

Patient participation in acute illness – a metasynthesis of the experiences of patients and health professionals

Michael 2020; 17: Supplement 24: 77–93.

This meta-synthesis shows that patient participation during acute illness can vary from the patient making autonomous choices to patients being met with paternalistic attitudes. When life-saving treatment must be carried out, there is a risk that health professionals must carry out treatment without the patient's consent. Then there is a danger that the patient may experience the situation as offending. Acute illness often leads to difficult coordination between the patient and health professionals, and health professionals experience ethical dilemmas. Patients experience a lack of information and need to talk about existential problems. Treatment of acute illness requires special care to prevent the patient from losing confidence in the health professionals.

Acute illness is an illness that begins abruptly and develops rapidly. Acute is also used to refer to an illness that subsides quickly (Store medisinske leksikon (comprehensive medical encyclopedia)). Acute illness that requires immediate treatment differs from chronic disease, which develops at a slower pace. A special feature of acute illness is that health professionals must act quickly and do not have the opportunity to plan the treatment in advance. In addition, healthcare professionals in acute situations will often need to take immediate action to save the patient's life. This means that acute and critical situations can present special challenges when it comes to ensuring patient participation (Schandl et al. 2017). It is therefore interesting to summarise research on the experiences of patients and healthcare professionals when participating in acute illness. Previous research has shown that patients and healthcare professionals may assess patient participation differently (Florin et al. 2006). It is important to have knowledge of both

perspectives in order to develop the knowledge base for this statutory task (Norwegian Patients' Rights Act 1999).

Research on patient participation reveals both obstacles and conditions for strengthening the patient's participation in healthcare. Some systematic review articles highlight challenges in relation to achieving patient participation (Angel & Frederiksen 2015, Oxelmark et al. 2018, Tobiano et al. 2015). The relationship between patients and health professionals, knowledge, time with the patient, severity of the illness and age have been identified as areas that are important for patient involvement (Angel & Frederiksen 2015). Angel & Frederiksen (2015) found that the competence and willingness of health professionals were fundamental to executing patient participation. Health professionals dominate in different situations, and it is challenging to establish a patient-nurse relationship that balances the power associated with the diverging roles (Angel and Frederiksen 2015).

The study carried out by Oxelmark et al. (2018) on the experiences of nurses in hospitals, emphasises the importance of collaboration between doctor and nurse in order to succeed with patient participation. The patient's insight into the illness, attitudes towards their illness and cultural background also had an impact on the extent to which patient participation could be carried out. The fact that the patient was included in the team was considered important (Oxelmark et al. 2018).

Time, information and knowledge are pointed out as important areas. Information was considered important without it being reflected on whether the patient could absorb the information (Angel and Frederiksen 2015). One study showed that the best information was given to the youngest and healthiest patients (Almborg et al. 2009). It has been found that participation and learning are dependent on the patient's competence and desire to participate (Aadal & Kirkevold 2011). Several studies indicate that the attitudes of nurses may contribute to involving patients in the treatment, but also that they can contribute to excluding the patient from participation (Angel & Frederiksen 2015).

Angel & Frederiksen (2015) point out five areas that are important for patient participation: 1. appreciation of patient participation at the political and organisational level, 2. establishment of contextual frameworks for participation, 3. work on developing the attitudes of health professionals towards patient participation, 4. assessment of the extent to which power can be transferred to the patient, 5. clarification of what the patient can handle.

The overview study carried out by Tobiano et al. (2015) shows that an obstacle to participation is the patient's preferences, rather than the patient's

medical state. Patients choose either an active, passive or collaborative approach. It was more common for patients to choose a passive or collaborative approach towards participation, than to take the initiative and come up with their own proposals. The attitudes of nurses may also have been an obstacle to patient participation, and it was difficult to achieve participation when the nurses were not supportive. If nurses appear to be busy and task-oriented, it prevents participation.

The purpose of this study is to develop a deeper understanding of patient participation in acute illness: How do patients and health professionals experience patient participation in acute illness? We have chosen primary studies on participation in acute exacerbation of chronic obstructive pulmonary disease (COPD), acute myocardial infarction and acute onset of hemodialysis.

Design and method

We have carried out a qualitative metasynthesis of research on the experiences of patients and healthcare professional in relation to patient participation during acute illness (Malterud 2017; Polit and Beck 2012). To show the systematics and transparency in how we have worked during the research process, we chose to use a model developed from metaethnography (Noblit & Hare 1988) which has been further developed and adjusted by Malterud (2017). The model has seven steps that we have followed during the research process and in the presentation of the article. Other articles on qualitative syntheses were also used in the work (Berg & Munthe-Kaas 2013, Lewin et al. 2015).

Search strategy

We started by conducting a broad search with the help of a librarian in the spring of 2019 where 'acute illness and patient participation' were combined. Two of the authors continued with the literature search after we had fine-tuned the research question. In the research literature, terms such as user participation, patient involvement, empowerment, shared decision-making are often used synonymously with patient participation. By using these terms in addition to keywords such as nursing, care, patient experience, we also found articles that deal with relational phenomena to participation. The keywords alone or in combination with myocardial infarction, COPD and haemodialysis were useful. We wanted qualitative primary studies, and therefore also used qualitative research and interview together with various keywords to find relevant articles.

We conducted a search on 24 September 2019 in ORIA where we combined patient participation and qualitative research with the three diagnoses we had chosen. This yielded 37 hits for patient participation in haemodialysis, 119 hits in acute myocardial infarction and 11 articles in COPD exacerbations. In addition, we did some systematic searches and found articles in bibliographies that we considered relevant.

Selecting articles

Table 1 shows the criteria that was used when selecting articles that could contribute to answering the research question.

1.	Qualitative studies based on interviews with patients and health professionals about participation in acute illness
2.	Articles that shed light on participation in acute illness in the diagnoses: acute myocardial infarction, acute exacerbation of COPD and acute onset of haemodialysis
3.	Articles after year 2000
4.	Articles that primarily have a Nordic context
5.	Primary studies
6.	Articles published in journals that are approved publication channels with peer reviews

Table 1: Inclusion criteria

We found 170 articles, of which, we initially read the abstract. Articles that did not highlight the research question or meet the inclusion criteria were excluded. After this, we had 17 articles. Based on this selection, we selected the articles enriched with data. In order for the diagnoses to have approximately the same weight, we chose four articles from each diagnosis. Table 2 shows an overview and relevant information about the 12 selected articles.

Initial author/year	Country	Title	Data collection	Context	Participants
Andersen-Hollekim et al. (2019)	Norway	Patient participation in the clinical pathway - Nurses' perceptions of adults' involvement in haemodialysis	Focus group Semi-structured interview guide	Three dialysis units in Central Norway	Thirteen nurses
Bårdsgjerde et al. (2019)	Norway	Patients' narratives of their patient participation in the myocardial infarction pathway	Individual in-depth interviews Interview guide with open-ended questions	Two cardiac out-patient clinics in Norway	Ten patients
Bårdsgjerde et al. (2020)	Norway	Nurses' perceptions of patient participation in the myocardial infarction pathway	Focus group Interview guide with open-ended questions	Two hospitals in Central Norway	Twenty-two nurses
Decker et al. (2007)	USA, Missouri	Acute Myocardial Infarction Patients' Information Needs Over The Course of Treatment and Recovery	Focus group Theme guide	One hospital in Kansas City, Missouri	Nineteen patients
Höglund et al. (2010)	Sweden	Patient participation during hospitalization for myocardial infarction: perceptions among patients and staff	Focus group Interview guide	Three hospitals in Stockholm, Sweden	Eight patients Seventeen health professionals (doctors, nurses and auxiliary nurses)
Jerpseth et al. (2018)	Norway	Older patients with late-stage COPD: Their illness experiences and involvement in decision-making regarding mechanical ventilation and noninvasive ventilation	Individual interviews with semi-structured interview guide with open-ended questions	Three hospitals in Norway	Twelve patients
Kvangarsnes et al. (2013a)	Norway	Intensive care unit nurses' perceptions of patient participation in the acute phase of chronic obstructive pulmonary disease exacerbation: an interview study	Focus group with open-ended questions	Two hospitals in western Norway	Seventeen nurses
Kvangarsnes et al. (2013b)	Norway	Narratives of breathlessness in chronic obstructive pulmonary disease	Individual in-depth interviews Interview guide with open-ended questions	Two intensive care units at two hospitals in western Norway	Ten patients

Initial author/year	Country	Title	Data collection	Context	Participants
Monaro et al. (2014)	Australia	A 'lost life': coming to terms with haemodialysis	Semi-structured interview	A dialysis unit at a hospital in Sydney, Australia	Eleven patients and five relatives
Silén et al. (2008)	Sweden	Nurses' conceptions of decision-making concerning life-sustaining treatment	Individual semi-structured interview	Three hospitals in Sweden	Thirteen nurses
Torheim and Kvangarsnes (2014)	Norway	How do patients with exacerbated chronic obstructive pulmonary disease experience care in the intensive care unit?	Individual interviews Semi-structured	Two intensive care units at two hospitals in Norway	Ten patients
Walker et al. (2015)	New Zealand	Patient and caregiver values, beliefs and experiences when considering home dialysis as a treatment option: a semi-structured interview study	Individual semi-structured interview	Three dialysis units in New Zealand	43 patients and 9 relatives

Table 2: Selected articles

This meta-synthesis was motivated by the fact that over time the authors have been involved in research on patient participation in various acute situations and had seen a need for a synthesis of the knowledge in this field. It is therefore natural that the meta-synthesis is based on research from the author group, and the literature search added new and important studies.

Usually, relatives do not participate in acute illness and treatment and we have therefore left them out in the search for articles. Some of the articles highlighted the perspectives of both the patient and relatives. We have also included knowledge about the experiences of relatives in the results section.

Quality assessment

The selected primary studies have been published in international journals with peer review. In addition, we used 'Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups' (Tong et al. 2007) to assess the quality of each individual article. Five articles were excluded because they did not meet the quality requirements. This applied to areas such as insufficient discussion of the research topic and theoretical framework, insufficient discussion of methods or unclear presentation of the findings.

Analysis/synthesis

First, we read all the articles to identify what the studies showed about patient participation in acute illness. As a frame of reference, we used the theoretical model of Thompson et al. (2007). The model indicates that there are different degrees of patient participation, from the patient not being involved in the choice of treatment to the patient making autonomous choices (0 - 4). The components of patient participation are: 1. contribution to the course of action, 2. participation in understanding the problem, 3. participation in the discussion of treatment, 4. involvement in the choice of treatment, 5. mutual emotional encounters. In addition, the model emphasises that patient participation is contextual and situation-dependent. This is a holistic model for understanding patient participation.

The model of Thompson et al. (2007) spans between paternalism and the patient making autonomous choices. Paternalism in a medical context suggests that it is the doctor who knows what is best for the patient (Beauchamp & Childress 2013; Store medisinske leksikon (comprehensive medical encyclopedia)). Autonomy is usually understood as self-determination, but in the literature, it is linked to concepts such as capacity and competence (Beauchamp & Childress 2013). Both capacity and competence will be important to problematise in acute illness.

We analysed articles on participation in acute illness related to the various diagnoses and identified experiences with the various components and degree of participation. Then we made a synthesis of the findings which presented participation in acute illness expressed by two themes: 1) patient participation varying between autonomy and paternalism and 2) difficult dialogue and ethical dilemmas.

Results

The findings show both similarities and dissimilarities in experiences associated with patient participation in acute exacerbation of COPD, acute myocardial infarction and acute onset of dialysis. Participation can vary from paternalism with the use of coercion to the patient making autonomous choices. Treatment in acute situations often involves difficult dialogues and ethical dilemmas.

Patient participation fluctuates between autonomy and paternalism

The primary studies showed that patient participation in acute illness could vary between paternalism and the patients making autonomous choices (Bårdsgjerde et al. 2020; Höglund et al. 2010; Kvangarsnes et al. 2013b). When health professionals feel that treatment is urgent, there is a risk that

they will have to carry out life-saving treatment without the patients' consent. A sequence from a focus group interview with intensive care nurses about acute exacerbation of COPD (Kvangarsnes et al. 2013a), illustrates how nurses experience this:

N17: Lack of oxygen, those who do not understand the situation

N14: You are forced to use coercion because they do not understand their own best interests

N17: And what we are talking about here is usually of short duration

N14: You just have to do this to save their lives

The patients, on the other hand, said that during the acute exacerbation of COPD, they were completely dependent on the health professionals, but also that they had a different perception of reality. One woman said that she experienced witches spinning colourful nets around her, and another patient experienced that he was lying on the bottom of a pool unable to swim to the surface of the water. He said: "It feels like you're in a dream world. You are at the bottom of a pool and you want to get to the top of the water to breathe. You just lie there."

The patients talked about good coordination and trust in the health professionals during the acute phase when they needed respiratory assistance. However, some patients reported that health professionals had been too cautious during the treatment situation (Kvangarsnes et al. 2013b). Torheim & Kvangarsnes (2014) point out that treatment in these situations is about vulnerable relationships and it must be taken care of in a way that gives the patient insight into the illness and learning how to cope with future exacerbations.

Myocardial infarction can be life-threatening, and patients are hospitalised for treatment. Patient participation in myocardial infarction from the perspectives of patients and health professionals has been studied, and it was found that both patients and health professionals perceive participation primarily as the transfer of information. Less emphasis was placed on involvement in treatment choices. Participation was considered particularly challenging in the first acute phase, although the health professionals also saw the importance of participation at this point in time. The positive effects of participation were that the patient experienced greater involvement in treatment and was motivated for the rehabilitation process (Höglund et al. 2010).

Bårdsgjerde et al. (2019) found that patients experienced a lack of information in the acute phase. Fragmented processes with helicopter transport created obstacles to continuity in the treatment. But the patients had confidence in the health professionals and experienced them as professional

and diligent practitioners. The patients also spoke of good and detailed information during the treatment.

A study (Decker et al. 2007) conveyed that patients with infarct pain did not want much information during the acute stage, but that it was important to receive it in an understandable language: "When speaking, make sure you use ordinary everyday terms... not medical terms, so the person really understands the procedure." The study showed that patients wanted more information and a more active role later in the patient pathway (Decker et al. 2007).

An interesting finding in one of the studies (Bårdsgjerde et al. 2020) was that health professionals conveyed that some elderly people undergoing a heart attack expressed that they did not want invasive treatment. The health professionals also expressed that these patients were largely listened to. One nurse put it this way: "It's important that elderly patients have the opportunity to say: I don't want invasive treatment. Let me live in peace for the remaining years of my life." This can be interpreted to mean that health professionals respect the patient's preferences and give them precedence over the usual treatment procedures.

The values, preferences and experiences of patients and relatives when choosing home dialysis have been studied (Walker et al. 2015). Despite the fact that all participating units had an established predialysis programme, the patients and relatives experienced that they did not have sufficient knowledge to choose treatment. The participants in the study requested nuanced information about the advantages and disadvantages of different treatment choices. Furthermore, they did not want to be pressured into choosing home dialysis. Some patients did not want to participate in decisions concerning the choice of treatment. The study points out the importance of individually tailored information that met the patient's own values and preferences. In addition, the importance of financial support and work support measures was pointed out, especially for patients in rural areas.

One study reveals the perception of loss characteristic for patients and their family early in dialysis treatment (Monaro et al. 2014). The findings from the study showed that patients and relatives were overwhelmed by shock and grief. Patients experienced loss of self-esteem, personal freedom, altered body image, changed family roles and loss of social connections. The treatment and the consequences it entailed prevent them from participating in family life and society. Relatives experienced always having to be on guard and never being able to relax.

In a study on participation in dialysis treatment, nurses conveyed that participation varied depending on whether the start of treatment was

planned or carried out acutely. The nurses conveyed that it could be difficult to involve patients in treatment choices in acute situations, partly because they could be cognitively impaired by the illness. One nurse put it this way: “Being able to choose the right treatment requires time and continuous dialogue” (Andersen-Hollekim et al. 2019).

Difficult communication and ethical challenges

Communication between the patient and health professionals may be challenging with acute illness. The nurses descriptions about what was important in the coordination with patients amid acute exacerbation of COPD illustrate this (Kvangarsnes et al. 2013a):

N6: Be calm.

N3: Don't press on the mask. Give them some time.

N1 Simple information. Don't talk too much, just enough for them to understand what is going to happen.

N2: But information is very basic.

The nurses talked about how they tried to help the patient feel as though they had control over the treatment situation. They said that it was important to have eye contact, interpret the patient's body language and have a cautious approach. They wanted to convey security and to involve the patient in what was to happen. Relatives are usually not participants in acute treatment, but health professionals convey that they used relatives as a resource in situations where the patient was not able to express themselves verbally (Kvangarsnes et al. 2013a).

The patients said that they had confidence in the health personnel in situations where they received breathing assistance, but they also talked about situations where they felt ignored and were not involved in conversations about the treatment. Patients reported that they experienced feelings of shame associated with the diagnosis and that health professionals had a condescending attitude towards them (Kvangarsnes et al. 2013b).

A patient who had undergone a heart attack conveyed that oral information was the most valuable way to get information in the acute stage: “Patient participation consists of a flow of information from one person to another. However, oral information is probably the most important” (Höglund et al. 2010). The doctors were concerned with how they could strengthen involvement in treatment choices. They considered it important to sit down with the patients to listen to their views and how they had perceived the given information. Thereby, it may be interpreted that the doctors meet the

emotional needs of the patient which is an important component in patient participation. Perceived obstacles to participation were lack of time, lack of personnel and the patient's own preconditions. The patient's need for control, language, cultural differences and age were also experienced as obstacles to participation. Höglund et al. (2010) also points out the importance of patients being informed about their right to participate. The study concluded that if patient participation is to be achieved, patients must be made aware of what rights they have to participate (Höglund et al. 2010).

In one of the primary studies, it emerged that health professionals could experience ethically difficult situations, especially when the chronically ill with advanced illness experienced acute exacerbation and treatment choices were not clarified beforehand (Kvangarsnes et al. 2013a). In some cases, this could lead to patients being connected to a respirator without the patient and family being involved in the decision-making process. In such situations, the importance of the presence of experienced doctors who knew the patient was emphasised (Kvangarsnes et al. 2013a).

Jerpseth et al. (2018) have highlighted the experiences and involvement of elderly patients with advanced COPD in decisions about the choice of treatment. The patients conveyed that their lives were vulnerable and burdensome with frequent and frightening deterioration. The patients experienced that they had unmet needs when it came to talking about how they would die and existential issues. "I don't think I want to live much longer, but no one has told me that my life will soon be over. Death in itself isn't frightening, but the thought of being strangled is." The patients experienced that neither doctors nor nurses invited them to participate in dialogue where transparency, comfort and hope for symptom relief were the topic. Instead of dialogue, patients described one-way communication in which they were informed about what the doctor thought was best for them (Jerpseth et al. 2018).

Acute onset of dialysis was also perceived as difficult in view of the fact that patients should ideally participate in choices about treatment. When treatment had to start acutely, patients could be so affected by the illness that they did not understand the consequences of different choices and health professionals chose the treatment method they themselves were most familiar with. Health professionals point out that patients often did not have the prerequisites to understand the consequences of different treatment choices (Andersen-Hollekim et al. 2019).

A study (Silén et al. 2008) reported that the nurses expressed ambivalence over the extent to which relatives could be involved in decisions to stop life-preserving dialysis treatment. The nurses also conveyed that they expe-

rienced a lack of communication between doctors, nurses, patients and relatives. This could mean that difficult talks were postponed, and that there was not enough time to develop a common understanding of the situation. Silén et al. (2008) also point out that the role of relatives can be difficult when faced with choosing a treatment, and that time pressure could mean that the patient's interests were not adequately safeguarded.

Discussion

The findings show both similarities and differences in experiences with patient participation in acute exacerbation of COPD, acute myocardial infarction and acute onset of haemodialysis. The model of Thompson et al. (2007) was valuable in the coding and synthesis of data from the various primary studies. One of the themes, patient participation, fluctuates between autonomy and paternalism, which are the first two components of Thompson et al. (2007). The other theme, difficult dialogue and ethical dilemmas, is linked to the last three components.

In acute situations, the patient's vital organs may be threatened, potentially requiring immediate treatment which may prevent the patient and relatives from participating. Health professionals have knowledge of what treatment the patient needs and determent over treatment. The patient may be completely dependent on health professionals to survive. Grimen (2008) problematised the risk patients must take when having confidence in health professionals and entrusting them with their health. Health professionals then have a position of power that makes the patient vulnerable. During acute illness, health professionals may have to act against the patient's will to carry out life-saving treatment. The patient may have anxiety or be cognitively impaired due to the illness, thereby making him incapable of cooperating about the treatment. This mean that the health professionals and the patient do not develop a common understanding of what is to happen. Therefore, the patient may find the treatment frightening with the subsequent risk that the patient may lose confidence in the health professionals. Trust is a condition for good coordination. Lost confidence may have a negative impact on future treatment relationships.

Our metasynthesis provides insight into the time aspect and its importance for participation during acute illness. Previous research has pointed out that a lack of time is an obstacle to participation and knowledge sharing between health professionals and patients (Almborg et al. 2009; Angel & Frederiksen 2015; Tobiano et al. 2015). The metasynthesis shows that both healthcare professionals and patients recognise that the time aspect can prevent knowledge sharing and patient participation in treatment. In acute

situations, health professionals may experience ethical dilemmas, especially when they do not have knowledge of the patient and relatives' desired choice of treatment. Different choices can have major consequences for the patient and health professionals must make important choices under time pressure. Legally, there are sections in the Norwegian Patients' Rights Act (Section 4A) that permits treatment in emergency situations when the patient does not have the competence to give consent (Patients' Rights Act, 1999) and the Norwegian Health Personnel Act (Section 7) orders health professionals to provide necessary healthcare in emergency situations (Health Personnel Act, 1999). Those with the medical responsibility in acute illness do not have the same knowledge as if the treatment is planned. It would be an improvement if the professional environment responsible for treatment of acute illness could establish meeting places where ethical and legal dilemmas related to patient participation in acute illness can be discussed.

Jerpseth (2017) has highlighted the involvement of relatives in acute exacerbation of COPD and highlights the importance of preparatory conversations. This metasynthesis supports the fact that it is important that the person with medical responsibility has preliminary discussions about the choice of treatment with patients and relatives with a chronic disease in calm phases of the illness. One finding in the metasynthesis was that the patients experienced a lack of information about the treatment, in addition to the fact that their needs with regard to talking about existential issues were not met.

Situations where the patient makes autonomous choices to refuse treatment also require thorough assessment by health professionals. It may be that the values of the patient diverge from those of the treatment ideology they encounter in the specialist health service. However, it may also be that the patient does not have enough knowledge about the consequences of refusing treatment. Beauchamp & Childress (2013) point out the complexity of assessing whether the patient has the competence to make autonomous choices. To what extent should health professionals influence the patient's choice? How to balance different considerations in a way that takes care of the patient's interests? These are ethical dilemmas that health professionals must balance with acute illness where lack of time is an obstacle to building relationships and sharing knowledge - factors that are presented as conditions for patient participation (Angel & Frederiksen 2015).

The view of the patient's role will vary from country to country and cultures (Boivin et al. 2010). The chosen primary studies were mainly carried out in the Nordic countries. This is because the welfare states in the Nordic countries have common features. In the Nordic countries, it is an ideal that everyone should have equal health services and egalitarian values are highly

respected (Klemsdal 2009). We consider it a strength that we have chosen primary studies from welfare states that were quite similar. Some of the primary studies are from other countries (Decker et al. 2007; Monaro et al. 2014; Walker et al. 2015), but we considered that the findings were valuable to a Nordic context. Although patient participation is an international phenomenon linked to patient safety (WHO 2013), the goal of the metasynthesis was to highlight the phenomenon from a Nordic perspective.

Strengths and weaknesses of the metasynthesis

It is a strength that we had a theoretical model as a starting point for analysing and synthesising the findings (Thompson et al. 2007). The model’s content components provided input for what we should emphasise in the search for experiences with patient participation in the primary studies. At the same time, it may be limiting to choose a particular theoretical model.

A limitation in the article is that we have not applied for and selected articles with the experiences of relatives. Since some of the selected articles also included the experiences of relatives, we have presented these findings in the results section. Relatives play an important role in chronic disease but have a less obvious role in acute illness.

The authors searched for literature collectively and independently. We had good knowledge of research on patient participation and experienced this as a strength when choosing articles. The literature search did not always produce the expected result. This may be related to which keywords were used for the varying articles in the databases. The authors read the varying articles separately and developed a common understanding of the synthesis and presentation of the findings.

<ul style="list-style-type: none"> • Health professionals must have knowledge and awareness of the ethical challenges that may arise during acute illness.
<ul style="list-style-type: none"> • Patients need simple information without professional concepts about the course of action in treatment during acute illness.
<ul style="list-style-type: none"> • Patients do not want to be involved in decisions about choosing treatment for acute illness.
<ul style="list-style-type: none"> • Preliminary discussions should be held with patients and relatives with advanced chronic disease where acute exacerbation is expected.
<ul style="list-style-type: none"> • Meeting places should be established where health professionals can reflect over ethical dilemmas that may arise during acute illness.
<ul style="list-style-type: none"> • Knowledge of patient participation in acute illness should be a topic in nursing education and medical education.

Table 3: Implications for practices.

Conclusion

The metasynthesis showed that the time dimension plays an important role in the degree to which it is possible to involve patients in the choice of treatment. Treatment of acute illness requires special care, as there is a risk that the patient will experience the treatment as threatening and may lose confidence in the health professionals. Arenas should be created where health professionals, who are responsible for acute illness, can participate and reflect on ethical dilemmas that may arise. In this way, healthcare professionals can be better prepared to look after the patient's interests with future acute illness.

Good communication between involved professionals, patients and relatives is required for the patient to experience a sense of involvement in a good way. In the case of chronic disease and exacerbation, it is important that health professionals hold conversations about the choice of treatment during calm phases of the illness, at the same time as they listen to and face the patients and relatives' concerns.

Implications for practices based on the metasynthesis are described in Table 3.

Literature

- Aadal L, Kirkeveld M. (2011) Integrating situated learning theory and neuropsychological research to facilitate patient participation and learning in traumatic brain injury rehabilitation patients. *Brain injury* 25: 717–728.
- Almborg AH, Ulander K, Thulin A et al. (2009) Patients' perceptions of their participation in discharge planning after acute stroke. *Journal of clinical nursing* 18: 199–209.
- Andersen-Hollekim TE, Kvangarsnes M, Landstad BJ et al. (2019) Patient participation in the clinical pathway—Nurses' perceptions of adults' involvement in haemodialysis. *Nursing open* 6: 574–82.
- Angel S, Frederiksen KN. (2015) Challenges in achieving patient participation: a review of how patient participation is addressed in empirical studies. *International journal of nursing studies* 52: 1525–38.
- Beauchamp TL, Childress JF. (2013) *Principles of biomedical ethics*, New York: Oxford University Press.
- Berg RC, Munthe-Kaas H. (2013) Systematiske oversikter og kvalitativ forskning. *Norsk epidemiologi* 23.
- Boivin A, Currie K, Fervers B et al. (2010) Patient and public involvement in clinical guidelines: international experiences and future perspectives. *Qual Saf Health Care* 19: e22–e22.
- Bårdsgjerde EK, Kvangarsnes M, Landstad B et al. (2019) Patient's narratives of their patient participation in the myocardial infarction pathway. *Journal of Advanced Nursing*.
- Bårdsgjerde EK, Landstad BJ, Hole T et al. Nurses' perceptions of patient participation in the myocardial infarction pathway. *Nursing Open*. Published online June 15th, 2020. <https://doi.org/10.1002/nop2.544>

- Decker C, Garavalia L, Chen C et al. (2007) Acute myocardial infarction patients' information needs over the course of treatment and recovery. *Journal of Cardiovascular Nursing* 22: 459–65.
- Florin J, Ehrenberg A, Ehnfors M. (2006) Patient participation in clinical decisionmaking in nursing: a comparative study of nurses' and patients' perceptions. *Journal of clinical nursing* 15: 1498–1508.
- Grimen H. (2008) Profesjon og tillit. Oslo: Universitetsforlaget: 197–215.
- Helsepersonelloven. (1999) Lov om helsepersonell m.v. I: omsorgsdepartementet H-o (ed).
- Höglund AT, Winblad U, Arnetz B et al. (2010) Patient participation during hospitalization for myocardial infarction: perceptions among patients and personnel. *Scandinavian journal of caring sciences* 24: 482–89.
- Jerpseth H. (2017) Involvering av pårørende i beslutninger om akutt behandling av alvorlig kronisk obstruktiv lungesykdom (KOLS) – etiske implikasjoner. *Michael quarterly: publication series of the Norwegian Medical Society* 14: 182–99.
- Jerpseth H, Dahl V, Nortvedt P et al. (2018) Older patients with late-stage COPD: Their illness experiences and involvement in decisionmaking regarding mechanical ventilation and noninvasive ventilation. *Journal of clinical nursing* 27: 582–92.
- Klemsdal L. (2009) Den nordiske modellen i tre deler. *Sosiologi i dag* 39: 3–10.
- Kvangarsnes M, Torheim H, Hole T et al. (2013a) Intensive care unit nurses' perceptions of patient participation in the acute phase of chronic obstructive pulmonary disease exacerbation: an interview study. *Journal of Advanced Nursing* 69: 425–34.
- Kvangarsnes M, Torheim H, Hole T et al. (2013b) Narratives of breathlessness in chronic obstructive pulmonary disease. *Journal of clinical nursing* 22: 3062–70.
- Lewin S, Glenton C, Munthe-Kaas H et al. (2015) Using qualitative evidence in decision making for health and social interventions: an approach to assess confidence in findings from qualitative evidence syntheses (GRADE-CERQual). *PLoS medicine* 12: e1001895.
- Malterud K. (2017) Kvalitativ metasyntese som forskningsmetode i medisin og helsefag, Oslo: Universitetsforlaget.
- Monaro S, Stewart G and Gullick J. (2014) A 'lost life': coming to terms with haemodialysis. *Journal of clinical nursing* 23: 3262–73.
- Noblit GW, Hare RD. (1988) *Meta-ethnography : synthesizing qualitative studies*, Newbury Park, Calif: Sage Publications.
- Oxelmark L, Ulin K, Chaboyer W et al. (2018) Registered Nurses' experiences of patient participation in hospital care: supporting and hindering factors patient participation in care. *Scandinavian journal of caring sciences* 32: 612–21.
- Polit DF and Beck CT. (2012) *Nursing research : generating and assessing evidence for nursing practice*, Philadelphia, Pa: Wolters Kluwer Health.
- Schandl A, Falk A-C, Frank C. (2017) Patient participation in the intensive care unit. *Intensive & Critical Care Nursing* 42: 105–09.
- Silén M, Svantesson M, Ahlström G. (2008) Nurses' conceptions of decision making concerning life-sustaining treatment. *Nursing ethics* 15: 160–73.
- Store medisinske leksikon. Akutt. <https://sml.sn.no/akutt>.
- Store medisinske leksikon. Paternalisme. <https://sml.sn.no/.search?query=paternalisme>.

- Thompson A, Ruusuvaori J, Britten N, et al. (2007) An integrative approach to patient participation in consultations In: Collins S, Britten N, Ruusuvaori J, et al. (eds) *Patient Participation in Health Care Consultations Qualitative Perspectives* Maidenhead: Open University Press 176–93.
- Tobiano G, Marshall A, Bucknall T, et al. (2015) Patient participation in nursing care on medical wards: an integrative review. *International journal of nursing studies* 52: 1107–20.
- 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: 349–57.
- Torheim H and Kvangarsnes M. (2014) How do patients with exacerbated chronic obstructive pulmonary disease experience care in the intensive care unit? *Scandinavian journal of caring sciences* 28: 741–48.
- Walker RC, Howard K, Morton RL et al. (2015) Patient and caregiver values, beliefs and experiences when considering home dialysis as a treatment option: a semi-structured interview study. *Nephrology Dialysis Transplantation* 31: 133–41.
- WHO. (2013) *Exploring patient participation in reducing health-care-related safety risks*. Copenhagen: World Health Organization.

Marit Kvangarsnes

Professor, PhD, Department of Health Sciences, Norwegian University of Science and Technology (NTNU) Ålesund

Research Advisor, Møre og Romsdal Hospital Trust

marit.kvangarsnes@ntnu.no

Torstein Hole

Director

Møre og Romsdal Hospital Trust

and

Associate Professor, PhD

Department of Diagnostic Imaging

Norwegian University of Science and Technology (NTNU)

torstein.hole@helse-mr.no

Elise Kvalsund Bårdsgjerde

PhD candidate, Master's in Advanced Clinical Nursing, Department of Health Sciences, Norwegian University of Science and Technology (NTNU) Ålesund

elise.k.bardsgjerde@ntnu.no

Bodil J. Landstad

Research manager, Nord-Trøndelag Hospital Trust

Professor, PhD, Department of Health Sciences, Mid Sweden University, Sweden

bodil.landstad@miun.se