

Patient participation in chronic disease – a metasynthesis

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Many people live with chronic and serious illnesses. This metasynthesis shows that the role of relatives in chronic and serious illness is not recognised and they are not seen as part of the treatment team. Information and dialogue with patients and relatives over time is a condition for participation. Patients in palliative care wanted emotional support and specific information about the last phase of life in order to plan their own death.

An aging population has led to many people living with chronic and serious illnesses (Øverland et al. 2018). Chronic diseases are long-lasting and often presented as the opposite of acute illnesses, which subside quickly (Store medisinsk leksikon (comprehensive medical encyclopedia)). Chronic diseases are immensely costly for society, patients and the affected families. Insufficient resources have led to debates about priorities between health services and patient groups. In this debate, it is also discussed what responsibility one can expect patients and relatives to have. Could it be that the rhetoric about “The patient’s healthcare services” and user participation lies in the underlying financial motive of the Government to reduce costs and health services for patients?

Patient participation is based on democratic values and legal rights of the patient (Collins et al. 2007; Nylenna 2020; Norwegian Patients’ Rights Act 1999). Other advantages are also highlighted. Patient participation will result in more satisfied patients, better coordination between health professionals and patients, stronger management of illnesses, increased patient safety and fewer complaints about the health services (Collins et al. 2007; Vahdat et al. 2014). What is not as often highlighted is that patient participation is related to health literacy. The WHO (2016) refers to health literacy as a level of knowledge, personal skills and confidence to take action

by changing personal lifestyles and living conditions. By strengthening people's access to health information and the capacity to benefit from it, health literacy becomes critical for patients' autonomy (WHO 2016).

Research shows that both patients and relatives with chronic diseases experience reduced quality of life, and physical, mental and social strain (Sav et al. 2015). This can reduce the capacity to take responsibility for participation in healthcare. The care burden and responsibility for one's own health can become too demanding. This is an important reason to highlight participation in chronic disease from the perspectives of relatives, patients and health professionals.

A review study on treatment choices for chronic disease shows that family members play an important role that has not been recognised in research on and theoretical models for participation (Lamore et al. 2017). They participate in both direct and indirect ways. Personal, cultural and family-related factors are important for how family members participate in palliative care. The study concludes that they play an important role in treatment decisions. Final decisions are often made after the family has been consulted. Family members can thus support both patients and the medical team in choosing treatment (Lamore et al. 2017).

A narrative synthesis sheds light on patient participation in palliative care (Bélanger et al. 2011). The results of this study show that the majority of patients wanted to be involved to some degree, but did not experience that they were involved to the degree they wanted. This is due to the fact that decisions were often delayed and alternative forms of treatment were not discussed. Further research to understand the patient pathway, interactions and interdisciplinary collaboration for co-determination in decision-making processes was sought (Bélanger et al. 2011). Taking care of the patient's identity was emphasised in order to strengthen autonomy for patients with a limited lifespan (Wakefield et al. 2018).

A metasynthesis of qualitative studies on the choice of treatment before starting dialysis, found that co-determination was dependent on the patient's life situation, family and their values. The study highlighted that professional support should emphasise preparing patients and families, giving knowledge about different treatment choices and the consequences of them (Harwood & Clark 2013). A systematic study on treatment choices for dialysis identified factors that impact treatment choices. The study found that patients made decisions with the help of assessments and intuitive feelings. Health professionals emphasised biomedical assessments and the choice was characterised by an instinct to prolong life. When it came to ending dialysis treatment, patients had either a problem-solving or emotional approach.

Families struggled with accepting different treatment choices (Hussain et al. 2015).

Research on emergency care in Municipal Acute Bed Units (MAU) in primary healthcare shows that health personnel experienced this service as patient-centered and flexible (Hole et al. 2015). They found that the service provided good conditions for patient participation and dialogue with patients about issues concerning values related to the treatment. Lappegard & Hjortdahl (2014) found that the patients experienced that this offer of treatment gave them an overall picture, continuity in healthcare and a homely atmosphere. As such, it may appear that care in MAU fulfilled important intentions in the Coordination Reform to strengthen the right of patients and relatives to participate in a good way (Ministry of Health and Care Services 2009).

The purpose of this qualitative metasynthesis is to develop an understanding of patient participation in chronic disease from the perspective of relatives, patients and health professionals. The following research question was formulated: How do relatives, patients and health professionals experience participation in chronic disease? We have chosen to focus on patients from major disease groups, such as cancer, kidney disease, Chronic Obstructive Pulmonary Disease (COPD) and heart failure (Øverland et al. 2018).

Theoretical perspectives

The patient participation model of Thompson et al. (2007), in addition to the theory of medical ethics, is used as a theoretical framework (Beauchamp & Childress 2013). From a health professional perspective, four moral principles are relevant: respect autonomy, do no harm, do the right thing and be fair. In newer and modern medicine, respect for patient autonomy and fairness has been given more priority (Beauchamp & Childress 2013). The principle of autonomy is transparent in the theoretical model of Thompson et al. (2007). The model splits patient participation into levels from 0-4 based on the patient not being involved to the patient making autonomous choices. Patient participation has five components: 1) contribution to action, 2) participation in the understanding of problems, 3) participation in discussions about treatment, 4) involvement in the choice of treatment and 5) mutual emotional reciprocity. Patient involvement is described as dynamic and complex (Thompson et al. 2007). Both Thompson et al. (2007) and Beauchamp & Childress (2013) are concerned that illness can affect and reduce the patient's ability to participate.

Design and method

We have performed a metasynthesis (Lewin et al. 2015; Malterud 2017) of research on the experiences of patients, relatives and health professionals with participation in chronic disease. In the research process and the presentation of this article, we have used a model with seven steps that Malterud (2017) has further developed from the metaethnographic model of Noblit & Hare (1988).

Search strategy

In November 2019, two of the authors conducted a broad search in PubMed where the keywords patient participation, chronic disease and qualitative research were combined. This yielded 63 hits. We went on with keywords related to specific diseases and combined the following: patient participation, qualitative research and heart failure, and we got 11 hits. Furthermore, we did a new search with the keywords: patient participation, haemodialysis and qualitative research which yielded 16 hits.

We did the same search in PubMed for COPD with these keywords: patient participation, qualitative research and COPD, and got 19 hits. Then we did a search for cancer with the keywords: patient participation, qualitative research and cancer. This search was limited to the last ten years and yielded 181 hits. We refined the search further by adding the keyword: palliative care and then got 16 hits. We also did a search with the keywords: palliative care, patient participation and qualitative research limited to the last 10 years. This search yielded 23 hits.

After the search in PubMed, we did a search in ORIA where we combined patient participation, palliative care, cancer, qualitative research limited to peer-reviewed articles in English in the last 10 years, and got 209 hits.

In addition, we did some systematic manual searches and found relevant articles in bibliographies and review articles. Two of these are more than ten years old (Bergs, 2002; Eldh et al. 2006), but we considered them to be significant. The authors have researched patient participation over time and have ample knowledge of research within the field.

Selecting articles

The table below shows the inclusion criteria that were used to select articles for the metasynthesis.

1.	Qualitative studies based on interviews with patients, relatives and health professionals regarding chronic disease
2.	Articles that shed light on patient participation in chronic and serious illness related to cancer, haemodialysis, COPD and heart failure
3.	Articles after year 2000
4.	Primary studies
5.	Articles that primarily have a Nordic context
6.	Articles from journals via approved publishing channels with peer reviews

Table 1: Inclusion criteria.

A total of 357 articles were evaluated based on the title and abstract. Fourteen of the articles were chosen because they were enriched with data that could provide answers to the research question. In the selection of articles, the perspectives of relatives, patients and healthcare professionals are elucidated in relation to the different diagnoses. Four articles are related to renal failure and haemodialysis, two articles to COPD, four to heart failure, one article has patients with COPD and heart failure in the sample, and three of the articles are related to cancer.

Initial author/ year	Country	Title	Data collection	Context	Participants
Aasen et al. (2012b)	Norway	The next of kin of older people undergoing haemodialysis: a discursive perspective on perceptions of participation	Individual interviews Interview guide with open-ended questions	Five hospitals in eastern and western Norway	Seven relatives of patients in need of dialysis
Aasen et al. (2012a)	Norway	Nurses' perceptions of patient participation in hemodialysis treatment	Individual narrative interviews	Five local hospitals in eastern and western Norway	Ten nurses divided between five hospitals
Andersen-Hollem et al. (2020)	Norway	Narratives of patient participation in the clinical pathway of haemodialysis	Individual interviews and interview guide with open-ended questions	Six dialysis units in central Norway	Eleven patients in need of dialysis
Bergs (2002)	Iceland	"The Hidden Client" – women caring for husbands with COPD: their experience of quality of life	Individual, unstructured in-depth interviews	Reykjavik and Akureyri	Six relatives of patients with COPD
Eldh et al. (2006)	Sweden	The meaning of patient participation for patients and nurses at a nurse-led clinic for chronic heart failure	Observations of consultations between patient and nurse, and individual interviews with patients and nurses	Nurse-run outpatient clinic for patients with heart failure at one hospital in Sweden	Three patients with heart failure and two nurses

Initial author/ year	Country	Title	Data collection	Context	Participants
Jerpseth et al. (2017)	Norway	Nurses' role and care practices in decision-making regarding artificial ventilation in late stage pulmonary disease	Focus group and interview guide with open-ended questions	Two university hospitals and three local hospitals in eastern and western Norway	Twenty-six nurses divided into six focus group interviews
Lin et al. (2019)	China and Australia	Perceptions of patient participation in symptom management: A qualitative study with cancer patients, doctors and nurses	Individual semi-structured interviews	Two hospital wards at one specialist hospital for cancer in Shanghai, China	Forty-one patients with cancer, five doctors and seven nurses
Lowey et al. (2013)	USA	Living With Advanced Heart Failure or COPD: Experiences and Goals of Individuals Nearing the End of Life	Individual interviews Semi-structured interview guide, all patients were interviewed twice four weeks between interviews	Two medical-certified home care agencies in western New York	Twenty patients with either heart failure or COPD
Metzger et al. (2013)	USA	Patient and family members' perceptions of palliative care in heart failure	Forty semi-structured in-depth interviews with patients and relatives, some of whom were interviewed twice	Medical centre in New York	Twenty-four patients with heart failure and sixteen relatives
Näsström et al. (2015)	Sweden	Heart failure patients' descriptions of participation in structured home care	Individual interviews and interview guide	Four home care districts in Sweden	Nineteen patients with heart failure
Sommerbakk et al. (2016)	Norway	Barriers to and facilitators for implementing quality improvements in palliative care - results from a qualitative interview study in Norway	Semi-structured interviews, seven individual interviews, two interviews with two participants and two focus group interviews	Two hospitals, one nursing home and two local medical centres in Norway	Twenty participants. Two CEOs, one charge nurse, three doctors and one professional development nurse. Interviews in pairs: Two charge nurses with either a deputy charge nurse or professional development nurse. Focus group interviews with nurses
Tarberg et al. (2019)	Norway	Silent voices: Family caregivers' narratives of involvement in palliative care	Individual interviews with open-ended questions	Central Norway	Eleven relatives of deceased cancer patients

Initial author/ year	Country	Title	Data collection	Context	Participants
Whitty et al. (2012)	Australia	Patient Preferences for the Delivery of Disease Management in Chronic Heart Failure A qualitative study	Individual semi-structured interviews	One hospital in Brisbane, Australia	Twelve patients with heart failure
Årestedt et al. (2019)	Sweden	Patient participation in dialysis care - A qualitative study of patients' and health professionals' perspectives	Focus group and interview guide with open-ended questions	Seven dialysis units at various hospitals	Fifteen patients in need of dialysis, eighteen nurses/doctors and nine managers participated in the focus groups

Table 2: Overview of selected articles.

Quality assessment

We assessed the quality with the aid of the ‘Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups’ (Tong et al. 2007). Articles that did not meet the quality requirements were excluded.

Analysis/synthesis

We identified articles with in-depth descriptions of experiences with patient participation in chronic disease. We created a code tree with three groups: relatives, patients and health professionals, and the corresponding code data (Tong et al. 2007). We analysed three themes that extracted the essence of the experiences with patient participation from the different groups (Malterud, 2017).

Results

The first theme deals with the experience of relatives, the second theme with patients and the third theme the experiences of health professionals.

Poor recognition of relatives

There is little research on how relatives of patients with cancer experience involvement in the palliative pathway. This was the starting point for a study that examined how relatives experienced involvement in different phases (Tarberg et al. 2019). Relatives received a lot of information about diagnosis and treatment in the first phase, but missed having more concrete information about how the disease would develop. Relatives experienced patient-

centered care, but found that their own needs were not met. Many of them did not accept enough healthcare services because the patient did not want health professionals in their home. Caring tasks could overshadow closeness in the relationship between the patient and relative. Relatives perceived that they lacked knowledge of the death process and expressed it in the following way: “If I had known how difficult the final phase would be, I would never have put myself through it.” In situations where the patient was admitted to a nursing home in the last phase of life, relatives experienced that they were well cared for (Tarberg et al. 2019).

Experiences with participation for relatives of elderly dialysis patients has been studied by Aasen et al. (2012b). Relatives experienced that their task was to provide care and to ensure that the patient complied with the treatment regimen. They struggled to get involved in the treatment, and felt forgotten, powerless and excluded. They missed dialogue with health professionals about the treatment and what challenges might arise in the future. One relative expressed the situation as follows: “You live on a volcano ... I’ve received a punishment without a judgment.” Patients in haemodialysis may be cognitively impaired and relatives experienced that the patient did not convey relevant information he had received from health professionals (Aasen et al. 2012b).

One study showed that women who were responsible for spouses with COPD experienced reduced quality of life (Bergs 2002). The women experienced ambivalence in relation to the care burden. On the one hand, they acknowledged that they were at the breaking point of what they could do at the same time as they wanted to take care of their spouse. They experienced that the relationship with the patient had changed in that they experienced emotional and physical distance. One woman missed having support, information and relief from health professionals (Bergs 2002).

Relatives and patients with heart failure experienced that they were poorly prepared for the palliative phase (Metzger et al. 2013). They experienced a lack of information and dialogue about palliative care. On the other hand, when they came in contact with palliative care personnel, they found the care emotionally supportive. They also said that they experienced that the health personnel saw the patient in a holistic perspective, where relief was more important than treatment (Metzger et al. 2013).

Information and dialogue over time as a condition for patient participation

Many patients with chronic disease are dependent on lifelong treatment and find this demanding. Prolonged treatment processes can be frustrating due to both the disease and the demands of the treatment.

The attitude towards patient participation for cancer patients has been studied from the perspective of patients, doctors and nurses (Lin et al. 2019). Patient participation was experienced as a joint action between patient and health professionals in the form of various activities, such as exchange of information, negotiation of treatment choices and self-care. The study concluded that health professionals must value the patient's role in decisions about treatment and care, and guide and facilitate how patients can participate (Lin et al. 2019).

Patient participation has been studied from the perspective of patients and nurses in chronic heart failure by Eldh et al. (2006). In this study, a discrepancy was found between how patients and nurses experienced patient participation. The experiences of patients were interpreted as a responsibility they feel they have and accept. For the nurses, participation was about providing support to enable the patients to make their own choices (Eldh et al. 2006).

Metzger et al. (2013) studied experiences of patients and relatives when encountering palliative care for patients with heart failure. This study indicates that it may be difficult for patients to take in the diagnosis, severity and prognosis. Nevertheless, they experienced that a palliative approach was better to meet their needs and relieve symptoms rather than a biomedical approach where treatment is the goal itself (Metzger et al. 2013).

Research shows that patients with heart failure experienced participation when health professionals knew them well (Näsström et al. 2015; Whitty et al. 2012). The patients in these studies reported that home visits instead of consultations at the hospital provided better preconditions for participation. Näsström et al. (2015) also found that patients perceived it important to be able to treat symptoms themselves, for example, increasing the dose of diuretics when needed. At the same time, they expressed that information and dialogue were more important than participating in decisions.

Patients undergoing haemodialysis experienced that they received information, but were not allowed to be involved in treatment choices (Andersen-Hollekim et al. 2020). A strict treatment regimen and paternalistic attitudes among health professionals prevent patient participation. In addition, they experienced a lack of cooperation between health professionals which led to reduced confidence in dialysis treatment (Andersen-Hollekim et al. 2020). Årestedt et al. (2019) have also examined experiences of both patients and health professionals in dialysis treatment. They experienced that dialysis is a form of treatment that gives continuity in treatment, and facilitates dialogue and individually adapted information. This provided good conditions for patient participation (Årestedt et al. 2019).

Experiences from patients with advanced heart failure and COPD were studied by Lowey et al. (2013). Respiratory problems were perceived the most difficult. Despite the fact that their condition was considered life-threatening by health professionals, the patients had hope and believed they still had time to live. They had clear expectations that the doctor would inform them when the situation was life-threatening. "I have a choice. I can either give up or decide to live with the situation. I choose to live." The patients knew that they were living on borrowed time, but wanted transparent information about diagnosis and prognosis. The patients experienced that the doctors could be hesitant in giving detailed information. "Sometimes the doctor comes in and listens, and when he's about to leave, I ask: How is my heart doing?" He replies, "It's still beating." I say: "That's not what I'm asking. You can't leave the room without talking to me. You can't just come in - listen - and then go. I want to know what awaits me." Many of the patients expressed that they wanted to plan their own death when the doctors informed them that the time had come (Lowey et al. 2013).

Undefined roles and lack of cooperation hinder participation

The role of nurses in decisions about artificial respiration in COPD during the last stage of the disease has been studied (Jerpseth et al. 2017). The nurses experienced that they were in a treatment culture that prevented them from standing up for care values. "There is an ethical dilemma about whether we should give the patient artificial respiration without knowing what the patient actually wants." They perceived their role and responsibility in the participation process as ambiguous and unsatisfactory. In addition, they experienced insufficient interprofessional cooperation in this difficult situation. Not knowing what the patient wanted was perceived as a dilemma. The nurses experienced that they had an undefined role in relation to informing the patient about treatment choices. Ending treatment was perceived as demanding where different interests and values had to be balanced to take care of the patient's wishes (Jerpseth et al. 2017).

The experience of nurses with haemodialysis has also been studied by Aasen et al. (2012a). The nurses conveyed that the treatment was characterised by a paternalistic approach where they used biomedical explanations and ethical principles to justify their actions. At the same time, some of the nurses conveyed that listening to the patients' stories could be a form of participation. It was conveyed that difficult decisions such as stopping dialysis treatment could be left to relatives (Aasen et al. 2012a).

Årestedt et al. (2019) have studied how health professionals and patients experienced patient participation in dialysis treatment. In this study, the

exchange of information between patients and health professionals, to show understanding of each other's perspectives and disease insight, was highlighted as prerequisites for participation. The nurses experienced that when the patients gained insight into the disease their motivation to follow the treatment plans increased in relation to food and drink restrictions (Årestedt et al. 2019).

A study by Sommerbakk et al. (2016) highlights barriers and what can strengthen quality in palliative care. The study was chosen in the metasynthesis because it sheds light on factors at system level. It is important that the head of a department involves the personnel early in an improvement process, and ensures that they have the necessary training in the use of palliative assessment tools and that the personnel's philosophy of care supports the change that is to be implemented. The study pointed out four obstacles for improvement in palliative care: the patient's condition, lack of validated assessment tools, lack of competence and resistance to implementing changes (Sommerbakk et al. 2016).

Discussion

The metasynthesis shows poor recognition of relatives in chronic disease. The patients experienced that information and dialogue over time provided good conditions for participation. Emotional support and specific information about the last phase of life are important for patients to plan their own death. Health professionals experienced undefined roles and a lack of inter-professional collaboration. This created ethical dilemmas. Difficult decisions such as ending treatment could be left to relatives.

Particularly interesting is the finding that relatives are not acknowledged and involved nor considered part of the treatment team in chronic and serious illness. The transfer of treatment tasks from specialist to municipal health services and downsizing of institutions has been happening for many years (Ministry of Health and Care Services 2009; Nylenna 2020). One of the goals is that patients shall receive treatment close to where they live and at home (Ministry of Health and Care Services, 2009). This means that the care burden for relatives has increased without it being problematised in health policy documents (Ministry of Health and Care Services 2009; Ministry of Health and Care Services 2014). This gives grounds to question the Government's motto that "The patient's healthcare services" take care of the interests and needs of relatives. Previous research shows that relatives play an important role in chronic disease (Lamore et al. 2017), but it seems that health professionals do not listen enough, involve relatives and see the value they may have for both the patient and health professionals.

The metasynthesis shows that it can be challenging to take care of patient participation in long-term and serious illness. Many chronically ill people experience periodic exacerbation and need to be admitted to the MAU for emergency care. Research shows that both patients and health professionals have good experiences with such services (Hole et al. 2015; Lappégard & Hjortdahl 2014). They experienced that closeness, continuity and dialogue provided good conditions for participation. This is consistent with the theory of Thompson et al. (2007), which states that patient participation is complex and contextual.

With chronic disease, patients and relatives may be affected by grief and fatigue (Monaro et al. 2014) and this may affect their preconditions for participation (WHO Health literacy). It is important for health professionals to be aware of this when assessing what and how they should be involved in healthcare. The health policy rhetoric portrays patient participation in a positively charged way (Ministry of Health and Care Services, 2009). Together with guidelines for providing cost-effective healthcare services, this can alleviate the risk that the patient and relatives will bear too much of the care burden and responsibility.

In the theoretical model of Thompson et al. (2007) for patient participation, and Beauchamp & Childress' theory of medical ethics (Beauchamp & Childress 2013), relatives are absent. Research shows that relatives play a major role in chronic and serious illness (Aasen et al. 2012b; Lamore et al. 2017; Tarberg et al. 2019), and it is therefore important that they are included in theoretical models and research on patient participation.

The metasynthesis shows what is important to the patient. In the last phase of life, patients are concerned with receiving specific information about the phase and the death process itself. Many people want to plan the end of their lives (Lowey et al. 2013). Health professionals must take this into account in order to facilitate palliative care in accordance with patients' wishes. Health professionals must be aware of the underlying value of the treatment that will or will not be offered. The consequences of the various choices must be clarified for the patient and relatives - and followed up. This requires that those involved in the treatment cooperate and that the roles between the professions are clarified. If not, health professionals may be hesitant to have the difficult conversations and take the measures that the patients and relatives need. Both doctors and nurses have a responsibility to develop good interdisciplinary collaboration that makes them confident when facing the needs of the patient and relatives. Clarified roles can make health professionals stronger when faced with seriously ill and dying patients.

Strengths and weaknesses of the metasynthesis

Views on the patient role will vary from country to country and cultures, however the health services in the Nordic countries are similar (Klemsdal, 2009). This was the reason why we chose studies performed in this context. In the Nordic countries, it is an ideal that everyone should have equal healthcare services and egalitarian values are highly respected. We consider it a strength that we chose to analyse primary studies from countries that are similar. Some of the studies are from other countries (Lin et al. 2019; Lowey et al. 2013; Metzger et al. 2013; Whitty et al. 2012), however we considered that the findings were valuable when transferred to a Nordic context.

The method that was used for the literature search may give the impression that this is a linear process yielding the 'correct results'. The literature search did not give the expected results, and we had to make a 'detour' to find relevant articles. This may be related to the keywords that were used for the various articles in the databases. The fact that the term patient participation has many synonyms also contributed to making the search difficult. Both our clinical experience and ample knowledge of research in the field were strengths when selecting articles.

The selected articles do not provide a complete account of patient participation in all chronic diseases, but we have highlighted articles with findings that we believe were valuable when transferred to other patient groups with long-term illness.

- The role of relatives must be transparent at all levels in health policy documents.
- Relatives must be seen as a resource and part of the treatment team for chronic disease.
- Chronic disease affects and intervenes in the daily life of the patient and relatives. It is therefore important that they are involved in decisions about where and when treatment shall take place.
- Patients and relatives must receive information about different treatment choices and knowledge about the consequences of these.
- Health professionals must listen to patients and provide specific information about what to expect in the last phase of life.
- Interprofessional cooperation with a holistic approach is an important prerequisite for participation.
- Patient and relative participation should be a topic in professional education in health and social sciences.

Table 3: Implications for practices.

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