiry involves interpretation and understanding based on two basic principles: an alternation between the parts and the whole, where the parts can be understood only from the whole and the whole can be understood only from the parts; and an alternation between pre-understanding and understanding. A pre-understanding is necessary to be open to and provide questions, and the resulting answers provide new insight for a new understand- ing (Alvesson & Sköldberg, 2018; Gadamer, 2004).

2.2 | Participants

Purposive sampling was used to recruit participants to the study (Tong, Sainsbury, & Craig, 2007). Both female and male nurses at different ages, with differences in education and length of work experiences, were included to increase variation and diversity (Polit & Beck, 2017). The inclusion criteria were that the nurses: (a) worked in cardiac care and (b) had at least 1 year of experience in cardiac care.

To recruit nurses, we contacted two hospitals in mid-Norway. Nurses at the two hospitals were invited because they were responsible for patient care in different phases of the MI pathway. Mostly, the nurses at the hospital without PCI facilities were responsible for patient care in the acute phase and rehabilitation phase. The nurses at the hospital with PCI facilities were responsible for patient care during the PCI treatment and at discharge. Nurses who met the inclusion criteria were invited face to face to participate in the study (Tong et al., 2007). Twenty-two nurses participated, including three men and 19 women aged from 24–58 years. The demographic data are presented in Table 1.

2.3 | Data collection

Focus groups were conducted to understand the insights and experiences of individuals through conversations and exchanges of experiences (Krueger & Casey, 2015). A questioning route (Krueger & Casey, 2015) based on the aim of the study, previous research and the theoretical framework was developed. The questioning route consisted of open-ended questions (Table 2). The question route was not used in a rigid way, and follow-up questions were asked when needed.

Focus groups 1, 2 and 3 were conducted at the hospital with PCI facilities, and each group consisted of nurses working in the catheterization laboratory and various cardiac wards. Focus groups 4 and 5 were conducted at the hospital without PCI facilities. Focus group 4 consisted of nurses working at an emergency unit, cardiac ward and in cardiac rehabilitation, while focus group 5 consisted of nurses working at a cardiac ward. The size of the focus groups varied from three–five participants.

TABLE 1 Demographic data

Demographic data	**Participants (N = 22)**
Age (years)	
21–30	5
31–40	7
42–50	8
52–60	2
Education	
Bachelor of nursing[a]	22
Specialized in cardiac nursing[b]	9
Specialized in intensive care nursing[c]	2
Master's degree in advanced clinical nursing[d]	1
Working place	
Emergency unit	3
Cardiac ward	13
Catheterization angiography laboratory	6
Outpatient cardiac rehabilitation clinic[e]	1
Experience as a nurse (years)	
1–5	4
6–10	5
11–15	3
16–21	7
>21	3
Experience with cardiac patients (years)	
1–5	4
6–10	5
11–15	3
16–21	9
>21	1

[a] Bachelor's degree in Nursing (180 ECTS credits).

[b] Further postgraduate education in cardiac nursing (60 ECTS credits).

[c] Further postgraduate education in intensive care nursing (90 ECTS credits).

[d] Master's degree in advanced clinical nursing (120 ECTS credits).

[e] Shared position in a cardiac ward and outpatient cardiac rehabilitation clinic.

TABLE 2 Question route

What experiences do you have with providing information in the myocardial infarction pathway?
How have you experienced patient participation in the myocardial infarction pathway?
Can you summarize the challenges with information provision and patient participation in the myocardial infarction pathway?
How can patient information and participation be strengthened in the myocardial infarction pathway?

The focus groups were conducted in meeting rooms at the hospitals between February–November 2018. During the interviews, the participants were engaged in the topic and openly shared and exchanged experiences and opinions with each other. Each interview lasted approximately 90 min. The interviews were led by a moderator, while a co-moderator observed the interactions in the groups and took notes. The interviews were audio-recorded and transcribed verbatim. After five focus groups, we identified patterns and preliminary themes across the interviews and therefore considered the data to be saturated (Krueger & Casey, 2015).

2.4 | Ethical considerations

The Norwegian Centre for Research Data approved the study. Prior to the interviews, the participants were informed in both oral and written formats and provided their written consent. The participants were informed that they could withdraw from the study without providing any reason. The participants were asked to anonymize examples and histories used during the interviews and to keep the content of the focus group confidential.

2.5 | Data analysis

The analysis was guided by the study aim, research question (Krueger & Casey, 2015) and the theoretical framework (Thompson, 2007; Thompson et al., 2007). Our analysis was inspired by the two hermeneutical principles to generate new insights and understanding based on interpretations (Gadamer, 2004).

The analysis was performed by the first and the last authors. First, each interview was read in its entirety to gain insight into the content. Then, data were collated into initial codes related to the different phases of the pathway: acute phase, treatment phase, discharge phase and rehabilitation phase. We used our pre-understanding, based on the theoretical framework, to question the data to identify discussions, meanings and expressions of patient participation (Gadamer, 2004). When the data were coded with the initial codes, we alternated between the parts of the pathway and the whole pathway in each interview and across the interviews. To collate the data into preliminary themes, we looked for patterns and diversity across the interviews. To structure the preliminary themes, we created subthemes for each theme. Then, each theme was abstracted and written in full, illustrated by suitable quotes, as shown in Table 3.

2.6 | Rigour

To enhance credibility, the method has been transparently described and the quotations were chosen carefully to substantiate the results (Lincoln & Guba, 1985). The co-moderator provided a summary of the main points at the end of each interview, and the participants were invited to provide comments or corrections (Krueger & Casey, 2015). To ensure confirmability (Lincoln & Guba, 1985), three of the other authors also read the transcripts and the findings were discussed. Three of the authors had specific clinical experience in cardiac care. The findings are presented through rich descriptions to increase transferability (Lincoln & Guba, 1985).

3 | RESULTS

Four themes related to the 22 nurses' perceptions of patient participation in different phases of the pathway were identified: (a) variation between paternalism and autonomy in the acute phase; (b) individualization of dialogue and patient participation during treatment; (c) lack of coherence in the pathway hinders patient participation at discharge; and (d) cardiac rehabilitation promotes patients' autonomous decisions in lifestyle changes.

3.1 | Variation between paternalism and autonomy in the acute phase

In the acute phase, the nurses reported that the severity of the situation made patient information challenging. The nurses described that they worked in teams with physicians and that it was of great importance to monitor patients and initiate the correct treatment: “Sometimes it is critical; you do not delay an angiography because the patient should be very well informed” (N 4, fg 3).

The nurses noted that most of their patients were admitted to the cardiac ward to be prepared for angiography. The nurses gave information in both oral and written formats to prepare patients before angiography and PCI. This was perceived as challenging for the patients. The patients were often not able to participate in their care and treatment, as stated by one nurse, “They are not receptive to much information; their focus is often here and now” (N2, fg 5). The nurses reported that they often needed to repeat information several times. The nurses at the hospital without PCI facilities told that the patients often were more concerned about the transfer to the PCI hospital than the PCI procedure itself.

The nurses perceived it as difficult for the patients to grasp essential information and that they often did not understand the severity of their conditions. The nurses explained that collaborating with physicians about information in this phase was important.

TABLE 3 Development of quotes into themes

Quotes	Subthemes	Theme
THEME 1		
"Sometimes it is critical; you do not delay an angiography because the patient should be very well informed" (N4, fg 3)	Severity of illness and lack of time prevent participation	Variation between paternalism and autonomy in the acute phase
"It seems to be a reassurance for the patients that the physician confirms the information that we have already given" (N1, fg 4)	Providing consistent and concrete information	
"It is important that elderly people have the possibility to say, 'I do not want any invasive treatment. Let me live in peace the last years of my life'" (N4, fg 2)	Elderly patients often take autonomous decisions	
THEME 2		
"Some will know everything; others do not want to know anything. Some will look at the screen; others will not. And some of them will just have it done without any questions" (N4, fg 1)	Individual information tailored to patients' preferences	Individualization of dialogue and patient participation during treatment
"I experience that the patients often are engaged and ask what they can do themselves to prevent another event" (N2, fg 2)	Acute illness increases patients' receptivity for secondary prevention	
"Sometimes it [the MI] cannot be treated with PCI, and then we have to give that information and tell them that it will be discussed in the heart team and that they will receive more information later about treatment options: surgery or PCI" (N2, fg 3)	Patients' lack of medical knowledge hinders shared decision-making in treatment	
THEME 3		
"First, they are admitted, then they go to the catheterization laboratory and then to the intensive care unit until the evening before they are coming back to the cardiac ward. And often, the next day, they are discharged" (N3, fg 2)	Fragmented and short pathway	Lack of coherence in the pathway hinders patient participation at discharge
Dialogue from focus group 4: N3: "I do not think it is that stupid to have checklists for information that should be given before discharge. If you have checklists, it is easier to have things done." N2: "At least for those with less experience that might be unsure about what information they are supposed to give." N1: "The trouble is that there are so many schemes and checklists."	Lack of routines and interprofessional collaboration in discharge planning	
"If the patients are supposed to take part in decisions, it requires a great deal of information and that the patients really understand the information they have received" (N1, fg 3)	Shared decision-making requires patient competence	
THEME 4		
"We revised the pamphlet and added information about the first period at home after an MI" (N5, fg 1)	Patients lacking information after discharge	Cardiac rehabilitation promotes patients' autonomous decisions in lifestyle changes
"I often say, 'If you believe that you are going to live a normal life again, it is smart to take your wife with you to the cardiac rehabilitation so she can hear that you are going to live like normal'" (N4, fg 3)	Involving the spouse in cardiac rehabilitation	
"We cannot make changes if the patients do not take part in it" (N1, fg 4)	Patient engagement and involvement in cardiac rehabilitation	

Consistent information from both physicians and nurses was considered important, as stated by one nurse: "It seems to be a reassurance for the patients that the physician confirms the information that we have already given" (N 1, fg 4).

The nurses described that in encounters with older and fragile patients, they often observed that these patients expressed a desire to participate in decisions about treatment, as illustrated by the following example: "It is important that elderly people have the possibility to say, 'I do not want any invasive treatment. Let me live in peace the last years of my life'" (N 4, fg 2). The nurses discussed how the patients' preferences were accounted for in planning the treatment. The nurses highlighted a special need for attentiveness to make sure that the patients really understood the consequences of their decisions.

3.2 | Individualization of dialogue and patient participation during treatment

Nurses working at the catheterization laboratory expressed that patients' conditions ranged from being fully awake and well informed to critically ill with reduced consciousness. When taking care of the most critical patients, the nurses reported that their focus was to keep the situation calm: "It is most important to give concise and clear information about what we are going to do and make sure that they are in safe hands" (N 1, fg 2). The nurses explained that patients had different reactions during procedures: "Some will know everything; others do not want to know anything. Some will look at the screen; others will not. And some of them will just have it done without any questions" (N4, fg 1). They said that they tried to respect and adjust the level of information provided during the procedure.

The nurses experienced some patients as being receptive to information in the treatment phase and that such patients often had questions about secondary prevention; as one nurse explained, "I experience that the patients often are engaged and ask what they can do themselves to prevent another event" (N2, fg 2). The nurses stated that the time and setting of a procedure might not be the best circumstances for dialogue. Nevertheless, the nurses expressed that if patients were motivated, they talked about secondary prevention alongside the procedure. As one nurse said, "We have the potential to guide people in the right direction" (N1, fg 2).

The nurses observed that physicians during the PCI procedure asked patients to give their consent before they implanted any stents. Nevertheless, the nurses revealed that patient participation was difficult to achieve in such situations, as the time was limited, and patients lacked knowledge to take part in decisions about treatment.

The nurses recounted that relaying information to patients was challenging when an angiography showed severe multivessel disease. Patients were not receptive to in-depth information at this stage; instead, the nurses described giving patients a small amount of information: "Sometimes it [the MI] cannot be treated with PCI and then we have to give that information and tell them that it will be discussed in the heart team and that they will receive more information later about treatment options: surgery or PCI" (N2, fg 3). The nurses expressed that it posed ethical challenges to balance information about the severity of the disease. They did not want to provide overwhelming information during PCI; therefore, they often experienced that the patients were not adequately informed about the severity.

3.3 | Lack of coherence in the pathway hinders patient participation at discharge

The nurses experienced that the time from PCI until discharge was short and fragmented, which could lead to challenges in meeting with patients. One nurse described the limited time and fragmentation as follows: "First, they are admitted, then they go to the catheterization laboratory and then to the intensive care unit until the evening before they are coming back to the cardiac ward. And often, the next day, they are discharged" (N 3, fg 2). Collaboration with physicians and between different wards was considered important to ensure that the patient received consistent information. One nurse explained, "I think it is important that the patients experience a common thread in the information" (N1, fg 1).

The nurses told that how involved the patients were in secondary prevention, such as control of risk factors, lifestyle changes and medication, varied. The nurses did not have standardized routines for what information the patient should receive before discharge. The nurses discussed whether they would have benefitted from checklists for providing patients with information. While some thought the use of checklists could be beneficial for patient safety and quality in the healthcare system, others thought it would be just another instance of increased bureaucracy. This is illustrated by a dialogue (fg 4):

> N3: "I do not think it is that stupid to have checklists for information that should be given before discharge. If you have checklists, it is easier to have things done."
>
> N2: "At least for those with less experience that might be unsure about what information they are supposed to give."
>
> N1: "The trouble is that there are so many schemes and checklists."

The nurses observed that patients' levels of receptiveness to secondary prevention varied. They noted that participation in medical decisions required that the patient had enough competence; as one nurse stated, "If the patients are supposed to take part in decisions, it requires a great deal of information and that the patients really understand the information they have received" (N1, fg 3). The nurses explained that patients' lack of medical knowledge could be a barrier to shared decision-making and that patients' lack of medical knowledge often led to healthcare professionals making decisions on behalf of patients. As one nurse explained, "We do not ask the patients whether they are interested or not in taking their prescribed medications" (N 4, fg 3).

Although participation in decisions was reported to be difficult, one situation was described differently, namely, when an angiogram showed multivessel disease that could be treated by PCI or bypass surgery. One nurse described the situation as follows: "When we consider which option is the best, bypass or several stent, we always listen to the patient's opinions and motivations" (N4, fg 3). In the focus group discussions, shared decision-making was especially emphasized in these situations, when the severity of disease made the decision challenging.

The nurses explained that it was usually physicians who gave information to the patients at discharge. The nurses expressed that they would have preferred to be more involved in this process, but that time and resource constraints made their greater involvement impossible. Nurses revealed that they spent a substantial amount of time organizing the journey home, as described by one nurse, "It is not easy to get people back home in the rural areas that you are not familiar with yourself" (N 5, fg 1).

3.4 | Cardiac rehabilitation promotes patients' autonomous decisions in lifestyle changes

The nurses were concerned for their patients after discharge because they knew that patients found the first period at home to be difficult and often needed information. Therefore, they had developed a pamphlet with information about each phase of the pathway, which had been recently revised: "We revised the pamphlet and added information about the first period at home after an MI" (N5, fg 1). Nevertheless, they reported that a well-known problem was that the patients left the pamphlets behind at discharge.

The nurses revealed that they felt the patients did not receive enough information about their medications. They explained that even if they focused on the importance of adherence to medications during the hospital stay, they still observed that patients were readmitted because they had ceased taking their medications.

Before discharge, the nurses asked the patients if they wanted to attend in cardiac rehabilitation at their local hospital. They tried to encourage the patients to attend. Nevertheless, the nurses observed that the patients who they considered to need the programme most often declined the offer.

The nurses explained that next of kin were also invited to the cardiac rehabilitation, which they considered important because next of kin did not always receive information at the hospital. One nurse noted: "I often say, 'If you believe that you are going to live a normal life again, it is smart to take your wife with you to the cardiac rehabilitation so she can hear that you are going to live like normal'" (N 4, fg 3). The nurses expressed that involving the spouse could have a positive impact on adherence to treatment.

One experienced nurse described patient participation as essential in cardiac rehabilitation. The nurse explained how they worked individually with each patient, going carefully through their risk factors and medications, and making sure that the patients truly understood everything. Nevertheless, the nurse emphasized that they were dependent on the patient's engagement: "We cannot make changes if the patients do not take part in it" (N1, fg 4). The nurse described patient engagement as crucial to achieving treatment adherence.

4 | DISCUSSION

The aim of this qualitative study was to explore nurses' perceptions of patient participation in different phases of the MI pathway. We determined that the level of patient participation differed both between phases and within phases due to the specific contexts.

Consistent with ESC guideline recommendations (Neumann et al., 2018), the nurses in our study revealed that priority was given to initiate treatment in the acute phase. Beauchamp and Childress (2013) argue that healthcare professionals often behave paternalistically out of beneficence and clear guidelines often support healthcare professionals to act with the intentions of doing what is best for the patients. The nurses reported that they provided patients with information but that patients often were not receptive to information in the acute phase. Hospital transfers were perceived by the nurses as an obstacle for patient information. Consistent and clear information from both nurses and physicians was considered important in this phase, which is in accordance with patients' preferences (Decker et al., 2007; Höglund et al., 2010).

However, notably, the nurses in our study revealed that older patients often declined invasive treatment and made autonomous decisions about their own treatment. Previous studies have found that in general, older patients compared with younger patients more seldom participate (Angel & Frederiksen, 2015; Arnetz & Arnetz, 2009; Vahdat et al., 2014), and therefore, this finding provides new insight into a context that might be different from what has been assumed. Nevertheless, similar findings were documented in a study exploring patients' preferences for treatment, where older patients suffering from angina often preferred treatment with medication over invasive treatment options (Bowling, Culliford, Smith, Rowe, & Reeves, 2008).

Our study provides insight into how nurses working in a catheterization laboratory involved the patients through a dialogue based on the needs of each patient. A dialogue is described in Thompson's (2007) taxonomy as a precondition for patient participation. This dialogue seemed to be trigged of the patients' awareness of the severity of the situation making them motivated to prevent new cardiac events.

The nurses in our study told that the patients were asked to consent to the treatment during the procedure, yet they did not label the consent as a form of participating in decisions. This is supported by Beauchamp and Childress (2013), who claim that informed consent should not be equalized with shared decision-making. An especially challenging ethical context was when multivessel disease was detected during angiography and treatment decisions needed to be discussed. The nurses emphasized that to discuss treatment options with the patients was important and that the final decision should be made based on the patients' preferences. This finding is consistent with previous studies that have found that patients often have preferences for treatment with medications, PCI or bypass surgery (Bowling et al., 2008; Doll et al., 2019).

Several barriers to participation at discharge were identified in our study. The pathway was described as short and fragmented. A mutual relationship where the patient and healthcare professionals experience emotional reciprocity is a prerequisite for patient participation (Thompson, 2007; Thompson et al., 2007), and fragmentation seemed to be a barrier in building such relations between the patient and healthcare professionals. Furthermore, a lack of routines made it difficult for the nurses to provide information, as they did not know what information patients had received earlier in the pathway. This finding is consistent with those of other studies that have stated that a lack of continuity and time are hindrances for patient participation (Angel & Frederiksen, 2015; Arnetz et al., 2008; Vahdat et al., 2014; Valaker et al., 2017).

Another finding was that when patients were not involved, whether due to organizational factors or patients' lack of knowledge, healthcare professionals often made decisions on behalf of the patients and then informed the patients afterwards. According to Thompson (2007), patient participation is dependent on the willingness of both patients and healthcare professionals. Healthcare professionals that out of beneficence exclude patients from taking part in their treatment may hinder patient participation. This finding gives us a deeper insight into the ethical challenges in the healthcare system that can explain why the level of participation is sometimes low or non-existent.

Our findings showed that the nurses perceived that patient's lack of knowledge often was an obstacle to patient participation in treatment decisions. Health literacy means that the patient develops knowledge, skills and confidence to change their lifestyle and living condition (WHO, 2016). Previous research has found that patients do not reach their treatment targets after an MI (Jortveit et al., 2019). Good information may strengthen patients' health literacy. Health literacy is an important prerequisite for patient participation and adherence to secondary prevention.

In our study, the nurses were not greatly involved in planning discharge and preparing patients for their early rehabilitation. Instead, the nurses described being responsible for organizing the journey home for patients. Arnetz et al. (2008) revealed that nurses less often than physicians discussed lifestyle changes with patients before discharge and this can be an explanation of how tasks are divided between nurses and physicians. There is a need to discuss how nurses' resources are distributed and whether the responsibility for planning the journey home should be placed in the nurse profession. Further, nurses and physicians should collaborate in preparing the patients for discharge, as both the nurses in our study and previous research have stated that patients lack information at discharge (Arnetz et al., 2008; Astin et al., 2008; Decker et al., 2007; Oterhals et al., 2006; Pettersen et al., 2018; Valaker et al., 2017).

As the MI pathway was described as short and fragmented, the nurses in our study highlighted the need for cardiac rehabilitation. In line with recommendations (Ibanez et al., 2017), the nurses invited patients to participate in cardiac rehabilitation. Previous research has found that participating in cardiac rehabilitation is crucial for patients to enhance their health literacy and increase adherence to secondary prevention (Bårdsgjerde et al., 2019; Valaker et al., 2017). Although both healthcare professionals and patients agree that participating in cardiac rehabilitation is important, the participation rates are low (Kotseva et al., 2016; Olsen et al., 2018). Our findings reveal that the nurses experience that it is the most motivated patients that want to attend in cardiac rehabilitation. A possible solution to increase participation rates could be to automatically refer all patients to cardiac rehabilitation. However, such a solution would not promote patient participation in decision-making, and as emphasized in our study, the key to successful cardiac rehabilitation is patients' own engagement. Findings from our study revealed that patient participation was best provided in cardiac rehabilitation, which the nurses described as providing continuity and individualization of care and treatment.

4.1 | Limitations

The interviews were conducted and transcribed in Norwegian. First translation of quotes from Norwegian to English was done by the authors. A text editing service was used to scrutinize the text.

A hermeneutical interpretation can never be absolute and must remain an interpretation (Patton, 2015). The understanding of the interviews took place in a process where the meaning of the separate parts was determined by the global meaning of the interviews (Alvesson & Sköldberg, 2018; Gadamer, 2004). The interpretation of the interviews was based on communicative validation among the researchers (Kvale & Brinkmann, 2009).

Using a theoretical framework (Thompson, 2007; Thompson et al., 2007) may be a limitation. However, the chosen theoretical framework contributes to an understanding of the content and meaning of the term patient participation, which makes it explicit what has been studied.

5 | CONCLUSION

This study provides new insight into nurses' perceptions of patient participation in the MI pathway. Patient participation varied in the different phases of the pathway. In the acute phase and during treatment, the nurses were committed to providing the right treatment. At discharge, the nurses revealed that the fragmented pathway and the lack of interprofessional cooperation hindered continuity in patient participation. We argue that there is a need to strengthen cooperation at the system level. In the rehabilitation phase, the nurses expressed that patient participation is essential to promote secondary prevention.

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CONFLICT OF INTEREST

No conflicts of interest have been declared by the authors.

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REFERENCES

Alvesson, M., & Sköldberg, K. (2018). *Reflexive methodology: New vistas for qualitative research* (3rd ed.). Los Angeles, CA: SAGE.

Angel, S., & Frederiksen, K. N. (2015). Challenges in achieving patient participation: A review of how patient participation is addressed in empirical studies. *International Journal of Nursing Studies*, *52*(9), 1525–1538. https://doi.org/10.1016/j.ijnurstu.2015.04.008

Arnetz, J. E., & Arnetz, B. B. (2009). Gender differences in patient perceptions of involvement in myocardial infarction care. *European Journal of Cardiovascular Nursing*, *8*(3), 174–181. https://doi.org/10.1016/j.ejcnurse.2008.11.002

Arnetz, J. E., Winblad, U., Arnetz, B. B., & Höglund, A. T. (2008). Physicians' and nurses' perceptions of patient involvement in myocardial infarction care. *European Journal of Cardiovascular Nursing*, *7*(2), 113–120. https://doi.org/10.1016/j.ejcnurse.2007.05.005

Arnetz, J. E., & Zhdanova, L. (2015). Patient involvement climate: Views and behaviours among registered nurses in myocardial infarction care. *Journal of Clinical Nursing*, *24*(3–4), 475–485. https://doi.org/10.1111/jocn.12629

Astin, F., Closs, S. J., McLenachan, J., Hunter, S., & Priestley, C. (2008). The information needs of patients treated with primary angioplasty for heart attack: An exploratory study. *Patient Education and Counseling*, *73*(2), 325–332. https://doi.org/10.1016/j.pec.2008.06.013

Bårdsgjerde, E. K., Kvangarsnes, M., Landstad, B., Nylenna, M., & Hole, T. (2019). Patient's narratives of their patient participation in the myocardial infarction pathway. *Journal of Advanced Nursing*, *75*(5), 1063–1073. https://doi.org/10.1111/jan.13931

Beauchamp, T. L., & Childress, J. F. (2013). *Principles of biomedical ethics* (7th ed.). New York, NY: Oxford University Press.

Bowling, A., Culliford, L., Smith, D., Rowe, G., & Reeves, B. C. (2008). What do patients really want? Patients' preferences for treatment for angina. *Health Expectations*, *11*(2), 137–147. https://doi.org/10.1111/j.1369-7625.2007.00482.x

Decker, C., Garavalia, L., Chen, C., Buchanan, D. M., Nugent, K., Shipman, A., & Spertus, J. A. (2007). Acute myocardial infarction patients' information needs over the course of treatment and recovery. *Journal of Cardiovascular Nursing*, *22*(6), 459–465. https://doi.org/10.1097/01.JCN.0000297391.11324.0f

Doll, J. A., Jones, W. S., Lokhnygina, Y., Culpepper, S., Parks, R. L., Calhoun, C., … Patel, M. R. (2019). PREPARED study: A study of shared decision-making for coronary artery disease. *Circulation: Cardiovascular Quality & Outcomes*, *12*(2), e005244. https://doi.org/10.1161/CIRCOUTCOMES.118.005244

Eldh, A. C. (2019). Facilitating patient participation by embracing patients' preferences—A discussion. *Journal of Evaluation in Clinical Practice*, *25*(6), 1070–1073. https://doi.org/10.1111/jep.13126

Eldh, A. C., Ehnfors, M., & Ekman, I. (2004). The phenomena of participation and non-participation in health care-experiences of patients attending a nurse-led clinic for chronic heart failure. *European Journal of Cardiovascular Nursing*, *3*(3), 239–246. https://doi.org/10.1016/j.ejcnurse.2004.05.001

Gadamer, H.-G. (2004). *Truth and method* (2nd rev. ed. translation revised by Joel Weinsheimer and Donald G. Marshall. ed.). London, UK: Continuum.

Hagen, T. P., Häkkinen, U., Belicza, E., Fatore, G., & Goude, F. (2015). Acute myocardial infarction, use of percutaneous coronary intervention and mortality: A comparative effectiveness analysis covering seven European countries. *Health Economics*, *24*(S2), 88–101. https://doi.org/10.1002/hec.3263

Höglund, A. T., Winblad, U., Arnetz, B., & Arnetz, J. E. (2010). Patient participation during hospitalization for myocardial infarction: Perceptions among patients and personnel. *Scandinavian Journal of Caring Sciences*, *24*(3), 482–489. https://doi.org/10.1111/j.1471-6712.2009.00738.x

Howell, K. E. (2013). *An introduction to the philosophy of methodology*. Los Angeles, CA: SAGE.

Ibanez, B., James, S., Agewall, S., Antunes, M. J., Bucciarelli-Ducci, C., Bueno, H., … Halvorsen, S. (2017). 2017 ESC Guidelines for the management of acute myocardial infarction in patients presenting with ST-segment elevation: The Task Force for the management of acute myocardial infarction in patients presenting with ST-segment elevation of the European Society of Cardiology (ESC). *European Heart Journal*, *39*(2), 119–177. https://doi.org/10.1093/eurheartj/ehx393

Jortveit, J., Halvorsen, S., Kaldal, A., Pripp, A. H., Govatsmark, R. E. S., & Langørgen, J. (2019). Unsatisfactory risk factor control and high rate of new cardiovascular events in patients with myocardial infarction and prior coronary artery disease. *BMC Cardiovascular Disorders*, *19*(1), 71. https://doi.org/10.1186/s12872-019-1062-y

Junehag, L., Asplund, K., & Svedlund, M. (2014). A qualitative study: Perceptions of the psychosocial consequences and access to support after an acute myocardial infarction. *Intensive and Critical Care Nursing*, *30*(1), 22–30. https://doi.org/10.1016/j.iccn.2013.07.002

Kähkönen, O., Kankkunen, P., Saaranen, T., Miettinen, H., Kyngäs, H., & Lamidi, M. L. (2015). Motivation is a crucial factor for adherence to a healthy lifestyle among people with coronary heart disease after percutaneous coronary intervention. *Journal of Advanced Nursing*, *71*(10), 2364–2373. https://doi.org/10.1111/jan.12708

Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing*, *69*(1), 4–15. https://doi.org/10.1111/j.1365-2648.2012.06064.x

Kotseva, K., Wood, D., De Bacquer, D., De Backer, G., Rydén, L., Jennings, C., … Castro Conde, A. (2016). EUROASPIRE IV: A European Society of Cardiology survey on the lifestyle, risk factor and therapeutic management of coronary patients from 24 European countries. *European Journal of Preventive Cardiology*, *23*(6), 636–648. https://doi.org/10.1177/2047487315569401

Krueger, R. A., & Casey, M. A. (2015). *Focus groups: A practical guide for applied research* (5th ed.). Los Angeles, CA: Sage.

Kvale, S., & Brinkmann, S. (2009). *Interviews: Learning the craft of qualitative research interviewing* (2nd ed.). Oaks, CA: Sage.

Lincoln, Y., & Guba, E. (1985). Establishing trustworthiness. In Y. Lincoln, & E. Guba (Eds.), *Naturalistic inquiry* (pp. 289–331). Beverly Hills, CA: Sage.

Neumann, F.-J., Sousa-Uva, M., Ahlsson, A., Alfonso, F., Banning, A. P., Benedetto, U., … Head, S. J. (2018). 2018 ESC/EACTS guidelines on myocardial revascularization. *European Heart Journal*, *40*(2), 87–165. https://doi.org/10.1093/eurheartj/ehy394

Olsen, S. J., Schirmer, H., Bønaa, K. H., & Hanssen, T. A. (2018). Cardiac rehabilitation after percutaneous coronary intervention: Results from a nationwide survey. *European Journal of Cardiovascular Nursing*, *17*(3), 273–279. https://doi.org/10.1177/1474515117737766

Oterhals, K., Hanestad, B. R., Eide, G. E., & Hanssen, T. A. (2006). The relationship between in-hospital information and patient satisfaction after acute myocardial infarction. *European Journal of Cardiovascular Nursing*, *5*(4), 303–310. https://doi.org/10.1016/j.ejcnurse.2006.01.004

Patton, M. Q. (2015). *Qualitative research & evaluation methods: Integrating theory and practice* (4th ed.). Los Angeles, CA: Sage.

Pettersen, T. R., Fridlund, B., Bendz, B., Nordrehaug, J. E., Rotevatn, S., Schjøtt, J., … Investigators, C. (2018). Challenges adhering to a medication regimen following first-time percutaneous coronary intervention: A patient perspective. *International Journal of Nursing Studies*, *88*, 16–24. https://doi.org/10.1016/j.ijnurstu.2018.07.013

Piepoli, M. F., Corrà, U., Dendale, P., Frederix, I., Prescott, E., Schmid, J. P., … Giannuzzi, P. (2016). Challenges in secondary prevention after acute myocardial infarction: A call for action. *European Journal of Preventive Cardiology*, *23*(18), 1994–2006. https://doi.org/10.1177/2047487316663873

Polit, D. F., & Beck, C. T. (2017). *Nursing research: Generating and assessing evidence for nursing practice* (10th ed.). Philadelphia, PA: Wolters Kluwer.

Radcliffe, E. L., Harding, G., Rothman, M. T., & Feder, G. S. (2009). 'It got right to the spot' The patient experience of primary angioplasty: A qualitative study. *European Journal of Cardiovascular Nursing*, *8*(3), 216–222. https://doi.org/10.1016/j.ejcnurse.2009.02.001

Roffi, M., Patrono, C., Collet, J.-P., Mueller, C., Valgimigli, M., Andreotti, F., … Windecker, S. (2015). ESC Guidelines for the management of acute coronary syndromes in patients presenting without persistent ST-segment elevation. *European Heart Journal*, *37*(3), 267–315. https://doi.org/10.1093/eurheartj/ehv320

Sampson, F., O'Cathain, A., & Goodacre, S. (2009). Feeling fixed and its contribution to patient satisfaction with primary angioplasty: A qualitative study. *European Journal of Cardiovascular Nursing*, *8*(2), 85–90. https://doi.org/10.1016/j.ejcnurse.2008.07.003

Thompson, A. (2007). The meaning of patient involvement and participation in health care consultations: A taxonomy. *Social Science & Medicine*, *64*(6), 1297–1310. https://doi.org/10.1016/j.socscimed.2006.11.002

Thompson, A., Ruusuvuori, J., Britten, N., & Collins, S. (2007). An integrative approach to patient participation in consultations. In S. Collins, N. Britten, J. Ruusuvuori, & A. Thompson (Eds.), *Patient participation in health care consultations qualitative perspectives* (pp. 176–193). Maidenhead, UK: Open University Press.

Tobiano, G., Bucknall, T., Marshall, A., Guinane, J., & Chaboyer, W. (2015). Nurses' views of patient participation in nursing care. *Journal of Advanced Nursing*, *71*(12), 2741–2752. https://doi.org/10.1111/jan.12740

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Vahdat, S., Hamzehgardeshi, L., Hessam, S., & Hamzehgardeshi, Z. (2014). Patient involvement in health care decision making: A review. *Iranian Red Crescent Medical Journal*, *16*(1), e12454. https://doi.org/10.5812/ircmj.12454

Valaker, I., Norekvål, T. M., Råholm, M.-B., Nordrehaug, J. E., Rotevatn, S., & Fridlund, B. (2017). Continuity of care after percutaneous coronary intervention: The patient's perspective across secondary and primary care settings. *European Journal of Cardiovascular Nursing*, *16*(5), 444–452. https://doi.org/10.1177/1474515117690298

WHO (2013). *Exploring patient participation in reducing health-care-related safety risks*. In D. Delnoij & V. Hafner (Eds.). Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0010/185779/e96814.pdf?ua=1

WHO (2016). *Health literacy*. Retrieved from https://www.who.int/healthpromotion/health-literacy/en/

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Paper III

Physicians' perceptions of patient participation in the myocardial infarction pathway

Running title: Patient participation in MI treatment

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Data Availability Statement:

The dataset generated and/or analysed during the current study is not publicly available due to confidentiality. It is available from the corresponding author on reasonable request.

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Appendices

Appendices

Appendix 1 – Permission from John Wiley and Sons

Appendix 2 – Permission from Norsk hjerteinfarktregister

Appendix 3 – Permission from Elsevier

Appendix 4 – Interview guide Paper I

Appendix 5 – Interview guide Paper II

Appendix 6 – Interview guide Paper III

Appendix 7 – REK Mid-Norway

Appendix 8 – Norwegian Centre for Research Data

Appendix 9 – Information letter Paper I

Appendix 10 – Information letter Paper II

Appendix 11 – Information letter Paper III

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Institution name	Norwegian University of Science and Technology (NTNU)
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From: Govatsmark, Ragna Elise Støre <Ragna.Elise.Store.Govatsmark@stolav.no>
Sent: Wednesday, April 21, 2021 10:24 AM
To: Elise Kvalsund Bårdsgjerde <elise.k.bardsgjerde@ntnu.no>
Subject: RE: Tillatelse til å bruke figur inspirert fra Norsk hjerteinfarktregister rapport 2019

Hei

Det er helt greit for oss at du lager en kopi av denne. Siden du ønsker å ta utgangspunkt i figuren ble jeg nysgjerrig på hva du skriver om?

Lykke til med avhandlingen.

Med vennlig hilsen
Ragna Elise Støre Govatsmark

Seksjonsleder Seksjon for medisinske kvalitetsregistre
Fagavdelingen
St. Olavs hospital
Tlf. 45030308
ST. OLAVS HOSPITAL
UNIVERSITETSSYKEHUSET I TRONDHEIM

From: Elise Kvalsund Bårdsgjerde <elise.k.bardsgjerde@ntnu.no>
Sent: Wednesday, April 21, 2021 9:47 AM
To: hjerteinfarktregisteret <hjerteinfarktregisteret@stolav.no>; Govatsmark, Ragna Elise Støre <Ragna.Elise.Store.Govatsmark@stolav.no>
Subject: Tillatelse til å bruke figur inspirert fra Norsk hjerteinfarktregister rapport 2019

Hei,

Jeg har i mitt doktorgradsarbeid laget en figur for pasientforløpet ved hjerteinfarkt i avhandlingen min. Figuren min er inspirert av følgende figur i Norsk hjerteinfarktregister Årsrapport 2019:

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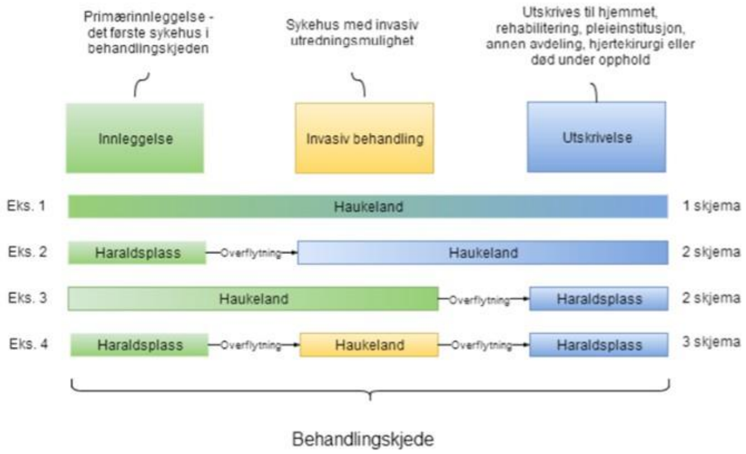
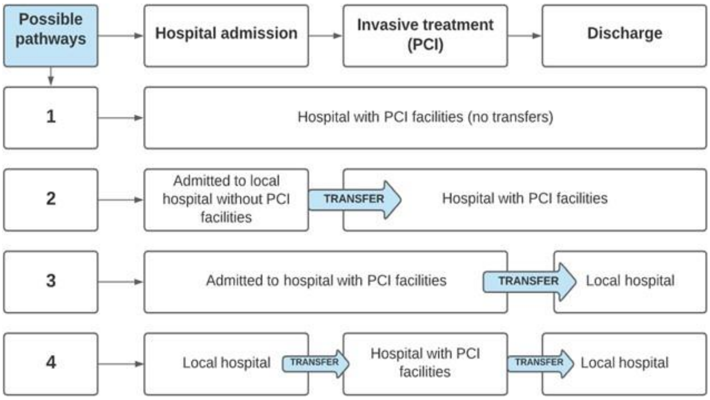
Figur 47 Eksempler på fire ulike behandlingskjeder. Norsk hjerteinfarktregister 2019.



Figuren jeg har utarbeidet er ikke identisk, men siden den er inspirert av deres figur ønsker jeg å be om tillatelse til å bruke figuren. Legger ved en kopi av figuren slik den er utarbeidet i avhandlingen min:



Håper å høre fra dere snarlig!

Med vennlig hilsen
Elise K. Bårdsgjerde
Ph.d. stipendiat Institutt for helsevitenskap Ålesund, NTNU
Tlf: 70161206/97095503

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Kan du fortelle hvordan du erfarte å bli innlagt med hjerteinfarkt?

Har du tidligere vært innlagt på sykehus for behandling av hjertesykdom?

Del 1 – Pasienter innlagt med hjerteinfarkt sine erfaringer om informasjon i forløpet

Kan du fortelle hvordan du fikk informasjon ved innleggelse?

Hvordan erfarte du den informasjonen du fikk i pasientforløpet?

Hva fikk du informasjon om?

Hvor og når fikk du informasjon?

Hvordan fikk du informasjon (muntlig/skriftlig)?

Hvem fikk du informasjon av?

Hvem var tilstede i ulike faser av pasientforløpet når du fikk informasjon?

Hvilken betydning hadde informasjonen for deg?

Del 2 – Pasientens behov for informasjon

Hvilke informasjonsbehov hadde du i pasientforløpet (f eks. ved innleggelse, ved overflytting til annet sykehus, dagene etterpå, ved utskrivelse)?

Hvordan erfarte du at informasjonen ble tilpasset dine behov?

Hvordan erfarte du at pårørende sine behov for informasjon ble ivaretatt?

Hvordan erfarte du å få medvirke i forhold til behandlingen i pasientforløpet?

Hvordan erfarte du informasjonen du fikk på sykehuset etter at du kom hjem?

Kan du fortelle hvordan du tenker at helsepersonell ideelt bør gi informasjon til pasienter med hjerteinfarkt?

Intervjuguide fokusgrupper – sykepleiere

Informasjon og medvirkning (samvalg)

- Hvilke erfaringer har dere med å gi informasjon i forløpet (akutt, behandlingsfase, utskrivelsesfase)?
- Hva er sykepleiers rolle/ansvar ift å gi informasjon?
- Hvilken informasjon blir gitt?
- I hvilken form gis det informasjon (skriftlig/muntlig)?
- Hvor gis det informasjon?
- Hvordan samarbeider ulike profesjoner om å gi informasjon?
- Hvordan gir dere informasjon til pårørende?
- Hvordan tilrettelegger dere for å møte informasjonsbehovet til pasient og pårørende (hvilke tanker har dere om dette?)?
- Hvilke erfaringer har dere med å gi medvirkning (samvalg) i forløpet (akuttfase, behandlingsfase, utskrivelsesfase)?
- Har dere opplevd pasienter som ikke ønsker behandling?
- Hva er sykepleiers rolle/ansvar ift pasientmedvirkning?
- Hvordan forstår dere pasientmedvirkning?
- Hvordan tilrettelegger dere for pasientmedvirkning?

Kan dere kort oppsummere litt om utfordringene med informasjon og medvirkning til pasienter med hjerteinfarkt (i de ulike fasene)?
Hvordan kan en styke informasjon og pasientmedvirkning (samvalg) på individ- og systemnivå?

Informasjon og medvirkning (samvalg)

- Hvilke erfaringer har du med å gi informasjon i forløpet (akutt, behandlingsfase, utskrivelsesfase)?
- Hva er din rolle/ditt ansvar som lege ift å gi informasjon?
- Hvilken informasjon blir gitt?
- I hvilken form gis det informasjon (skriftlig/muntlig)?
- Hvor gis det informasjon?
- Hvordan samarbeider du med andre kollegaer om å gi informasjon?
    - Andre leger
    - Sykepleiere og andre profesjoner
- Hvordan gir du informasjon til pårørende?
- Hvordan tilrettelegger du for å møte informasjonsbehovet til pasient og pårørende (hvilke tanker har du om dette?)
- Hvilke erfaringer har du med å gi medvirkning (samvalg) i forløpet (akuttfase, behandlingsfase, utskrivelsesfase)?
- Har du opplevd pasienter som ikke ønsker behandling?
- Hva er din rolle/ditt ansvar som lege ift pasientmedvirkning?
- Hvordan forstår du pasientmedvirkning?
- Hvordan tilrettelegger du for pasientmedvirkning?

Kan du kort oppsummere litt om utfordringene med informasjon og medvirkning til pasienter med hjerteinfarkt (i de ulike fasene)?
Hvordan kan en styrke informasjon og pasientmedvirkning (samvalg) på individ- og systemnivå?

Appendix 7

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK midt	Marit Hovdal Moan	73597506	15.12.2015	2015/2002/REK midt
			Deres dato:	**Deres referanse:**
			27.10.2015	

Vår referanse må oppgis ved alle henvendelser

Marit Kvangarsnes
Helse Møre og Romsdal

2015/2002 Informasjon til pasienter med hjerteinfarkt gjennom pasientforløpet - pasientperspektivet

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK midt) i møtet 27.11.2015. Vurderingen er gjort med hjemmel i helseforskningsloven § 10, jf. forskningsetikkloven § 4.

Forskningsansvarlig: Helse Møre og Romsdal
Prosjektleder: Marit Kvangarsnes

Prosjektomtale (original)
Hensikten med studien er å få innsikt i og belyse pasienter innlagt med hjerteinfarkt sine erfaringer om informasjon gjennom forløpet i spesialisthelsetjenesten. Funn fra studien kan ha verdi for helsepersonell som skal ivareta pasientens rettigheter til informasjon, og kan bidra til nye retningslinjer for informasjon i praksis. det er planlagt et kvalitativt design med kvalitative forskningsintervju med 10-15 pasienter. Studien vil belyse hvordan pasienter erfarte informasjon og informasjonsbehov i ulike faser av forløpet i spesialisthelsetjenesten. For å besvare forskningsspørsmålene vil data bli samlet inn ved hjelp av intervju med tidligere pasienter.

Vurdering

Komiteens prosjektsammendrag
Formålet med studien er å få innsikt i og belyse hvordan pasienter innlagt med akutt hjerteinfarkt (STEMI) erfarer informasjonen de får gjennom pasientforløpet i spesialisthelsetjenesten (innskriving til utskriving). Innsamling av data vil skje ved bruk av individuelle semistrukturerte intervju (60-90 minutter) av 15-20 personer som har vært behandlet for STEMI, og som nå går til hjerterehabilitering. Respondentene vil bli forespurt ca. 6 uker etter sykehusoppholdet. Rekruttering: Helsepersonell i spesialisthelsetjenesten ved de utvalgte sykehusene vil forespørre aktuelle respondenter om å delta i studien. Studien er samtykkebasert og er en masteroppgave.

Vurdering av framleggingsplikten
Komiteen viser til prosjektprotokoll, målsetting og plan for gjennomføring. Komiteen vurderte først hvorvidt prosjektet er framleggingspliktig for REK. Komiteen var delt i sitt syn vedrørende framleggingsplikten. Det ble derfor foretatt en avstemning, der flertallet (6 mot 3) vurderte at prosjektet har karakter av å være annen type forskning enn medisinsk og helsefaglig forskning.

Flertallets vurdering:
Formålet med prosjektet er ikke primært å skaffe til veie ny kunnskap om medisin og helse, men heller undersøke hvordan pasienter innlagt med akutt hjerteinfarkt erfarer informasjonen de får gjennom

Besøksadresse:
Det medisinske fakultet
Medisinsk teknisk
forskningssenter 7489
Trondheim

Telefon: 73597511
E-post: rek-midt@medisin.ntnu.no
Web: http://helseforskning.etikkom.no/

All post og e-post som inngår i saksbehandlingen, bes adressert til REK midt og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK midt, not to individual staff

pasientforløpet i spesialisthelsetjenesten. Selv om en skal intervjue pasienter, søkes det ikke å innhente helseopplysninger eller studere effekt av en bestemt behandling.

Mindretallets vurdering:
Mindretallet var i noe tvil, men mener at en studie om pasienters erfaringer om informasjon gitt i pasientforløpet vil kunne etablere kunnskap om medisin og helse. God informasjon har stor betydning for ens egen helse og forståelsen av den. Studien kan dermed forstås som medisinsk/helsefaglig forskning i lovens forstand.

Konklusjon:
Prosjektet er ikke omfattet av helseforskningslovens saklige virkeområde, jf. helseforskningslovens §§ 2 og 4. Prosjektet kan derfor gjennomføres og publiseres uten godkjenning fra REK. Vi minner imidlertid om at dersom det skal registreres personopplysninger, må prosjektet meldes til Norsk Samfunnsvitenskapelig Datatjeneste (NSD).

Vurderingen er gjort på grunnlag av de innsendte dokumenter. Dersom det gjøres endringer i prosjektet, kan dette ha betydning for REKs vurdering. Det må da sendes inn ny søknad/framleggingsvurdering.

Vedtak
Regional komité for medisinsk og helsefaglig forskningsetikk, Midt-Norge har funnet at prosjektet faller utenfor komiteens mandat, jf. helseforskningsloven § 2.

Komiteen var delt i sin vurdering (6 mot 3).

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK midt. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK midt, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Sven Erik Gisvold
Dr.med.
Leder, REK midt

Marit Hovdal Moan
Seniorrådgiver

Kopi til:berit.kvalsvik.teige@helse-mr.no

Elise Kvalsund Bårdsgjerde

6025 ÅLESUND

Vår dato: 11.12.2017 Vår ref: 56617 / 3 / LH Deres dato: Deres ref:

Tilrådning fra NSD Personvernombudet for forskning § 7-27

Personvernombudet for forskning viser til meldeskjema mottatt 16.10.2017 for prosjektet:

56617	*Pasienter og helsepersonells erfaringer med informasjon og pasientmedvirkning ved akutt hjerteinfarkt*
Behandlingsansvarlig	*NTNU, ved institusjonens øverste leder*
Daglig ansvarlig	*Elise Kvalsund Bårdsgjerde*

Vurdering

Etter gjennomgang av opplysningene i meldeskjemaet og øvrig dokumentasjon finner vi at prosjektet er unntatt konsesjonsplikt og at personopplysningene som blir samlet inn i dette prosjektet er regulert av § 7-27 i personopplysningsforskriften. På den neste siden er vår vurdering av prosjektopplegget slik det er meldt til oss. Du kan nå gå i gang med å behandle personopplysninger.

Vilkår for vår anbefaling

Vår anbefaling forutsetter at du gjennomfører prosjektet i tråd med:

- opplysningene gitt i meldeskjemaet og øvrig dokumentasjon
- vår prosjektvurdering, se side 2
- eventuell korrespondanse med oss

Meld fra hvis du gjør vesentlige endringer i prosjektet

Dersom prosjektet endrer seg, kan det være nødvendig å sende inn endringsmelding. På våre nettsider finner du svar på hvilke endringer du må melde, samt endringsskjema.

Opplysninger om prosjektet blir lagt ut på våre nettsider og i Meldingsarkivet

Vi har lagt ut opplysninger om prosjektet på nettsidene våre. Alle våre institusjoner har også tilgang til egne prosjekter i Meldingsarkivet.

Vi tar kontakt om status for behandling av personopplysninger ved prosjektslutt

Ved prosjektslutt 31.12.2021 vil vi ta kontakt for å avklare status for behandlingen av personopplysninger.

Se våre nettsider eller ta kontakt dersom du har spørsmål. Vi ønsker lykke til med prosjektet!

Vennlig hilsen

Marianne Høgetveit Myhren

Lise Aasen Haveraaen

Kontaktperson: Lise Aasen Haveraaen tlf: 55 58 21 19 / Lise.Haveraaen@nsd.no
Vedlegg: Prosjektvurdering

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 56617

BAKGRUNN OG FORMÅL

Prosjektet skal belyse og beskrive pasienter og helsepersonell sine erfaringer med informasjon og medvirkning i pasientforløpet ved akutt hjerteinfarkt. Prosjektet vil kunne gi verdifull kunnskap om informasjon og medvirkning på individ- og systemnivå. Funn kan ha betydning for helsepersonell i møte med den enkelte pasient, men også i arbeidet med å utvikle gode og helhetlige pasientforløp. Det er ulikt syn blant pasienter og helsepersonell, og ved å undersøke de ulike perspektivene kan en få utfyllende kunnskap.

REK har vurdert at prosjektet faller utenfor helseforskningslovens bestemmelser (2015/2002 REK midt).

DESIGN

Prosjektet består av 3 delprosjekter, hvor del 1 allerede er tilrådd av personvernombudet (prosjektnr. 46138). I delprosjekt 1 ble pasienter intervjuet angående deres erfaring med pasientmedvirkning ved akutt hjerteinfarkt. Datainnsamling i delstudie 1 er allerede gjennomført og datamaterialet oppbevares i avidentifisert form fram til 2021,jf. eposter fra forsker datert 17.11.2017. Informantene er informert om oppbevaring av data fram til 2021, jf. epost fra forsker. I det påfølgende vurderes delprosjekt 2 og delprosjekt 3.

Utvalget utvides nå til å inkludere sykepleiere (delstudie 2) og leger (delstudie 3).

INFORMASJON OG SAMTYKKE

Utvalget (sykepleiere og leger) informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivene vi har mottatt for delstudie 2 og 3 er godt utformet.

SENSITIVE PERSONOPPLYSNINGER

Det behandles sensitive personopplysninger om helseforhold i prosjektet.

TAUSHETSPLIKT

Sykepleiere og leger har taushetsplikt. Det er derfor viktig at intervjuene gjennomføres slik at det ikke samles inn opplysninger som kan identifisere enkeltpersoner eller avsløre taushetsbelagt informasjon. Vi anbefaler at dere er spesielt oppmerksom på at ikke bare navn, men at også identifiserende bakgrunnsopplysninger må utelates, som for eksempel alder, kjønn, tid, diagnose og eventuelle spesielle hendelser. Vi forutsetter også at dere er forsiktig ved å bruke eksempler under intervjuene. Vi ber om at du opplyser informantene om dette i forkant av intervjuene.

Personvernombudet forutsetter at det ikke innhentes personopplysninger om pasienter eller pårørende, og at taushetsplikten ikke er til hinder for den behandling av opplysninger som finner sted.

SAMARBEIDSPROSJEKT

Personvernombudet forstår det slik at prosjektet er et samarbeid mellom NTNU i Ålesund og Helse Møre og Romsdal, med førstnevnte som behandlingsansvarlig institusjon. Ombudet forutsetter at ansvarsforhold, sikring og evt. eierskap av data er avklart mellom de to institusjonene, og anbefaler at forholdet formaliseres.

INFORMAJSONSSIKKERHET

Personvernombudet legger til grunn at forsker etterfølger NTNU sine interne rutiner for datasikkerhet.

PROSJEKTSLUTT OG ANONYMISERING

Forventet prosjektslutt er 31.12.2021. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:

- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)
- slette digitale lydopptak

Forespørsel om deltakelse i forskningsprosjektet

”En intervjustudie om informasjon til pasienter med hjerteinfarkt i pasientforløpet - pasientperspektivet”

Bakgrunn og formål
Denne studien er en mastergradsoppgave, og formålet er å øke kunnskapen til helsepersonell om pasienters erfaringer med informasjon ved hjerteinfarkt. Ansvarlig virksomhet er NTNU i Ålesund (tidligere Høgskolen i Ålesund) i samarbeid med Helse Møre og Romsdal.

Dette er et spørsmål til deg om å delta i dette forskningsprosjektet. Du er valgt til å forespørres om deltakelse fordi du nylig har vært innlagt og behandlet for hjerteinfarkt.

Hva innebærer deltakelse i studien?
Prosjektet innebærer at du deltar i et individuelt intervju, med varighet på kanskje 60-90 minutter. Intervjuet vil bli tatt opp på lydbånd.

Hva skjer med informasjonen om deg?
Alle personopplysninger vil bli behandlet konfidensielt.

Det vil ikke bli innhentet noen opplysninger om deg og din helsetilstand, annet enn det du forteller selv under intervjuet.

Prosjektet skal etter planen avsluttes 9. juni 2016.

Ved eventuell senere publikasjon av resultater fra undersøkelsen vil ikke ditt navn eller dine opplysninger bli gjengitt på en slik måte at det er mulig å identifisere deg. Dersom resultatene skal publiseres vil opplysningene du har gitt gjennom intervju bli oppbevart på et sikkert sted (passordbeskyttet server). Ved publisering vil datamaterialet (lydfiler og transkriberinger) bli oppbevart i inntil fem år, og deretter slettet.

Frivillig deltakelse
Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert. Deltakelse i prosjektet vil ikke ha innvirkning på din behandling.

Dersom du ønsker å delta leverer du signert skjema og telefonnummer du kan nås på til kontaktperson ved hjerterehabiliteringen. Deretter vil du bli kontaktet for å avtale tidspunkt for intervju av Elise Kvalsund. Har du spørsmål til studien, ta kontakt med Elise Kvalsund, på epost: elkv@ntnu.no eller telefon: 97095503. Veileder for prosjektet: Marit Kvangarsnes, kan kontaktes på epost: mk@hials.no.

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta

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(Signert av prosjektdeltaker, dato)

Forespørsel om deltakelse i forskningsprosjektet

Helsepersonells erfaringer med informasjon og pasientmedvirkning ved akutt hjerteinfarkt

Bakgrunn og formål
Dette prosjektet er et doktorgradsstudie. Ansvarlig virksomhet er NTNU, Institutt for helsevitenskap Ålesund. Formålet med prosjektet er å beskrive erfaringer til pasienter, sykepleiere og leger om informasjon og pasientmedvirkning ved behandling av hjerteinfarkt. Prosjektet er delt i tre deler, hvor del 1 ser på pasienterfaringer, del 2 på sykepleiere sine erfaringer og del 3 på leger sine erfaringer. Målet er at prosjektet skal bidra med ny kunnskap som kan ha betydning for utvikling av gode og helhetlige pasientforløp.

Dette er et spørsmål til deg om å delta i forskningsprosjektet, del 2. Du er valgt fordi du er sykepleier og har kunnskap og erfaring om temaet gjennom ditt arbeid med pasienter med hjerteinfarkt.

Hva innebærer deltakelse i studien?
Prosjektet innebærer at du deltar i et fokusgruppeintervju sammen med 3-7 av dine kollegaer. Intervjuet vil ha en varighet på ca. 60-90 minutter, og det vil bli tatt opp på lydband. Spørsmål i intervjuet vil være i forhold til erfaringer dere har med informasjon og medvirkning i pasientforløpet.

Hva skjer med informasjonen om deg?
Alle personopplysninger vil bli behandlet konfidensielt. Personlige opplysninger som navn og samtykke til deltakelse i studien vil bli oppbevart i låsbart skap, og lagres adskilt fra lydfiler og transkripsjoner av intervjuet.

Personlige opplysninger (som kjønn, alder, utdanning, erfaring og arbeidsplass) vil ikke bli gjengitt på en slik måte at det kan identifisere deg ved publisering av resultater.

Prosjektet skal etter planen avsluttes 31.12.2021. Ved prosjektets slutt vil alle data og opplysninger bli slettet.

Frivillig deltakelse
Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli fjernet.

Dersom du ønsker å delta eller har spørsmål til studien, ta kontakt med Elise K. Bårdsgjerde på telefon 97095503 eller epost: elise.k.bardsgjerde@ntnu.no. Studien er meldt til Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS.

Samtykke til deltakelse i studien
Jeg har mottatt informasjon om studien, og er villig til å delta

- -
(Signert av prosjektdeltaker, dato)

Forespørsel om deltakelse i forskningsprosjektet

Helsepersonells erfaringer med informasjon og pasientmedvirkning ved akutt hjerteinfarkt

Bakgrunn og formål
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Dette er et spørsmål til deg om å delta i forskningsprosjektet, del 3. Du er valgt fordi du er lege og har kunnskap og erfaring om temaet gjennom ditt arbeid med pasienter med hjerteinfarkt.

Hva innebærer deltakelse i studien?
Prosjektet innebærer at du deltar i et individuelt intervju. Intervjuet vil ha en varighet på ca. 60 minutter, og det vil bli tatt opp på lydband. Spørsmål under intervjuet vil være i forhold til hvilke erfaringer du har med informasjon og medvirkning i pasientforløpet.

Hva skjer med informasjonen om deg?
Alle personopplysninger vil bli behandlet konfidensielt. Personlige opplysninger som navn og samtykke til deltakelse i studien vil bli oppbevart i låsbart skap, og lagres adskilt fra lydfiler og transkripsjoner av intervjuet.

Personlige opplysninger (som kjønn, alder, utdanning og erfaring) vil ikke bli gjengitt på en slik måte at det kan identifisere deg ved publisering av resultater.

Prosjektet skal etter planen avsluttes 31.12.2021. Ved prosjektets slutt vil alle data og opplysninger bli slettet.

Frivillig deltakelse
Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert.

Dersom du ønsker å delta eller har spørsmål til studien, ta kontakt med Elise K. Bårdsgjerde på telefon 97095503 eller epost: elise.k.bardsgjerde@ntnu.no. Studien er meldt til Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta

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(Signert av prosjektdeltaker, dato)

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