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## Physicians' perceptions of patient participation in the myocardial infarction pathway

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### Abstract

*Myocardial infarction is an acute, frightening and life-threatening condition for patients who are affected. They need plain and simple information about the disease and the treatment, yet patient participation might be challenging in acute situations. Previous studies have shown that patient participation leads to improved patient satisfaction, cooperation with healthcare professionals and better management of the disease. Physicians have a key role in facilitating patient participation in the healthcare services. This study explores physicians' perceptions of patient participation in the myocardial infarction pathway. In 2018 we interviewed nine experienced physicians in Norway working in different phases of the pathway. Hermeneutics was chosen as the underpinning analytical framework. Four themes illustrated patient participation in the myocardial infarction pathway. Paternalism characterised the acute phase. During hospitalisation the physicians perceived a lack of continuity in physician–patient communication. In the discharge phase, the physicians focused on strengthening health literacy. In the rehabilitation phase, dialogue and shared decision making was central to achieving treatment adherence. We found variations in the level of patient participation along the different phases of the myocardial infarction pathway. Strengthening continuity to ensure patient participation and collaboration between healthcare professionals is essential. The physicians proposed introducing checklists for patient information*

*to enhance interprofessional collaboration and strengthen patient participation.*

*Keywords: cardiology; myocardial infarction; patient participation; patient information; qualitative research; shared decision making*

### 1. Introduction

Myocardial infarction (MI) is a frightening and life-threatening condition for patients who are affected (Dullaghan *et al.* 2014; Fors *et al.* 2014). Treatment of MI consists of acute lifesaving percutaneous coronary intervention (PCI), in addition to long-term treatment with medications and lifestyle changes to prevent recurrence (Neumann *et al.* 2018; Grovatsmark *et al.* 2020). Patient participation is important to motivate patients to adhere to the long-term treatment (Piepoli *et al.* 2016). The hospital stay is short, and in addition an acute and fragmented pathway may limit the opportunities for patient participation (Piepoli *et al.* 2017; Valaker *et al.* 2017). This problem creates a niche regarding how experienced physicians perceive patient participation in different phases of the MI pathway.

Medical treatment normally follows a clinical pathway, which is a standardised procedure to reduce the variability in clinical practice and improve outcomes (Lawal *et al.* 2016). The MI

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pathway consists of four phases. The acute phase includes the symptom debut and first medical contact and is followed by the hospitalisation phase, where treatment is initiated. Invasive treatment with PCI is performed by trained operators and is commonly centralised in high-volume centres (Neumann *et al.* 2018). Therefore, many patients are transferred between hospitals in these phases (Hagen *et al.* 2015; Grovatsmark *et al.* 2020). The two final phases are the discharge phase and the rehabilitation phase, the latter requiring lifetime maintenance through medications and lifestyle changes (Piepoli *et al.* 2017).

Patient participation is often dependent on encouragement and initiative from healthcare professionals (Longtin *et al.* 2010; Angel and Frederiksen 2015; Tobiano *et al.* 2015; Halabi *et al.* 2020). Variations in the perception of patient participation and its content exist between patients and healthcare professionals (Florin *et al.* 2006; Höglund *et al.* 2010; Tobiano *et al.* 2015). The present study explores physicians' perceptions of patient participation in the MI pathway. As our research question, we ask: *how do physicians perceive patient participation in the different phases of the MI pathway?*

In the following we first present previous research on patient participation in the MI pathway. Then, in the data and methodology section, we describe the participants in the study and how the interviews were conducted and analysed. The results section presents physicians' perceptions of patient participation in the different phases of the MI pathway. The discussion and conclusion focus on the most important findings of the study.

## 2. Literature review

Patient participation may lead to improved patient satisfaction, cooperation with and trust in healthcare professionals and self-management of disease (Vahdat *et al.* 2014; Castro *et al.* 2016). Patient participation is a specific form of involvement occurring through mutual relationships, dialogue and, eventually, shared decision making (Thompson 2007). It is a dynamic and complex phenomenon, in which the level of involvement is dependent on the treatment context and can change over time.

Illness may temporarily reduce patients' ability to participate (Thompson *et al.* 2007; Beauchamp and Childress 2019).

Research has shown that healthcare professionals and patients view relevant information as more important than participation in the form of dialogue and shared decision making in the acute phase of an MI (Decker *et al.* 2007; Arnetz *et al.* 2008; Arnetz and Arnetz 2009; Höglund *et al.* 2010; Bårdsgjerde *et al.* 2019; Bårdsgjerde *et al.* 2020). Patients have reported that they need concise and clear information about the clinical pathway (Decker *et al.* 2007; Höglund *et al.* 2010). Studies have shown that a lack of information in the acute phase may create increased fear in patients in an already stressful situation (Bårdsgjerde *et al.* 2019); despite this, though, patients expressed having trust in healthcare professionals and the treatment they received (Arnetz and Arnetz 2009; Dullaghan *et al.* 2014; Valaker *et al.* 2017; Bårdsgjerde *et al.* 2019).

Other studies have highlighted difficulties in achieving shared decision making during acute situations (Müller-Engelmann *et al.* 2011; Pollard *et al.* 2015), especially when the treatment is based on detailed guidelines (Ofstad *et al.* 2014; Pollard *et al.* 2015). MI treatment is based on evidence-based guidelines that provide physicians with clear recommendations regarding initiation of treatment (Neumann *et al.* 2018): involving patients in decision-making processes regarding life-saving treatment may lead to a conflict between enacting the principles of autonomy and beneficence (Beauchamp and Childress 2019). However, one study found that nurses reported instances where elderly and frail patients had declined invasive PCI treatment for MI (Bårdsgjerde *et al.* 2020).

Few studies have explored patients' and healthcare professionals' experiences of patient participation during PCI treatment. One study assessed cardiologists' and patients' perceptions about the informed consent process prior to PCI and their understanding of anticipated treatment benefits. The results showed that patients forgot information they received in this process and seldom participated in treatment decisions (Astin *et al.* 2020). Another study exploring nurses' perceptions of patient participation found similar findings regarding patient information and involvement prior to PCI. The nurses reported that the patients were less

receptive to information in this phase (Bårdsgjerde *et al.* 2020). Studies from patients' and nurses' perspectives have shown that patients, during PCI, are often involved through continuous information (Bårdsgjerde *et al.* 2019; Bårdsgjerde *et al.* 2020). MI is commonly caused by underlying cardiovascular disease (CVD); therefore, secondary prevention, consisting of life-long medication and lifestyle changes, is an important part of the treatment. Despite this, patients experience a lack of information and involvement during hospitalisation (Grovsatmark *et al.* 2020; Mentrup *et al.* 2020). Patients perceive the general information given to them to be satisfactory, yet they find it difficult to adapt it to their individual needs. Generally, patients lack information about lifestyle changes, medications, follow-up after discharge and possible future problems after an MI (Hanssen *et al.* 2005; Oterhals *et al.* 2006; Pettersen *et al.* 2018; Bårdsgjerde *et al.* 2019). Hospital discharge represents a critical moment for therapeutic recommendations and planning of secondary prevention and further follow-up (Zimarino *et al.* 2010). However, Arnetz *et al.* (2008) found that only 62% of physicians discussed lifestyle changes with patients before discharge.

A large majority of patients with MI fail to achieve treatment targets for secondary prevention (Kotseva *et al.* 2016; Piepoli *et al.* 2016; Kotseva *et al.* 2019). A Norwegian study found that on average half of the treatment targets are attained, and that only 1% of patients with MI achieve all of them (Jortveit *et al.* 2019). Cardiac rehabilitation is recommended for patients after MI to increase adherence to medication and lifestyle changes (Piepoli *et al.* 2016; Piepoli *et al.* 2017), although there is a global concern that the participation rate in cardiac rehabilitation programmes is low (Kotseva *et al.* 2016; Olsen *et al.* 2018). No in-depth research has been conducted regarding physicians' perceptions of patient participation in the different phases of the MI pathway.

### 3. Data and methodology

#### 3.1. Participants

The participants were physicians recruited from two hospitals in Norway. The included hospitals were part of the same hospital trust and cooperated

to provide treatment for patients with MI. The hospitals were of different sizes and functions, and it was the larger one that had PCI facilities. These hospitals were chosen because we aimed to cover all phases of the MI pathway. The contact persons were appointed by the management, who recruited the participants. Written informed consent was obtained prior to data collection. The participants were informed that they could withdraw from the study without providing any reason. The study was approved by the Norwegian Centre for Research Data (project number 56617) and by the hospital management.

Purposive sampling was used to select the participants (Patton 2015). To ensure variation and diversity in the sample (Patton 2015; Polit and Beck 2020), female and male physicians of different ages and educational backgrounds were invited to participate. The inclusion criteria were that participating physicians needed to (a) work within cardiac care and (b) have a minimum of one year of experience in cardiac care. Nine physicians participated; demographic data, including information about gender, age, workplace, education and work experience, are presented in Table 1.

Table 1. Demographic data

Demographic data	Participants (N = 9)	
<b>Gender</b>	Men	5
	Women	4
<b>Age (years)</b>	21–30	1
	31–40	4
	41–50	3
	>50	1
<b>Workplace</b>	Hospital with PCI facilities	3
	Hospital without PCI facilities	6
<b>Education</b>	Medical education	9
	Specialised cardiologist/internist	4
	PhD	1
<b>Experience as a physician (years)</b>	1–5	3
	>5–10	1
	>10–15	2
	>15–20	1
	>20	2

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### **3.2. Data collection**

Based on previous research and the research question, an interview guide was created. The main questions were about the physicians' perceptions of providing patient information and patient participation in the different phases of the MI pathway. For the complete interview guide, see Appendix 1.

The individual interviews were conducted from February to June 2018 in meeting rooms at the hospitals with the participant and the interviewer present. The interviews had a mean duration of 43 minutes, ranging between 27 and 58 minutes. A member check was conducted at the end of the interviews to increase credibility (Lincoln and Guba 1985). The interviews were audio-recorded and transcribed verbatim. First translation of quotes from Norwegian to English was done by the authors. After nine interviews, the data were considered saturated after identification of redundancies and patterns (Polit and Beck 2020).

### **3.3. Analytical framework**

A qualitative design with a hermeneutic approach was chosen (Gadamer 2004; Howell 2013; Alvesson and Sköldbberg 2018). This approach involves understanding and interpreting texts. These activities are bound to the context; both the historical and cultural context are important for understanding a phenomenon (Howell 2013).

One key concept in hermeneutics is the hermeneutic circle (Alvesson and Sköldbberg 2018; Landstad and Kvangarsnes 2020). This consists of an alternation between the parts and the whole, indicating that the parts can only be understood based on the whole, and contrarily the whole must be understood based on the parts (Alvesson and Sköldbberg 2018). Gadamer (2004) highlights that prejudices shape our preunderstanding and may promote or inhibit a new understanding. However, 'prejudice' here is a neutral term meaning the conditions of gaining knowledge; prejudice enables us to gain new understanding as our preunderstanding melts together with new insights, which is labelled 'fusion of horizons' by Gadamer (2004). The challenge is to separate valid prejudices from the invalid ones. Prejudices must be tested in dialogue with the past and how we previously looked at a case. Researchers' preunderstanding must be tested with the help of time intervals, and

consequently their understanding will change and adjust in the light of new experiences (Gadamer 2004). A hermeneutic understanding is developed when researchers are exposed to their data and ask questions to interpret the underlying meaning. The goal in hermeneutics is to gain a deeper understanding than what the text in itself expresses (Landstad and Kvangarsnes 2020).

To clarify our preunderstanding of the phenomenon of patient participation, Thompson's (2007) taxonomy of patient participation and the integrative approach to patient participation of Thompson *et al.* (2007) were chosen as a conceptual framework. The taxonomy divides patient involvement into levels, ranging from no involvement to information-seeking/receptive, to information giving, to dialogue and shared decision making and finally to autonomous decision making (Thompson 2007). In the integrative approach, patient participation is understood based on three elements: components, levels and contexts. The components consist of five key areas where the patient may participate: (1) contribution to action; (2) definition of the problem; (3) the reasoning process; (4) decision making and (5) emotional reciprocity. Depending on the context and patient characteristics the level of involvement may vary within and across these five areas for patient participation (Thompson 2007; Thompson *et al.* 2007). Our analysis applied the principle of the hermeneutic circle through an iterative process between the whole and the parts of the interviews in which we utilised our preunderstanding to provide new insight to the physicians' perceptions of patient participation in the MI pathway (Gadamer 2004; Alvesson and Sköldbberg 2018). The analysis was performed by the first and the second authors. To achieve confirmability, the co-authors read the transcripts and all authors discussed the findings (Lincoln and Guba 1985).

To obtain a sense of the whole interview, each interview was read in its entirety. To structure the analysis, the data was coded according to the different phases of the MI pathway: acute, hospitalisation, discharge and rehabilitation. Here, we alternated between the parts (phases) and the pathway as a whole within each interview and across the interviews. To collate the data into preliminary themes, we looked for patterns and diversity across the interviews. We used subthemes

Table 2. *Development of quotes into themes*

Phase	Quotations	Subthemes	Themes
Acute	'You should give them quick and good treatment. Because of the clear recommendations, there will be less information and fewer choices for the patients' (Physician 8)	Clear guidelines for acute treatment	Paternalistic approach in the acute phase
	'We show that we are present, and understand the severity and take control of the situation' (Physician 6)	Non-verbal communication	
Hospitalisation	'On the doctor's round, it is difficult to know what information the patient already has been given' (Physician 6)	Lack of continuity and structure	Lack of continuity in physician–patient communication
	'There is not much time for information, and sometimes you wonder what the patients are able to take in' (Physician 3)	Lack of time and resources	
Discharge	'I say that it is the fuel hoses that are narrowed' (Physician 3)	Knowledge about risk factors	Strengthening health literacy through providing information at discharge
	'It is important that some information is written; then, the patients can take it with them and review it' (Physician 5)	Patient information at discharge	
Rehabilitation	'After all, patients with MI need cardiac rehabilitation programmes with follow-up over time, because it is all about long-term changes' (Physician 7)	Knowledge about lifestyle changes	Dialogue and shared decision making in rehabilitation
	'Most people know what's best for them, but it is hard to put it into practice' (Physician 3)	Motivating patients	

to structure the preliminary themes. These sub-themes were abstracted into four main themes. The analytical process is illustrated in Table 2.

#### 4. Results

The results showed the perceptions of physicians regarding patient participation in the MI pathway. Four themes illustrated the characteristics in patient participation during different phases of the pathway: (1) paternalistic approach in the acute phase; (2) lack of continuity in physician–patient communication; (3) strengthening health literacy through providing information at discharge; and (4) dialogue and shared decision making in rehabilitation.

##### **4.1. Paternalistic approach in the acute phase**

The physicians described the acute phase as streamlined, with standardised recommendations and clear guidelines for treatment. They emphasised that their responsibility in the acute phase was to initiate the appropriate treatment within the time limit (Extract 1).

###### **Extract 1**

You should give them quick and good treatment. Because of the clear recommendations, there will be less information and fewer choices for the patients. (Physician 8)

This suggests that a paternalistic approach was employed by the physicians during the acute phase.

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The physicians considered that there were fewer time constraints for patients diagnosed with non-ST-segment elevation myocardial infarction (NSTEMI) compared to patients with ST-segment elevation myocardial infarction (STEMI). However, only a few physicians provided a detailed discussion of the PCI procedure, even for patients with NSTEMI. Extract 2 is an example of this.

**Extract 2**

Just a simple explanation of the procedure. No details or information about complications and risks. (Physician 7)

Additionally, the physicians reported that patients seldom express interest in discussions regarding their treatment. Nevertheless, some physicians found that elderly patients were more sceptical of invasive treatments, especially treatment that involved being transported over long distances by air ambulance.

No physician reported conducting treatment discussions during the acute phase; despite this, however, they emphasised the importance of the continuous provision of information. The physicians noted that an overwhelming amount of information could lead to a reduction in patients' understanding of the information provided to them; therefore, it was necessary to balance information in the acute phase (Extract 3).

**Extract 3**

Too much information can become overwhelming. (Physician 4)

Acting with professional authority was deemed important (Extract 4).

**Extract 4**

We show that we are present, and understand the severity and take control of the situation. (Physician 6)

The physicians perceived that most patients trusted medical decisions, and that this may result in reduced participation during decision making regarding acute treatment.

The physicians explained that during PCI, patients were given precise information regarding diagnosis and the treatment. They also noted that patients often felt positive at the end of the procedure (Extract 5).

**Extract 5**

The pain is gone, and the patient may experience it as magic. (Physician 1)

The physicians said that most patients were informed of the results and were shown images of their arteries pre- and post-PCI.

**4.2. Lack of continuity in physician–patient communication**

The physicians noted that they rarely met a patient more than once during the patient's hospital stay. Patients often met several physicians due to fragmentations caused by hospital transfers and organisation of the physician's workload. A challenge to continuity was the non-documentation of patient information in their records (Extract 6).

**Extract 6**

On the doctor's round, it is difficult to know what information the patient already has been given. (Physician 6)

Furthermore, the physicians were reliant on nurses regarding the information received by patients, patients' comprehension of such information and the presence of unanswered questions. The physicians thought that checklists for information in the record could be beneficial (Extract 7).

**Extract 7**

I wish we had a checklist in the record that could be ticked for information provided. (Physician 1)

Additionally, some of the physicians emphasised the need for a common checklist shared between hospitals, nurses and physicians.

Another shortcoming was the lack of time to provide patients with information that limited the allowance for patient participation (Extract 8).

**Extract 8**

There is not much time for information, and sometimes you wonder what the patients are able to take in. (Physician 3)

The physicians reported that lack of time and patients' inability to receive information led to a reduction in the communication of information. The physicians reported that the next-of-kin were

often involved when patients had difficulties in understanding information due to age or frailty.

Additionally, the physicians reported a lack of required facilities to allow adequate information provision and patient participation. The hospitals had very few rooms available for private conversations, which hindered dialogue with patients and their next-of-kin.

### **4.3. Strengthening health literacy through providing information at discharge**

The physicians perceived that patients struggled to understand their medical condition and their risks of new cardiac events. They reported that a common misconception among patients is the curative nature of PCI treatments. To better relay this issue to patients, one physician likens the long-term consequences of acute MI to a car engine (Extract 9).

#### **Extract 9**

I say that it is the fuel hoses that are narrowed. (Physician 3)

The physicians noted that they often balanced information regarding disease severity, in order to avoid frightening the patient. However, they found that most patients rarely express their opinions or ask questions about the disease; often, it is the next-of-kin who seek more information. This underscores the importance of the involvement of next-of-kin in increasing the patient's understanding of their medical condition.

The physicians also reported advanced planning of discharge conversations, wherein they summarise the most significant information for patients, in verbal and written form. Written information was considered a necessity (Extract 10).

#### **Extract 10**

It is important that some information is written; then, the patients can take it with them and review it. (Physician 5)

One purpose of written information is to relay the information to next-of-kin. During discharge conversations, physicians focus on providing a summary of the patient's hospital stay, further medications and follow-up.

At discharge, the physicians reported an emphasis on educating patients about their new

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medications. The physicians were concerned that patients would be non-compliant, especially with the antiplatelet medications that prevent the stent from becoming clogged. However, they stated that they tried to educate the patients regarding the side effects as clearly as possible (Extract 11).

#### **Extract 11**

I think it might be a disadvantage to stress side effects too much because then the patient may start fearing those side effects and thus bring on side effects. (Physician 6)

However, the physicians found that some patients were reluctant to take all prescribed medications and would often negotiate regarding which medications were truly necessary.

### **4.4. Dialogue and shared decision making in rehabilitation**

The physicians emphasised the importance of patients participating in cardiac rehabilitation programmes, which they described as the key to achieving the treatment goals of the MI pathway successfully. According to the physicians, these programmes compensated for what was lacking from patients and their next-of-kin during hospitalisation: time and continuity (Extract 12).

#### **Extract 12**

After all, patients with MI need cardiac rehabilitation programmes with follow-up over time, because it is all about long-term changes. (Physician 7)

The physicians associated patient participation with patient responsibility for risk factors and lifestyle changes. They observed challenges in motivating patients to take responsibility for lifestyle changes (Extract 13).

#### **Extract 13**

Most people know what's best for them, but it is hard to put it into practice. (Physician 3)

The physicians also emphasised the importance of motivating patients and following up to achieve lifestyle changes.

The physicians were often surprised by patients' lack of knowledge regarding their disease and treatment upon enrolling in the cardiac rehabilitation

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programme. They noted that patients often had misconceptions regarding PCI treatment and little knowledge of their prescribed medications. The physicians therefore associated participation in cardiac rehabilitation programmes with increased patient medical knowledge and health literacy to improve shared decision making in their treatment. Additionally, the physicians were concerned about the significant number of dropouts from the cardiac rehabilitation programmes (Extract 14).

#### **Extract 14**

We often see that it is the patients who need it the most who decline the offer to participate in cardiac rehabilitation programmes. (Physician 5)

The physicians admitted that taking part in the regular cardiac rehabilitation programmes did not suit every patient. They thought that some patients might attend only certain parts of the programme, e.g., only the theoretical courses. However, the physicians also said that for some parts of the programme patients were rarely invited to attend.

## **5. Discussion**

This study has explored the perceptions of physicians in two hospital settings in Norway regarding patient participation in the different phases of the MI pathway. In the acute phase, the physicians acted paternalistically and prioritised making a correct diagnosis and initiating treatment. Acting for the benefit of the patient was considered more important than patient participation during this phase. During hospitalisation, lack of continuity, time and facilities were barriers to patient participation. At discharge, the physicians focused on strengthening the patients' health literacy through information provision. The physicians considered that cardiac rehabilitation programmes increased health literacy and shared decision making.

This paternalistic approach is common when physicians are committed to acting out of beneficence (Beauchamp and Childress 2019). Guidelines for the treatment of MI are evidence-based with the aim of ensuring provision of the appropriate treatment within strict time limits to achieve the best possible medical outcomes for patients (Neumann *et al.* 2018). The physicians in our study stressed

the necessity of acting with professional authority to ensure that patients received the appropriate treatment.

It is challenging to involve patients during acute situations (Thompson 2007; Kvangarsnes *et al.* 2020). Some patients may lack experience and knowledge, which is an important prerequisite for patients' participation in treatment and care (Cahill 1996; Thompson 2007; Sahlsten *et al.* 2008). The physicians in our study perceived that patients seldom expressed the desire to participate in decision making, except for one population. In some instances, elderly patients wanted to participate in treatment decisions and declined specific management methods, including invasive treatment. This is consistent with previous research (Bowling *et al.* 2008; Doll *et al.* 2019; Bårdsgjerde *et al.* 2020). Therefore, healthcare professionals should be aware of age-related differences in patient participation. Situations where elderly patients decline invasive treatment can be ethically challenging for healthcare professionals, especially when the PCI treatment may be essential. Balancing the principle of respect for autonomy and beneficence (Beauchamp and Childress 2019) requires healthcare professionals to be trained in patient communication and to pay attention to patients' health literacy, including the patient's understanding of the consequences of declining invasive treatment. Although patients' need for participation in the form of dialogue and shared decision making regarding treatment may be low in the acute phase, several studies have shown that information is important (Decker *et al.* 2007; Höglund *et al.* 2010; Bårdsgjerde *et al.* 2019). The physicians in our study emphasised the importance of continuous information provision; however, they experienced that patients were less receptive to information during this phase. This is in line with previous research from a nursing perspective (Bårdsgjerde *et al.* 2020).

This study provides valuable insights into how a physician's ability to promote patient participation is influenced by the fragmentation of the MI pathway caused by hospital transfers and the organisational structure of physicians' work. Lack of time and resources have been identified as obstacles to patient participation (Arnetz *et al.* 2008; Höglund *et al.* 2010). Our study indicates that there is a need to improve the facilitation of



patient participation in the pathway. This is consistent with previous research which has also shown that patients experience a lack of information, participation and coordination in the MI pathway (Oterhals *et al.* 2006; Decker *et al.* 2007; Astin *et al.* 2008; Arnetz and Arnetz 2009; Valaker *et al.* 2017; Pettersen *et al.* 2018; Bårdsgjerde *et al.* 2019; Mentrup *et al.* 2020; Valaker *et al.* 2020). In particular, physicians expressed the view that including checklists in patient records may improve the provision of patient information and participation, resulting in better treatment continuity, patient safety and healthcare quality

As noted above, another concern raised by the physicians in our study was the lack of rooms available for private conversations. The most modern hospital buildings often have single-patient rooms that are suitable rooms for conversations. However, in Norway, many hospital buildings were built before patient participation became a legal right. Shortcomings in the physical environment have previously been reported as an obstacle to patient participation in nursing care (Sahlsten *et al.* 2005).

At discharge, the physicians tried to avoid misunderstandings of the disease, by focusing on treatment issues to strengthen patients' health literacy. Understanding the complex pathophysiology of MI may be difficult for some patients. A common misunderstanding is that the PCI treatment is curative, so that the patient did not understand that prolonged treatment with medication and lifestyle changes are required to prevent new cardiac events (Alsén *et al.* 2008; Astin *et al.* 2009; Sampson *et al.* 2009). The physicians in our study stressed the importance of providing patients with both written and oral information at discharge that summarised the hospital stay, further medication and follow-up. They planned and structured the discharge conversations in advance and reported that patients seldom verbalise questions or thoughts.

The physicians also said that in their experience next-of-kin often demanded more information than patients. Studies have shown that patients have challenges in absorbing the information they receive during hospitalisation (Astin *et al.* 2008; Svavarsdóttir *et al.* 2015). Previous research has also shown that involving next-of-kin in secondary prevention is important, as relatives are often of great support for the patients after discharge

(Nilsson *et al.* 2013; Kähkönen *et al.* 2015). We argue that next-of-kin may be a resource for patients after discharge and should be involved when patient information is provided.

Another concern within the MI pathway is that some patients become non-compliant regarding their medications after discharge (Pettersen *et al.* 2018). One-third of patients with cardiac disease in Norway express strong concerns regarding medication use (Viktil *et al.* 2014). In our study, the physicians seemed to be aware of these challenges; however, they said that they tried to avoid focusing on side effects, though research has shown that these may lead to medication cessation (Pettersen *et al.* 2018). It can be assumed that the physicians' strategy of minimising discussions regarding medications has a detrimental effect on compliance. However, a discussion of each medication may be limited due to time restraints. We believe that pharmacists and other experts are well equipped to support physicians in educating patients in the MI pathway.

The physicians in our study associated patient participation with patients' responsibility for risk factor control and lifestyle changes. They highlighted the importance of patients attending a cardiac rehabilitation programme to increase their health literacy, which is supported by previous research (Valaker *et al.* 2017). The physicians expressed the view that these programmes were designed with time, space and continuity and thus provided a better framework for patient participation. However, the physicians shared a concern regarding the large number of dropouts, which is also a known international problem (Kotseva *et al.* 2016; Olsen *et al.* 2018).

This study has shown that there are several challenges to patient participation in the MI pathway, especially during hospitalisation. The results have revealed new and interesting findings, showing that certain frame factors such as clear clinical guidelines for treatment, a lack of time and resources, patient health literacy and the organisational structure of physicians' workload all have an impact on patient participation. These frame factors are related to the system level, and are not emphasised in the integrative approach to patient participation of Thompson *et al.* (2007), which is a model developed to study patient participation at the micro level.

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## 6. Conclusion

This study has offered new insights regarding physicians' perceptions of patient participation in the MI pathway. A hermeneutic approach was valuable for gaining insights into how the context and a patient's health condition provide premises for patient participation in the different phases of the MI pathway (Patton 2015). It may be, of course, that patient participation as described in our study is influenced by cultural factors (Vahdat *et al.* 2014), but results from a Norwegian context may be applicable to other countries with similar health services.

The use of a conceptual framework can narrow the focus of a study; however, it also makes the studied phenomenon explicit. Thompson and colleagues (Thompson 2007; Thompson *et al.* 2007); relevant conceptual approaches for medicine and healthcare, as they focused on patient participation in the clinical setting. In this study, patient participation was explored from the physicians' perspective. The perspectives of patients and other healthcare professionals on patient participation may vary (Florin *et al.* 2006; Höglund *et al.* 2010; Tobiano *et al.* 2015). We acknowledge this limitation and call for further studies inclusive of other perspectives.

Patient participation is challenging to achieve in the acute and fragmented MI pathway. There is a need to strengthen continuity in patient information and participation. One practical suggestion noted above from the physicians is that implementing checklists in patients' records may be a way to strengthen continuity and ensure patient participation within different phases of the MI pathway and across hospitals when patients are transferred.

We argue that there is a need to develop a new model for patient participation in addition to the three existing elements of components, levels and context. In our study, frame factors were revealed as important for understanding the complexity of patient participation. Our conclusion is that patient participation is complex, and that frame factors at the individual and systemic levels are important for facilitating patient participation.

## Appendix 1: Interview guide

Which experiences do you have in providing patient information in different phases of the MI pathway?

What information was provided?

- In what form was information provided?
- Where and when was information provided?

How do you perceive your role/responsibility as a physician in providing patient information?

How do you cooperate with colleagues in providing patient information?

How do you provide information to next-of-kin?

How do you plan and facilitate meeting the information needs of the patients and their next-of-kin?

Which experiences do you have in providing patient information in different phases of the MI pathway?

How do you understand patient participation?

- Have you encountered patients who do not wish to participate?

How do you perceive your role/responsibility as a physician in promoting patient participation?

How do you plan and facilitate patient participation?

Can you briefly summarise the challenges in providing information and promoting participation among patients with MI (in the different phases of the pathway)?

How can information and patient participation be strengthened ...

- at an individual level?
- at a system level?

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