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Doctoral thesis

NTNU
Norwegian University of Science and Technology
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Contents

Summary

Patient participation represents a shift in the health care system from the previous paternalistic models towards a more democratically oriented practice. This includes value-based interaction models in which the patient and healthcare professionals share decisions regarding the patient’s health. In several countries, including Norway, patient participation is a statutory right, frequently cited, for example, in policy documents. Involving patients and their next of kin has several potential benefits and is particularly relevant for patients with long-term disease trajectories in frequent contact with health services, such as patients on hospital haemodialysis. These patients may be involved in various areas, for example, in treatment decisions and in determining the goals of treatment. Despite being promoted as an ideal for several decades, practical implementation of patient participation has been challenging. This doctoral thesis explores patient participation in different phases of the end-stage renal disease trajectory when patients require dialysis. The thesis comprises three articles that provide knowledge about patient participation based on the experiences of both patients and healthcare professionals. The patients were of working age and were treated with hospital haemodialysis. Their experiences included patient participation with regard to the choice of dialysis modality. The healthcare professionals included nephrologists and registered nurses working in dialysis wards. Our findings indicate different experiences with patient participation in the patient trajectory. Healthcare professionals recognised the choice of dialysis modality as difficult but emphasised that the modality decision should be made by the patient. By contrast, patients did not experience to have made this decision. Patients’ choice was influenced by healthcare professionals following recommended guidelines for dialysis treatment. Some professionals used shared decision-making to reach a modality decision, emphasising the patients’ lifestyle and preferences. The patients in the study experienced to receive good information. Within hospital haemodialysis, they felt safe and cared for, albeit limited regarding their scope of action. Both nephrologists and nurses emphasised the patient’s individual responsibility to adhere to the prescribed treatment and encouraged active participation. Inconsistent values between patients and professionals created tensions that necessitated negotiations. Healthcare professionals focused on evidence-based values. Patients’ priorities were additionally related to life outside the dialysis ward. The patients experienced collaboration within and across the organisation as fragmented. This entailed individual responsibility for navigating the systems. For some patients, this led to a lack of trust in the healthcare system. Both nurses and nephrologists experienced that they worked within organisational frameworks in which efficiency requirements limited their opportunities to promote patient participation.

Norsk sammendrag

Pasientmedvirkning representerer et skifte i helsevesenet fra tidligere paternalistiske modeller mot en mer demokratisk orientert praksis. Dette inkluderer verdibaserte hensyn der pasient og helsepersonell deler beslutninger om pasientens helse. I flere land, inkludert Norge, er pasientmedvirkning en lovfestet rett, mye omtalt blant annet i politiske dokumenter. Å involvere pasienter og pårørende kan gi ulike fordeler og er særlig aktuelt for pasienter med langvarige sykdomsforløp som har hyppig kontakt med helsevesenet. Dette gjelder for eksempel pasienter i sykehusdialyse. Selv om pasientmedvirkning har vært fremmet som et ideal gjennom flere tiår har praktisk gjennomføring vist seg å være utfordrende. Denne doktorgradsavhandlingen utforsker pasientmedvirkning i ulike faser av sykdomsforløpet når pasienter med kronisk nyresvikt trenger dialysebehandling. Avhandlingen består av tre artikler som bidrar med kunnskap om pasientmedvirkning ut fra erfaringene til både pasienter og helsepersonell. Pasientene var i yrkesaktiv alder, ble behandlet med hemodialyse på sykehus og hadde erfaring med pasientmedvirkning i valg av dialysebehandling. Helsepersonell i studien inkluderte leger og sykepleiere i dialyseavdelinger. Resultatene fra avhandlingen viser ulike erfaringer med pasientmedvirkning i pasientforløpet. Helsepersonell erkjente at valg av dialysebehandling var vanskelig, men var opptatt av at pasientene selv skulle bestemme. Pasientene opplevde likevel ikke å ha tatt denne beslutningen. Helsepersonell påvirket pasientenes valg i tråd med anbefalte retningslinjer for dialysebehandling. I noen tilfeller var delte beslutningsprosesser aktivt benyttet i behandlingsvalget, og pasientenes preferanser og livsstil vektlagt. Pasientene opplevde å få god informasjon. De følte seg trygge og ivaretatt på dialyseavdelingen, selv om behandlingen begrenset livsutfoldelsen deres. Både leger og sykepleiere vektla

pasientens egenansvar for å etterleve behandlingen, og oppmuntret aktive pasienter. Ulike verdier mellom pasienter og helsepersonell bidro til spenninger og dannet grunnlag for forhandlinger. Leger og sykepleiere var opptatt av evidens-baserte verdier mens pasientenes prioriteringer var relatert også til livet utenfor dialyseavdelingen. Pasientene opplevde samarbeidet i og på tvers av organisasjonen som fragmentert og tok selv ansvar for å navigere i systemene. For noen pasienter førte dette til utrygghet og manglende tillit til helsevesenet. Både sykepleiere og leger erfarte at de jobbet innenfor organisatoriske rammer hvor krav om effektivitet begrenset mulighetene for å fremme pasientmedvirkning.

Situating my position

I did not enter this field of research with a blank state. Below, I will give a brief description of my position. I graduated as a registered nurse (RN) in Tromsø, Norway, in 1992. When introduced to the field of hospital haemodialysis at the University Hospital of Northern Norway (UNN) in 2000, I found the dependency of patients with end-stage renal disease (ESRD) undergoing hospital haemodialysis to be remarkable. Patients attended their scheduled treatment three to four days a week for months and years. Placed in rows with tubes connecting their bodies to the dialysis machine, they awaited the sessions as the dialyser and the dialysis machine did the job of cleaning their blood of waste and excess fluid. Then two days later, they repeated it. Then again. Most working age patients dialysed temporarily, pending kidney transplant. However, even some individuals in this age were considered too comorbid to receive a donor kidney and would thus require lifelong dialysis treatment. People undergoing hospital haemodialysis were commonly on sick leave or permanently out of work. Education and family could be put on hold. Based on the patients' age, my impression was that older patients more easily seemed to adjust to the units' routines and handle their strict fluid and food restrictions. Some of the younger patients tended to arrive in the dialysis unit with heavy fluid overloads. Sometimes they did not attend their scheduled sessions at all. In addition, they often questioned treatment decisions. Of course, there were individual differences, but my impression was that patients of "younger ages" showed more resilience towards adapting to a patient role.[1] I remember attending a congress presentation entitled "Why Don't They Do As We Tell Them To," concerning medical non-adherence within haemodialysis patients. The presentation was recognisable to me because I was acquainted with nurses' focus on ensuring patients followed the prescribed treatment and the frustration when they did not. I cannot exactly recall the conclusion of this presentation, but because I still remember it, I must have found it interesting. It moreover evoked a curiosity in investigating and questioning the behaviours of patients undergoing haemodialysis.

During my work as a dialysis nurse, I met a woman in her early thirties who had her third kidney transplant rejected and was about to enter haemodialysis again. Experienced with various forms of dialysis, she had now become aware of the possibility of home haemodialysis (HHD) and requested this treatment for herself. In the dialysis unit, none of the staff members was familiar with home haemodialysis. However, to accommodate the patient's wish, staff members, including a nephrologist, a medical technician, the head nurse, and me, visited the University Hospital of Lund, Sweden, to learn from their long-term experiences of home haemodialysis. Being this patient's contact nurse enabled me to contribute to the establishment of home haemodialysis as a treatment option for patients in need of dialysis. To me, this woman represented an empowered patient with self-efficacy[2] and a strong urge to be involved in her own treatment. She skilfully navigated through complex health systems with an extraordinary and impressive determination, refusing to align herself with the traditional patient role. Today, I would say she performed a pioneering work in line with the expert patient. Moreover, she represented a turning point for me in the way I as a nurse viewed my patients – from passive recipients of care to active participants.[3]

My former nursing experiences have shaped the research presented in this thesis. I derived both the study design and the research questions from an interest in

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[1] Role (*sociology)*: the rights, obligations, and expected behaviour patterns associated with a particular social status ("Role," n.d.).

[2] Perceived self-efficacy refers to beliefs in one's abilities to organize and execute the courses of action required to effectuate given aims (Bandura, 1997).

[3] This story has been reproduced with permission from the patient in question.

understanding the complexity of human behaviour. Hence, my nursing experiences from hospital haemodialysis have affected the research tools I chose. Deciding on the study design and research questions further influenced the research methods. When choosing to do qualitative research, one acknowledges the idea of multiple truths (Creswell, 2014; Patton, 2002). Hence, when conducting the sub-studies, I aimed to explore and report these multiple truths of patient participation, as experienced by patients and healthcare professionals. Gaining a deeper understanding of how people experience or perceive the same phenomenon in different ways felt appealing. As a former dialysis nurse, it became important for me to give voice to patients' experiences. Understanding the broader setting of hospital haemodialysis, in which nurses and physicians have their work environment, also entailed the exploration of the professionals' experiences and perceptions.

When initiating this PhD journey, the road ahead was in no way clear to me. I have relied on advice and input from my supervisors both in designing the study and in making the choices I did along the way. Some choices turned out to be wise, while others were not that wise. Therefore, my supervisors' background as well as my own – related to education, employment, and personal experiences – have been central in shaping the study as presented in this thesis.

Acknowledgements

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Thanks to the inspiring people I have met and talked to at congresses and courses. I remember many faces, but unfortunately, I am not very good at names.

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Scientific environment

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List of papers

This thesis is based on the following three sub-studies:

Sub-study I Andersen-Hollekim, T. E., Kvangarsnes, M, Landstad, B. J., Talseth-Palmer, B. A., & Hole, T. (2019). Patient participation in the clinical pathway - Nurses' perceptions of adults' involvement in haemodialysis. *Nursing Open*, *6*(2), 574–582. https://doi.org/10.1002/nop2.241

Sub-study II Andersen-Hollekim, T., Solbjør, M., Kvangarsnes, M., Hole, T., & Landstad, B. J. (2020). Narratives of patient participation in haemodialysis. *Journal of Clinical Nursing*, *29*(13–14), 2293–2305. https://doi.org/10.1111/jocn.15238

Sub-study III Andersen-Hollekim, T., Landstad, B. J., Solbjør, M., Kvangarsnes, M., & Hole, T. (2021). Nephrologists' experiences with patient participation when long-term dialysis is required. *BMC Nephrology*, 22, 58. https://doi.org/10.1186/s12882-021-02261-w

Abbreviations

CKD – Chronic kidney disease
ESRD – End stage renal disease
HD – Haemodialysis
HHD – Home haemodialysis
HRQoL – Health-related quality of life
IHI – Institute for Healthcare Improvement (United Kingdom)
NPM – New Public Management
PD – Peritoneal dialysis
RN – Registered nurse
RRT – Renal replacement therapy
WHO – World Health Organization

1. Introduction

This thesis engages with patient participation when the patient is suffering from end-stage renal disease (ESRD). The overall aim of this thesis was to investigate patients' and healthcare professionals' experiences and perceptions of patient participation in different phases of the ESRD trajectory requiring dialysis. This endeavour comprised a qualitative exploration of patient participation as experienced by working age patients on haemodialysis (HD), dialysis nurses, and nephrologists.

In chapter 2, I will introduce the reader to chronic kidney disease (CKD), ESRD, and what happens when the kidneys fail. Loss of kidney function may be acute or chronic (National Kidney Foundation, n.d.). This thesis does not include acute renal injury (which comes with the potential of remission); rather, the focus is on kidney disease as a chronic long-term condition. CKD progressing into ERSD may still in some cases require emergent dialysis commencement.

Subsequently, I will introduce the concept of patient participation, focusing on current definitions, terms, and approaches. I aim to show the development of patient participation through history and elucidate arguments for patient participation followed by challenges related to practical implementation.

Next, I account for patient participation when dialysis is required, including choice of treatment modality and participation when hospital HD is chosen. The context involves Norwegian hospitals offering HD, although ESRD patients often have contact with other parts of healthcare services as well. I end the background section with stating the overall aim of the study and the aims of the three sub-studies.

2. Background

2.1. When the kidneys fail

The healthy kidneys are organs to filter waste products from the blood and remove excess fluid. They are involved in regulating blood pressure, balancing electrolytes, and promoting red blood cell production (National Kidney Foundation, n.d.). Loss of function may thus result in symptoms related to these areas followed by high mortality rates.

CKD is called an insidious disease; it initially does not show symptoms (National Kidney Foundation, 2015). However, the disease is progressive by nature, diminishing the kidney function over time and eventually requiring renal replacement therapy (RRT) in order for patients to survive (Chan et al., 2019). RRT involves kidney transplantation and/or various forms of dialysis (Chan et al., 2019; Kramer et al., 2019). The World Health Organization (WHO) classifies CKD in stages from 1 to 5. Within stages 1–4, treatment focuses on slowing the disease progression and preventing or treating complications and comorbid conditions (National Kidney Foundation, 2013). Stage 5 represents the end stage of the disease and requires RRT (Chan et al., 2019). Patients with ESRD are afflicted with symptoms of terminal renal failure such as body swelling, dyspnoea, metabolic acidosis, hyperkalaemia, arrhythmias, and anaemia (Mitch, 2007).

Complications from CKD may affect all organ systems (National Kidney Foundation, 2015). Cardiovascular complications represent a frequent cause of morbidity and mortality among CKD/ESRD patients no matter their primary diagnosis (Saad et al., 2015). A healthy lifestyle with physical activity, dietary changes, and adherence to complex medication regimes is recommended to reduce the risk for disease progression and the development of comorbidities (Roberti et al., 2018; Saad et al., 2015). Co-morbidities are still common. Mental health symptoms such as anxiety, depression, and suicidal ideation are reported in addition to sexual dysfunction (Cukor, Rosenthal, Jindal, Brown, & Kimmel, 2009; Ossareh, Tabrizian, Zebarjadi, & Joodat, 2014; Saad et al., 2015). Uremic symptoms like fatigue, loss of appetite, constipation, lethargy, pruritus, altered senses of smell and taste, anorexia, cramps, sleep disturbances, and confusion are all associated with ESRD (National Kidney Foundation, 2015). Maintenance dialysis, to some extent, reduces these ailments, although it does not cure the disease (Chan et al., 2019). ESRD patients have high mortality rates, and the expected remaining lifetime between the general population and those receiving dialysis differs substantially (Kramer et al., 2019). For example, patients aged 20–44 years receiving dialysis are expected to live one-third of the expected remaining lifetime of the age-matched general population, which is about 33 years less. Patients aged 45–64 years are expected to live only a quarter as long as their age-matches in the general population (about 21 years less). Having a kidney transplant gives a far better prognosis, although the expected life span for kidney recipients is still lower than for the general population (Kramer et al., 2019).

2.1.1. Extent and distribution

CKD represents an issue of increasing public health concern (Chan et al., 2019). Worldwide, about 500 million people are affected by CKD and an estimated 3 million people with ESRD receive RRT (Chan et al., 2019; Roberti et al., 2018). Modelling data has suggested that the rates will increase (Liyanage et al., 2015). Several factors have contributed to the expansion, such as improved survival of the general population, reduction in mortality of patients on dialysis, and increased CKD incidence. Broadening the RRT acceptance criteria and greater access to dialysis in low- and middle-income countries have also contributed (Chan et al., 2019).

In 2016, quantifications from the European Renal Association – European Dialysis and Transplant Association (ERA-EDTA) showed that the incidence of RRT for patients with ESRD was 121 per million population (Kramer et al., 2019). Almost two thirds of the patients were men, and over half were aged > 65 years. Nevertheless, 48% of patients commencing RRT in 2016 were aged between 20 and 64 years. Almost a quarter of Europeans (23%) had diabetes mellitus as their primary renal diagnosis, and the initial treatment modality was HD for 84% of patients, peritoneal dialysis for 12%, and pre-emptive transplantation for 4% (Kramer et al., 2019).

2.1.2. Treatment options

Besides kidney transplantation, the choice of RRT applies to hospital HD, home-based dialysis, or, in cases where RRT may be inappropriate – for example, due to severe co-morbidity – conservative non-dialytic care (Chan et al., 2019; Seah, Tan, Srinivas, Wu, & Griva, 2015). Receiving a donor kidney is considered the superior RRT for patients with ESRD (Tonelli et al., 2011). Despite medical follow-up after the transplantation, consequences for daily life are better in terms of physical functioning, engagement in social and recreational activities, independence, work ability, and quality of life compared with patients on dialysis (Purnell et al., 2013). Pre-emptive transplantation, defined as elective transplantation prior to the requirement for chronic dialysis (Brennan & Miller, 2019), allows the patient to avoid dialysis completely (National Kidney Foundation, 2015). Moreover, pre-emptive transplantation improves patient survival compared with transplantation after commencing dialysis. However, the majority of patients who are waiting for a kidney transplant require and receive dialysis pending transplantation (Kramer et al., 2019).

With regard to people who require dialysis, there are two main options: HD, which is a treatment to cleanse the blood outside the patient’s body by means of a dialyser membrane and a dialysis machine (National Kidney Foundation, 2015), or peritoneal dialysis (PD), where dialysis fluid is installed in the abdominal cavity to draw out waste products from the blood passing through vessels lining, before removed manually or by using a machine (National Kidney Foundation, n.d.). The patient can perform both these treatments at home after a period of training, while hospitals offer HD in which healthcare providers run the treatment. Hospital HD dominates as the most common RRT throughout the world (Chan et al., 2019). Performed thrice a week or more, it represents an intensive, time-consuming treatment and influences several aspects of life outside the dialysis unit that affect both patients and their families (Reid, Seymour, & Jones, 2016; Roberti et al., 2018).

Due to the high frequency of co-morbidities, ESRD patients are dependent on coordinated healthcare involving inter-professional teams and clinicians across several disciplines (Murray, Bissonnette, Kryworuchko, Gifford, & Calverley, 2013). This may differ from other chronic conditions. For example, diabetes mellitus require self-care, though patients may continue their preferred lifestyle with some adjustments (Lambrinou, Hansen, & Beulens, 2019). When people commence hospital HD, they experience that activities they previously took for granted are now limited due to the treatment schedules (Moran, Scott, & Darbyshire, 2011; Roberti et al., 2018). Many of these patients are temporarily or permanently out of employment (Hallab & Wish, 2018).

Frequent and/or extended HD results in significant improvements in the patient's physical condition and health-related quality of life (Kliger & Suri, 2016; National Kidney Foundation, 2015). For example, the Haemodialysis Centre of Tassin, France, is well known in the field of nephrology for its beneficial treatment outcomes due to longer and individually adjusted dialysis sessions: 85% of patients undergoing HD in this centre are normotensive without the use of antihypertensive medication (Anvari, Mojazi Amiri, Aristimuno, Chazot, & Nugent, 2013). While longer dialysis sessions represented the 1970s standard, modern in-centre HD is more or less equivalent to a total of 12 hours divided into three treatment sessions a week (Kliger & Suri, 2016; Roberti et al., 2018). Increasing rates of patients with ESRD combined with more effective dialysis are considered the main reasons for this standardisation (Anvari et al., 2013). In the United Kingdom, there is an ongoing randomised controlled trial – "Does NIGHT-time dialysis improve quality of LIFE?" (ISRCTN87042063; https://doi.org/10.1186/ISRCTN87042063) – investigating whether 6-month overnight dialysis improves the quality of life of patients with kidney failure compared with patients undergoing shorter dialysis sessions during the day.

Home-based dialysis is recommended through Norwegian policy documents (The Norwegian Directorate of Health, 2011), providing possibilities for improved clinical and patient-reported outcomes similar to the Haemodialysis Centre of Tassin patients (Anvari et al., 2013; Chan et al., 2019; Chan et al., 2018). In addition, home-based dialysis may be less resource intensive and costly to the healthcare system (Chan et al., 2019; Van den Bosch, Warren, & Rutherford, 2015; Young et al., 2012). Researchers suggest that more patients could be dialysed at home or undertake self-care than are presently doing so (Chan et al., 2019). For instance, PD is suitable for most ESRD patients (Mendelssohn et al., 2009). Frequent treatment sessions reduce the patients' need for medication and provide more flexibility regarding diet and fluids (Anvari et al., 2013). Furthermore, as they decide on when to perform the prescribed treatment themselves, people are not dependent in the same way as when attending hospital HD. Hence, home treatment offers the possibility for people to continue work or education (Cases, Dempster, Davies, & Gamble, 2011). Patients on home-based treatment have been reported to have higher health-related quality of life (HRQoL) compared with patients undergoing hospital HD (Cases et al., 2011; Karkar, Hegbrant, & Strippoli, 2015; Zee et al., 2018).

Some hospitals offer self-care units in which patients themselves perform their dialysis, eventually with various levels of staff assistance if required. For patients living in rural areas, local HD at satellite units is an option (Bennett, 2011a). Dialysis satellites are nurse-run dialysis units in which HD nurses provide most of the care, based on prescriptions made by nephrologists from parent hospitals. Dialysis satellites thus work as an extension of hospital services (Bennett, 2011a).

2.2. Patient participation – what is it?

Tell me and I will forget.
Show me and I will remember.
Involve me and I will understand.
Step back and I will act.[4]

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[4] Several individuals throughout history have been credited with the three first lines in this quotation: Confucius, Xunzi, Hsüntze, Shuo Yuan, and Benjamin Franklin. I have, however, not been able to figure out from where the sentence "Step back and I will act" has arisen.

Patient participation is internationally recognised as a key factor in healthcare processes (Longtin et al., 2010; World Health Organization, 2013), payed widely attention to in both research and health care policies (Barello, Graffigna, & Vegni, 2012). In some countries, including Norway, patient participation is a statutory right for patients and their next of kin (Norwegian Ministry of Health and Care Service-Patients and User Rights Act, 1999). Evidence suggests that patients can be involved and contribute to healthcare in various ways, including choosing an appropriate treatment, reaching a diagnosis, identifying and acting upon side effects, and self-care management (Ocloo & Matthews, 2016). Involving patients and their families can have a number of concrete benefits such as enhanced understanding of illness and treatment, better cooperation and partnership with health providers, increased patient–professional trust, increased patient independency, and improved satisfaction with health care services (Barello et al., 2012; Barnes, Hancock, & Dainton, 2013; Donaldson, 2003). Patient participation is suggested to enhance patient safety by preventing and reducing medical errors (Longtin et al., 2010) and may contribute to changes in service delivery and patient outcomes (Ocloo & Matthews, 2016). In emergency situations, patients may be less able or willing to participate (Ladin et al., 2018; Thompson, 2007). Hence, attention has primarily been given to patient participation with regard to long-term chronic conditions, because this issue is central to treatment decisions and self-care (Barello et al., 2012; Protheroe, Brooks, Chew-Graham, Gardner, & Rogers, 2013). In research, there has been a move from investigations with regard to *whether* patients should be involved to providing attention to favourable circumstances and enablers *for* patient involvement (Snyder & Engström, 2016).

Despite decades of attention and the many expected benefits, there is no established agreement on how to define patient participation (Barello et al., 2012; Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016). An extensive body of literature describes several concepts of the relationship between patients and healthcare systems, such as patient participation, patient-centred care, patient education, patient empowerment, patient engagement, patient involvement, patient activation, and patient partnership (Halabi et al., 2020). All concepts emphasise an active patient or user and take into account that the healthcare system no longer treats patients solely based on their disease but considers each patient’s uniqueness, values, and experiences (Armstrong, 2014; Halabi et al., 2020; Weiss & Britten, 2009). In their review, Castro et al. (2016) characterised individual patient participation by the patients’ involvement at different participation levels in decision-making processes affecting their lives. Based on 13 definitions in the literature – incorporating shared decision-making accomplished through dialogue and validation of experiential as well as expert knowledge – they suggested the following definition: “Individual patient participation revolves around a patient’s rights and opportunities to influence and engage in the decision-making about his care through a dialogue attuned to his preferences, potential and a combination of his experiential and the professional’s expert knowledge” (Castro et al., 2016, p.1929).

In Pub-Med’s MeSH database (https://www.ncbi.nlm.nih.gov/mesh/), “Patient Participation” is defined as “patient involvement in the decision-making process in matters pertaining to health.” It includes the terms “Patient Involvement,” “Patient Empowerment,” “Patient Activation,” and “Patient Engagement.” The definition refers to an involved patient and the decision-making process but excludes the term “*shared* decision-making.” “Decision-making” is defined as “the process of making a selective intellectual judgment when presented with several complex alternatives consisting of several variables, and usually defining a course of action or an idea.”

Coulter and Collins (2011) explained *shared* decision-making as processes in which clinicians and patients work together to make decisions about treatments and management, based on clinical evidence and the patients’ preferences. They further suggested areas where shared decision-making is appropriate, such as whether to undergo screening or diagnostic tests or a medical or surgical procedure, participate in self-management education, take medication, or attempt a lifestyle change (Coulter & Collins, 2011). Shared decision-making is thus especially suitable when there is more than one viable treatment or screening option (Rowland & Politi, 2016). To facilitate a shared decision-making approach, healthcare professionals encourage patients to convey their personal values and preferences and may provide decision aids to raise patients’ awareness and understanding of treatment options and possible outcome (Barry & Edgman-Levitan, 2012).

2.2.1. Levels of patient participation

Patient participation may occur at different levels. According to Castro et al. (2016) these levels are: “micro (individual care), meso (service development; planning, delivery and evaluation of care; education and training of health care providers) and macro (healthcare policy).” Each level is associated with a range of activities (Castro et al., 2016). A recent review by Halabi et al. (2020, p. 7) similarly suggested these levels to be: “the micro level (day-to-day operational management of care), the meso level (hospital governance and institutional decisions that takes place within healthcare institutions) and the macro level (government decisions that determine the basic structure, organisation and funding of the overall healthcare system and healthcare sector).” In Norwegian legal regulations, patient participation is described to take place at three levels. Each level is regulated by its own law. The levels are (1) individual, (2) service, and (3) political/system (Helsebiblioteket.no, 2019).

In this thesis, I consider patient participation on an individual (micro) level, and I have chosen to omit further detailing on the other levels. However, the levels are not mutually exclusive, because meso and macro levels of patient participation come with the potential to affect patient participation on individual (micro) level and vice versa. For example, patient organisations increasingly take an active role at more strategic levels, such as the organisation of care (Castro et al., 2016). I will later account for factors that affect patient participation on the individual level, related to patients as well as healthcare providers.

2.2.2. Patient or user: choice of terms

There are different views with regard to people in need of medical treatment. The “patient” concept has historically been dominant, while the term “user” is a response to consumer-oriented directions in health services, which I account for in section 2.3.2. In their scoping review, Costa, Mercieca-Bebber, Tesson, Seidler, and Lopez (2019) showed how the preference for the term “patient” has persisted over time despite the movement towards person-centred care and shared decision-making. In the reviewed studies, terms like “consumer” and “client,” which may be associated with the commodification of healthcare, were preferred by neither patients nor professionals.

A medical dictionary definition of “patient” is “a person who is undergoing treatment for disease” (“Patient,” n.d.). It adds that a considerable debate is going on about the appropriate use of the patient term. In some institutional settings, the term “patient” is not used because it is assumed to indicate a dependent relationship from the person being treated. Words such as *client*, *resident*, and even *guest* may be used to refer to a person receiving treatment. The term “user” is defined as “a consumer of healthcare or social services” (“User,” n.d.).

So, are people in need of dialysis “patients” or “users”? The term “patient” may indicate a dependent relationship with healthcare professionals. Dependency does not conform to modern ideals of human beings and may thus be considered something that one should avoid. People undergoing hospital HD are nevertheless dependent because their very lives depends on the treatment and the healthcare professionals providing it (Roberti et al., 2018). As I will show later, recent literature has brought in “person,” for example, through the term person-centred care (Håkansson Eklund et al., 2019), to see the whole individual.

The Oxford English dictionary defines the adjective form of patient as “able to accept or tolerate delays, problems, or suffering without becoming annoyed or anxious” (“Patient [adjective],” n.d.).

In this thesis, I rely on Costa et al.’s (2019) use of the term “patient”.

2.3. Patient participation in a historical perspective

Healthcare services have not always expected ill people to participate in matters concerning their own health – nor have the ill themselves. Through times, the patient role has developed from being a passive care recipient to actively seeking information and participating in treatment. These changes have compelled professionals to alter their role. To give the reader a picture of how the concept of patient participation has developed, I would like to frame it from a historical perspective.

2.3.1. Democratisation of health care

Historically, healthcare services have been organised as expert systems, where healthcare professionals held exclusive knowledge of health and disease. The sociologist Talcott Parsons’s concept of the sick role, which dates back to 1951, provided patients with features such as helplessness, technical incompetence, and emotional involvement, depending on medical expertise to solve their health problems (Armstrong, 2014). Parsons equalled the sick role to a patient who presents her or his symptoms to the doctor, accepts the physician’s diagnosis, and then follows the prescribed treatment and does her or his best to restore good health as soon as possible (Armstrong, 2014; Tjora, 2008). The physician was viewed as an expert whose role was to make the decisions to guard the patients’ interest. This implicated that the physician, by profession, knew what was best for patients. By following the doctor’s order, the patient would regain health. Not obeying the doctor’s order, no matter the rationale for doing so, was seen as defaulting from treatment (Armstrong, 2014). This is in accordance with a biomedical model that considers body and mind should be treated separately and neglects the social and psychological factors of the disease (Nettleton, 2013). Parsons idealised the patient–physician relationship, casting both the patient and the professional as archetypes. He did not take into account that not all illness is diagnosed or that many people who suffer from chronic conditions are equipped with knowledge about their illness. Nor did he consider that the unbalanced power, knowledge, and status between patients and professionals influence their relationship, and that physicians do not relate universally to patients (Tjora, 2008). This understanding of roles was nevertheless sustained until late last century, although research in the 1950s to 1960s showed that patients, for different reasons, do not always follow the physician’s recommendations, and that they as individuals possess resources that could be mobilised by disease (Armstrong, 2014).

In accordance with an active patient role, different participating theories and approaches have emerged from dissimilar social movements, policies, and practices (Ocloo & Matthews, 2016). In the 1960s, the empowerment ideology gained a foothold among, for example, civil rights activists in the United States. It was based on the idea of equalising social inequalities and differences of power in society, including in health (Calvès, 2009; Castro et al., 2016). Within this context, Arnstein (1969) developed her well-known framework on patient participation. Representative of the time it was formulated, her "Ladder of Citizen Participation" model is founded in a hierarchical approach in which each ladder rung represents increased citizen power and, thereby, increased influence. Citizen power is accomplished when power is redistributed from the professional to the patient. The lowest rung represents no power at all while the top of the ladder represents full autonomy, or what she calls citizen control (Arnstein, 1969).

In the 1970s and 1980s, the primary-care-oriented Alma Ata Declaration (World Health Organisation, 1978) and the Ottawa Charter for Health Promotion (World Health Organization, 1986) promised "health to all," stating that it is a fundamental human right. The outcome of these movements was a greater democratisation of health services. For instance, the Alma Ata Declaration stated that "the people have the right and duty to participate individually and collectively in the planning and implementation of their health care" (World Health Organisation, 1978). Democratic privileges are emphasised in westernised countries; hence, patient participation is an answer to the idea of democracy. Patients received statutory cooperative rights and were expected to participate actively in issues related to their own health. Increased access to information sources led to higher levels of knowledge among lay people. Thus, the previous steep inequality between the physicians and their patients diminished. In what has been called "information age healthcare," lay people are presumed to have knowledge and skills to care for themselves (Nettleton, 2013). Patient participation represents a shift in healthcare from previously paternalistic[5] models towards a more democratic,

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[5] Paternalism: "attitude and practice that are commonly, though not exclusively, understood as an infringement on the personal freedom and autonomy of a person with a beneficent or protective intent" ("Paternalism, n.d.).

humanistic-oriented practice. This includes value-based considerations in which the patient and the professional share the decisions.

This shift is apparent in language as well. For example, until the 1970s, the medical discipline, in accordance with Parsons, labelled patients not following medical advices as “defaulters” or “non-compliers.” These expressions remained until the 1990s, when they were overtaken by the term “non-adherent,” which still indicates that the “failure” lays with the patient (Armstrong, 2014). Together with the development of patient-centred care, the term “concordance” appeared. Concordance implicates an agreement between the patient and the physician regarding the nature of the problem, possible treatments, and appropriate medication. Lack of concordance thus reflects a failure in the consultation, not a failure in the patient (Armstrong, 2014; Weiss & Britten, 2009).

2.3.2. Health reforms and new roles

New Public Management (NPM) comprises reforms aiming to improve the efficiency of the public sector through market-oriented, neo-liberal forms of governance and may be considered central when conceptualising patient participation. Enacted to increase efficiency and control costs, this change redefined the patient role, considering patients as selective consumers of healthcare, customers, users, clients, and co-producers of health (Lian, 2008).

In Norway, several reform processes in the NPM aftermath have shaped the specialist health service, starting with the 1997 intervention-driven funding in somatic hospitals, in which hospitals’ income depends on the number of patients being treated and their diagnoses (Lian, 2008). This incentive was meant to increase the number of hospital treatments. The Patients’ and Service Users’ Act (Helse- og omsorgsdepartementet-Lov om pasient og brukerrettigheter, 2015) took effect in 2001; it ensures patients’ participation and freedom of choice – for example, the right to choose among treatments and hospitals. In 2002, the hospital reform (Helse- og omsorgsdepartementet-Lov om helseforetak m.m. (helseforetaksloven, 2013)) led to the Norwegian state taking over hospital ownership to improve efficiency and provide greater freedom of action and more patient-centredness. NPM pays attention to privatisation, co-payment, and individual rights, providing patients with the privilege of choosing among services and treatments and the ability to complain if they are not satisfied with health services (Nettleton, 2013; Ravn et al., 2020). Patients, as active citizens, are considered to be responsible for their own health and are expected to act accordingly. Although focusing on the patients' choice, NPM implies that patients may be considered profitable or less profitable for the organisation based on their diagnoses – and they may be prioritised accordingly (Lian, 2008). Furthermore, viewing patients as customers reframes the role of professionals, positioning physicians and nurses as service providers or salespeople who defer to the consumer's demand (Lian, 2008; Pilnick & Dingwall, 2011).

Theorising patient participation in the NPM era, Hickey and Kipping (1998) distinguished between the *consumer* approach and the *democratisation* approach. Their consumer approach concerns providing patients with information but not including them in the process of decision-making. The democratisation approach emphasises patient control, in which the patient makes the decision and decides whether to involve others. In between these approaches are consultation and partnership. Consultation comprises professionals seeking the patients' views and deciding whether these should be considered in the decision-making. Partnership involves patients and professionals negotiating and making shared decisions. As Arnstein (1969), Hickey and Kipping (1998) emphasise the redistribution of power from healthcare professionals to patients.

Reforms related to cooperation – for example, the Norwegian Coordination Reform (Helse-og omsorgsdepartementet-St.meld. nr. 47, 2008–2009), have further contributed to focus on "the patients' health care system," adopting slogans such as "no decision about me, without me"[6] (Coulter & Collins, 2011). Likewise, introducing the concept of asking *what matters to you?* rather than *what is the matter?* (Barry & Edgman-Levitan, 2012) in healthcare consultations increases awareness among professionals about how patients' values and preferences could drive customised plans of care through shared

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[6] "Nothing about me without me" (Billingham, 1998).

decision-making. The idea of this concept is to address the patient as a person with needs and preferences beyond just the medical perspective considered when asking *What is the matter?* Hence, it fits in with person-centred care (Håkansson Eklund et al., 2019), a term I will discuss in section 2.4.1. According to the United Kingdom Institute for Healthcare Improvement (IHI) the four words “what matters to you” are key to create personal engagements with patients and their family members, to get a deeper understanding of what is important to them, as a means to develop partnerships for co-creating health.

With respect to the complexity of modern healthcare, Tritter (2009) criticised Arnstein and other frameworks inspired by her work, arguing that the complex nature of power is not amenable to redistribution. By focusing unilaterally on power, there is a danger of undermining the value and potential that lies within the involvement process itself. In previous models, patient participation becomes a contest between two parties competing over power control, but Tritter (2009) claimed that hierarchising knowledge will not facilitate patient participation. Rather, layperson and professional knowledge should be viewed as complementary, accompanied by a willingness to recognise the differences. His proposed model distinguishes between direct and indirect and proactive and reactive patient involvement. Indirect participation, he claimed, represents most of the participation. In this approach, patients’ views are sought but health service managers and clinical staff make the decision. In direct participation, patients take part in actual decision-making. Reactive participation determines whether participation is responding to a pre-existing agenda, while proactive participation considers whether participation shapes the agenda. Ultimately, he suggested an alternative analogy to comprehend patient participation – the “mosaic” rather than the “ladder” – claiming that the mosaic creates a picture that underpins the complex, dynamic nature of patient participation (Tritter, 2009).

As I have shown in this section, patient participation may be considered from two directions that stem from divergent ideologies. The former is democratic oriented and comprises involving patients along different levels of healthcare. The latter is consumerist oriented, viewing patients as customers or consumers of healthcare, responsible for their own health, and equipped with the freedom of choosing between services. In this setting, theories have arisen as an answer to time-related issues.

2.4. Terms related to patient participation

The development of “the patient’s health care system” comes with various terms that can be understood as a response to earlier perceived limitations of biomedical traditions and traditional perceptions of patients as passive care recipients (Armstrong, 2014; Håkansson Eklund et al., 2019). Thus, I would like to account for the terms patient-centred care, patient empowerment, and the expert patient.

2.4.1. Patient-centred care

Introduced by Michael and Enid Balint in 1969, patient-centred care requires the carer to understand holistically the patient as a unique human being when forming a diagnosis of the patient’s illness. It stems from the idea that a solely biomedical perspective is insufficient to understand the patients’ problem or experience of illness and treatment (Håkansson Eklund et al., 2019). The later term person-centred care precisely backs the idea of patients entailing different roles besides being patients (Håkansson Eklund et al., 2019). The terms are similar in the way they consider the ill person. In their review, Håkansson Eklund et al. (2019) disclosed the following factors appearing in both terms: (1) empathy, (2) respect, (3) engagement, (4) relationship, (5) communication, (6) shared decision-making, (7) holistic focus, (8) individualised focus, and (9) coordinated care. However, the goal of *patient*-centred care is a functional life while the goal of *person*-centred care is a meaningful life. Hence, person-centred care broadens and extends the perspective of patient-centred care because it considers the whole life of the patient. A functional life may be important for having a meaningful life, and the two concepts could therefore be used as parallels (Håkansson Eklund et al., 2019). Acquainted with the person behind the disease, healthcare providers may better support the patients’ own capacity to restore autonomy and regain control of life areas that are important to them (Eldh, Ekman, & Ehnfors, 2006; Gulbrandsen et al., 2016; Håkansson Eklund et al., 2019).

The World Health Organization suggests the term people-centred care: care that is focused and organised around the health needs and expectations of people and communities rather than on diseases. People-centred care extends the concept of patient-centred care to individuals, families, communities, and society. Whereas patient-centred care is commonly understood as focusing on the individual seeking care – the patient – people-centred care encompasses these clinical encounters and also includes attention to the health of people in their communities and their crucial role in shaping health policy and health services (WHO, n.d.-a).

In their review, Castro et al. (2016, p.1930) proposed the following definition for patient-centredness: “a biopsychosocial approach and attitude that aims to deliver care that is respectful, individualized and empowering. It implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy and shared knowledge.”

Patient-centred care brings forth the term “integrated care”. Integrated care is considered to be the opposite to fragmented and episodic care; it is synonymously used with terms like “coordinated care” and “seamless care”. The World Health Organization (2008) proposed one working definition, in which the focus is to provide the “right care” in the “right place.” Integrated service delivery is “the organization and management of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money” (World Health Organization, 2008). Integrated care considers the patient in a holistic perspective and is hence related to patient-centred care.

Integrated people-centred health services means putting the comprehensive needs of people and communities, not only diseases, at the centre of health systems, and empowering people to have a more active role in their own health (WHO, n.d.-b).

2.4.2. Patient empowerment

The 1960s empowerment ideology was based on the idea of equalising social inequalities and differences of power in society, including in health (Calvès, 2009; Castro et al., 2016). The World Health Organization (1998) defines empowerment as “a process through which people gain greater control over decisions and actions affecting their health.” Although related to patient participation and patient-centredness, patient empowerment is considered a broader concept (Castro et al., 2016), viewed as a process as well as an outcome (O'Byrne, 2018). Processes – for example, an individual’s actions and engagement within a certain context – may lead to an outcome of either empowerment or disempowerment. When individuals feels empowered, they have a greater sense of intrinsic motivation and self-confidence, while a feeling of disempowerment may lead to decreased levels of this motivation and self-confidence (O'Byrne, 2018). According to the review of Castro et al. (2016), four antecedents are necessary for the patients’ empowerment. These are co-creation of knowledge through dialogue between patients and healthcare providers, a patient-centred approach, promoting a sufficient level of health literacy in patients (I account for the term “health literacy” in section 2.5.4), and active patient participation. The authors emphasised that patient empowerment is a *personal* process that patients complete independently –for example, by being involved in their health care decisions (Castro et al., 2016). Empowerment does not involve doing something to patients, such as convincing, persuading, “empowering,” or changing patients – or making them change (Anderson & Funnell, 2010). Hence, healthcare professionals cannot empower their patients, although they may facilitate factors that could lead to patient empowerment, such as patient participation.

2.4.3. The expert patient

The concept of the expert patient is based on the idea of equipping patients with chronic diseases with the skills to manage their long-term condition (Donaldson, 2003; Greenhalgh, 2009). The term first appeared in a report presented to the United Kingdom Parliament in 1999 as an initiative to help deal with chronic illness. Expert patients are "people living with a long-term health condition who are able to take more control over their health by understanding and managing their conditions, leading to an improved quality of life" (Tidy, 2015, p.1). The advantages of being an expert patient suggest that patients trained in self-management tend to be more confident and less anxious (Lorig et al., 2001). Patients with confidence in their ability to manage their condition are considered likely to have better treatment outcomes (Donaldson, 2003; Greenhalgh, 2009). As holders of personal and experiential knowledge about their illness, expert patients can identify needs potentially not considered by healthcare professionals. These could, for example, relate to illness experiences, not only by means of being burdened by ill health, but also meaning given to these experiences and influenced by patients' social and cultural background (Cordier, 2014). Disease, by means of pathological changes in the function and/or structure of the body's organ systems, could be present with or without illness (Cordier, 2014). This may be the case for CKD patients in early stages of the disease. Identifying and solving problems successfully enhances the patients' sense of self-efficacy, and being in control of the disease should improve HRQoL (Lorig & Holman, 2003).

The expert patient initiative was commenced to help people manage chronic illness. However, the increasing number of people suffering from chronic diseases has led to financial challenges related to health service overloads (van de Bovenkamp & Dwarswaard, 2017). Transferring responsibility from healthcare services to the patient is considered to be a way of solving issues related to the individual's need for healthcare (Ravn et al., 2020; van de Bovenkamp & Dwarswaard, 2017). The self-efficacy of expert patients is suggested to improve the patients' health status, increase their coping with features of chronic disease such as role limitation, and, finally, reduce their dependence on as well as their need for healthcare services (Donaldson, 2003; Lorig & Holman, 2003). Although the expert patient model has been prominent in the face of chronic illness, Greenhalgh (2009) claimed that it is time to move beyond the self-management programmes and emphasise more holistic models that focus on individual health challenges. This may be considered to be in accordance with patient-centred care.

2.5. Factors affecting patient participation

Despite policy drivers stimulating a shift towards patient-centred care, patient participation has proven difficult to implement as part of the healthcare services' regular practice (Castro et al., 2016; Elwyn et al., 2012; Légaré, Ratté, Gravel, & Graham, 2008). In a study related to implementation of shared decision-making in Germany, France, Spain, the Netherlands, and the United Kingdom, all countries had employed research groups to work on shared decision-making issues, patient groups called for its wider use, and professional standards emphasised it. However, the study found no evidence of a systematic approach to implementation in any of the countries (Coulter, Härter, Moumjid-Ferdjaoui, Perestelo-Perez, & Van Der Weijden, 2015). In Scandinavia, The Swedish Agency for Health and Care Services Analysis (2017) concluded in their evaluation that the patient's position had not been strengthened since the 2015 introduction of the Swedish Patient Act; they called it an "act without impact." The analysis disclosed no "pooled improvement in the patient's actual position in any of the areas covered by the Patient Act." For example, patients experienced that their information requirements were not being met, nor did the healthcare service seek their participation. There seemed to be a continuing lack of awareness of patient participation among healthcare providers (The Swedish Agency for Health and Care Services Analysis, 2017). With patient participation being advocated in westernised healthcare for decades, these results may raise the question: why is it so?

Several factors may affect or complicate patient participation, such as factors linked to the design of healthcare services, presumptions of roles, power imbalance, and interpersonal characteristics of both healthcare professionals and patients (Joseph-Williams, Elwyn, & Edwards, 2014). Patient participation also provides the possibility for patients not to participate, although patients who prefer a passive role represent a minority (Frosch, May, Rendle, Tietbohl, & Elwyn, 2012; Protheroe et al., 2013). In this section, I focus on factors with potential to affect patient participation on individual level, including patients and healthcare professionals. Other factors than those accounted for may still be present.

2.5.1. Lack of conceptual consensus

One important obstacle to the implementation of patient participation may be healthcare professionals' lack of a conceptual understanding and agreement of what patient participation is, as stated by Barello et al. (2012) and Castro et al. (2016). Not having a conceptual consensus leads to poor communication, and professionals may believe that they are practicing patient participation while they practice in a conventional way (Castro et al., 2016). The variable understandings among professionals may also differ substantially from the patients' understanding. Thórarinsdóttir and Kristjánsson (2013) emphasised this point: they considered patient participation from the perspective of patients with varying diagnoses to be a broad concept including dialogue, involvement in care, mutual shared knowledge, and management of self-care. The authors stated that communication difficulties with healthcare professionals could, on the one hand, lead to healthcare professionals not allowing patient participation or, on the other hand, force patients into unwanted participation. Hence, patient participation was not always patient-centred (Thórarinsdóttir & Kristjánsson, 2013).

2.5.2. Role expectations

The maintenance of well-implemented and normative roles for both patients and professionals are among key obstacles in patient participation (Frosch et al., 2012). In paternalistic healthcare, professionals make the decisions and expect patients to follow medical recommendations (Armstrong, 2014). On the one hand, professionals could find it difficult to accept patients' wishes and needs if they do not follow medical recommendations or professional assessments (Solbjør & Steinsbekk, 2011). They may feel that an active, questioning patient undermines their professional competence and judgements (Frosch et al., 2012). On the other hand, patients could expect that professionals are responsible for their patients and, in return, position themselves as passive care recipients awaiting medical advice (Protheroe et al., 2013). Normative expectations of a passive patient preclude patients from activities like seeking information or asking questions (Protheroe et al., 2013).

2.5.3. Power inequities

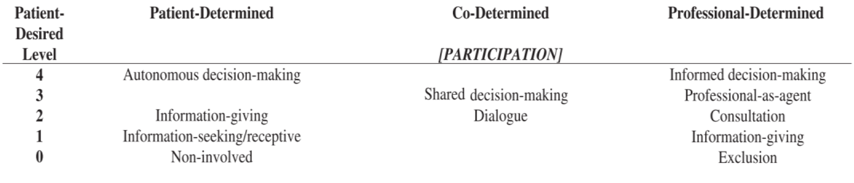
Illness generates insecurity, vulnerability, and powerlessness. It puts the patient in a dependent position and creates an imbalance in the patient–professional relationship, as described in a Norwegian study by Gulbrandsen et al. (2016). Being ill implicates obeying the structural hierarchy of healthcare, which may jeopardise patients' autonomy (Gulbrandsen et al., 2016). Depending on medical treatment implies trusting the system on which you depend. Patients' trust depends on expectations about both professionals' individual competence and the general competence of institutions, including their willingness to act in the patients' interest (Rowe & Calnan, 2006). To maintain a healthy relationship with those providing treatment and care, patients may avoid opposing or disagreeing with medical recommendations (Beedholm & Frederiksen, 2019; Frosch et al., 2012). They may leave decisions to professionals despite wanting to have a say in their treatment (Frosch et al., 2012; Joseph-Williams et al., 2014).

2.5.4. Patients' health literacy

Health literacy is considered to be an important factor to achieve patient participation (Longtin et al., 2010; Protheroe et al., 2013). Health literacy refers to the individual's capacity to obtain, process, and understand health information and the services needed to make an appropriate decision related to one's own health (Rowland & Politi, 2016). Research has demonstrated that patients with limited health literacy are overrepresented among patients with chronic illness (Rowland & Politi, 2016). Nevertheless, there are nuances in health literacy related to, for example, socioeconomic levels. Protheroe et al. (2013) showed how patients with chronic illness and of higher socioeconomic levels were more health literate – and therefore more likely to participate – by means of asking questions or manoeuvre themselves through healthcare services. Patients of lower socioeconomic levels tended to adopt passive and traditional patient roles (Protheroe et al., 2013). Thus, and despite health policy encouraging participation, patients may not be equally disposed to participate. However, professionals have been shown to subject patients of lower socioeconomic levels to more directive consultations, expecting them to not want to or have the capacity to participate (Longtin et al., 2010). Hence, healthcare providers possess power to encourage or hinder participation (Angel & Frederiksen, 2015). The study of Frosch et al. (2012) included highly educated and socially privileged participants likely to assert themselves in a medical consultation but who still positioned themselves as deferent to their physicians.

2.5.5. Context

The clinical context influences patient participation (Street & Gordon, 2006). For example, emergencies in which the patient is unfamiliar with the situation may require lower levels of patient participation. Long-term conditions in which patients are familiar with both the disease and the context require higher levels of participation (Greenup & Peppercorn, 2016; Thompson, 2007). Patients typically do not prefer the extremes, such as autonomous decision-making or no involvement; rather, their desired level is in the middle (Greenup & Peppercorn, 2016). The framework of Thompson (2007) details different levels of patient participation (Figure 1). Thompson derived his taxonomy of patient-desired involvement from an exploration of which levels patients preferred. He contrasted this level with professional-determined levels of involvement identified from the literature. He emphasised context as an important factor for patient participation, suggesting patients may want to participate in some areas and leave decisions to professionals in others. Context could depend on the type and seriousness of the illness, personal characteristics, and patient–professional relationships. The patients’ need to participate may change over time, even in a similar context, and patients may move between different levels of participation. In his taxonomy, he viewed patient participation as co-determined between patients and professionals and occurring through dialogue and shared decision-making (Thompson, 2007).



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

Fig. 2. Levels of involvement.

Figure 1. The taxonomy of patient involvement (adapted from Thompson (2007).

2.5.6. Other factors

Not all patients are aware of their legal right to participate, or language, culture, ethnic origin, and former healthcare experiences could be barriers (Joseph-Williams et al., 2014; Protheroe et al., 2013; Schinkel, Schouten, Kerpiclik, Van Den Putte, & Van Weert, 2019). For example, African- and Hispanic-Americans are less inclined to participate in decision-making compared with Caucasians. The reasons for this disparity remains unclear, although issues related to language, communication style, education, and autonomy in matters of health are suggested to play a role (Longtin et al., 2010).

Age and gender likewise influence whether patients participate in which younger female patients may prefer higher levels of participation (Longtin et al., 2010; Protheroe et al., 2013). However, older patients do want to have a say, albeit to a lesser extent than younger cohorts (Greenup & Peppercorn, 2016). Similarly to the way they may behave towards patients with a lower socioeconomic status, professionals may be reluctant to encourage participation among their older patients, believing older people prefer passive roles (Longtin et al., 2010). There are also sliding transitions to when people should be considered of “older ages” versus of “younger ages.” Patients are more confident in making decisions that do not require medical knowledge and may want to leave medical decision to professionals (Longtin et al., 2010; Rowland & Politi, 2016). However, patients with long-term conditions have extensive knowledge about their illness, a factor that enables them to make even complicated decisions (Snyder & Engström, 2016).

2.6. Patient participation in the ESRD trajectory

The ESRD trajectory provides CKD patients with several potential opportunities to participate. Participation could be related to pre-dialytic treatment decisions, including the choice of dialysis modality, or considerations when adapting dialysis treatment to everyday life, such as determining the goals of care (Chan et al., 2019; Roberti et al., 2018). In this section, I will map the field of patient participation in the ESRD trajectory, as experienced by patients, physicians, and nurses. Their experiences are not mutually exclusive – for example, in hospital HD, how healthcare professionals provide their treatment will affect the patients' experiences. With regard to the treatment trajectory, there may be sliding transitions. Nurses remain close to patients and are responsible for delivering in-centre dialysis treatment. Dialysis treatment is prescribed by the nephrologist; thus, patient participation requires inter-disciplinary collaboration. Experiences from nurses and physicians may apply to healthcare professionals in general. Given that they work in the same field, the physicians' experiences may also be recognisable to nurses and vice versa. There are special challenges to patient participation in the ESRD trajectory, as I will discuss in the subsequent sections. In addition, the aforementioned universal challenges of patient participation are present for patients requiring dialysis and healthcare professionals providing their treatment and care.

In accordance with the design of this study, I will account for patient participation in the phases of the ESRD trajectory. The first phase is when dialysis is required and the choice of dialysis modality (HD or PD) must be made. The second phase is when hospital HD is the choice.

2.6.1. Participation when dialysis commences

Patients with CKD commonly follow a planned schedule with regard to when they commence dialysis (Chan et al., 2019). When dialysis initiation is planned, patients have a permanent vascular access (determined by PD or HD) and a carefully organised preparation of their preferred and chosen modality to provide the best clinical outcome

(Chan et al., 2019; Machowska et al., 2017). A planned approach provides patients with the possibility to engage in the modality decision prior to the need for dialysis (Chan et al., 2019). Because the choice between dialysis modalities is recommended to include patient preferences, it is important that patients engage in this decision (Chan et al., 2019; Russell & Boulware, 2018; Zee et al., 2018). Thus, patient participation by means of choice may be particularly present during this phase. There are advantages and disadvantages to all dialysis modalities; thus, the most appropriate treatment is the one that works with the patient's clinical and personal situation (Russell & Boulware, 2018). A shared decision-making approach is especially relevant when there is more than one applicable treatment option and the options are considered equal with regard to the outcome (Rowland & Politi, 2016). It is thus suitable in the choice of modality because it brings forth the patients' preferences along with clinical evidence and makes it possible to identify which treatment modality fits into the patients' preferences and life situation (Zee et al., 2018). The modality decision is ideally made well before ESRD symptoms render patients unable to decide adequately (Morton, Tong, Howard, Snelling, & Webster, 2010).

Patients' experiences

Although a Danish study found that ESRD patients experienced being involved in the modality decision (Erlang, Nielsen, Hansen, & Finderup, 2015), other studies have reported that decision-making regarding the dialysis modality is problematic. Decision-making is complex and patients' abilities to make treatment decisions may be affected by emotional distress (Combes, Sein, & Allen, 2017). A lack of thorough information about treatment options seems to be a recurrent issue. Mehrotra, Marsh, Vonesh, Peters, and Nissenson (2005) relayed that 48% of the studied patients reported that treatment options were presented either after the first dialysis or close to the dialysis initiation. Many patients felt unprepared and incompletely informed with regard to the benefits and burdens of the dialysis modalities and how their choice of treatment would come to affect their everyday life (Song et al., 2013). Some patients found the staff to be overly positive when presenting treatment options, thus not elucidating the disadvantages of treatments (Combes et al., 2017). In particular, patients on hospital HD have experienced being less acquainted with treatment disadvantages (Zee et al., 2018). Song et al. (2013) reported that patients experienced to receive information from their nephrologists, although they perceived less engagement with regard to shared decision-making.

A common issue for patients with chronic diseases, including CKD patients, is limited health literacy (Taylor et al., 2017). Even though they are provided information, they may have difficulties understanding or processing this information. Winterbottom, Bekker, Conner, and Mooney (2014) reported that patients perceived their choice to be between dialysis and no dialysis. Hence, they did not expect that they would have to make an active choice and felt no need to engage with the decision. A recently published Norwegian study on CKD patients' health literacy suggested that patients may both assess and understand information but still avoid the information as a strategy to cope with their disease. Hence, providing additional information would not necessarily be the best solution to increase health literacy. Rather, a good and trusting relationship with healthcare professionals could facilitate understanding (Stømer, Wahl, Gøransson, & Urstad, 2020).

Morton et al. (2010) found that dialysis initiation was often synchronised with the creation of a vascular access. Patients perceived this as predetermining HD and inhibiting their choice for other treatments. In addition, the timing of the modality decision was problematic. Patients experienced receiving information at a stage when they felt unwell and thus unable to process it. Receiving information when dialysis was imminent could lead to a time-pressured decision in which patients felt rushed into a certain treatment. The physician's preferences, medical contraindications, and in-centre limitations are additional factors that affect patients' choice (Morton et al., 2010). Within emergent situations, hospital HD is the standard treatment, and ESRD that progresses to the need for acute HD may thus be a factor limiting the patients' choice (Dahlerus et al., 2016; Morton et al., 2010). Once patients have started on hospital HD, a preference to maintain status quo often makes them reluctant to switch treatment (Chan et al., 2018; Morton et al., 2010).

ESRD patients have different concerns when choosing the dialysis modality. In a study comparing the values of patients choosing PD versus hospital HD, independence, issues related to life quality and quantity, and flexibility in their treatment schedule were highly valued in both groups (Dahlerus et al., 2016). The reasons that patients decided on hospital HD were fear of infections and wanting to have their treatment delivered by trained personnel. For patients who chose PD, factors such as independence and quality of life were important (Dahlerus et al., 2016). It is notable that patients may consider the medical outcome, and hence their longevity, as less important than factors affecting their quality of life (Chan et al., 2019; Morton et al., 2010).

The influence from other patients' treatment experiences markedly affect the treatment modality decision of both patients and carers (Combes et al., 2017; Morton et al., 2010). Patients may experience peer information as unbiased, with more credibility than information received from professionals (Combes et al., 2017). Other factors affecting decision-making include opinions from family and providers, patient–provider interactions, trust in professionals, the ability to preserve the current lifestyle, and self-perceived burden to family, among others (Morton et al., 2010; Murray et al., 2009; Harwood & Clark, 2013).

Researchers have emphasised the use of decision aid tools to help patients choose the dialysis modality best suited to their current lifestyle (Cassidy et al., 2018; Prieto-Velasco, Quiros, & Remon, 2015; Winterbottom, Bekker, & Mooney, 2016). A Cochrane review of decision aids for people facing treatment or screening decisions found high-quality evidence that sharing decisions by means of decision aids such as pamphlets, videos, and web-based tools all had positive benefits regarding the decision-making process (Stacey et al., 2017). Moreover, decision aid tools stimulated patients to take a more active role in the decision-making process and minimised variable practices among staff in pre-dialysis education (Morton, 2016; Stacey et al., 2017). A recent Danish study showed that patients experienced being involved in the choice of dialysis modality when a shared decision-making approach was employed (Finderup, Dam Jensen, & Lomborg, 2019).

Professionals' experiences

Healthcare professionals represent facilitators as well as constrictors to patient participation (Angel & Frederiksen, 2015), and this section presents how nurses and physicians' experience the dialysis modality decisions.

Nurses

In ESRD care, nurses supply information about the different treatment modalities, both individually and through pre-dialytic education programmes. Hence, nurses are uniquely suited to ensure that patients choose the dialysis modality best suited to their lifestyle preferences, needs, and capabilities (Key, 2008). By instructing patients – for example, through pre-dialysis education programmes – they have the potential to influence the patients' decision on the dialysis modality. Nurses' views on the ideal treatment modality may be determined by their area of experience and expertise, as shown by Tennankore, Hingwala, Watson, Bargman, and Chan (2013). For example, home dialysis nurses were likely to favour home-based treatment such as PD, while HD nurses likewise recommended in-centre HD. The nurses in this study considered physicians to have the most influence on patients' modality choice and were less aware of their own impact. The nurses wanted more knowledge about their colleagues' work: HD nurses wanted more knowledge about the PD nurses work and vice versa (Tennankore et al., 2013). A survey study showed how nurses' availability impacted patients' choice of the dialysis modality, with people preferring home-based dialysis when they were provided with unlimited nursing support, including phone support and home visits (Walker et al., 2018). A Swedish study (Sturesson & Ziegert, 2014) showed that nurses, due to lack of education in this area, failed to give patients emotional support during the transition to HD. Combes et al. (2017) found that healthcare professionals including nurses and nephrology specialists felt less equipped to talk about treatment options in a way that was balanced and unbiased.

Nephrologists

Nephrologists learn about their patients’ values and lifestyle preferences through long-term medical follow-up before dialysis commences (Tuso, 2013). Hence, they can optimise patient participation throughout the ESRD trajectory, including the choice of dialysis modality. Nephrologists have different practices regarding the modality decision; their decision-making approaches may be influenced by how they perceive their role as a physician. A study on older ESRD patients showed four different decision-making approaches in clinical practice (Ladin et al., 2018). In the *paternalistic* approach, nephrologists viewed themselves as patient protectors. Patient autonomy and values were less important than improving health through active treatment. In the *informative* approach, nephrologists viewed themselves as patient educators. They prioritised patient autonomy in decision-making and accepted patients’ choices. In the *interpretive* approach, nephrologists perceived themselves as a guide, steering their patients to an optimal treatment selection based on patient values. Nephrologists following an *institutional* approach focused on treating patients within the norms and culture of the institution (Ladin et al., 2018).

Nephrology practice implies providing commonly recommended dialysis modalities to patients, although these recommendations do not necessary ensure the most suitable treatment for the patient (Winterbottom et al., 2016). Within modality decisions related to the patients’ age, Song and Ward (2014) found that more elderly patients experienced that the decision was made by the physician rather than on their own, with their family, or collaboratively with the physician. This is in line with research related to patient participation in general, in which professionals may expect less participation from older patients and thus make decisions on their behalf (Longtin et al., 2010). We found no studies that supported this finding in working age individuals.

2.6.2. Participation in hospital HD

Patients' experiences

Previous research on patient participation in hospital HD has focused on older patients, often elucidating participation in treatment withdrawal or decisions regarding dialysis versus conservative kidney management (Mandel, Bernacki, & Block, 2017; Seah et al., 2015). Many of these studies showed that older patient experience little involvement within hospital HD. For example, in a Norwegian study by Aasen, Kvangarsnes, and Heggen (2012b), elderly patients struggled for shared decision-making, experiencing that healthcare providers exercised power and control in order to accomplish treatment goals.

Fewer studies have examined working age individuals' experiences of participating in hospital HD, in which treatment schedules require patients to adjust their lives to dialysis (Laudański, Nowak, & Niemczyk, 2013; Roberti et al., 2018). Coping strategies may include regaining personal autonomy, for example, through participating in decision-making (Gulbrandsen et al., 2016). Patients may experience that staff underestimate their knowledge and values (Roberti et al., 2018). Confusion about the patient role, and what is expected of people in the role of a patient, may prevent ESRD patients from asking questions and rather wait for professionals to inform them (Stømer et al., 2020). People undergoing HD have been shown to be unsatisfied with their treatment situation and everyday life, experiencing that their lives are put on hold (Monaro, Stewart, & Gullick, 2014). Patients have reported a lack of thorough information about the causes and progression of their disease, disease symptoms and their impact, and social and financial support (Palmer et al., 2014). Some patients experienced that the decision about HD had not been their own (Dahlerus et al., 2016; Morton et al., 2010; Zee et al., 2018).

There are different conceptual understandings of patient participation among patients and healthcare professionals. Årestedt, Martinsson, Hjelm, Uhlin, and Eldh (2019) explored the patients' and professionals' perspectives on patient participation in HD care. In their study, patients' perspective differed from those of professionals. For example, healthcare providers considered patients who performed their own dialysis as the ultimate form of patient participation, while patients perceived the choice of having the staff run their dialysis, at certain times or continuously, as an act of participation (Årestedt et al., 2019).

Professionals' experiences

Nurses

HD nurses are a core component in the organisational aspects of care, including care coordination, continuity, and exchange of health information. In HD, nurses are responsible for treatment administration, information, and guidance on topics such as fluids, diet, and medication (Bennett, 2011b; Bevan, 1998; Polaschek, 2003). Dialysis nurses may develop close relations with their long-term patients (Barello et al., 2012; Bennett, 2011b; Thomas-Hawkins, Latham, & Hain, 2017). Thus, nurses are well-positioned to facilitate patient participation when the preferred or chosen treatment is HD (Bennett, 2011b).

However, the HD environment is highly technological, and it may be challenging for nurses to over time maintain a focus on patients while being surrounded by highly complex technology (Bennett, 2011b; Bevan, 1998). If professionals become subsumed by the technology, they run the risk of meeting the needs of the technology, not the patient (Bennett, 2011a; Tong et al., 2017). For example, dialysis nurses may over time view the patient and the dialysis machine as one entity (Bennett, 2011b). A study by Tranter, Donoghue, and Baker (2009) found that the nursing culture within hospital HD provided a major focus on technological procedures and the dialysis machine. The nurses considered that the specialist medical model dominated the units, and this model did not provide for the management of non-dialysis issues like psychosocial considerations. Thus, the nurses' job became performing the dialysis treatment. A shift from care associated with the dialysis procedure ("dialysis-centred care") to a more holistic patient-centred model was required (Tranter et al., 2009). A Norwegian study by Aasen, Kvangarsnes, and Heggen (2012a) explored nurses’ perceptions of patient participation within elderly patients undergoing HD. In their study, nurses acted with power and control, using biomedical values and ethical principles to justify their actions. For example, nurses argued that it was in their patients’ interest to remove the fluid as programmed, sometimes overriding opposing wishes from patients. A minority of nurses supported engaging in dialogue and shared decision-making. Årestedt et al. (2019) reported that both nurses and physicians perceived patients running their own dialysis as the superior form of patient participation. When patients did not engage in hands-on tasks, the professionals considered information about food and fluid restrictions and adherence to these to be patient participation (Årestedt et al., 2019).

Educating nurses in patient participation may ensure that patients are offered the opportunity to be involved in their treatment. Barnes et al. (2013) showed how a training course for nurses resulted in a stronger collaborative relationship between patients on HD and nurses. Patients were empowered to become active participants in their own care by nurses trained in facilitating patient participation (Barnes et al., 2013).

As healthcare professionals, nurses are part of a work environment that may promote or inhibit their opportunities to provide care in accordance with guidelines (International Council of Nurses, 2012). This includes facilitating patient participation. However, long-term care providers are in particular subjected to occupational stress and burnout is common (Hayes, Douglas, & Bonner, 2015; Prezerakos, Galanis, & Moisoglou, 2015; Woodhead, Northrop, & Edelstein, 2014; Yaman, 2017). Prezerakos et al. (2015) investigated correlations between HD nurses’ work environment and patients’ outcomes. Dialysis nurses reported several concerns related to their work environment, including a mismatch between workload and staff resources. Poor staffing increased workload and prevented nurses from having enough time to interact with patients or provide physicians feedback about patients’ care. The unmet nursing care needs in this study led to medication errors affecting patients (Prezerakos et al., 2015).

Nephrologists

As the primary physicians caring for patients on dialysis, nephrologists have a central role in delivering evidenced-based healthcare that integrates patients’ preferences and values (Tong et al., 2017). However, patient participation may be difficult to achieve in a field driven by biomedical and measurable targets (Chan et al., 2019; Hussain, Flemming, Murtagh, & Johnson, 2015; Tong et al., 2017).

For nephrologists, factors such as individual experiences and attitudes, as well as healthcare policy and tensions in health services, affect their priorities and approaches to patient participation (Tong et al., 2017). Similarly to dialysis nurses (Prezerakos et al., 2015), nephrologists face daily conflicts between ideals and reality, including stressful and demanding work situations where increasing administrative workload comes at the expense of patient contact (Grönlund, Dahlqvist, & Söderberg, 2011). Involving patients may be constricted by ambiguities about how to prioritise, measure, and manage critical comorbidities and quality of life outcomes in a technically demanding context (Hussain et al., 2015; Tong et al., 2017). Treatment guidelines that universally schedule hospital HD three times a week allow less individual treatment adaption (Chan et al., 2019). Seeing and treating patients individually may therefore be challenging (Tong et al., 2017; Vandenberg et al., 2019). In addition, nephrologists face ethical dilemmas in which they are forced to make decisions about life or death (Grönlund et al., 2011). Pawłowicz and Nowicki (2020) showed that nephrologists treating comorbid and poor prognosis patients on hospital HD experienced high levels of depersonalisation and emotional exhaustion, which over time could lead to occupational burnout.

Inconsistent values between nephrologists and their patients may be the cause of tensions or conflicts in ESRD care (Chan et al., 2019; Vandenberg et al., 2019). Standardised clinical ESRD outcomes may differ from outcomes that are important for patients (Tong et al., 2017). For example, biomedical targets, which are important for nephrologists to evaluate and adjust dialysis treatment, may not be valued in the same way by patients, who may prioritise a maintained lifestyle and personal well-being

(Chan et al., 2019; Reid et al., 2016). Nephrologists may perceive these priorities as non-adherent behaviour (Clark, Farrington, & Chilcot, 2014). Tong et al. (2017) reported that nephrologists allowed fewer treatment compromises when patients were eligible for transplantation compared with patients on life-long dialysis, weighing patient flexibility against the need to minimise morbidity and mortality.

Other tensions are associated with the patient–professional communication style. Vandenberg et al. (2019) found that many nephrologists practised a standardised "one size fits all" way of communicating, while patients favoured a personalised approach. This discrepancy suggests a mismatch between values. However, some nephrologists preferred private consultations over traditional ward rounds, because private consultations provided information that patients were likely to conceal when in front of others (Vandenberg et al., 2019). Nephrologists may focus on issues that come with the potential for correction, such as laboratory values. Issues important for patients, such as maintained lifestyle, may be considered to be out of the nephrologists' reach (Tong et al., 2017).

2.7. Overall aim of the study

The overall aim of the study was to investigate patients' and health care professionals' experiences and perceptions of patient participation in different phases of the ESRD trajectory for working age adults requiring dialysis. The study comprised a qualitative exploration of patient participation as experienced by patients on HD, dialysis nurses, and nephrologists.

Why was the study important?

I have found no previous studies exploring patient participation for working age individuals in different phases of the ESRD trajectory. Exploring experiences of participation when dialysis is required involves decision-making regarding the choice of dialysis modality. Decisions that are made at this stage impact the subsequent trajectory.

In addition, exploring patient participation in hospital HD provides a broad perspective that could identify areas for improving the quality of ESRD care throughout the trajectory.

Much of the previous research contains studies about patient participation in older patients or in patients regardless of age. There is little knowledge of how patient participation in ESRD is experienced in the working age patient. Experiences from both patients and healthcare professionals provide divergent perspectives that are important to gain a deeper understanding of central issues related to patient participation in the ESRD trajectory.

The specific aim in each sub-study was to explore the following research questions:

1. How do nurses perceive and experience patient participation in different phases of the ESRD trajectory for working age patients requiring dialysis?

2. How do working age adults undergoing hospital HD experience patient participation in different phases of the ESRD trajectory?

3. How do nephrologists experience patient participation in different phases of the ESRD trajectory for working age patients requiring dialysis?

3. Methods

In this section, I provide the philosophical basis with regard to the methods chosen for my thesis.

3.1. Qualitative studies

Qualitative studies aim to investigate how social experiences are created and given meaning; they involve several empirical materials, often interviews or observations (Denzin & Lincoln, 1994; Patton, 2002). As suggested by Brinkmann and Kvale (2014), if you wonder how people understand their world and their lives, why not talk to them? The qualitative approach of this thesis was considered purposeful to gain in-depth knowledge on the healthcare professionals’ and working age patients’ experiences of patient participation within different phases of the ESRD trajectory.

A common factor in qualitative studies is to apply a purposive rather than a random sample of study participants (Patton, 2002). Purposive sampling allows including study participants who are familiar with the studied topic; thus, they are considered to have multiple experiences and perceptions to share about the topic. Both focus groups and individual interviews are frequently used to collect data (Patton, 2002). Saturation (Creswell, 2014; Patton, 2002) is a criterion to limit the sample size, and in qualitative studies, saturation is considered accomplished when “no new knowledge” is being provided (Creswell, 2014).

3.2. Research approach

This thesis built upon an understanding of reality as socially constructed (Berger & Luckmann, 1967; Patton, 2002). The philosophy of social constructivism relies on the theory of ontological relativity, meaning that humans only have access to reality as they interpret it (Patton, 2002). Within social constructivism, one assumes that knowledge is constructed through interpersonal interactions, in which the context and involved individuals influence the developed meaning. People produce and reproduce their social world through their subjective meanings, actions, and interactions. Phenomena we perceive as universal and timeless, upon closer examination, turn out to be humanly constructed through thought patterns, language, and social practice (Moses & Knutsen, 2007). People's views are shaped by the historical and cultural context in which they live; consequently, they have the potential to shift over time (Patton, 2002).

Recognising reality as socially constructed does not mean that it is not real in the way it is perceived and experienced by the people who live in it. The sociologist William Isaac Thomas and his wife Dorothy Swaine Thomas stated, in what has become known as the Thomas theorem: "what is defined or perceived by people as real, is real in its consequences" (Thomas & Thomas, 1928, p. 572). Thus, our knowledge about reality forms the basis of how we react to reality. Following this ontology implies that the empirical field is socially constructed and constantly undergoing changes. The introduction of patient participation in healthcare could be viewed as a socially constructed phenomenon that has arisen in light of historical events in the recent decades (see section 2.3). The patient role has been changed, or reconstructed, from passive to active, and the role brings forth new expectations. This change in the patient role also alters and reframes the role of professionals. The roles of patients and professionals may be considered part of a social consensus in which people think, believe, and act as expected by the society of which they are part. Eventually, health organisations are included as social constructions – for example, the NPM rotation, where expectations of function and roles have mutually changed. This becomes explicit when the patient is referred to as a *user* or a *customer.*

In keeping with a social constructivist approach, all sub-studies in this thesis are founded on the study participants' subjective experiences and perceptions related to patient participation. The findings are constructed as themes, which are based on the ongoing interaction between the interviewees and the interviewer during the interviews.

The subsequent interpretations of the findings are based upon collaboration with the co-authors. As such, the knowledge gained from the sub-studies may be viewed as a co-construction between the study participants, me as a researcher, and my co-authors.

3.3. Research design

This thesis includes three qualitative studies, all applying an interpretative/constructivist approach (Patton, 2002). We chose focus groups (Sub-study I) and individual interviews (Sub-study II and III) when collecting data.

Focus groups are composed of a homogenous group of people – as determined by the purpose of the study (purposive sampling). Focus groups are suitable to explore how people of a certain characteristic, in our study HD nurses, understand a pre-determined topic of interest through focused discussions (Krueger & Casey, 2015). The intention of grouping people is to encourage group members to share experiences and perceptions on the topic, empowered and supported by their peers (Barbour, 2007; Krueger & Casey, 2015). The dynamic and interactions among focus group participants should provide insight that differs from individual interviews (Barbour, 2007). Focus groups are suitable for several occasions, for example, when investigating experiences and perceptions from healthcare professionals (Malterud, 2012). When conducting a focus group, a moderator is present in addition to the researcher and the focus group participants. The moderator observes interactions, takes notes, and summarises the group sessions (Krueger & Casey, 2015).

Individual in-depth interviews is another way to collect data (Patton, 2002; Polit & Beck, 2012). Participants are chosen because they have experienced the topic of interest and the idea is that they share their detailed accounts of experiences through open-ended face-to-face interviews (Polit & Beck, 2012). Individual interviews are commonly used when conducting qualitative research. This approach is suitable for example if there is a potential that sensitive information will be shared or if conflicting issues are expected to appear (Patton, 2002; Brinkmann & Kvale, 2014).

We analysed the collected data using several approaches, such as hermeneutics (Gadamer, 2010) in sub-study I, narrative analysis (Josselson, 2011; Riessman, 2008) in sub-study II, and interpretative phenomenology (Brinkmann & Kvale, 2014) in sub-study III. The analyses are described in each paper and later in this thesis. Here, I will briefly account for the different approaches.

Hermeneutics focuses on interpretations of texts (Gadamer, 2010), in which the hermeneutic circle is central. The hermeneutic circle is based on preconceptions as a prerequisite for new understanding, which constitutes an ongoing process. Through putting one's preunderstanding at play, new knowledge is achieved (Knotts, 2014). In the hermeneutic circle, parts are considered to be important to understand the whole and vice versa (Gadamer, 2010). Diverse experiences and perceptions constitute one's worldview, or what Gadamer (2010) calls one's horizon of understanding. Through the process of fusing horizons, new understanding occurs between minds (Knotts, 2014). We thus considered hermeneutics suitable to explore the dialysis nurses' different experiences and perceptions of patient participation

Narratives concern the meaning people make of their lives through storytelling, connecting events in a plot with beginning, middle, and end points (Josselson, 2011; Riessman, 2008). In narratives, focus is given to how events are experienced by the individual, not a record of what "really" happened (Josselson, 2011). Narrative interviews enable the teller to select events that are of importance to her or him (Riessman, 2008). Thus, we considered narratives suitable to understand patient participation as experienced and voiced by people in need of dialysis.

Interpretative phenomenology is valuable when examining complex and ambiguous topics (Brinkmann & Kvale, 2014; Smith & Osborn, 2015). Phenomenological by nature, it attempts to explore a personal experience and a personal perception or account of an object or event. Interpretation is part of the analysis because the researcher tries to make sense of the other person's world as the other constructs this world. Interpretative phenomenology is thus connected to hermeneutics (Brinkmann & Kvale, 2018; Smith & Shinebourne, 2012). We considered the method suitable when exploring nephrologists' experiences with patient participation. By applying a phenomenological approach, we focused on nephrologists' individual experiences, while the interpretative approach allowed interpretation of how the nephrologists made sense of their experiences.

3.4. Study setting

Since 2002, Norwegian specialist healthcare has been organised in regional health authorities, in which each authority owns several hospitals. The sub-studies in this thesis were conducted in the Central Norway Regional Health Authority. This health authority encompasses three hospital trusts, which are Møre and Romsdal, Nord-Trøndelag, and St. Olav's University Hospital. It also encompasses the Central Norway Pharmaceutical Trust. The aforementioned hospitals include one academic medical centre, namely St. Olav's University Hospital, and several local hospitals.

The Central Norway Regional Health Authority comprises rural and urban areas, including Norway's third largest city. Central Norway has a population of approximately 730,000 (Statistisk sentralbyrå, 2020). Satellite dialysis has been established in rural areas, in which patients have their dialysis performed by nurses in smaller venues. Satellite dialysis is a well-known concept in rural parts of the westernised world, providing patients' healthcare services close to their homes. I have described dialysis satellites in section 2.1.2. The Central Norway Regional Health Authority encompasses a total of 12 dialysis satellites run by four hospitals that employ nephrologists.

3.5. The study

This thesis comprises three sub-studies. Below, I will account for the methodological choices regarding design, recruitment and study participants, data collection, and analyses in each sub-study.

In the first study, we conducted focus groups with registered nurses (RNs) working with patients on hospital HD. We employed focus groups to gather a wide range of information and insight through group discussions, where RNs got to state their points of view stimulated by interactions in the group (Krueger & Casey, 2015).

In the second study, we conducted narrative interviews with people undergoing hospital HD. In addition to their experiences from their current treatment, these patients provided knowledge about how the choice of hospital HD had been made. We considered narrative interviews to voice individual experiences of patient participation (Riessman, 2008).

In the third study, we conducted individual interviews with nephrologists treating patients in hospital HD. Nephrologists are also responsible for dialysis initiation, which involves decisions about dialysis modality. We considered individual in-depth interviews (Brinkmann & Kvale, 2018) relevant to acquire knowledge about nephrologists' individual experiences with patient participation.

3.5.1. Recruitment and study participants

Sub-study I

We chose purposive sampling (Krueger & Casey, 2015) of Norwegian-speaking RNs of different ages and with experience working with patients undergoing hospital HD. We excluded nurses with leadership roles, considering power inequities between the leaders and the other participants as a possible limitation to the dynamics in the focus groups. We carried out recruitment in four dialysis units including satellites in Central Norway. The units were small, comprising 5–16 nurses. The head nurses forwarded written information and consent forms to relevant informants and collected their informed consent. We invited 25 RNs to participate in the study, of whom 15 accepted and 13 participated. The two withdrawals were due to private time constraints. Seven informants were kidney nurses or intensive care nurses. Participants nursing experience varied between 3 months to more than 30 years. All nurses were female. Each focus group consisted of 4–5 participants, in accordance with recommendations (Krueger & Casey, 2015; Tong, Sainsbury, & Craig, 2007).

Sub-study II

We employed purposive sampling (Creswell, 2014) of patients on hospital HD. Patients included in this study were working age adults between 18 and 65 years and capable of providing informed consent. The patients had been undergoing HD for more than 3 months. This means we excluded patients on emergency dialysis but included patients who planned to receive a kidney transplant as well as patients on lifelong HD. We carried out recruitment at 6 dialysis departments, including satellites, in Central Norway. Staff nurses identified and informed relevant participants and collected their consent forms. Nineteen patients agreed to participate but eight withdrew. I will present my reflections on the withdrawals later. We do not have information on whether all patients who fit the inclusion criteria were asked to participate. Altogether, 11 patients participated in the study, four of whom were women. The participants' time on HD varied from 6 months to 6 years. Eight of them were waitlisted for transplantation when the interviews took place. Some had to lose weight in advance of the transplantation due to the body mass index criteria ≤ 30 kg/m^2. Three patients had to commence dialysis emergently, while six started on a planned approach. Seven were married or in a relationship, and three had underage children.

Sub-study III

We employed a purposive sampling strategy (Kvale & Brinkmann, 2015), including physicians and nephrologists treating working age adults on HD in academic or local hospitals. We carried out recruitment at four dialysis units in Central Norway and invited 13 physicians who met the criteria. Altogether, nine nephrologists and one nephrologist trainee participated, four of whom were women. Their clinical nephrology experience varied between 5 and 20 years. The reason for non-recruitment was lack of response to the letter of invitation and was not questioned further.

3.5.2. Data collection

For all sub-studies, I explained the study’s purpose for the participants attending. I encouraged study participants to convey their individual experiences and/or perceptions about patient participation and ensured that there was no “right” or “wrong” answer. All focus groups and interviews were carried out in Norwegian language.

Sub-study I

Data were collected during the spring of 2015 through focus groups comprising 13 RNs employed in three different dialysis units in Central Norway. We chose focus groups to provide a wide range of information and insight through group discussions, where participants stated their viewpoints stimulated by interactions in the group (Krueger & Casey, 2015). Based on previous literature, the theoretical framework (Thompson, 2007), and the aim of the study, we developed a semi-structured questioning route (Krueger & Casey, 2015), see Appendix, focusing on the nurses’ perceptions of participation for patients treated with HD and their next of kin. The participants, an interviewer, and a moderator were present during the focus groups (Krueger & Casey, 2015). The three focus group sessions were audio recorded and lasted from 58 to 71 minutes. The moderator took field notes and summarised what had been said. Subsequently, the participants were given the opportunity to supplement. I transcribed the recordings verbatim. We experienced that the research question was thoroughly illuminated through the three focus groups: at the end of the third, no new information was provided. Hence, we considered the data to be saturated (Krueger & Casey, 2015).

Sub-study II

I conducted face-to-face interviews from January to June 2018. Based on previous research and the aim of the study, we employed an interview guide with open-ended questions (Riessman, 2008) related to patient participation in different phases of HD. Following the patients’ wishes, six interviews were conducted at HD departments during their treatment sessions. Two interviews took place in a meeting room at the hospital, and three were done in the patient’s home or workplace. Only the interviewee and I were present. Although I was prepared with an interview guide (see Appendix), the initial question “How do you experience to live with kidney failure and dialysis treatment?” resulted in a cascade of memories coming to the surface. I followed their narratives, adding questions when I considered it necessary to cover the themes of the interview guide. In addition, I used follow-up questions to confirm that I had interpreted the narratives as intended by the interviewees, for example, “Is it so that…?” or “I understand this to be … is that correct?” Each interview lasted between 48 and 81 minutes and was audio recorded. I took field notes and later transcribed the interviews verbatim. The interviews provided rich and diverse data and we considered the data to be saturated (Creswell, 2014) after 11 interviews.

Sub-study III

I conducted face-to-face interviews from November 2019 to May 2020, with only myself and the interviewee present. Based on previous research and the aim of the study, we employed a semi-structured interview guide (Brinkmann & Kvale, 2014) see Appendix, related to patient participation in different phases of the treatment trajectory. I used follow-up confirmatory questions to clarify the nephrologists’ experiences, for example, “Do you mean that…?” Eight interviews were conducted in a sheltered area in the nephrologists’ workplace. Due to the Covid-19 pandemic, two interviews were conducted via Skype. The interviews lasted between 32 and 86 minutes; they were audio recorded and then transcribed verbatim. Having both variance and patterns, we considered the data to be saturated after 10 interviews (Brinkmann & Kvale, 2014).

3.5.3. Data analysis

Sub-study I

We analysed the data using hermeneutics, which focuses on interpretations of texts to achieve understanding (Gadamer, 2010). We interpreted the nurses’ perceptions of patient participation as expressed through focus groups by considering the structure of the transcribed text (Wernet, 2014). We read the transcripts several times. The first reading was to form an overall impression of the text. In further readings, we aimed to grasp the participants' world (Gadamer, 2010), looking beyond what is close at hand to develop a new understanding. Notes from the interactions between study participants were emphasised (Krueger & Casey, 2015). We emphasised reading the text carefully, focusing on quotations and common and distinguishing features. The movement of understanding was constantly from the whole to part and back to the whole (Gadamer, 2010). The data were coded according to patient participation in various phases of the clinical pathway and the nurses' suggestions on how to strengthen participation. In the analysis, we applied Thompson's (2007) framework for patient participation (see Figure 1, p. 34). In accordance with Thompson (2007), we thus considered components, levels, and context when identifying themes. We constantly confirmed the themes by comparing them with the transcripts (Krueger & Casey, 2015). We discussed the findings and interpretations throughout the entire process to achieve a common understanding.

Sub-study II

We applied a narrative approach, focusing on what participants told and how they told it (Riessman, 2008), to examine the data. When analysing data, we read each transcript closely and used in vivo coding, meaning we grouped transcribed text into codes by choosing words or short phrases used by the interviewees (Miles, Huberman, & Saldaña, 2014). We identified codes with similar meanings and looked for common threads and recurring phrases that formed patterns in the text. One pattern was formed by what the interviewees said about receiving good information when commencing dialysis. Another pattern was their experiences of interdisciplinary collaboration. Next, we organised codes into categories according to their patterns. We named each category according to its content and reconstructed the participants' stories by compiling their individual narratives into one story. Based on the categories developed from the stories, we constructed three themes, chronologically following the ESRD trajectory. We looked for similarities and contradictions, explicit meanings and possible underlying meanings, turning points or shifts in the teller's voice (Riessman, 2008). We constantly rechecked the developing themes with the transcripts and discussed the themes until we achieved consensus. We used quotations to underpin the themes.

Sub-study III

We approached the data by using interpretative phenomenological analysis (Brinkmann & Kvale, 2014), which involves five key stages: familiarisation, coding, theme development, defining themes, and reporting. First, we read the transcripts to get an overall impression of the data. We then inductively identified meaning units in each interview. These meaning units were coded by connecting key words to the phrases used by the interviewees (Brinkmann & Kvale, 2014). Next, we clustered our coding by content – we grouped codes with similar meaning together. These codes formed the foundation for the theme development. We based the theme development on two phases of the ESRD trajectory. The first phase was related to patient participation in the choice of dialysis modality. This choice implicated hospital HD or home treatment by means of PD or home haemodialysis (HHD). The second phase was related to patient participation in hospital HD. The analysis was an iterative process, in which we continuously rechecked the developing sub-themes with the transcripts. We looked for patterns within the data as well as diversity and contradictions to break these patterns. All authors participated in defining themes and agreed upon the final themes presented. We provided selected quotations to underpin each theme.

3.6. Ethics

3.6.1. General ethics

This study was conducted in accordance with the ethical principles of the Declaration of Helsinki (World Medical Association, 2001). The study was submitted for review within the Norwegian Research Ethics Committees in Central Norway (ref. 2017/1206). The committee concluded that the studies were not within their mandate. The

Norwegian Centre for Research Data approved all sub-studies (ref. 40366/59530/702797). Sub-study I-III were approved by the Data Protection Official in Møre and Romsdal (ref. 2017/1206), while sub-studies II and III were approved by the Data Access Committee in Nord-Trøndelag (ref. 2018/1038-12073/2019 and 2018/344-19742/2019) before being approved by the Norwegian Centre for Data Research. In sub-study III, an assistant who signed a declaration of confidentiality was hired for transcriptions. In line with the Norwegian Centre for Research Data, this research material will be stored in 5 years after the project’s completion before being deleted. De-identified data (audio-recordings, transcripts, and field notes) are being kept on a password-secured server. Written consents are being stored in a locked cabinet in the Møre and Romsdal Hospital Trust. To ensure participants’ confidentiality, we have replaced their names, ages, and gender with Participant A, B, C, etc.

All participants in this study signed an informed consent form. They were informed that participating in the study was voluntarily and that they with no further explanation could withdraw from the study. It was emphasised that withdrawing from the study would represent no consequences for the individual.

In addition to the general ethics reported above, I will account for specific ethical challenges that arose during recruitment and in the interview setting.

3.6.2. Ethical reflections regarding recruitment

In sub-study II, 19 ESRD patients accepted the invitation and signed the informed consent form. However, eight of these were not available when I tried to reach them for the interviews. I have information about the reason for two of the withdrawals. However, patients could possibly have felt obliged to accept the invitation when it was provided by nurses responsible for their dialysis treatment and subsequently changed their minds. The time aspect is indeed relevant. Patients undergoing hospital HD are scheduled for treatment several times a week, and some of the study participants agreed to participate only if the interviews could take place during dialysis treatment. Unforeseen events or illness progression might likewise have caused patients to reconsider their study attendance. With respect to the individual's right to withdraw from the study, I did not make efforts to reach the participants besides one or two attempts. In sub-study I, head nurses carried out the recruitment process. This may have affected the process; however, because the units were small, we proceeded to gather as many participants as possible.

3.6.3. Ethical reflections regarding interviews

The predetermined asymmetry between the researcher and the study participant creates an inevitable power imbalance (Brinkmann & Kvale, 2018). The ethical concerns pertaining to this imbalance have commonly been emphasised (Brinkmann & Kvale, 2018; Råheim et al., 2016). Asymmetry may be especially prominent when the study participants are patients. Several participants in sub-study II presented emotionally touching stories that made me consider my own nursing practice. Not blurring my role as a researcher with the nursing role involved reminding myself that the purpose of the conversations was to gain new knowledge and not to care for the patient as through a therapeutic nurse–patient conversation. However, for the narrator, the outcome of the interviews still has a therapeutic potential. Telling one's story, no matter the purpose, involves structuring the flow of experiences in order to understand one's life that may have a therapeutic or redemptive effect on the storyteller (Josselson, 2011).

In sub-study I, the participants in one of the focus groups were my colleagues. Working within the same organisation implies that participants may be familiar with the values and interests of the organisation as well as those of their colleagues (Krueger & Casey, 2015). Thus, expressing opinions that diverge from what they consider expected may be experienced as difficult (Brinkmann & Kvale, 2018). Focus groups come with the potential of revealing sensitive issues to the individual (Barbour, 2007). Thus, before starting the focus groups, I encouraged the study participants to keep what had been conveyed within the group.

3.7. Summary of findings

Sub-study I: Patient participation in the clinical pathway – Nurses' perceptions of adults' involvement in haemodialysis

The aim of this study was to explore nurses' perceptions of participation for patients undergoing hospital HD and their next of kin. The findings were presented through the following themes: (1) between non-involvement and shared decision-making; (2) restricted self-determination; (3) absent next of kin; and (4) the nurses' role in shared decision-making. Nurses in this study experienced patient participation to vary between non-involvement and shared decision-making. The initial phase of long-term hospital HD was characterised by information loads and treatment decisions. Within emergency dialysis commencements, the patients' illness limited their ability to participate. Patients undergoing hospital HD had their lifestyle restricted by rigid treatment protocols. The nurses experienced sparse contact with the patients' next of kin and finally discussed their role in how to strengthen the involvement of patients and their families.

Sub-study II*:* Narratives of patient participation in haemodialysis

The aim of this study was to explore working age ESRD patients' experiences of patient participation along their treatment trajectory. The patients' narratives comprised three themes following their healthcare trajectory: (1) informed, but not involved in treatment choices; (2) duality of care and control; and (3) frail trust reflecting collaborative deficiencies. The patients experienced receiving good information about dialysis. However, they did not experience that they had been involved in choice of dialysis modality. Professional way of working, as well as the nature of treatment, contributed to restricted patient autonomy. Patients' trust suffered from collaborative deficiencies that led to delays in their treatment trajectories. As a way of coping with these issues, patients extended their responsibility into the coordination of transitions.

Sub-study III: Nephrologists' experiences with patient participation when long-term dialysis is required

The aim of this study was to explore nephrologists' experiences with patient participation along the patients' treatment trajectory. Their experiences comprised two themes with subthemes following the ESRD trajectory. Theme 1 was the dilemma of guiding treatment choices, with subthemes 1.1, a slightly steered choice; and 1.2, a shared decision. Theme 2 was patient participation action focused, not value driven, with the subthemes 2.1, participation through self-management; 2.2, negotiated values; and 2.3, ideals versus practice. Theme 1 relates to the patient participation in the modality decision, while theme 2 relates to the patient participation in HD. During decision-making on the dialysis modality, nephrologists emphasised patients' choice via two divergent approaches. In the first approach, they expected patients to choose the modality based on the provided information. In the second approach, they recognised the patients' values and lifestyle preferences through shared decision-making. Within hospital HD, nephrologists considered patients' self-care activities equivalent to patient participation, seeing self-care as a source of patient empowerment. Nephrologists identified divergent patient–professional values and organisational structures as barriers to patient participation.

4. Discussion

In this section, I will consider the methods chosen to collect and analyse the data and discuss the findings.

4.1. Methodological considerations

There is a range of criteria for evaluating the quality of qualitative research (Patton, 2002). However, there is no consensus about which criteria to apply (Denzin & Giardina, 2008). This thesis is based upon the idea of social constructivism, meaning that multiple truths exists. Lincoln and Guba (1985) suggested the term trustworthiness when evaluating studies employing a constructivist approach, with the following criteria: credibility (as an analogue to internal validity), transferability (as an analogue to external validity), dependability (as an analogue to reliability), confirmability (as an analogue to objectivity), and self-reflectiveness to underscore authenticity. I used these criteria as the foundation for my methodological considerations.

The purposive sampling in this study ensured participants with experiences from patient participation in the ESRD trajectory. In this study we triangulated our sample (Patton, 2002), including the both patients' and healthcare professionals' experiences and perceptions, to strengthen credibility. Triangulating the data sources provides divergent perspectives because it enables studying a phenomenon from different points of views, thus elucidating the topic of interest from different angles (Patton, 2002). In our study, each sample provided experiences that were important to gain a deeper understanding of central issues related to patient participation in the ESRD trajectory.

The participants gave rich and detailed descriptions of their experiences and perceptions. In sub-study I, the experienced nurses' engaging experiences triggered other group members to express their stories, thus letting multiple voices surface, in accordance with the intentions of focus groups (Barbour, 2007; Krueger & Casey, 2015). I encouraged less talkative participants to elaborate on their perceptions and participants verified the summary (Krueger & Casey, 2015). As a dialysis nurse, I recognised many of the experiences conveyed by the focus group attendees. However, as the attendees emphasised patient participation, I was surprised by utterances reflecting a more paternalistic mindset, such as “and if the doctor says you must have four hours then that is how it should be.” This quote does not allow shared decision-making. Similarly, when newly employed nurses conveyed perceptions that differed from those of the long-term nurses, I became aware of how professional socialisation forms the nurses’ identity, and how role-modelling practices may differ from professional values. It also made me reflect on my own nursing practice. Thus, in accordance with hermeneutics, my preconceptions and my horizon were challenged, and I achieved new understanding. I recognise that interpersonal constellations could have inhibited nurses from elaborating potential controversial views and that individual interviews could have allowed a more in-depth exploration of the topic (Malterud, 2012; Michell, 2001). Given that pre-established groups of colleagues over time may have developed a uniform way of seeing things, a mix of nurses from different dialysis units could have benefitted the focus groups (Krueger & Casey, 2015). In sub-study I, I had a collegial relationship with the participants in one of the focus groups. This represents a methodological as well as an ethical challenge. Acquaintance with my nursing background and interest in HHD could have influenced the participants’ answers. However, as a nurse, I was “one of them.” This position created a non-hierarchical space for the participants to express themselves. Some nurses stated that the focus group discussions had made them reflect on their practice and made them more aware of their own role in relation to their patients.

In sub-study II, the participants were encouraged to tell their stories about being an ESRD patient in need of dialysis. This is in accordance with narrative interviews that enable participants to choose individually which stories to tell (Riessman, 2008). However, the participants being given opportunity to speak freely resulted in stories that I considered less relevant for the purpose of the study. Råheim et al. (2016) suggested that if the researcher is also a healthcare professional, this may “fuel the fire of disclosure” when study participants are patients. Although not in accordance with a narrative approach, I sometimes felt it necessary to be slightly directive during the conversations. This could have made participants exclude parts of their stories. However, the interviews provided rich data in which everyone conveyed wide experiences of illness and treatment.

In each sub-study, I posed confirmatory questions that attempted to clarify the participants' experiences and perceptions and ensure that I had understood what they intended to express. Data in all sub-studies are derived from the transcribed text and selected quotations underline the findings (Patton, 2002). I have adapted the quotations to only a small extent, and they largely appear as expressed by the participants. The findings in this study are based on the participants' recalled experiences as interpreted by the researchers. I acknowledge that other interpretations could be possible. Credibility could have been strengthened through providing participants the opportunity to provide feedback on the findings as through a member check (Lincoln & Guba, 1985). This was not accommodated due to time constraints.

The research team comprised experienced researchers from different fields in accordance with researcher triangulation (Miles et al., 2014; Patton, 2002). Each has contributed throughout the research process, both regarding the study design, in various discussion rounds concerning recruitment and study participants, data collection, analyses, and interpretation of the findings.

I have attempted to present the study with transparency (Polit & Beck, 2012) – that is, I have aimed to detail the steps made throughout the research process. I have accounted for my philosophical stance and field experience. I have documented the research process regarding the study design, recruitment procedures, data collection, and analyses of the transcribed text. I have described the study setting and have justified the methodological choices. I acknowledge that other directions could have been taken – both when planning the study and during the research process – and that these could have influenced on the findings. For example, in sub-study III, we chose individual interviews over focus groups due to logistics and our anticipation of nephrologists' time constraints.

In qualitative research, transferability emphasises whether a study has a larger impact than to the studied cohorts (Lincoln & Guba, 1985). Our sub-studies included purposive samplings of patients and professionals within different ages and with different experiences. Our findings include thick descriptions, showing patterns as well as diversity and contradictions. Some of our findings are consistent with previous research on the topic, indicating that our findings may be applicable to other contexts of HD. For example, the environment of hospital HD is internationally comparable: it predominantly provides treatment in large, open rooms (Bennett, 2011b; Bevan, 1998). This indicates that individualised care including patient participation may suffer in other HD units than those studied. In sub-study III, nephrologists steered the patients' modality choice through promoting PD. Given that this is in line with international guidelines (Chan et al., 2019), the finding may be internationally transferable. Sub-study II showed how collaborative issues in healthcare compelled patients to extend their own responsibility, which Størner et al. (2020) also recently found. Given that this finding points to the design of modern healthcare in several westernised countries, it may be transferable to other healthcare contexts. Similarly, both nephrologists and nurses claimed that their timeframes inhibited their ability to promote patient participation. The general focus on efficiency requirements in healthcare may thus make patient participation suffer within the context of hospital HD as well as within other specialties besides nephrology. However, the findings in our study are constructions based on knowledge/experiences as held by the study participants when data collection took place. Meanings are influenced by time and context and may change over time, as new experiences and interactions take place (Lincoln & Guba, 1985).

4.1.1. Reflections on my field experience

In qualitative studies, the researcher is deeply involved in the co-construction of knowledge (Patton, 2002). Reflexive consciousness is therefore important to make the research process transparent and to acknowledge that the position of the researcher influences the research process (Patton, 2002). Reflexivity includes analytic self-awareness of the researchers' experiences, reasoning, and overall impact throughout the research process (Råheim et al., 2016).

As I stated when situating my position, I acknowledge that my background shaped the design of this study. I consider that my field experience and acquaintance with medical terminology, the ESRD trajectory, and the context of hospital HD has been valuable throughout the research process. However, field acquaintance represents a pitfall concerning what Malterud (2011) called field blindness. This implies that the researcher may only find what is already known and ignore new knowledge. As stated by Silverman (2000, p. 825), “every way of seeing is also a way of not seeing.” Due to being socialised into the same field, the researcher and the study participants may have an implicit agreement of reality (Malterud, 2011). Being familiar with my background, participants attending this study could believe that I, due to my profession, understood what they told me, and thus avoid elaborating their views and experiences. This could be the case for patients as well as healthcare professionals. The “insider” role could likewise have led me to ignore threads to follow or overlook strands that would have been obvious to other researchers with different backgrounds. Hence, there is a potential for losing information. I have attempted to be aware of this throughout the research process. Having co-authors from other fields has been valuable to see and discuss patient participation in the field of nephrology through lenses other than those of my own. However, as individuals we can hardly free ourselves from the baggage each of us carries, which makes us view and interpret the world with divergent lenses (Patton, 2002). The researchers’ backgrounds, experiences, knowledge, and preconceptions to see things in a certain way thus inevitably influence the analysis of data in qualitative research. Completely avoiding bias may be considered impossible. However, while an unrecognised bias may invalidate the findings, a recognised bias may bring forth new dimensions and contribute to multi-perspective knowledge construction (Brinkmann & Kvale, 2018).

4.2. Discussion of findings

The overall aim of the current study was to explore patient participation for working age adults requiring dialysis. The experiences and perceptions of patients as well as nurses and nephrologists provided divergent perspectives of patient participation in different phases of the ESRD trajectory. The phases related to participation when dialysis was about to commence, involving the choice of the dialysis modality, and participation when the modality decision had been hospital HD. I discuss the main findings in accordance with these phases of the trajectory.

This thesis elucidated the complexity of choosing between dialysis modalities – for the patient and healthcare professionals. Within hospital HD, one finding was patients' dependency and limited scope of action. Second, our study showed how divergent values between patients and healthcare professionals compete and potentially result in tensions between patients and providers. Third, collaborative deficiencies experienced by patients led them to distrust the healthcare on which they depended. These are all factors that complicate patient participation.

Duality of choice

Out findings showed that when dialysis was determined to be required, healthcare professionals associated patient participation with the choice of dialysis modality (papers I and III). Our study showed how providing patients with choice may come with dualities.

The individual's freedom of choice is emphasised as an intrinsic value throughout westernised societies, including healthcare (Zolkefli, 2017). This was prominent in our study, where professional consensus was that patients themselves should make the final decision regarding the dialysis modality (papers I and III). To enable the patients' choice, both nurses and nephrologists emphasised thorough information about the dialysis modalities (HD and PD) within ample time before commencing dialysis (papers I and III). Patients received their initial information from nurses as well as nephrologists, in addition to pre-dialysis education programmes, and experienced this information as good and understandable (paper II).

Information and education increase patients' health literacy and enables them to engage in decision-making processes (Longtin et al., 2010; Protheroe et al., 2013; Rowland & Politi, 2016). Even though patients experienced being well informed, our analyses showed deficiencies related to information about home treatment, as some patients received information about this option after commencing hospital HD (paper II). This finding is in accordance with previous research (Chan et al., 2018; Mehrotra et al., 2005). Once they commence hospital HD, patients are typically concerned with maintaining stability and are thus reluctant to switch the dialysis modality (Morton et al., 2010).

Despite professional efforts to deliver thorough patient information, both nurses and nephrologists underlined the patients' difficulties in choosing dialysis modality (papers I and III). Information may therefore not be enough for patients to make sound choices (Joseph-Williams et al., 2014; Roberti et al., 2018; Russell & Boulware, 2018). The ability to choose between treatment options is associated with a consumerist approach (Hickey & Kipping, 1998), which has become prominent in healthcare in recent decades (Gusmano, Maschke, & Solomon, 2019; Lian, 2008; Nettleton, 2013; Ravn et al., 2020). In the consumerist approach, information is emphasised, albeit without involving patients in the decision-making process (Hickey & Kipping, 1998). Excluding patients and their families from healthcare discussions leaves it up to the patient to navigate available treatment options (Barry & Edgman-Levitan, 2012). In our study, patients about to commence dialysis did not experience being involved in the choice of dialysis modality (paper II). Some lacked awareness about the possibility of choosing among treatment options and perceived their choice to be between dialysis and no dialysis. Winterbottom et al. (2014) reported similar findings, in which patients were unable to distinguish between the modality options. They did not expect themselves to make an active choice and felt no need to engage with the decision. Various decision aid tools are shown to stimulate patients to take a more active role in the decision-making process and minimise staff variable practices in pre-dialysis education (Morton, 2016; Stacey et al., 2017).

The neo-liberal shift has constituted a challenge to the healthcare professionals' authority and power and reframed the role of both patients and professionals (Cahill, 1998; Lian, 2008; Pilnick & Dingwall, 2011). In the past, physicians made decisions on behalf of their patients (Armstrong, 2014). In the current study, some of the nephrologists instead viewed themselves as the patients' supervisors or counsellors (Paper III). Likewise, the shift has positioned patients in the roles of customers or consumers of healthcare (Lian, 2008; Pilnick & Dingwall, 2011). Construing patients as consumers may appear valid if they were operating in a traditional market (Gusmano et al., 2019). However, healthcare is not a market, and patients are not equipped with the power that consumers have to shape the market (Gusmano et al., 2019). Furthermore, healthcare professionals are not salespeople, whose role is to defer to consumers' demands (Pilnick & Dingwall, 2011). Contrary to the consumer metaphor, patients seek care under circumstances when they do not have the time or emotional strength to shop healthcare services based on quality and price. Hence, the consumerist approach fails to take into account the vulnerability and insecurity that may follow in the footsteps of illness (Gulbrandsen et al., 2016; Gusmano et al., 2019). It marginalises groups who are unable to consume (Dahlborg Lyckhage, Pennbrant, & Boman, 2017; Nettleton, 2013) and transfer the responsibility that traditionally has been upheld by professionals to patients (Gusmano et al., 2019). However, patients may not want an autonomous role; albeit rather want to share the decision with professionals (Deber, Kraetschmer, Urowitz, & Sharpe, 2007).

Modern healthcare focuses on patient responsibility and patients as co-producers of health (Lian, 2008). In our study, healthcare professionals could hold patients responsible for making their modality decision in ample time before dialysis commenced (papers I and III). Lack of preparedness and urgent dialysis commencement are associated with lower survival and higher morbidity (Chan et al., 2019), and ESRD patients may feel that they are rushed into making the modality decision (Morton et al., 2010). Nephrologists in the current study could have emphasised appropriate timing of the modality decision to avoid this. By contrast, nurses experienced that the modality decision could take place too close to dialysis commencement, thus requiring a swift decision. They considered information giving as an ongoing and repetitive process for pre-dialytic patients to make a sound decision (paper I).

Having more than one treatment option confers a greater cognitive burden to patients (Gulbrandsen et al., 2016; Tamura & Periyakoil, 2013; Zolkefli, 2017). For ESRD patients, coping with fear and denial evoked by the diagnosis of chronic kidney failure while facing the choice of the dialysis modality adds substantial stress to the individual (Chan et al., 2018). Professionals may underestimate patients' ambivalence and reduced decision-making capacity when faced with the unfamiliar arena of medicine (Gulbrandsen et al., 2016). Hence, there is a delicate balance between involving patients in medical decisions without leaving them feeling abandoned during the process (Rowland & Politi, 2016). Considered to be in between informed choice, where decisions are left to the patient, and traditional paternalistic medical decision making, shared decision making comes with this potential (Jordan, Ellis, & Chambers, 2002). Sharing the decision is especially suitable when more than one applicable treatment option exists, and the options are considered equal with regard to the outcome (Coulter & Collins, 2011; Rowland & Politi, 2016). To facilitate a shared decision-making approach, healthcare professionals incorporate patients' personal preferences with clinical evidence (Coulter & Collins, 2011; Elwyn et al., 2012; Rowland & Politi, 2016). As suggested by Gulbrandsen et al. (2016), shared decision-making supports patient autonomy by acknowledging the vulnerability that follows in the footsteps of illness and ensures that the professional does not evade responsibility. In our study, still emphasising the individuals' freedom of choice, some nephrologists practised shared decision-making when choosing the dialysis modality. This included learning about the patients' work situations and family lives as well as their individual preferences (paper III). This finding is consistent with the interpretive approach of Ladin et al. (2018), in which nephrologists guided their patients to an optimal treatment selection based on the patients values. Studies have shown that ESRD patients do not experience being involved in the modality decision (Dahlerus et al., 2016; Morton et al., 2010; Winterbottom et al., 2014; Zee et al., 2018). However, as reported by Finderup et al. (2019), patient involvement in treatment choices could increase when healthcare professionals apply a shared decision-making approach.

Patient choice swayed by expert advice

In our study, nurses and nephrologists supported home dialysis, preferably PD (papers I and III). As shown in paper III, the nephrologists actively steered their patients towards PD to fulfil policy goals of increased home treatment. Some stated that people of a certain age should take care of their own treatment. This finding is consistent with the consumer ideology, which has provided patients with statutory rights and in return expects them to be responsible for their own health (Lian, 2008; Nettleton, 2013). Healthcare professionals may support home treatment for different reasons. One reason may be the rise of chronic conditions, in which professionals come to term with their own limitations and recognise the importance of care and social support (Nettleton, 2013). Indeed, patients on home treatment often have higher HRQoL and better treatment outcomes (Kliger & Suri, 2016; Schatell & Alt Stec, 2008) compared with patients on hospital HD (Palmer et al., 2014; Song et al., 2013; Zee et al., 2018). Home treatment is also considered to be cost effective (Treharne, Liu, Arici, Crowe, & Farooqui, 2014; Walker, Marshall, Morton, McFarlane, & Howard, 2014), and policy goals of home treatment may thus be linked to economic issues and efficiency requirements in healthcare (Holmqvist & James, 2019; Vandenberg et al., 2019). In paper II, many patients evaluated themselves as non-competent in running their own dialysis at home and considered hospital HD their best treatment option. Such a lack of confidence is a commonly reported reason for patients declining home treatment, indicating deficiencies related to modality education that typically lead to hospital HD (Chan et al., 2018).

The act of steering patients towards a certain treatment contains elements of paternalism (Solberg, 2021). Moreover, the paternalism is partly hidden, because the patients' choice is not abandoned, but promoted, by healthcare professionals (papers I and III). From an ethical point of view, hidden paternalism may be more problematic than strategies in which paternalism is fully visible (Solberg, 2021). Professionals may still consider it legitimate to steer patients in a certain direction when the direction is in accordance with best practices. A directive approach (Winterbottom et al., 2016) may, on the one hand, be associated with paternalism – because it accounts for what professionals and policy makers consider best for patients in a one-size-fits-all approach, without investigating the individual's values and preferences. On the other hand, presenting the different dialysis modalities as equal without clarifying the impact of each choice in relation to lifestyle, morbidity, and mortality does not convey current knowledge about the modalities (Chan et al., 2018; Palmer et al., 2014; Schatell & Alt Stec, 2008). No dialysis modality comes without potential complications. However, certain modalities may substantially improve the patients' ability to work, eat and drink normally, take fewer medications, stay out of the hospital, and perhaps live longer (Cases et al., 2011; Karkar et al., 2015; Schatell & Alt Stec, 2008). Hence, neutrality when presenting the modality options may neither be ethically justified nor possible.

Hostages to care

Hospital HD became the patients' way of escaping death while waiting – and remaining eligible – for a transplant kidney. However, the treatment implied invasive consequences to the patients' lives (paper II). This finding is supported by other research (Monaro et al., 2014; Roberti et al., 2018; Saad et al., 2015). Our study additionally showed the patients' ambivalence towards dialysis treatment. This ambivalence could be summarised as "needing it without wanting to" (Koekkoek et al., 2010). On the one hand, patients were grateful for the possibility of receiving life-saving treatment. On the other hand, the treatment limited life-enabling activities within their family or community. Healthcare professionals were construed with similar ambivalence (paper II). Even though the close bonds between patients and providers may work as a facilitator for patient participation (Barello et al., 2012; Bennett, 2011b; Thomas-Hawkins et al., 2017), the patients' dependency upon the provider disrupt equality in the patient-professional relationship. This may jeopardise patient participation (Beedholm & Frederiksen, 2019; Frosch et al., 2012). For example, when patients are highly dependent on treatment, they may, to maintain a healthy relationship with the providers, avoid opposing or disagreeing with medical recommendations (Berry, Danaher, Beckham, Awdish, & Mate, 2017; Frosch et al., 2012).

Bevan (2000) depicted patients on hospital HD as subjected to the obligations of Parsons' sick-role. To prolong life, or avoid death, patients must submit to life-saving medical expertise provided through the dialysis machine. In return, this endeavour requires patients to follow the prescribed treatment and do their best to restore good health (Armstrong, 2014; Tjora, 2008). The individual is technologically enframed in the social structures of hospital HD, in which professional control of the uncontrollable element – the patient – creates an environment conducive for success (Bevan, 2000). This analysis is 20 years old, and it could be argued that dialysis technology has undergone development. However, monitoring hospital HD remains largely identical today. In our study, both nephrologists and nurses recognised the in-centre patient role as passive (papers I and III) and sought to change passive behaviours by activating patients in self-care tasks. This was similarly found in the study of Årestedt et al. (2019), where healthcare professionals perceived patients running their own dialysis as the superior form of patient participation. This is in line with an understanding of the patient as an active co-producer of health (Lian, 2008), contrary to the passive patient role of Parsons (Armstrong, 2014; Tjora, 2008).

Because patient participation is contextual and includes the right not to be involved, a seemingly passive behaviour may be patients' choice (Thompson, 2007). However, Berry et al. (2017) suggested that patients affected by a life-threatening condition could come to feel like hostages to their care. They refer to this as "hostage bargaining syndrome," which describes a state that may occur when people are deeply dependent on the healthcare system. Persistent and escalating over time, the result of this hostage syndrome may be a condition of learned helplessness, taking root as the individual feels incapable of controlling his or her situation. In turn, the state of learned helplessness leads to passivity, neglect of health maintenance activities, and depression (Berry et al., 2017), the latter a common co-morbid condition in ESRD (Cukor et al., 2009; Ossareh et al., 2014). Professionals may misread the patients' behaviour as disengagement and lack of interest in treatment (Clark et al., 2014).

Competing patient-professional values

The present study shows how divergent patient–professional values created tensions between patients and healthcare providers (papers I–III). For example, nurses and nephrologists considered scheduled treatment and patients' treatment adherence important to achieve optimal treatment outcome, and they paid attention to shaping and controlling this adherence (papers I and III). Patients strived to combine adherence to treatment with maintaining their everyday life (paper II). The potential of patient-professional tensions was recognised by Freidson (1974), who argued that the views of laymen and the view of professionals represent a clash of perspectives. Hence, patient–professional relationships are characterised by conflicts rather than consensus (Freidson, 1974).

In line with a democratic stance, patient participation idealises experience-based knowledge as equal to professional expert knowledge (Castro et al., 2016). Hence, when patients and professionals advocate their respective views, both views may be justified. While the patients' need for life-saving treatment is indisputable, so is healthcare professionals' obligation to provide their treatment. However, other factors may also be indisputable, such as patients' commitments to under-age children and family relations. The present study shows how patients and healthcare professionals negotiate their respective values (papers I–III). Even though medical guidelines increasingly emphasise strengthening the patients' voice (Krumholz, 2014), evidence-based approaches continue to be the dominant paradigm in medical practice, favouring populations over individuals (O'Hare, Rodriguez, & Bowling, 2016). Population-level treatment goals do not always align with what matters most to the individual. However, it provides professional knowledge the potential to override experiential knowledge, as shown in our study (papers I–III).

Behavioural factors are the antecedents of many illnesses and points to an understanding held by professionals about how certain patient behaviours are necessary to accomplish health (Nettleton, 2013). In the present study, both nurses and nephrologists emphasised patient information to shape patient behaviour (papers I and

III). Healthcare professionals may consider information as equal to patient participation when patients act according to the information they are provided – for example, regarding food and fluid restrictions and how to adhere to these (Årestedt et al., 2019). Providing patients with responsibility regarding their own health may be seen as treating people as autonomous individuals (Solberg, 2021), as found in our study (papers I–III). However, it may also lead to patients being blamed if they do not live up to the ideals of self-management (van de Bovenkamp & Dwarswaard, 2017) and cause patients to feel guilty about their symptoms. This eventuality illustrates a paradox within patient participation. On the one hand, patient participation encourages patients to take an active role. On the other hand, patient participation must ensure that patients do as they are told in accordance with professional requirements (Beedholm & Frederiksen, 2019; Nettleton, 2013). When confronted with these conflicting demands, patients are put in a "double bind" (Nettleton, 2013).

However, both nurses and nephrologists in our study experienced conflicting requirements when they, on the one hand, wanted to accommodate their patients' interests, while on the other hand were obliged to provide their patients optimal treatment (papers I and III). Thus, professionals may also be placed in a "double bind" (Nettleton, 2013). If professional expertise is avoided or devaluated in healthcare decisions, this may weaken medical professionalism and lead to poorer patient outcomes (Gusmano et al., 2019). Hierarchising knowledge may result in patients and professionals competing over power to force through their own views and considerations, instead of recognising expert and experiential knowledge as complimentary (Tritter, 2009). The power asymmetry between patients and healthcare professionals (Frosch et al., 2012) may complicate the ideal of equalising knowledge and thus the application of patient participation. For example, professionals may be reluctant to accept patients' views if they do not correlate with medical recommendations. They may similarly value expert knowledge over experience (Solbjør & Steinsbekk, 2011). This eventuality became explicit when one of the nephrologists underestimated the patients' competence about fluid removal (paper III). Challenging the asymmetry undermines the patients' reasons for seeking medical help in the first place (Pilnick & Dingwall, 2011).

Collaborative aspects in healthcare

Inter-professional collaboration is expected to improve efficiencies and quality of care but is associated with challenges such as the professionals' differing routines, knowledge, and identities, as well as hierarchies and time constraints in healthcare (Dahlke et al., 2020). Contrary to person-centred, integrated care (Castro et al., 2016; Håkansson Eklund et al., 2019; World Health Organization, 2008), we found that patients experienced collaborative deficiencies related to their treatment trajectories. These experiences jeopardised their trust in the healthcare services (paper II).

In healthcare, a patient–professional relationship based on trust is essential (Choy & Ismail, 2017). Trust moreover influences patient participation. For example, although patients with greater trust in healthcare professionals may submit to a deferential role, greater trust is also consistent with more active patient roles (Thompson, 2007; Trachtenberg, Dugan, & Hall, 2005). High trust is associated with greater willingness to seek care, follow recommendations, and let professionals make decisions. Patients with a past disagreement or conflict with professionals may be less likely to adhere to medical recommendations, rely on professional judgment, or seek professional medical help. Rather, they are likely to take control and make medical decisions themselves (Trachtenberg et al., 2005).

In our study, patients extended their responsibility into coordinating their healthcare transitions as a way of coping with the experienced collaboration deficiencies (paper II). Similar findings were present in the study of Stømer et al. (2020), in which experiences of a fragmented healthcare system resulted in insecurity and a need for patients to be in control themselves. For some people, coordinating their own care may be a way of participating in healthcare, leading to regained control over circumstances in which little is in their control. However, because undergoing hospital HD already provides major responsibility related to adherence and self-management (Roberti et al., 2018), the stressor of constantly having to be on top of things adds to patients' burden. Although unintentional, providing patients with such a responsibility excludes those who lack the resources required to navigate the complex structures of healthcare.

Specialisations in healthcare involves medical specialists who have detailed knowledge of specific conditions and parts of the body. However, practitioners from different specialities have little common knowledge or shared practice (Bradby, 2012). Many patients have had excellent experiences with healthcare, but for those who have not, their experiences may be deeply distressing (Dixon-Woods, 2019). Even though medical specialisation has brought indisputable benefits into clinical care, it has simultaneously introduced organisational, institutional, and cultural barriers to holistic patient care (Bradby, 2012). Despite policy proposals of integrated care (World Health Organization, 2008), medical specialisation may be less compatible with the holistic model of person-centred care. As a paradox, there is, due to the many co-morbid conditions affecting people with chronic illness, a growing need for integrated care (Axelsson & Axelsson, 2006). Integrated care supports patient participation. Thus, when care is fragmented and episodic, the ideals of patient participation may suffer.

5. Conclusion

This thesis indicates that patient participation is challenging throughout the ESRD trajectory. The choice of dialysis modality was experienced as complex by patients as well as healthcare professionals. In accordance with the current focus on patient autonomy, both nurses and nephrologists emphasised that patients themselves should make the modality decision. By contrast, patients experienced being included in a predestined treatment decision of hospital HD. Consequently, they had no experience being involved in the treatment decision.

In hospital HD, healthcare professionals associated patient participation with self-care tasks and emphasised the patient’s individual responsibility to ensure a successful treatment. This is consistent with an understanding of patients as active co-producers of health and patient participation as action focused. Patients held other roles beside being a patient and this study suggest deficiencies with regards to organising the treatment based on patient values and preferences. Divergent priorities between patients and professionals brought about negotiations in which both parties strived to justify their views. Experiences of fragmented care entailed extended patient responsibility and diminished the patients’ trust in healthcare, while organisational structures and efficiency requirements inhibited practical implementation of patient participation.

6. Implications for practice

This thesis shows several areas for improving patient participation for working age ESRD patients requiring dialysis. Accommodating individual needs involves withdrawing the “one size fits all” approach that has dominated ESRD care (Chan et al., 2019) for a more person-centred care, systematically involving patients and their families. Sharing decisions throughout the ESRD trajectory (except from within emergency decisions that require immediate actions) is a way to ensure patients’ voice, share responsibility, and mitigate patient–professional tensions in the plethora of required choices.

Patients about to commence dialysis would benefit from shared decision-making in the complex choice of the dialysis modality. Incorporating the patients’ and their families’ lifestyle preferences and values when deciding on the dialysis modality is possible through person-centred communication (Håkansson Eklund et al., 2019), allowing patients to steer the modality choice based on their individual values and preferred lifestyle (Winterbottom et al., 2016). This may be especially important when patients are of working age. The use of decision aid tools is recommended to minimise staff variable practices (Morton, 2016; Stacey et al., 2017). In addition, educating healthcare professionals in patient participation, including shared decision-making, is necessary.

When the patient chooses hospital HD, individualised care should accommodate the patient’s life situation with regard to education, work, and family life, among other factors. In accordance with person-centred care, which involves mutual trust, sensitivity, empathy, and shared knowledge (Castro et al., 2016), patients should be involved in every decision in their healthcare trajectory. Expanding the professionals’ conceptual understanding could strengthen patient participation in hospital HD. As suggested by Coulter and Collins (2011), this endeavour could include sharing decisions in self-management education, medication, or in attempting a lifestyle change. Patient participation could further involve individual reviews of test results and current treatment, planning further treatment, and regularly evaluating the transplant process.

Scheduled and private individual consultations allow patients to speak of sensitive topics that could be withheld in traditional ward rounds.

Collaborative deficiencies lead to fragmented or episodic healthcare (World Health Organization, 2008). Addressing these issues requires emphasising continuous integrated care involving several medical disciplines. Developing an individual care plan (Bjerkan, Vatne, & Hollingen, 2014) in collaboration with the patient may ensure patient participation in healthcare planning and incorporate multidisciplinary collaboration. Implementing tools to measure patient-reported data involving outcomes and experiences with the health service emphasise the patients' voice and may increase patient participation. Patient Reported Outcome Measures (PROM) and Patient Reported Experience Measures (PREM) are such tools (Black, 2013). For example, PROM seek to ascertain patients' views of their symptoms, functional status, and HRQoL. PREM focus on experiences of the humanity of care, involving factors such as waiting time and healthcare providers' professional skills and communication skills (Black, 2013).

As a former nurse, I cannot refrain from considering the healthcare professionals' working conditions when suggesting implications for practice. Promoting patient participation adds to multiple requirements imposed on healthcare professionals, including the challenges of clinical work, time constraints, competing demands, minor control in work processes, conflicting roles, and relations with leadership (Lyndon, 2015). Pressures upon healthcare service budgets cause growing concerns around working conditions and the staff members' wellbeing (Hall, Johnson, Watt, Tsipa, & O'Connor, 2016). Both nurses and nephrologists in the current study underlined discrepancies between the provided resources and the imposed requirements. Hence, implementing patient participation in ESRD care requires facilitating the working conditions of healthcare professionals so that they can successfully manage this part of their job. This may even be an appropriate place to start.

Long-term care providers including dialysis nurses and nephrologists are in particular subjected to occupational stress, compassion fatigue, and burnout (Pawłowicz &

Nowicki, 2020; Prezerakos et al., 2015; Woodhead et al., 2014; Yaman, 2017). In addition, there are growing concerns about shortages of healthcare professionals (Hall et al., 2016). Preventing occupational dropout by providing frontline professionals with support, education, time, and optimal working conditions to provide person-centred care is a well-founded investment in every part of healthcare service, including ESRD care. This endeavour requires attention on a broader level and involves addressing healthcare management and policy makers as well as accentuating the voice of ESRD patients and frontline healthcare providers.

7. Suggestions for future research

There is a need for extensive research on the younger adults' experiences of patient participation in ESRD care. Given that people have individual needs that are dependent on their age and current life situation, experiences from the 18–35-year-old age group would be valuable. On basis of the current study, I would suggest an online survey with a set of structured questions related to the topic to investigate whether the findings from the current study are present in other HD units in Norway. With respect to the patients' time resources, an online survey requires only a minimum amount of time. With regard to the ongoing campaign "What matters to you?" in Norwegian healthcare, I would suggest including this question to investigate what matters the most to patients in need of dialysis. In our studies, patients voiced collaborative deficiencies related to their healthcare trajectory. Hence, there is a need to investigate collaborative issues and solutions to these in ESRD care from the viewpoints of patients as well as healthcare professionals and stakeholders within different levels of healthcare services. With the implementation of patient evaluation tools like PROM and PREM, I suggest future research should involve studies concerning the patients' and professionals' experiences with these tools.

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Appendix: Interview guides sub-study I-III

Sub-study I

Questioning route:
1. What happen when it is decided that the patient has to start on dialysis treatment?
2. What kind of information do you provide?
3. How are patients and next of kin involved in decision–making regarding treatment choices?
4. How do you practice person-centred care?
5. Which experiences do you have from home treatment?
6. What are your overall perceptions on patient participation in the initial phase?
7. How is the patient involved in their treatment?
8. What challenges do you experience in patient participation?
9. How can patient participation be strengthened?
10. Is there anything else you want to tell related to patient participation?

Sub-study II

Interview guide:
How would you describe to live with kidney failure and dialysis treatment?
Explain how you experienced the start-up?
Which information did you receive before you started?
How did you get involved in the choice of treatment?
How are you on a daily basis involved in your treatment?
In what way are you included in decisions that concern yourself / your treatment?
How do you experience to be seen and heard by the staff members?
How do you experience the coordination of your healthcare services to be?
Is there anything else you want to convey?

Sub-study III

Semi-structured interview guide:
How do you prepare your patients for dialysis?
How is the decision about dialysis modality made?
How do you involve patients and next of kin in this decision?
What do you consider important for patients to know before they commence dialysis?
How can patients undergoing hospital haemodialysis participate?
How would you describe the term patient participation?
How do you consider nephrologists' role in patient participation?
How do you promote patient participation in your clinical work?
Is there anything else you would like to convey?

Paper I

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RESEARCH ARTICLE

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Patient participation in the clinical pathway—Nurses' perceptions of adults' involvement in haemodialysis

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Abstract

Aim: To develop knowledge of nurses' perceptions of participation for patients treated with haemodialysis and their next of kin.

Design: A qualitative study with a hermeneutic approach.

Methods: The data were collected in 2015 through focus groups with 13 nurses in Central Norway.

Results: The nurses reported that patient participation ranging from non-involvement to shared decision-making was related to whether dialysis was initiated as acute or scheduled. The restrictions required in chronic haemodialysis limited participation. The next of kin were not involved. The nurses highlighted interventions on both the individual and system levels to strengthen participation.

Conclusion: Dialysis units should develop strategies for participation related to individual needs and design treatment in cooperation with patients and their families, ensuring involvement early in the clinical pathway. Further research is needed on issues related to next of kin, including their desired level of involvement.

KEYWORDS
haemodialysis, next of kin, nurses, patient involvement, patient participation, shared decision-making

1 | INTRODUCTION

Chronic kidney disease (CKD) is a progressive, irreversible renal impairment (Jansen et al., 2013). The disease is divided into stages 1–5, where patients in stage 5 are dependent on dialysis treatment for symptom relief and survival (Jansen et al., 2013). Haemodialysis (HD) is the most common form of dialysis treatment worldwide (Ortiz et al., 2014; The Norwegian Directorate of Health, 2011). The treatment is rigorous and imposes physical and mental burdens on patients and their families (Saad et al., 2015). Comorbidities such as

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diabetes, complications of the cardiovascular system, loss of self-esteem, anxiety, depression, sexual dysfunction and sleep disorders are common with CKD patients (Laudański, Nowak, & Niemczyk, 2013; Saad et al., 2015; The Norwegian Directorate of Health, 2011; Vazquez et al., 2003) and contribute to higher mortality and a poorer health-related quality of life than that of the general population (Gerogianni et al., 2016; Hemmett & McIntyre, 2017; Jansen et al., 2013; Saad et al., 2015; Vazquez et al., 2003). Patient participation may improve symptom burdens such as anxiety and depression and provide patients with better treatment outcomes (Saad et al., 2015).

2 | BACKGROUND

Patient' rights have been formulated in several documents and guidelines worldwide, and in Norway, patient participation is imposed by law (The Patients' Rights Act, 2015; World Health Organization, 2013). The law indicates that patients are entitled to participate in the implementation of their health care and includes the right to participate in choosing between available and medically sound methods of examination and treatment (The Patients' Rights Act, 2015). Actively participating in decisions related to own health issues is an important element of self-management in chronic diseases (Protheroe, Brooks, Chew-Graham, Gardner, & Rogers, 2012). Patients who are involved in their own treatment are reported to be less anxious and depressed, are less vulnerable, show better adherence to treatment protocols and have more insight into their own disease (Algilani, James, & Kihlgren, 2016; Barello, Graffigna, & Vegni, 2012; Orsino, Cameron, Seidl, Mendelssohn, & Stewart, 2003; Sahlsten, Larsson, Sjöström, & Plos, 2008; World Health Organization, 2013).

However, there are several internationally identified challenges to participation, such as nurses' attitudes and beliefs, insufficient training, differences in role expectations, context and illness severity (Aasen, Kvangarsnes, & Heggen, 2012, 2012; Longtin et al., 2010; Thompson, 2007). In a traditional patient role, patients are expected to be passive and "looked after" (Joseph-Williams, Elwyn, & Edwards, 2014; Protheroe et al., 2012). These expectations may result in patients under-communicating knowledge and desire to participate to not be perceived as a "difficult patient" (Frosch, May, Rendle, Tietbohl, & Elwyn, 2012). Low health literacy may prevent patients from participating, and some patients will have cultural backgrounds without traditions for autonomous decisions (Elwyn et al., 2012).

Prolonged illness experience was demonstrated to provide a greater desire for involvement; thus, a patient with a chronic illness is more likely to participate than a patient with an acute illness (Thompson, 2007). The patient–professional relationship is important and a greater trust in professionals gives the patient the confidence to allow health workers to act on his or her behalf. Trust often appears when the patient has little experience or knowledge or has serious illnesses. The patient's wish for involvement reflects a combination of these dimensions (Thompson, 2007). Potential barriers to patient participation were found to be modifiable by addressing attitudinal changes at the levels of the healthcare team, organization and patient (Joseph-Williams et al. 2014). Eldh, Ekman, and Ehnfors (2006) showed that good conditions for patient participation occurred when information was based on individual needs and accompanied by explanations. Professionals should recognize each patient's unique knowledge and respect the individual's description of the situation, rather than just inviting the patient to participate in decision-making (Eldh et al., 2006).

Earlier studies on participation in haemodialysis have mainly focused on older patients or on dialysis patients as a group regardless of age (Aasen, Kvangarsnes, & Heggen, 2012, 2012; Muthalagappan, Johansson, Kong, & Brown, 2013; Stryckers, Nagler, & Van Biesen, 2016; Tuso, 2013; Van Loon, Boereboom, Bots, Verhaar, & Hamaker, 2015). A study on participation from the perspectives of patients >75 years of age, next of kin and nurses suggested that participation was not well integrated in dialysis units and that both the elderly and their families struggled for their right to participate (Aasen, Kvangarsnes, & Heggen, 2012; Aasen, Kvangarsnes, & Heggen, 2012; Aasen, Kvangarsnes, Wold, & Heggen, 2011). Younger patients may have a greater interest in participating, possess more treatment knowledge and are more confident in decision-making situations than older (Orsino et al., 2003; Yalamanchili et al., 2013).

In-centre HD largely affects the lifestyle and family life of patients and the next of kin (Gerogianni et al., 2016). Patients on HD are dependent on treatment several days a week and are imposed with numerous restrictions that create a burden on everyday life (Gerogianni et al., 2016). Education, careers and family life may be put on hold, leading to a lower social and economic status, the development of psychological disorders and a lower quality of life (Gerogianni et al., 2016; Saad et al., 2015; Yalamanchili et al., 2013). The next of kin of patients with long-term illness may perceive their role as a valuable part of being human but also a burden or an inevitable obligation (Liedstrom, Kihlgren, Skovdahl, & Windahl, 2014). The next of kin who perceived their role as a burden expressed feelings of isolation, anxiety and anger and were at risk of developing depression. These symptoms were more prominent in female spouses (Liedstrom et al., 2014). Ebadi, Sajadi, Moradian, & Akbari (2018) found that the next of kin of patients undergoing haemodialysis experienced unpredictable, uncontrollable stressors such as time conflicts between caregiving and occupational affairs, care-induced fatigue and fear of the future. Aasen et al. (2011) showed that the next of kin of elderly patients on HD felt excluded and forgotten by health providers.

Nurses work closely with patients and, therefore, hold a key position in terms of patient participation (Coulter & Collins, 2011; Longtin et al., 2010; Thompson, 2007; Tobiano, Bucknall, Marshall, & Chaboyer, 2015). A close therapeutic relationship may be developed between nurses and patients on long-term dialysis because they spend several hours a week together during treatment (Shahgholian & Yousefi, 2015). The dialysis nurses are responsible for treatment administration, information and guidance on topics such as fluids, diet and medication, among others. Nurses' perceptions of patient participation are thus central.

Although several studies have been presented on patient participation in HD (Erlang, Nielsen, Hansen, & Finderup, 2015; Hemmett & McIntyre, 2017; Van Loon et al., 2015), we found no study regarding nurses' perceptions of participation for patients aged 18–65 years through different phases of the clinical pathway. The current study adds new knowledge on nurses' perceptions of patient participation for adults undergoing HD and their next of kin relationships, both in the initial and established phases of dialysis treatment. Adults and younger adults are likely to have needs and concerns that differ from those of older patients and lack of participation may have major consequences. The results from this study will provide knowledge to the field that may improve health care for ESRD/HD patients and their next of kin through adding a broader understanding of patient participation in different phases of the clinical pathway. The study posed the following question: how do nurses perceive participation for patients undergoing HD and their next of kin?

3 | THE STUDY

3.1 | Aim

We aimed to develop the knowledge of nurses' perceptions of participation for patients treated with haemodialysis and their next of kin.

3.2 | Design

The study was framed using a hermeneutic approach (Gadamer, 2010), focusing on how a new and holistic understanding is created from text through pre-understanding and fusions of horizons within the hermeneutic circle.

3.3 | Theoretical framework

We used Thompson's (2007) framework to understand nurses' perceptions of patient participation. The framework forms a base of patient-desired involvement, with three elements important for understanding: components, levels and context. The components are described as contributions to action, participation in defining the problem, participation in the reflection process, participation in decision-making and mutual emotional meetings. These components are connected to five levels of participation, ranging from non-involvement to autonomous decision-making. Patient participation is contextual, meaning patients may wish to be involved in some areas but not necessarily in others. The desire for participation may change over time, even in a similar context and the patient may move between the different levels.

3.4 | Participants

We conducted a purposive sampling to answer the research question (Krueger & Casey, 2015). The inclusion criterion was registered nurses (RNs) working with patients on HD. Both experienced and less experienced Norwegian-speaking nurses with different ages were included. Nurses with leadership roles were excluded because the power imbalance between leaders and the other participants may limit the dynamics in the focus groups. The units were small, comprising 5–16 nurses. Two of the units employed nephrologists and had an outpatient function and one unit was responsible for the education of patients and the next of kin through "kidney school," initiation of acute dialysis and PD. Recruitment was carried out by the head nurses who communicated written information and consent forms to relevant informants. Twenty-five RNs were invited to participate in the study: 15 accepted and 13 participated. Seven informants were kidney nurses or intensive care nurses with experience between 3 months to more than 30 years. All nurses were females. Each focus group consisted of four to five participants in accordance with recommendations (Krueger & Casey, 2015; Tong, Sainsbury, & Craig, 2007).

3.5 | Data collection

The data were collected during the spring of 2015 through focus groups comprising 13 nurses employed in three different dialysis units in Central Norway. We considered focus groups to provide a wide range of information and insight through group discussions, where participants could state their points of view stimulated by interactions in the group (Krueger & Casey, 2015). Based on previous literature, the theoretical framework (Thompson, 2007) and the aim of the study, we developed a semi-structured questioning route (Krueger & Casey, 2015), focusing on the nurses' perceptions of participation for patients treated with haemodialysis and the next of kin (Table 1). The informants, the interviewer and an assistant were present during the focus groups (Krueger & Casey, 2015). The three sessions were audio recorded and lasted from 58–71 min. The assistant took field notes and summarized what had been said. The informants were given the opportunity to supplement. The recordings were transcribed verbatim by the first author. We experienced the research question to be thoroughly illuminated through the three focus groups. At the end of the third, no new information was

TABLE 1 Questioning route

1. What happen when it is decided that the patient has to start on dialysis treatment?
2. What kind of information do you provide?
3. How are patients and next of kin involved in decision-making regarding treatment choices?
4. How do you practice person-centred care?
5. Which experiences do you have from home treatment?
6. What are your overall perceptions on patient participation in the initial phase?
7. How is the patient involved in their treatment?
8. What challenges do you experience in patient participation?
9. How can patient participation be strengthened?
10. Is there anything else you want to tell related to patient participation?

provided, and we considered the data as saturated (Krueger & Casey, 2015).

3.6 | Ethical considerations

The study was approved by the Regional Committee for Medical and Health Research Ethics (REK 2014/1586) and approved by the Norwegian Data Inspectorate (case number 40336). Informed consent was obtained from all participants. The informants' anonymity was ensured by giving informants the letters A, B, C, D and E and numbering the focus groups 1, 2 and 3.

3.7 | Data analysis

We analysed the data using hermeneutics, which focus on interpretations of texts (Gadamer, 2010). The researchers interpreted the nurses' perceptions of patient participation as expressed through focus groups by considering the structure of the transcribed text (Flick, 2014). The authors read the transcripts several times. Notes from the interactions between participants were emphasized (Krueger & Casey, 2015). The first reading was performed to form an overall impression of the text. In further reading, we aimed to grasp the informants' world (Gadamer, 2010), looking beyond what is close at hand to develop a new understanding. We emphasized reading the text carefully, focusing on quotations and common and distinguishing features. The movement of understanding was constantly from the whole to part and back to the whole (Gadamer, 2010). The data were coded according to the patient participation in various phases of the clinical pathway and the nurses' suggestions on how to strengthen participation. In the analysis, we considered Thompson's (2007) components, levels and context. We then identified four themes and show an example of the development of one of the themes in Table 2. We emphasized confirming the themes through constantly comparing them with the transcripts (Krueger & Casey, 2015). The authors had several discussions of the findings and interpretations throughout the whole process before reaching a common understanding.

3.8 | Rigour

In qualitative studies, the presence of the researcher deeply influences the reality studied (Flick, 2014). The first author is an experienced dialysis nurse whose knowledge provided an understanding of the topics, field access and a sound basis for the development of an adequate questioning route (Krueger & Casey, 2015). However, the close field position caused pre-established beliefs important to acknowledge and clarify (Wernet, 2014). A constructive outlook from co-authors was important to develop an intersubjective understanding and assessment of the results. The use of focus groups provided rich data while evolving into engaging discussions, where comments triggered others to express their perceptions on the topic. We noticed that nurses with less experience expressed perspectives that somewhat differed from the experienced nurses, although no disagreements arose. We recorded the focus groups and took field notes and the participants verified the oral summary. The findings reflected what the participants said, and we used quotations to validate the themes (Krueger & Casey, 2015).

4 | FINDINGS

Thirteen nurses from three local hospitals in Central Norway conveyed their perceptions of patient involvement in HD through focus groups. We identified the following themes: (a) between non-involvement and shared decision-making; (b) restricted self-determination; (c) absent next of kin; and (d) the nurses' role in shared decision-making.

4.1 | Between non-involvement and shared decision-making

The nurses experienced differences in involvement related to whether dialysis treatment was initiated acutely or was scheduled. The informants expressed that acute kidney failure required fast treatment initiation, implicating a vascular catheter and, thus, no time to discuss treatment options. The nurses mediated that patients entering the emergency room were severely ill and were often overwhelmed by the situation: "They are just thrown into it and do not know about the future" (A, group 1). The nurses conveyed it was difficult to involve patients who required acute dialysis. This indicates less involvement in acute situations. It was stated that patients with acute kidney failure had no actual treatment choices because patients initiated in HD tended to stick to this treatment throughout the course.

TABLE 2 Example of developing the first theme

Quotations	Subthemes	Theme
"They are just thrown into it, and do not know about the future" (A, group 1)	Acute treatment and lack of involvement	Between non-involvement and shared decision-making
"Being able to choose the right treatment requires time and continuous conversations. Ten minutes with a busy doctor answering phone calls at the same time is not enough" (D, group 1)	Information giving	
"We have this patient who is a fisherman... he connects to a night machine when he is at home sleeping. He is on the transplant waiting list, but is very happy with life as it is now." (C, group 3)	To be in control	

The nurses expressed that the situation was different for patients with scheduled dialysis. These patients were provided with much information during the initial phase and were expected to make decisions about in-centre HD or home treatment. The decisions were initiated as patients approached dialysis by the nephrologist and/or the outpatient nurse. One nurse suggested this was not the optimal time: "Being able to choose the right treatment requires time and continuous conversations. Ten minutes with a busy doctor answering phone calls at the same time is not enough" (D, group 1).

Other obstacles to decision-making were highlighted—that is, when the disease progressed to require acute HD treatment or when decision-making failed to occur because patients did not initiate it themselves. The nurses reported how even CKD patients at the time of dialysis initiation could be too affected by the disease to make sound treatment decisions.

The nurses perceived that it could be difficult for patients to fully understand the dialysis modalities and this complicated their treatment decisions. Outpatients about to start on dialysis were invited to visit the HD unit and, if possible, the nurses arranged for a meeting between the new patient and a patient already on PD, a "PD ambassador." However, the units had a low percentage of home treatment and the nurses reported how the number of patients on PD was decreasing. The nurses reflected on this and explained how the hospital could appear such as a haven, making patients choose in-centre HD:

> For a patient with no medical background, it is not so easy to see the choices equally. Outpatients get to meet the staff on a regular basis and may choose in-centre HD because other patients have it and it feels like a safe solution. (A, group 2)

However, the nurses gave examples about patients who had decided on PD and felt satisfied with the treatment: "We have a patient who is a fisherman...he connects to a night machine when he is at home sleeping. He is on the transplant waiting list but is very happy with life as it is now." (C, group 3).

This indicates that initial situations differ between non-involvement and shared decision-making.

4.2 | Restricted self-determination

When in-centre HD was established, the nurses reported about how patients were required to follow a time-consuming treatment schedule and were restricted on fluid and diet. HD was largely predetermined—typically, 4 hr three–four times a week. Additionally, the patients spent time on transportation to and from the hospital. The nurses expressed that the patients' opportunities to influence treatment were limited to changing their days on dialysis and, to a certain degree, their hours of attendance:

> They do need the dialysis. We cannot let them do everything they want, you know (….) That is a bit of a challenge (…) And if the doctor says you must have four hours then that is how it should be and most patients will accept it. (D, group 3)

Some nurses referred to patients requiring extra dialysis due to fluid overload or low clearance and reflected on how patients could be reluctant to increase treatment: "It is like a punishment, you know. Elsewhere in health care it is like; the more treatment the better. Here the extra treatment is a reminder of not being clever enough" (E, group 1). The nurses conveyed that the lack of adherence could be major problems among patients on HD and reported how they spent time repeating information on fluid and diet restrictions and medication. However, they experienced that patients often struggled to manage their restrictions, sometimes resulting in dangerous fluid overloads or potassium levels. According to the nurses, patients had problems processing the information provided: "We tell them over and over again, but still...they do not seem to remember much of what we say" (B, group 3). The nurses believed that patients who were involved in their own treatment would have a greater understanding of why they were subjected to restrictions. They welcomed patients' interest in treatment, although it sometimes challenged the nursing role. However, the nurses experienced that patients on HD easily adopted a passive role.

4.3 | Absent next of kin

According to the nurses, staff interaction with the patients' next of kin was absent. The "kidney school" was mainly the only arena for nurses to meet with patients' relatives. The nurses conveyed worries about the burden on the next of kin because dialysis treatment affected the whole family. They reported how spouses could be reluctant towards home treatment, worrying that the patients would not be able to manage it, thus create an extra burden on the spouses. The nurses expressed that they had tried to arrange for meetings with the next of kin and encouraged patients to bring their spouse or other family to consultations, without success:

> It is astonishing that we do not see more of the next of kin. I am thinking of the spouses ... if my husband had been on dialysis three days a week, I would like to see what was happening. (B, group 1)

4.4 | Nurses' role in shared decision-making

The nurses suggested strengthening participation by offering patients flexible hours for dialysis attendance, night-time dialysis, a self-care unit and home treatment and highlighted that their awareness of patient participation had to be raised: "I think we have to discuss it. Change the framework. We cannot do things the way we always have...We work quite traditionally. We are the nurses and they are the patients" (A, group 2).

They expressed their role to be well incorporated and difficult to abandon. One of the less experienced nurses conveyed that patients should experience participation from their very first meeting with the staff: "I think it is important. If not, they may easily feel that they are in a system where they do not have much to say in the matter… the doctors and nurses are the ones who decide" (A, group 3). The nurses experienced a contradiction between what they considered important in patient treatment and what was possible to achieve due to provided resources: "Sometimes I feel that we work on assembly lines. There is no time for reflection. We just have to get through the day" (B, group 3).

5 | DISCUSSION

The analysis showed how nurses perceived participation for dialysis patients and the next of kin. Participation varied between non-involvement and shared decision-making. In acute situations, the patients' illness limited participation. The initial phase of chronic HD was characterized by information loads and treatment decisions and patients on in-centre HD had their lifestyle limited by strict treatment protocols. The nurses experienced sparse contact with the patients' next of kin and finally discussed their role in how to strengthen the involvement of patients and their families.

In Norway, the ability to choose between different treatment modalities is mandatory (The Patients' Rights Act, 2015). Dialysis treatment strongly affects the lives of the patients and their next of kin and it is important that they are involved in treatment decisions. Patients approaching dialysis were expected to make decisions about a preferred treatment, although this was not considered to be the optimal time for decision-making. The nurses emphasized timing and ample time. This finding is in accordance with that of Tuso (2013) who claimed that shared decision-making and discussion about "life with kidney disease" should occur among the patients, their families and healthcare team as early as CKD stage 4, in sufficient time before dialysis initiation. Poor timing may cause patients to rush into treatment without having had time to discuss the options (Morton, Tong, Howard, Snelling, & Webster, 2010).

The informants in the present study perceived that patients struggled to figure out which treatment was the most suitable. We argue that information about treatment itself may not be sufficient for new patients to imagine what effect the different treatments have on their everyday lives. Sound treatment solutions may be achieved when the patients' values and preferences are considered and when health providers actively share their knowledge about treatment impact and outcome (Schatell & Alt Stec, 2008). Patients together with the next of kin should consider whether in-centre or home treatment would be best suited according to their lifestyle. This situation requires dialogue and is consistent with Thompson's (2007) components that are important for participation. However, the nurses expressed how treatment traditions influenced patients' choices and made them choose in-centre HD because this was the common and available treatment. Previous research has shown how treatments may be excluded due to in-centre limitations, lack of information about the options or the physician's treatment preference (Morton et al., 2010; Young et al., 2012).

In our study, the nurses perceived patients on in-centre HD as passive. This perception differs from previous research showing that younger patients are likely to participate (Orsino et al., 2003). Thompson (2007) describes the context as an important element for patient participation. HD units are technically oriented and dialysis nurses may appear as experts in the way they handle the dialysis machines and possess knowledge about advanced illness. This might create a distance towards patients and limit participation. The physical conditions and placing patients in a row during treatment may cause reluctance towards bringing up sensitive issues. In this context, patients may feel vulnerable and not in control and become passive (Larsson, Sahlsten, Segesten, & Plos, 2011). Dependency on scheduled treatment protocols to survive adds mental pressure on patients and may cause psychological problems such as anxiety and depression (Theofilou, 2011).

The nurses in our study perceived themselves in traditional nursing roles where the nurses are the experts who actively take care of, or treat, whereas the patients passively receive treatment and this is consistent with previous study findings (Barnes, Hancock, & Dainton, 2013; Longtin et al., 2010). Although the nurses valued more active patients, they also conveyed that patients who wanted involvement could challenge the nurses' professional judgements, or undermine their competences. Previous research has shown that health providers worry about how patient involvement might make patients decide too much, although patients emphasized the value of making decisions jointly (Solbjør, By Rise, Westerlund, & Steinsbekk, 2011). Our findings indicate that a consensus does not exist concerning patient participation in the dialysis units studied. Some nurses conveyed their concerns about involving patients, while others reported how the nurses worked in traditional nursing roles. We argue that patient involvement should be rooted in clinic management and not being solely dependent on individual nursing preferences.

Dialysis nurses may develop close bonds to their long-term primary patients and hereby feel a personal responsibility for patients' adherence to treatment. When experiencing a mismatch between the role expectations—that is, when patients do not conform to treatment protocols—-conflict may arise between respecting patients' autonomous rights and nurses' mandatory health-promoting nursing practice (International Council of Nurses, 2012). This may result in a controlling behaviour. The nurses' perceptions of themselves as "the nurses" and patients as "the patients" exhibit an "us" against "them" thinking (Meulen, 2015), which creates distance and obstacles to involvement. Additionally, this concept fits with traditional roles as nurses-as-experts and passive patients adhering to the nurses' advices. If patients do not adhere, they are seen as lacking insight into what is best for them (Solbjør et al., 2011) and nurses may feel it necessary to correct this. According to Thompson (2007), providing information is not equal to patient involvement. When nurses provide information, they are facilitating participation at a low level. Transferring knowledge to patients through providing information remains an important part of nurses' tasks. However, to facilitate involvement, nurses must additionally engage in dialogue, allowing patients themselves to define their needs (Thompson, 2007).

Our study showed that nurses experienced sparse contact with the patients' next of kin. Previous research has revealed how long-term illness imposes a heavy psychological burden on the patients' families (Ebadi et al., 2018; Liedstrom et al., 2014). The next of kin may be forced to adjust their life to the patients' scheduled treatments, neglecting themselves and constantly having to cope with a sense of unfulfilled tasks and worries about the future (Ebadi et al., 2018). The nurses in our study invited patients' families to the units, without success. In our interpretation, this may indicate how health providers determine what is important, without consulting those concerned. We suggest that Thompson's (2007) framework focusing on components may also be applied to the next of kin. Ebadi et al. (2018) called for improved interaction among professional caregivers to understand the conditions of the next of kin, thereby improving the quality of life for both patients and their families.

The nurses in this study suggested several options to strengthen patient participation, including the willingness among nurses to abandon their traditional roles and involve patients at a higher level (Thompson, 2007). However, nurses are part of the healthcare team and should not be solely responsible for patient participation. A clear leadership is a key to developing understanding and acceptance for departmental changes (Rokstad, Vatne, Engedal, & Selbæk, 2015), and the overall responsibility for implementation of patient participation lies mandatory in the management (Health Authorities & Health Trusts Act, 2013; The Patients' Rights Act, 2015).

The nurses in the current study experienced an imbalance between tasks and resources provided. This may cause patient participation to be of less priority, as supported by the Eurobarometer Qualitative Study (2012) where the time aspect was emphasized. There is a general agreement that the growing demands and expectations towards health care are placing extra pressure on limited resources (Légaré, Ratté, Gravel, & Graham, 2008). Research has demonstrated a link between the work environment, including staff levels and patient outcomes (Prezerakos, Galanis, & Moisoglou, 2015; Rafferty et al., 2007). However, no robust evidence has been found, indicating more time is required on the engagement in patient participation than in usual clinical practice (Légaré et al., 2008). There is a need to discuss new ways of involving patients and the next of kin in participating in different phases in the clinical pathway.

5.1 | Limitations

The current study presents nurses' perceptions of patient participation and does not consider the patients' own experiences. The nurses may have hesitated to express controversial views in front of focus group members, and different answers may have been provided in individual interviews. The units' head nurses carried out the recruitment process. This may have affected the process; however, because the units were small, we proceeded to obtain as many informants as possible. This study has a qualitative design and our findings are not intended for generalization (Krueger & Casey, 2015; Polit & Beck, 2012). Our findings may still be applicable to other dialysis units.

6 | CONCLUSION

Our study showed that nurses experienced challenges related to patient participation throughout the clinical pathway. Participation differed between non-involvement and shared decision-making, without next of kin involvement. Knowledge from the present study indicates that new approaches to patient participation are needed for HD patients. We suggest that dialysis units should accommodate the needs of patients where education, work and family life are particularly important and treatments should be designed individually in close cooperation with the patients and their families. This requires altering traditional nursing roles and involving patients more, implicating a clear leadership. Further research on how the next of kin would like to be involved in different phases of the clinical pathway is needed.

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CONFLICT OF INTEREST

No conflicts of interests have been declared by the authors.

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Narratives of patient participation in haemodialysis

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Abstract

Aim and objective: To explore how working-age adults experience patient participation in hospital haemodialysis.

Background: End-stage kidney disease is a progressive, chronic condition imposing patients with high treatment burdens and low health-related quality of life. Patients face multiple medical decisions related to living with kidney failure. Given their frequent interaction with health services, patient participation may be of special value.

Design: Qualitative design with a narrative approach.

Methods: In 2018, eleven patients aged 35–64 years undergoing hospital haemodialysis participated in individual interviews. All interviews were analysed using a narrative approach. Reporting followed the Consolidated criteria for Reporting Qualitative Research guidelines.

Findings: The patients' narratives of participation comprised three themes following their healthcare trajectory: Informed, but not involved in treatment choices; Duality of care and control; and Frail trust reflecting collaborative deficiencies. The patients received good information about dialysis, but were not involved in choice of treatment modality. Professional work, as well as the nature of treatment, contributed to restricted patient autonomy. Patients' trust suffered from collaborative deficiency generating delays in their treatment trajectories, and patients extended their responsibility into the coordination of transitions as a way of coping with these issues.

Conclusions: The study identified challenges related to patient involvement and interdisciplinary collaboration. Involving patients through dialogue and acknowledging their experiences, preferences and lifestyles may strengthen the mutual patient–professional understanding of treatment. Despite increased focus on seamless trajectories, patients face obstacles regarding interdisciplinary collaboration and coordination of health services.

Relevance to clinical practice: The findings indicate a want of individually customised care for people requiring dialysis. Patients need to be involved in the choice of treatment modality as well as decisions related to the current treatment. Information must include potential consequences of the different treatment modalities. Health services need to strengthen collaboration in order to secure treatment continuity and patient involvement.

KEYWORDS
decision-making, healthcare trajectory, narration, patient participation, renal dialysis, working-age adults

1 | INTRODUCTION

With their kidneys failing, people suffering from end-stage kidney disease (ESKD) are constantly reminded of their own mortality (Roberti et al., 2018). Kidney replacement therapy is their lifeline, with hospital haemodialysis as the most common form (Chan et al., 2019). Patient participation is idealised as a core element in health care for people with chronic illness, providing possibilities for patients with ESKD who face several decisions in different phases of their healthcare trajectory (Russell & Boulware, 2018; Tuso, 2013). In this article, we explore how working-age adults experienced patient participation in hospital haemodialysis.

What does this paper contribute to the wider global clinical community?

This study addresses issues that may improve health care for patients in need of dialysis.

- Patient participation through shared decision-making is especially relevant when choosing dialysis modality. This decision should take place well before patients reach the end stage of the disease.
- Patients who have chosen hospital haemodialysis as their preferred treatment may benefit from individually customised treatment designed in collaboration between health services, patients and their families.
- Deficiencies in collaboration might evoke distrust in health services and complicate patient participation. It is necessary to strengthen collaborative and coordinated care for people who require dialysis.

2 | BACKGROUND

Chronic kidney disease (CKD) is a leading cause of global mortality and morbidity (Roberti et al., 2018). Worldwide, about 500 million people are affected by CKD and an estimate of 3 million people with ESKD receive kidney replacement therapy, including transplantation or various forms of dialysis, in which hospital haemodialysis dominates (Chan et al., 2019; Roberti et al., 2018). The majority of people with ESKD live in low- or middle-income countries and receive only fragmented treatment or no treatment at all (Roberti et al., 2018).

ESKD is associated with high mortality and comorbidity, including cardiovascular complications, diabetes, anxiety, depression, suicidal ideation, sexual dysfunction and the myriad symptoms of ESKD affecting health-related quality of life (Roberti et al., 2018). The expected remaining lifetime between the general population and those receiving dialysis differs radically (Kramer et al., 2019). Due to comorbidity, patients are dependent on coordinated health care involving inter-professional teams and clinicians across several disciplines (Murray, Bissonnette, Kryworuchko, Gifford, & Calverley, 2013).

The ESKD trajectory begins as the kidney disease progresses into requiring renal replacement therapy (Chan et al., 2019). However, patients typically benefit from predialysis care through earlier stages of the kidney disease (Tuso, 2013) and are thus familiar with healthcare services even before treatment starts. In addition to kidney transplantation, treatment choices involve hospital haemodialysis, home treatment and, in cases where renal replacement therapy may be inappropriate, for instance due to severe comorbidity, conservative nondialytic care (Chan et al., 2019). Patients in rural areas are offered haemodialysis locally at satellite units that are managed by the specialist healthcare services. These satellites are an extension of hospital services (Bennett, 2011).

Hospital haemodialysis is commonly performed as a four-hour treatment three to four days a week, and patients are restricted regarding fluid and diet (Roberti et al., 2018). Combining this intensive treatment with key areas of everyday life such as employment, education and family life represents major challenges (Laudański, Nowak, & Niemczyk, 2013). Managing ESKD influences several aspects of life outside the dialysis unit, affecting both patients and their families (Reid, Seymour, & Jones, 2016; Roberti et al., 2018).

2.1 | Patient participation

Patient participation has been a worldwide healthcare goal for the last three decades (World Health Organization, 2013). Within the traditional sick role, historically conferred by the discipline of medicine, patients were passive figures with no responsibility other than to comply with medical advice (Armstrong, 2014). Rooted in empowerment thinking, and later influenced by market-oriented forms of public sector governance, patient participation reflects a democratisation of healthcare services (Frankham & Tracy, 2012). Consequently, patients may be presented as experts on their own bodies, symptoms and situations, and are requested to participate in different levels of health care (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016).

Despite the focus on patient participation provided by both research and healthcare policies, no conceptual agreement exists (Castro et al., 2016). Patient participation is largely used interchangeably with terms like patient involvement, user participation and user involvement, and may occur at different levels. Overlapping with terms like patient empowerment and patient-centred care, the concept implies an activated patient and balanced power in patient–professional interactions (Armstrong, 2014; Castro et al., 2016). In their review article, Castro et al. (2016) proposed the following definition of individual patient participation: "A patient's rights and opportunities to influence and engage in the decision-making about his [sic] care through a dialogue attuned to his preferences, potential and a combination of his experiential and the professional's expert knowledge" (p. 1929). Their definition implicates sharing decisions through dialogue that values both experiential and expert knowledge, as well as considering patients' preferences. Hence, shared decision-making goes beyond informed consent, presenting risks, benefits, alternatives and probabilities to support a specific treatment (Murray et al., 2013).

Previous research has documented that patients with chronic diseases are likely to take active roles regarding their own health care (Protheroe, Brooks, Chew-Graham, Gardner, & Rogers, 2013; Thompson, 2007). Likewise, healthcare providers generally are in favour of patient participation (Grünloh, Myreteg, Cajander, & Rexhepi, 2018). However, implementing patient participation in everyday healthcare practice has proven difficult (Castro et al., 2016). Complicating factors are linked to the design of healthcare services, presumptions of roles, power imbalance and interpersonal characteristics of both healthcare professionals and patients (Joseph-Williams, Elwyn, & Edwards, 2014).

The organisation of healthcare services, for instance time available in consultations, continuity of care, workflow organisation and the setting itself, is shown to influence (Joseph-Williams et al., 2014). Healthcare management has an overall and mandatory obligation to facilitate patient participation. However, little attention has been given to this area, and a Swedish report claims that patients' position is weakened in hospital care (The Swedish Agency for Health & Care Services Analysis, 2017). Lack of private consultations and the involvement of too many clinicians in one patient trajectory are further complicating elements (Joseph-Williams et al., 2014).

The power imbalance between patients and healthcare professionals represents a major challenge. Professionals, for instance nurses, have the power to encourage or hinder participation (Angel & Frederiksen, 2015). Sometimes healthcare providers' implicit expectations and patients' own wishes for their care differ. When this happens, patients can experience that expressing disagreement or opposition is challenging, fearing damaged relationship with those providing their treatment and care (Beedholm & Frederiksen, 2019). Patients may thus adhere to a traditional passive sick role when facing authoritarian healthcare systems and leave decisions to professionals despite wanting to have a say in their treatment (Frosch, May, Rendle, Tietbohl, & Elwyn, 2012; Joseph-Williams et al., 2014). The disease itself is an important aspect of the unequal power structures typical of these relationships. The transition from being a person in good health to becoming a patient suffering from illness is often accompanied by feelings of uncertainty, vulnerability and lack of power (Gulbrandsen et al., 2016). The medical profession holds the power to intensify or rectify this situation, by means of being able to impact patients' health, and the patient is obliged to trust professionals (Rowe & Calnan, 2006). Thus, unequally distributed power is a characteristic of healthcare services (Angel & Frederiksen, 2015). For patients, leaving their health in the hands of professionals may lead to a loss of autonomy. Being involved through, for instance, shared decision-making may help to restore patients' autonomy (Gulbrandsen et al., 2016).

Changing the patient role implies altering the professional role. Hence, implementation of patient participation requires healthcare professionals to accept greater self-determination among patients (Andreassen, 2018). However, many healthcare providers consider patient participation too time-consuming, not in line with clinical medical guidelines or patients' preferences, or they may perceive patient participation as something already fulfilled (Légaré & Thompson-Leduc, 2014). Healthcare professionals may feel uncomfortable in situations where patients want to participate, and physicians may feel that an active and questioning patient undermines their authority and mistrusts their expertise (Grünloh et al., 2018). The Eurobarometer Qualitative Study (2012) found that both patients and professionals perceived patients providing basic information on symptoms to a healthcare professional as patient involvement. Interactive dialogue or opportunity for patient feedback was not given attention.

A few patients may prefer a more passive role, relying on healthcare professionals as the experts or believing that their own experiential knowledge is superfluous in decision-making processes (Joseph-Williams et al., 2014). Patients may prefer to be involved in some areas and not in others, and their need for involvement may change and vary over time. Patient participation is thus context-bound. In situations where patients are highly dependent on healthcare professionals—for instance during emergencies—active participation will often decrease (Thompson, 2007). Not all patients are aware of their legal right to participate, and language or culture could be barriers to participation (Joseph-Williams et al., 2014; Schinkel, Schouten, Kerpiclik, Van Den Putte, & Van Weert, 2019).

Patients initiating their ESKD journey face decisions regarding treatment modality followed by multiple social and medical decisions related to living with kidney failure (Murray et al., 2013; Roberti et al., 2018). The predialysis period is a critical time, where the choice of treatment modality represents a major decision that significantly affects patient experiences and outcomes (Chan et al., 2019; Russell & Boulware, 2018). Patients face the choice between being treated in-centre by healthcare professionals and treating themselves at home. Home-based dialysis may be particularly suitable for working-age adults, providing advantages such as flexibility and potential for continued employment (Laudański et al., 2013; Walker, Howard, & Morton, 2017). A shared decision approach regarding the choice of dialysis modality ensures coverage of patients' preferences and lifestyle along with professional expertise (Castro et al., 2016).

The rigid treatment schedule of hospital haemodialysis leaves patients with less ability to influence their everyday lives (Van den Roberti et al., 2018; Bosch, Warren, & Rutherford, 2015). Patients must consider what to eat, how much fluid to drink, when to attend treatment and how to combine medical recommendations with everyday life (Laudański et al., 2013; Roberti et al., 2018). Their decisions evolve over time, responding to complex situational and relational interactions (Murray et al., 2013). Given these individuals' intense and frequent long-term interactions with health services, patient participation may be of special value (Tong & Craig, 2016).

Previous studies on patient participation within ESKD have focused on older patients, often elucidating participation in treatment withdrawal or decisions regarding dialysis versus conservative kidney management (Mandel, Bernacki, & Block, 2017; Seah, Tan, Srinivas, Wu, & Griva, 2015). Given most people affected by ESKD are of older ages (Chan et al., 2019; Kramer et al., 2019), this focus is understandable, and studies demonstrate that older patients often lack participation (Aasen, Kvangarsnes, & Heggen, 2012; Ladin et al., 2018). However, there is a considerable amount of people 18–65 affected with ESKD (Kramer et al., 2019), whose lives are altered by the invading nature of dialysis treatment (Roberti et al., 2018). To the best of our knowledge, this study is the first to explore how working-age adults on hospital haemodialysis experience patient participation. Through examining patients' experiences in different phases of the ESKD trajectory, this study adds knowledge with potential to improve health care for patients in need of dialysis.

3 | THE STUDY

3.1 | Aim

The aim of this study was to explore how working-age adults experience patient participation in hospital haemodialysis.

4 | METHODS

4.1 | Design

This study has a narrative design (Josselson, 2011; Riessman, 2008). Founded in hermeneutics, narratives draw upon social constructivism in which meaning is seen as co-construction between participants and researcher, rooted in interpersonal, institutional, cultural and historical contexts (Josselson, 2011). Thus, narratives reflect peoples' subjective understanding of an event and are not "the truth" of experience (Riessman, 2008). In a classic narrative, the story is structured with a beginning, a middle and an end, and causal incidents are ordered in a plot (Riessman, 2008).

4.2 | Recruitment and study participants

We employed a purposive sampling (Creswell, 2014) of patients on hospital haemodialysis. Patients included in this study were consent competent working-age adults 18–65 who had been treated with haemodialysis for more than three months, thus excluding acute ill patients, but including patients planned for a kidney transplant as well as patients on lifelong haemodialysis. We carried out recruitment at six dialysis departments, including satellites, in Central Norway. Staff nurses identified and informed relevant participants and collected their written consent forms. Nineteen patients agreed to participate but eight withdrew. We do not have information on whether all patients who fit the inclusion criteria were asked to participate. Altogether, eleven patients participated in the study. Their time on haemodialysis varied from six months to six years. Eight patients were on the transplant waiting list when the interviews took place. Some patients had to lose weight in advance of the transplantation (body mass index criteria ≤ 30). Three patients had their treatment initiated acutely, and eight were scheduled. Seven were married or in a relationship, and three had underage children.

4.3 | Data collection

First author conducted face-to-face interviews from January–June 2018. Based on previous research and the aim of the study, we employed an interview guide with open-ended questions (Creswell, 2014) related to patient participation in different phases of the ESKD trajectory (Table 1). Following the patients' wishes, six interviews were conducted at haemodialysis departments during the patients' treatment sessions. Two interviews took place in a meeting room at the hospital, while three were done in the patient's home or workplace. Only the interviewer and the interviewee were present.

TABLE 1 Interview guide

Questions
How would you describe to live with kidney failure and dialysis treatment?
Explain how you experienced the start-up?
Which information did you receive before you started?
How did you get involved in the choice of treatment?
How are you on a daily basis involved in your treatment?
In what way are you included in decisions that concern yourself/your treatment?
How do you experience to be seen and heard by the staff members?
How do you experience the coordination of your healthcare services to be?
Is there anything else you want to convey?

Each interview lasted between 48–81 min and was audio-recorded. The interviewer took field notes and later transcribed the interviews verbatim. The interviews provided rich and diverse data, and we considered data to be saturated after eleven interviews (Creswell, 2014).

4.4 | Analysis

Narrative analysis focusing on what participants told and how they told it (Riessman, 2008) was applied to examine the data. We read each transcript closely and used in vivo coding, grouping transcribed text into codes by choosing words or short phrases used by the interviewees (Miles, Huberman, & Saldaña, 2014). We identified codes with similar meanings and looked for common threads and recurring phrases that formed patterns in the text. One pattern was formed by what the interviewee said about receiving good information when they initiated dialysis. Another pattern was about their experiences of interdisciplinary collaboration. The next step was to organise codes into categories according to their patterns. We named each category according to its content.

We reconstructed the participants' stories by compiling their individual narratives into one story. Based on the categories developed from the stories, we constructed three themes, chronologically following the ESKD trajectory. We looked for similarities and contradictions, explicit meanings and possible underlying meanings, turning points or shifts in the teller's voice (Riessman, 2008). All authors had experiences from doing qualitative research. First author had previously served as a haemodialysis nurse. Being familiar with the complex context of haemodialysis was an advantage. However, a reflexive attitude was necessary to balance experiences and pre-established beliefs against data (Creswell, 2014). Hence, we constantly rechecked the development of themes with the transcripts, discussing the themes until we achieved consensus. Table 2 exemplifies the development of one of the themes.

4.5 | Ethical considerations

The study was approved by the Norwegian Centre for Research Data (ref. 59530). We obtained written informed consent from all participants. The data were de-identified and kept on a password-secured server. Because the sample represents a small group in a similarly small professional environment, we replaced the participants' names, gender and age with Participants A, B, C, and so on, and did not add individual demographic data. To ensure transparency, we applied the Consolidated criteria for Reporting Qualitative Research checklist (see Appendix S1).

5 | FINDINGS

Eleven participants aged 35 to 64 conveyed their narratives of patient participation in the complex field of hospital haemodialysis. For these patients, a clear-cut clinical pathway does not exist. Their narratives represent their respective treatment trajectory experiences, including haemodialysis initiation and establishment. Their stories show how initiating hospital haemodialysis impacts on their life outside the hospital, limiting activities previously taken for granted, such as going to work, spontaneous weekend trips, socialising with friends or going to the gym. Their stories included experiences of being well cared for, but also feelings of guilt, grief and anger based on memories of certain incidents. We present their narratives through the following themes: *Informed, but not involved in treatment choices; Duality of care and control; and Frail trust reflecting collaborative deficiencies*.

5.1 | Informed, but not involved in treatment choices

Common to the participants' narratives about initiation of dialysis treatment was that they experienced to be well informed. Responding to follow-up questions about choice of dialysis modality, participants were not involved in these decisions. Being well informed did not equal being involved. Providing information represented a one-way transferral of knowledge from healthcare professionals to patients, without dialogue in treatment modality decisions.

As most patients had been prepared for the possibility of having to start dialysis, their treatment initiation had a planned approach. Haemodialysis initiation nevertheless represented a major turning point altering patients' life. Becoming aware of how the actual treatment would affect their future lives made them want to postpone it as long as possible. Treatment relieved patients of the physical burden of their symptoms, but initiating hospital haemodialysis incurred the emotional burden of giving up their freedom and life as they knew it for spending their days connected to a machine. This critical moment was illustrated with statements such as, "I felt imprisoned" (Participant J).

TABLE 2 Example of the analytical process from narrative to analytical theme

Trajectory phase	Exemplifying quotes	Categories	Theme
Treatment initiation	*I think the information was good. I cannot complain about anything.* (Participant A) *I was not* [involved]. *I was told that I should have haemodialysis. And, at that moment, I was too exhausted to ask any questions.* (Participant G)	Good information Not involved in the choice of treatment modality	Informed, but not involved in treatment choices

The participants had received good and understandable information about treatment, provided by both physicians and nurses. Moreover, the patients were offered a visit to the haemodialysis unit ahead of treatment initiation as a means of preparing them for their own treatment.

> *I think the information was good. I cannot complain about anything.*
>
> *(Participant A)*

Seeking knowledge from other sources such as the Internet, friends or family members with dialysis experiences was common. The patients were satisfied with the information provided at the hospital, though some patients were offered information about the option of home treatment only after they were established in hospital haemodialysis. A typical dialysis start-up entailed the physician telling the patient it was time to initiate dialysis. Thus, some patients experienced that choice was a question of haemodialysis or no treatment, leaving them without any actual choice.

> *I felt I had no choice. That's what the doctor says - that now, you have to start on dialysis.*
>
> *(Participant B)*

When recalling experiences of how they had been involved in decisions about treatment modality, the interviewees positioned themselves as passive. Most patients initiated dialysis through a planned approach. However, phrases like "I was told…" or "they just told me…" indicated that the modality decision had not been the patients' choice. Some patients had their blood access made in advance, for instance an arteriovenous fistula, which indicates that it had been determined that they would receive haemodialysis. Others had difficulties recalling the initial stage, or they had been too ill to question the decisions.

> *I was not [involved]. I was told that I should have haemodialysis. And, at that moment, I was too exhausted to ask any questions.*
>
> *(Participant H)*

Other participants provided stories of receiving information about both peritoneal dialysis and home haemodialysis as alternative modality options before the start-up. However, the patients generally perceived themselves as not being competent in performing treatment without healthcare professionals present. Needle phobia, unsuitable housing conditions and concerns about bringing medical equipment into their homes were other obstacles. Hospital haemodialysis made patients feel "imprisoned," but they still considered it their best treatment alternative.

5.2 | Duality of care and control

Contrasts and ambivalence became important aspects of life as a patient on dialysis. Hospital haemodialysis implied four hours of treatment three to four days a week. The patients' lives revolved around the dialysis sessions, and they carefully adjusted all other plans to treatment. Some stated that haemodialysis controlled their life. However, as they depended on the treatment to stay alive, they had to accept its' nature as being both life-saving and restricting. The patients' narratives also elucidated the controlling aspects of care received from professionals. Their stories demonstrated contradictions between patients' attempts to continue their everyday lives and professionals expecting them to adhere to treatment and routines.

During adulthood, people are typically busy with careers, family and leisure. Illness is generally associated with older age, while people of working ages are expected to be healthy, active and resourceful. However, these patients' illness and treatment affected every part of life outside the hospital and led to losses in several areas. Those who previously had fulfilled family duties now lacked time and energy, and some even felt they had become a burden to their spouse and children. Patients with an arteriovenous fistula experienced how this access, fundamental for good medical treatment, limited their everyday life because they had to shield the fistula from heavy work that they normally carried out. Some patients felt isolated in their homes when symptoms like itching and "restless legs" made them reluctant to participate in social activities. Time became utterly precious due to the high number of hours spent in the hospital.

Only a few participants managed to combine employment and hospital haemodialysis. Those who did expressed gratitude towards their employer for adjusting their workload to the dialysis treatment. For people in this age group, being compelled to leave work was a major loss with several consequences, including the loss of collegial friendships, followed by social withdrawal, financial stress and worries about the future. The contrast between their former life and current existence was striking as they watched peers continuing with their lives. Hence, meeting former colleagues became a burden, a reminder of their own incapacity and renunciation. These patients were sidelined, watching life pass by while their blood circulated through the machine.

> *You lose your colleagues when you're not at work and they are…I could have called them, but…[…] And when I'm done with this [dialysis] I'm too old for work, at least in my profession, there aren't many employees over 50, they're worn out.*
>
> *(Participant G)*

However, as haemodialysis represented their lifeline, the patients quickly adapted to the treatment schedules. They typically arrived in the morning, weighed and waited to be connected to the machine. On some days, their sessions started in the afternoon. Within the haemodialysis unit, the patients felt safe and cared for. Due to the number of hours spent there, some referred to the unit as their "second home," including healthcare providers as "friends and family." The staff nurses played an important role.

They were generally portrayed as friendly and skilled, performing tasks beyond their instructions to serve patients, while at the same time dealing with unfavourable working conditions and low staff resources.

> *The nurses, they are fantastic […] They welcome us with a smile every the morning […] They have a compassionate relationship with their patients, and I feel cared for. You are not just a number in line to them, as you are to the doctors.*
>
> *(Participant K)*

However, even a good relationship could become tensed or conflicted. Nurses were said to not listen to patients, show them disrespect and value medical knowledge over patients' lived experience. One story involved nurses who spent their workdays in the ward office, checking their patient only when the dialysis machine alarmed. The machine became the patient's ally, not only in terms of keeping him or her alive but also in ensuring the professional contact beyond being put on and off the machine.

As part of their work instructions, the nurses paid attention to inter-dialytic weight gain and blood pressure as soon as the patients arrived at the unit. The frequent weight control and blood samples revealed patients' actions outside the hospital and their degree of adherence to medical advice. Struggling with food and fluid restrictions and the professional monitoring of their adherence were sources of guilt and resulted in stories of not being "good enough" managing their restrictions.

> *I know as soon as I step on the scale that I've had too much fluid. Then I hear it from the nurses. They're not happy about it. But they praise you if you've been good […] I know what I'm dealing with.*
>
> *(Participant F)*

Despite their best efforts, patients blamed themselves for not being able to control their fluid intake and felt responsible for having to increase the dialysis sessions, for instance from four to five days a week.

As monitoring patients was a priority task in the haemodialysis unit, measurable values could dominate and overrule other considerations. Phrases such as "I hear it from the nurses" or "they praise you if you've been good" indicate that patients felt acknowledged by the staff based on their adherence to treatment. However, many patients balanced their adherence to restrictions against health-related life quality and eventually learned which restrictions they had to follow and which not to. Resisting or testing the boundaries put up by professionals could be a way for patients to restore some of their lost autonomy. Some participants told how a new contact nurse had made the days on haemodialysis easier to endure, elucidating the power contained in the professional role. These different stories illustrate the complexity of relationships between long-term patients and healthcare providers.

The narratives also included descriptions of patient–professional collaboration, for instance, regarding fluid removal, where the patient's experience of previous dialysis sessions formed the basis for decisions made in the current treatment. The dialysis machine automatically programmed for fluid removal based on the patient's overload, but the nurse could override the machine settings in favour of the patient's previous experiences. In such cases, the nurse and the patient collaborated in making the fluid removal as gentle as possible. A few patients had access to the machine themselves by means of, for instance, resetting the alarm. Some patients conveyed their stories adopting medical vocabulary or a "dialysis jargon," which could have made it easier to participate in treatment.

> *The first years I was not very good at restricting my fluid intake. When I came to dialysis […] and there were four litres to take off, we chose to start at quite a high rate and decrease as we went on. That's one of the biggest mistakes we made. We fixed that by starting at a lower rate, and then letting the machine decide to increase the rate in the middle, and then decrease again towards then end. So we manage to take off the fluid that we need to. I've also become more restrictive about ice cubes and drinks.*
>
> *(Participant C)*

The participant's use of the pronoun "we" when referring to the collective actions of the patient and the healthcare team could symbolise a close relationship with healthcare providers. Other participants used words as "they," "those" and "them" when describing nurses and physicians. Their choice of words could indicate a more distant relationship or less of a partnership with professionals, which is another demonstration of the complex relationship between long-term patients and healthcare providers.

Hospital haemodialysis was strictly scheduled, but the nurses provided flexibility through accommodating patients' needs to change their dialysis schedule, mainly through changing their days of treatment. This could be relevant for different occasions, for instance in coordinating a weekend trip or family activities with the treatment schedule. However, staff resources could limit individual choice. For patients in this age group, everyday obligations like transporting their children to and from school could sometimes conflict with haemodialysis treatment and necessitate negotiation of dialysis duration. The nurses had the power to decide when patients were ready to finish dialysis. If numbers were too high, nurses would be reluctant to allow patients' personal affairs override medical decisions. They could refuse to disconnect patients from the machine ahead of scheduled time, arguing that it was in the patients' best interest to complete the dialysis sessions. If they considered it necessary, the nurses could even put up extra time in dialysis without discussing it with the patient. The stories revealed tensions between professional rationalities of treatment outcomes, and patients' aims to maintain autonomy and keep everyday life going.

> *I get that we have nurses in this unit who have done this for 35 years, but they can never truly understand the patient's situation […]…they don't know how I feel when I'm sitting here. And it's very clear to me that they're not accustomed to being challenged. That's very clear. […] When they [the nurses] don't listen to what I have to say, when they insist that they're the ones who are right, then I get frustrated. And it's an unnecessary frustration, because they could try to be a bit more open-minded to the idea that others might see things differently.*
>
> *(Participant A)*

Speaking up for oneself may be equivalent to self-advocacy when facing a powerful healthcare system. It is a way of asserting personal needs, participating in making decisions in areas of personal interest, and a way of facing and solving problems. However, patients could feel that healthcare providers avoided them if they strayed too far from a traditional patient role, which indicates that self-advocacy might have its costs.

5.3 | Frail trust reflecting collaborative deficiencies

The patients had broad experiences with health services, as living with multi-morbidities implicated interdisciplinary healthcare needs beyond haemodialysis. They credited healthcare professionals with skills and competence. However, their narratives included several incidents related to lack of collaboration between hospital units or disciplines, leading to negative consequences for patients' treatment and overall trajectories. For instance, problems coordinating transportation to and from treatment increased the burden of a long day of dialysis. Additionally, failures of coordination and communication between departments could stall transplant evaluations and even delay surgical procedures, sometimes resulting in significantly longer time as a dialysis patient. Stories of delays and postponements within their trajectories were common, generating insecurity for the patients. Distrust in healthcare services followed. Extending their responsibility as patients by means of trying to coordinate the transitions between health services became a way of coping with these issues.

> *I would say the departments could talk more together. You know, when you have such a thick chart, with stuff that they [the various departments] need to know about … They should be more on top of things. It is not my job to tell professionals…doctors and such… what they should and should not do. What they have to be aware of. But I often have to.*
>
> *(Participant F)*

Some patients accepted this as a way of securing their own healthcare trajectories. Others felt this responsibility overwhelming, as their life as haemodialysis patients already implicated a major responsibility related to illness and treatment. Though it required energy that patients often lacked, making an extra phone call could be necessary to accelerate appointments or fit other medical appointments into their dialysis schedule.

> *They [the departments] don't talk together. I notice it in other departments as well, they are… I have to address things myself. It takes a lot of energy. I've grown used to being in a fight. I have to fight to get things the way I want it.*
>
> *(Participant H)*

The patients suggested a more collaborative approach to care, in which healthcare providers showed interest in individual experiences of illness rather than instructing patients in what to do. They valued professionals' personal characteristics in addition to medical skills and knowledge and appreciated healthcare providers who saw them as "more than a patient" by means of acknowledging their life outside the hospital. An informal attitude among healthcare personnel was key to sharing details of their illness, for instance when physicians stopped by for informal conversations, illustrated with phrases such as "…you wouldn't find a better doctor" (Participant G).

In the busy haemodialysis units, some patients suppressed their needs in solidarity with peers whom they considered to need the physician more. Instead, they sought solutions to their problems through other knowledge sources, for instance the Internet. Rare access to medical resources, especially at satellites, led to ward rounds by phone, which included the satellite nurse and the physician from the specialist health service, but not the patient. Afterwards, the nurse informed the patient about the decisions that had been made. The patients valued nurses' work, but still called for face-to-face consultations with the physician.

> *You need conversations…structured moments that you can prepare for. When the doctor just pops in every couple of weeks… then you're not going to take up their time with unimportant questions, you just don't do that. The nurses are great when I ask, but they can't answer every question. Some things have to be answered by the doctor.*
>
> *(Participant D)*

Accessing the transplant waiting list was considered a major step forward because it provided hope of returning to a life without dialysis. However, delays in their transplant evaluation could entail additional months on haemodialysis before being admitted to the waiting list. In these cases, patients tended to blame themselves for not being active enough in accelerating the process. Statements such as "I should have demanded to be referred" (Participant K) show how patients felt responsible for achieving a smooth treatment trajectory. Being open about not getting along with physicians was challenging, and patients would sometimes feel compelled to accept an unsatisfying relationship. Some perceived physicians as people who they should respect due to their profession, underlined with statements, as “A doctor is a doctor you know...you're supposed to respect them” (Participant B). When physicians in charge refused to admit that a mistake had been made, this not only increased the burden of treatment but also evoked distrust affecting the patient–professional relationship.

> *One of the doctors messed up, so I was delayed to get on the waiting list [...] I admit I was disappointed. And he knew it as well, but he wouldn't talk to me - just avoided me every time he saw me. You lose trust when it becomes like that.*
>
> *(Participant I)*

Distrust could further appear when long-term patients started doubting whether they would ever receive a donor kidney. Many of these patients felt left alone with their illness, attending their haemodialysis schedules month-by-month, year by year. This sometimes led to suspicions towards the staff, as they wondered whether the professionals knew something about their condition that they did not share. Complications related to comorbidity enhanced these feelings. The patients did not experience to be involved during the waiting process, and when they asked professionals for updates, they were told to have patience. As time passed by, their powerlessness increased.

> *I have this heart failure as well, you know, and I've been thinking, maybe they won't do the operation [the kidney transplant] due to that? Is my heart so weak that I won't be able to tolerate a transplant? That's the kind of thing that's going through my head all the time. Maybe I’ll just have to keep on going [to dialysis] as I have done. It's pretty depressing. They say it's not supposed to matter, but who's telling the truth? I think about things like that, I have to admit [...] I would have liked to have had some... good years....*
>
> *(Participant J)*

Despite these experiences, participants tended to end their selected stories by expressing gratitude for the possibility of receiving hospital haemodialysis. They apologised for having complained and mentioned that others were worse off than they were.

The future perspective lies implicit in everyone's story throughout his or her trajectory. Our study participants comprised patients who, even when affected with severe comorbidity, expressed hope of one day receiving a donor kidney, and thus be able to end haemodialysis treatment. Holding on to a hope of life without dialysis is of particular relevance for patients of younger age. Hope enables them to endure the intensive, complex and life-altering nature of hospital haemodialysis. They stand food and fluid restrictions, heavy medication, strict treatment schedules and controlling care, believing a better future lies ahead of them, in which they can reclaim life, as they once knew it.

6 | DISCUSSION

The narrative approach of this study allowed us to explore patients’ experiences with participation within the complex situation of hospital haemodialysis. Our findings show diversity and contradictions in patients’ experiences. Experiences of having received good information when initiating dialysis was contrasted by not being involved in the choice of treatment modality. Patients struggled to maintain autonomy in the context of hospital haemodialysis. Experiences of deficiencies in interdisciplinary collaboration weakened patients’ trust in healthcare services. Extending their responsibility as patients to coordinate the transitions between health services became a way of coping with issues of uncertainty that emerged in their trajectories.

Participants in this study experienced how initiating hospital haemodialysis triggered a cascade of consequences that came to control their entire life. In addition to the bodily effects of illness and treatment, they had their autonomy threatened or decreased by dependency on medical staff and machines to maintain life. Shock and grief followed. Our findings are consistent with previous research showing how illness and treatment, as well as professionals, contribute to restricted lives outside the control of patients (Reid et al., 2016).

Shared decision-making may be a way to restore patients’ autonomy in the context of illness (Gulbrandsen et al., 2016). Fulfilling the goal of shared decision-making requires professionals to engage in patients’ preferences and lifestyles, goals and values (Castro et al., 2016). To be involved in decisions about treatment modality is important since the choice of dialysis modality influences patients’ lives with different intensity (Chan et al., 2019). Our study shows that the patients received information about treatment, but they were not involved in decisions about treatment modality. Providing information is a one-way communication based on what professionals consider would be important for patients to know and follows a paternalistic mindset (Ladin et al., 2018; Tuso, 2013). The narratives indicates that patients with ESKD emphasise a personalised approach to communication. To collaborate with professionals was preferred over receiving informative instructions. Sufficient knowledge about available options is necessary for decision-making, but patients’ needs are not met by solely providing information (Joseph-Williams et al., 2014; Roberti et.al., 2018; Russell & Boulware, 2018). Sound treatment solutions rely on shared decision-making achieved through dialogue where patients’ preferences are brought forth and professionals share their knowledge of treatment impact and outcome (Castro et al., 2016; Ladin et al., 2018). The approach of shared decision-making is relevant throughout the trajectory, not least in the choice of treatment modality. However, the model is not appropriate within the context of emergent dialysis where there is no time to explore patients’ preferences (Ladin et al., 2018).

The lack of a common understanding of patient participation (Castro et al., 2016) may cause healthcare providers to perceive that they are facilitating it while still operating in a traditional work frame. Policy documents in developed countries widely emphasise patient-centred care, while the health services largely focus on productivity and efficiency (Holmqvist & James, 2019). This may be prominent within busy haemodialysis units designed for efficiency (Andersen-Hollekim, Kvangarsnes, Landstad, Talseth-Palmer, & Hole, 2019). If the main focus is on production, professionals may not acknowledge patients' experiential knowledge of illness. Hence, person-centred care via seeing and treating patients individually may clash with efficiency requirements (Holmqvist & James, 2019; Vandenberg et al., 2019).

Patients in the current study mainly told of good relationships with healthcare providers in the haemodialysis units. Nevertheless, conflicts could arise—for instance, when patients attempted to maintain their autonomy. To avoid the burden of being exposed to conflicts with healthcare providers who provide life-saving treatment, patients may feel compelled to behave in a way they feel professionals expect and accept. Even well-educated and health-literate patients conform to socially sanctioned roles and avoid questioning advice or recommendations due to fear of implications if straying from the role of a "good patient" (Frosch et al., 2012). One intention of modern health care is more equality between patients and professionals (Armstrong, 2014; Castro et al., 2016). However, the relationship between patients and professionals preserves power asymmetry in several areas, including that healthcare providers have chosen their role (as professionals), while patients have not. Thus, patients are vulnerable in a way that professionals are not (Angel & Frederiksen, 2015). In this study, the participants repeatedly ended critical statements by reassuring that they did not mean to complain and that they were grateful for receiving treatment. This indicates how patients may feel discomfort in criticising professionals or the system they depend on, thus underscoring the complexity in patient–professional relationships.

A patient–professional relationship based on trust is essential in health care where life and death are major concerns (Choy & Ismail, 2017). For patients, trust is dependent on expectations about professionals' individual competence, general competence of institutions and their willingness to act in the patients' interest (Rowe & Calnan, 2006). In ESKD care, trust is enabled through long-standing relationships, but may still be fragile. Failing to keep one's words or perform deceitful acts may diminish or destroy trust, and rebuilding it may be difficult (Choy & Ismail, 2017). Patients' trust in healthcare services and professionals depends on several factors, including patient participation that may enhance trust through a mutual understanding of illness and treatment (Yang & Wu, 2018). The narratives in this study disclosed how experiences of low interdisciplinary collaboration affected patients' trajectories, hereby evoking mistrust. Patients mistrusting the healthcare system's willingness to act in their interest may undertake responsibility, to assure that they obtain correct treatment. For some patients, this behaviour promotes a sense of control in a context where much is out of their control. However, this responsibility is not compatible with definitions of patient participation, as it adds to their burden and excludes patients who do not have the resources required to navigate in the structures of health care.

This study demonstrates how experiencing low collaboration weakened patients' trust in health care. However, trust is mutual—that is, professionals may trust or mistrust patients (Cook & Stepanikova, 2008). In a paternalistic healthcare system, patients are expected to follow medical instructions (Armstrong, 2014). Healthcare professionals may perceive patients who adhere to treatment to be more trustworthy and thus provide them with better services (Cook & Stepanikova, 2008). On the other hand, a history of nonadherence might be factored in when considering further treatment options (Cook & Stepanikova, 2008). The reciprocity of trust is evident in how patients being shown trust are likely to honour this trust by following professional advice (Cook & Stepanikova, 2008). Our study participants experienced healthcare professionals to be highly focused on patients' treatment adherence as measured by laboratory tests, weight and blood pressure. Some of the nurses used verbal rewards or penalties to make patients adhere. Bedside nurses may experience to be drawn between respecting patients' autonomy and provide life-saving treatment (International Council of Nurses, 2012). Biomedical values are important to evaluate and adjust treatment, but patients may not be concerned about these in the same way as professionals (Reid et al., 2016). To enable health-related quality of life, patients may adopt health behaviours in a more dynamic process (Vandenberg et al., 2019). Not following prescribed treatment may be fatal for patients with ESKD (Hemmett & McIntyre, 2017), and professionals are regulated by law to intervene if a patient's actions put him or her at risk. However, in this study, patients carefully learned to select which advice they had to conform to, for instance regarding diet—and balanced this against their health-related quality of life. Paradoxically, health policy promotes patients' independence as an ideal, while expecting them to behave as directed by medical traditions (Longtin et al., 2010).

To experience deficiencies regarding inter-professional collaboration may be surprising, because recent healthcare reforms aim to ensure coordinated care through seamless trajectories for patients with complex and long-term conditions. Nevertheless, increasing numbers of specialised units and the high number of professions involved create challenges for coordination and collaboration within and between hospital units, as well as for the transition between service levels (World Health Organization, 2012).

Illness and treatment place unavoidable restrictions on patients' lives and limit their autonomy. Healthcare professionals hold the key to mitigate the burden of disease by optimising patient participation and facilitating purposeful interdisciplinary coordination of care and treatment. In accordance with Chan et al. (2019), we argue that it is time to move away from a "one-size-fits-all" approach to patients who require dialysis, towards providing individualised care that acknowledge patients' preferences while maintaining best practices for quality and safety.

7 | METHODOLOGICAL CONSIDERATIONS

Purposive sampling ensured the recruitment of participants with experiences from hospital haemodialysis, varying in age and gender. By limiting the study to Central Norway, we did not reach any patients between 18–34 years of age. This is a limitation, because experiences from younger patients could have contributed to even wider perspectives. The findings represent patients' experiences with participation as they recalled it and as interpreted by the researchers. In narrative analysis, other interpretations could be possible. Having both variance and patterns in the data indicates that these findings may be transferable to other contexts of haemodialysis.

8 | CONCLUSION

This study identifies challenges related to patient involvement and interdisciplinary collaboration. To involve patients through dialogue, and to acknowledge their experiences, preferences and lifestyle may enhance patients' autonomy and strengthen the mutual patient–professional understanding of illness and treatment throughout the trajectory. Despite increased focus on seamless trajectories in healthcare policy, patients still face obstacles regarding interdisciplinary collaboration and coordination of their healthcare services.

9 | RELEVANCE TO CLINICAL PRACTICE

The findings indicate a need for individually customised care for patients requiring dialysis. Clinical practice systematically needs to explore patients' preferences and values in a process of shared decision-making throughout their trajectories. Patients should be involved in the choice of treatment modality as well as decisions related to the current treatment. Patients lack understanding of how their choice of dialysis modality may affect their lives. Information must include potential consequences of the choices made. Home-based dialysis could benefit working-age adults and help them to participate in work life and family activities. It is necessary to address inadequate cooperation both in and across health institutions to secure treatment continuity and strengthen patient involvement.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHORS' CONTRIBUTION

Study draft: TAH, TH and MK; Interview coding and conduct, and in charge of writing the article: TAH; Manuscript drafts, data analysis and interpretation : TAH, MS, TH, MK and BJL; and approval of final version of the manuscript: MS, TH, MK and BJL.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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Paper III

Title page

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Nephrologists' experiences with patient participation when long-term dialysis is required

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Nephrologists' experiences with patient participation when long-term dialysis is required

Abstract

Background For individuals in need of long-term dialysis, patient participation is important when determining care goals and in decision making regarding dialysis modality. Nephrologists hold a key role in delivering evidence-based healthcare that integrates patient preferences and values throughout the trajectory, and their experiences with patient participation are important for improving health care. The aim of this study was to explore nephrologists' experiences with patient participation in different phases of the end-stage renal disease trajectory for working-age individuals who require dialysis.

Methods This explorative study comprised interviews with ten nephrologists from four different dialysis units in Central Norway. We analysed the interviews by applying an interpretive phenomenological approach.

Results Nephrologists had varied experiences with patient participation throughout the different phases of the treatment trajectory. During decision making on the dialysis modality, nephrologists emphasised patients' choices in two divergent approaches. In the first approach, they expected patients to choose the modality based on the provided information, which could be actively steered. In the second approach, they recognised the patients' values and lifestyle preferences through shared decision-making. Within hospital haemodialysis, nephrologists considered patients' self-care activities equivalent to patient participation, seeing self-care as a source of patient empowerment. Nephrologists identified divergent patient–professional values and organisational structures as barriers to patient participation.

Conclusion Our study shows that nephrologists have different approaches to patient participation in different phases of the end-stage renal disease trajectory. Individual understanding as well as organisational structures are important factors to address to increase patient participation in end-stage renal disease care. Shared decision making, in which patient values are balanced against biomedical treatment targets, allows for mutual agreement between patients and healthcare professionals concerning medical plans and minimises the potential for patient–professional tensions.

Key words: Patient participation, end-stage renal disease, nephrologists

Background

The patient's position has been increasingly strengthened throughout the recent decades, making patient participation as facilitated by healthcare professionals an essential part of medical treatment and care for people with chronic illness (Longtin et al., 2010; World Health Organization, 2013). In end-stage renal disease (ESRD) care, nephrologists prescribe and monitor dialysis treatment, collaborate closely with other healthcare disciplines, and learn about their patients' lifestyles and preferences through long-term medical follow-up (Tuso, 2013). Hence, they are in a position to optimise patient participation throughout the ESRD trajectory. However, their role in facilitating patient participation is scarcely addressed in research. In this study, we explored nephrologists' experiences with patient participation in different phases of the treatment trajectory.

Patient participation is internationally recognised as a key factor in improving the delivery and quality of health services (Barello, Graffigna, & Vegni, 2012). However, paternalistic practices are still present, although healthcare professionals may not be aware of this (Grünloh, Myreteg, Cajander, & Rexhepi, 2018). According to Longtin et al. (2010), barriers in clinical implementation relate to both patients and professionals. Among professionals, a desire to maintain control, time constraints, personal beliefs and insufficient training are suggested as factors hindering patient participation (Longtin et al., 2010). Deficiencies in clinical implementation are moreover sustained by lack of a common conceptual understanding (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016). For instance, the term patient participation could be used interchangeably with shared decision-making. Shared decision-making is one of several approaches to patient participation, especially suitable when more than one applicable treatment option exists (Rowland & Politi, 2016). From the patient's perspective, patient participation may be considered a broader concept that includes dialogue, involvement in care, mutual shared knowledge and management of self-care (Thórarinsdóttir & Kristjánsson, 2013). Patients living with chronic conditions acquire experience as well as knowledge about their illness and develop skills to manage their condition. This may position them as experts by experience (Cordier, 2014; Greenhalgh, 2009). To accomplish patient participation, this experiential knowledge should be included as a supplement to expert professional knowledge (Castro et al., 2016). Patient participation is contextual—meaning patients may prefer involvement in one situation while leaving decisions to healthcare professionals in others (Thompson, 2007). In emergencies, patients may be less able to participate (Ladin et al., 2018; Thompson, 2007) and patient participation has thus gained its major attention within chronic, long-term health conditions (Barello et al., 2012; Protheroe, Brooks, Chew-Graham, Gardner, & Rogers, 2013).

Nephrologists have a central role in delivering evidence-based healthcare that integrates patients' preferences and values (Tong et al., 2017). However, they work in a care setting driven by biomedical and measurable targets in which patient participation may seem difficult to achieve (Chan et al., 2019; Hussain, Flemming, Murtagh, & Johnson, 2015; Tong et al., 2017). Time and availability of private medical consultations, continuity of care, workflow organisation and the healthcare setting itself are all factors with the potential to impact patient participation (Joseph-Williams, Elwyn, & Edwards, 2014). Nephrologists describe stressful and demanding work situations in which an increasing administrative workload comes at the expense of patient contact. Additionally, they may face ethical dilemmas in which they are forced to make decisions about life or death (Grönlund, Dahlqvist, & Söderberg, 2011). Individual experiences and attitudes, as well as healthcare policy and tensions in health services, affect their priorities and approaches (Tong et al., 2017). Efforts to involve patients may be constricted by ambiguities about how to prioritise, measure and manage critical comorbidities and the broader quality of life outcomes within a technically demanding context (Hussain et al., 2015; Tong et al., 2017). Hospital haemodialysis involves guidelines that universally schedule treatment three times a week (Chan et al., 2019), and seeing and treating patients individually may therefore be particularly challenging in the context of hospital haemodialysis (Tong et al., 2017; Vandenberg et al., 2019).

Regardless of age, ESRD patients face frequent, long-term healthcare interactions and a plethora of decisions throughout their treatment trajectory (Tong & Craig, 2016; Tong, Winkelmayer, & Craig, 2014). However, for people at a stage in life where education, employment and development of relationships may be pivotal, entering dialysis may limit their life choices and put their values at stake. Multiple social and medical considerations are required in order to adapt intensive treatment to everyday life (Laudański, Nowak, & Niemczyk, 2013; Roberti et al., 2018). Although considered challenging, patient participation may be more pressing in ESRD care than within other chronic diseases (Tong & Craig, 2016). The choice of dialysis modality relies on home or hospital treatment, and represents a major decision with divergent care as the outcome may depend on the choice. It is therefore beneficial that the decision accommodates patients' lifestyles and preferences (Chan et al., 2019; Russell & Boulware, 2018). Nephrologists are involved in long-term pre-dialysis follow-up and thus have several opportunities to discuss treatment options with their patients before dialysis becomes necessary. Nonetheless, patients commencing dialysis report suboptimal satisfaction with the process of selecting a dialysis modality (Cassidy et al., 2018). They possess insufficient knowledge about the benefits and burdens of different treatments, including how treatment might affect their lives (Tamura & Periyakoil, 2013). Even though nephrologists provide patient information and recommend dialysis modalities (Winterbottom, Bekker, & Mooney, 2016), they to a lesser degree engage in shared decision making with the patient (Andersen-Hollekim, Solbjor, Kvangarsnes, Hole, & Landstad, 2020; Hussain et al., 2015; Song et al., 2013).

The patient–professional relationship is essential in patient participation (Cassidy et al., 2018). However, divergent values between nephrologists and their patients may be the cause of tensions or conflicts in ESRD care (Chan et al., 2019; Vandenberg et al., 2019). For instance, biomedical targets, important for nephrologists in evaluating and adjusting dialysis treatment, may not be valued in the same way by patients who may prioritise a maintained lifestyle and personal wellbeing (Chan et al., 2019; Reid, Seymour, & Jones, 2016). Nephrologists may perceive this as a non-adherent behaviour (Clark, Farrington, & Chilcot, 2014). In a study by Tong et al. (2017), nephrologists allowed fewer treatment compromises when patients were eligible for transplantation compared to patients on life-long dialysis, weighing patient flexibility against the need to minimise mortality and morbidity. Other tensions are associated with patient–professional communication. A study by Vandenberg et al. (2019) showed that many nephrologists practised a standardised, ‘one size fits all’ communication style, while patients favoured a personalised approach. This suggests a mismatch between values. However, some nephrologists preferred private consultations over ward rounds, as private consultations provided information that patients were likely to conceal when in front of others (Vandenberg et al., 2019).

Nephrologists’ perceptions of their role may affect the way they approach patient participation. A study on decision-making approaches in older ESRD patients showed four different approaches in clinical practice (Ladin et al., 2018). In the paternalist approach, nephrologists considered themselves as patient protectors. Patient autonomy and values were less important than improving health through active treatment. In the informative approach, nephrologists viewed themselves as patient educators. They prioritised patient autonomy in decision-making and accepted patients’ choices. In the interpretive approach, nephrologists perceived themselves as a guide, steering their patients to an optimal treatment selection based on patient values. Nephrologists following an institutional approach focused on treating patients within the norms and culture of the institution (Ladin et al., 2018).

Although not unique for ERSD care, the imbalanced patient–professional power represents a challenge to patient participation. Physicians may view themselves as the ones to take on the responsibility, determine treatment options, and be trusted by patients (Grünloh et al., 2018) When patients question their treatment or want more information, this may be interpreted as criticism and mistrust toward the physician (Grünloh et al., 2018). Patients may also fear harming their relationship with the provider if they express disagreement about treatment and thus leave decisions to professionals despite wanting to have a say in issues that concern them (Frosch, May, Rendle, Tietbohl, & Elwyn, 2012; Joseph-Williams et al., 2014).

In ESRD care, nephrologists’ long-term relationships with their patients comes with the potential of promoting patient participation. Although some studies explore nephrologists’ experiences with patient participation in ESRD, they mainly focus on elderly patients (Ladin et al., 2018) or on patients regardless of age (Tong et al., 2017) and often involve end-of-life discussions (Eneanya et al., 2015; Mandel, Bernacki, & Block, 2017). Little is known about nephrologists’ experiences with patient participation for working-age individuals who require dialysis. By examining nephrologists’ experiences with patient participation in the choice of dialysis modality as well as patient participation in hospital haemodialysis, we aimed to identify areas for improving quality of care throughout the ESRD trajectory. The aim of this study was, therefore, to explore nephrologists’ experiences with patient participation in different phases of the end-stage renal disease trajectory for working-age individuals who require dialysis.

Methods

This explorative study comprised interviews with ten nephrologists from different dialysis units in Central Norway. We analysed the interviews by applying an interpretive phenomenological approach (Brinkmann & Kvale, 2014)

Recruitment and study participants

We applied a purposive sampling strategy (Brinkmann & Kvale, 2014) that included physicians and nephrologists who treat working-age adults who are on hospital haemodialysis. We carried out recruitment at four dialysis units in Central Norway. Inclusion criteria were as follows: Norwegian-speaking nephrologists or physicians of various ages and genders with a minimum of one-year experience in dialysis care. Out of 13 invited participants, nine nephrologists and one nephrology trainee participated, four of whom were women. The reason for non-recruitment was a lack of response to the letter of invitation. Participants had clinical nephrology experience varying between 5 and 20 years. We refer to all participants as nephrologists in the following paragraphs.

Data collection

The first author conducted face-to-face interviews in November 2019–May 2020. Based on previous research and the aim of the study, we applied a semi-structured interview guide (Table 1) related to patient participation in different phases of the ESRD trajectory. We conducted the interviews either in a sheltered area in each nephrologist's workplace or via internet video calls. Each interview lasted between 32 and 86 minutes, was audio recorded and then transcribed verbatim. The interviews provided rich and diverse data. With data being repetitive, we considered saturation accomplished after ten interviews (Brinkmann & Kvale, 2014).

Analysis

We approached data by using interpretative phenomenological analysis (Brinkmann & Kvale, 2014) that involved five key stages: familiarisation, coding, theme development, defining themes and reporting. First, we read the transcripts to get an overall impression of the data. We then inductively identified meaning units in each interview. These meaning units were coded by connecting key words to the phrases used by the interviewees (Brinkmann & Kvale, 2014). Next, we clustered our coding by content, that is, we grouped together codes with similar meanings. These codes formed the foundation for the development of themes. We based theme development on two different phases of the ESRD trajectory. The first phase was related to the dialysis commencement, in which patient participation was associated with choosing dialysis modality. This choice involved hospital- or home treatment. The second phase was related to patient participation in hospital haemodialysis. We performed the analysis in an iterative process in which we continuously rechecked development of subthemes with the transcripts. We looked for patterns within the data as well as diversity and contradictions that broke these patterns. All authors participated in defining themes and agreed upon the final themes presented. We provide selected quotations to underpin each theme. Table 2 exemplifies the development of themes.

Ethical considerations

The study was approved by the Norwegian Centre for Research Data (ref). We obtained written informed consent from all participants. De-identified data was stored on a password-secured server provided by the hospital trust. To ensure confidentiality, we replaced the nephrologists' names, ages and gender with Participant A, B, C and so on.

Results

We present the experiences of ten nephrologists with patient participation in different phases of the ESRD trajectory based on the following themes and subthemes: Theme 1. The dilemma of guiding treatment choices*: A slightly steered choice* and *A shared decision;* and Theme 2. Patient participation action focused, not value driven: *Participation through self-management, Negotiated values* and *Ideals versus practices.* The first theme relates to patient participation in the choice of dialysis modality, while the second theme relates to patient participation in haemodialysis.

Theme 1. *The dilemma of guiding treatment choices*

Nephrologists focused on pre-emptive transplantations for their working-age patients. Such transplantations were not always achievable, leading patients to the choice of dialysis modality. The nephrologists considered time important to allow patients to prepare for the necessity of dialysis and to avoid the rushing of decisions. We found two approaches to patient participation. In the first approach, nephrologists anticipated patients would choose treatment based on the information provided by healthcare professionals. In the second approach, nephrologists recognised patient values and lifestyle preferences through shared decision-making.

A slightly steered choice

Consensus existed among nephrologists that patients should make the modality decision themselves or in collaboration with their families. Thorough information was emphasised as a means of enabling patients to make a choice. Information was provided by nephrologists, but also by dialysis nurses and through pre-dialytic education programmes. After providing information, the nephrologists commonly encouraged patients to *go home and think it over* (Participant B) before deciding. They equalled this approach to informed choice. There was, however, a duality in the decision-making process. On the one hand, nephrologists emphasised individual patient choice. On the other hand, they influenced the decision-making by advocating certain treatments.

As a rule, we let patients choose the modality they want. Of course, you can try to influence them a bit towards the direction you think wise. If people are active, we promote home-based treatment. However, the patients themselves should make the final choice. (Participant G)

The nephrologists considered thorough information about haemodialysis (HD) and peritoneal dialysis (PD) vital in the decision-making process. Their way of presenting the information could direct patients towards a specific treatment modality. Nephrologists generally preferred PD as a first choice. Some suggested that people of a certain age should take care of their own treatment, if capable. Additionally, policy goals and guidelines led them to weight their presentation of treatment modalities in favour of PD.

Laypeople don't usually know anything about kidney failure and dialysis or the difference between HD and PD —it all depends on what information they get… and we think it's okay to start with PD…so I would say it is a slightly steered choice. (Participant H)

We present peritoneal dialysis in a slightly more positive way than haemodialysis. In this county, we have less home dialysis than recommended. Thus, we may be pushing the patients a little towards home treatment, to meet the policy goals (Participant D)

Although a PD-first approach was favoured, factors such as traditions and staff resources often moved patients in the direction of hospital haemodialysis. The nephrologists considered the process of initiating patients in hospital haemodialysis as well integrated, requiring less work by the staff compared to home-based treatment.

Many nephrologists found it difficult to provide patients with the complete picture of what the different modalities implied for the individual. The complexity of modality decision was emphasised through statements such as: *You don't know what you have agreed to until you have started* (Participant B), indicating that patients had to physically undergo treatment in order to fully understand it. According to the nephrologists, patients often considered hospital haemodialysis a manageable treatment option, without being aware of the intensity of treatment, nor how it would come to influence their lives. Nephrologists could be reluctant to emphasise such consequences, as they considered it would increase patients' burden of treatment.

Timing the decision-making against the ESRD progression was sometimes challenging. The nephrologists expected patients to decide on treatment modality before biomedical measurements rose towards dialysis initiation. In addition, preparing patients for the chosen treatment was necessary, for instance through having an arteriovenous fistula surgery. Patients who *could not make up their minds* (Participant F) could be held responsible for postponements of the modality decision, leading to unwanted emergency commencements.

A shared decision

In the second approach, nephrologists considered themselves as supervisors, guiding patients towards a choice through dialogue. Nephrologists who applied this approach emphasised spending time to learn about patients' work situations and family lives as well as their individual preferences and values. Thus, they were able to consider the decision from a holistic perspective.

I have to become familiar with patients' daily lives to the extent that is possible. I then inform about the different options ... it's sort of a process…a dialogue… where I challenge the patients with questions to get to know their priorities. (Participant I)

Paying attention to how each modality would affect patients' lives allowed nephrologists to consider individual circumstances, such as whether the patient was a single parent or wanted to continue their employment, in order to select the treatment that was the best fit for the patient.

I ask about the situation at home. Whether they have kids and whether they want to continue work. And if there are other things that are important to them. And then it's important to get them well informed about both the dialysis modalities. (Participant A)

According to these nephrologists, achieving shared decision making required sensitivity to patients' unspoken issues as well as those explicitly expressed. Additionally, nephrologists had to acknowledge patients' insecurity when facing the unknown area of medicine. Time was emphasised. They suggested that patients who had reached the final decision themselves would adapt to their treatment more easily, thereby achieving better treatment results.

Theme 2. ***Patient participation action focused, not value driven***

Within hospital haemodialysis, the nephrologists associated patient participation with self-management, for instance the performance of hands-on self-care tasks. Tensions occurring from divergent patient–professional values as well as organisational structures complicated patient participation.

Participation through self-management

The nephrologists recognised that hospital haemodialysis required adaptation, which could provide patients with a passive role. Engaging patients in their care was seen as a way of making them responsible for their own health. This could implicate training them in hands-on activities such as self-cannulating. At a higher level, patients could run their own dialysis.

As a haemodialysis patient, you can of course participate in your own treatment. You can learn to cannulate the fistula, to set up the machine and to a certain extent run the dialysis. (Participant D)

Other nephrologists referred to patient self-management as a way of decreasing health costs, as training patients in preparing the dialysis machine had the potential to save staff resources. In patients’ absence, nephrologists and nurses typically discussed and assessed patient ability to perform self-care activities. Subsequently the nurses encouraged participation from patients they had evaluated as able to participate, for instance, in self-cannulating. One of the nephrologists expressed, *It`s not appropriate for everyone to be trained and involved. But I think they should get the chance* (Participant H). From this perspective, patient participation was limited to people willing to exercise hands-on tasks.

Patient self-management included following food and fluid restrictions and administering medication as prescribed. Hence, the nephrologists emphasised thorough patient information. They argued that well-informed patients would be equipped with the rationale to act responsibly, associating responsible patients with better adherence and, hence, better treatment outcomes.

They have to be allowed to make informed choices. They have to know why we do things and why they get this treatment, the point of coming here so frequently, the point of the medications. (Participant F)

Nephrologists thus provided patients with a personal responsibility for making choices about lifestyle and healthcare to support clinical treatment and accomplish treatment goals.

Negotiated values

Within hospital haemodialysis, divergent aims and interests could create tensions between patients and healthcare professionals. Shaping patient behaviour concerning, for instance, fluid restrictions was experienced as challenging, especially for patients of younger ages, as they wanted to live their life to the fullest. Not adhering to restrictions could result in dangerous fluid overload or hyperkalaemia. The nephrologists had experienced that patients negotiated with respect to fluid removal, presenting a different opinion than the machine automatically programmed. Patient preferences were not always taken into account. One of the nephrologists expressed:

We don't feel that all of them have enough knowledge about the treatment to have an opinion about it [the fluid removal]*, so no, we don't always discuss it with them* […] (Participant F)

Despite the attention the nephrologists paid to providing information as a means of increasing patient knowledge, some paradoxically doubted patient evaluations of their own treatment. Professional expertise thus overrode patients' experiential knowledge. Similarly, although they saw patient engagement as positive, the nephrologists could limit the engagement by considering some patients to *decide too much themselves* (Participant E). 'Deciding too much' was associated with not following prescribed treatment. Other tensions could relate to patients negotiating on their dialysis schedules by means of disclosing their sessions ahead of time or changing days of treatment. According to the nephrologists, adjusting hospital haemodialysis to employment or family life could be challenging for patients. Sometimes patients did not reach their scheduled appointments and thus delayed the units' workflow.

Although paying attention to treatment schedules and biomedical quantifications, some nephrologists considered the clinical goals to be parts of a whole, allowing patient experiences to influence treatment adjustments. Hence, they avoided being overly guided by biomedical targets and emphasised listening to patients' individual experiences of health and wellbeing between the dialysis sessions.

Dialysis isn't a pre-set treatment impossible to adjust to individual needs… many are unaware of that... but dialysis is about so much more than just prescribing a time-scaled treatment with this or that dialysate solution and this or that filter [dialyzer membrane]. (Participant I)

Individual adjustments to treatment could decrease tensions, though the nephrologists had to balance adjustments with what they considered adequate treatment. This illustrates the span nephrologists faced when providing evidence-based healthcare while aiming to integrate patients' preferences and values. When reflecting on their own practices, not all nephrologists considered patient experiences or issues without the potential for clinical adjustment to be their concern. For instance, they saw hospital haemodialysis as a 'take it or leave it' treatment offer and preferred standardisation to individually customised treatment. Some experienced patient needs as never-ending and told of having to put up boundaries as to the issues with which they as nephrologists should engage and which issues they could leave to nurses or the general practitioner.

Ideals versus practices

The nephrologists claimed that the increased focus provided by policy documents had made them more aware of patient participation. Some spoke of a shift in the role of physicians towards more person-centred care. However, they considered the organisation of healthcare services an obstacle to accomplish patient participation. They experienced that the number of patients increased without additional resources being provided. Some claimed that the organisational system did not allow for true patient participation.

You want to provide patient flexibility, but it is not always possible when you don't have enough machines and there are cut-backs in addition and—it just makes it difficult. (Participant A)

The clinics' efficiency focus was prominent and the nephrologists experienced time pressure as an inhibitor to involving patients. To ensure the accomplishment of everyday priorities in a busy unit, nephrologists considered it most effective to make the decisions themselves. Thus, their ideals of patient involvement suffered.

If you are concerned with people and your patients, you should be concerned with patient participation as well. However, it takes more of your time. If you just decide on behalf of the patients, you get things done faster. (Participant G)

According to the nephrologists, busy schedules could lead to loss of valuable information, for instance when patients did not want to bother healthcare professionals by conveying their symptoms. Thus, nephrologists could fail to notice negative treatment trends in the patients, such as fluid overload.

Existing ways of working could likewise hinder patient participation. For instance, nephrologists and nurses usually discussed the patient's treatment in scheduled meetings without the patient's presence. Nephrologists experienced professionals' meetings to be more effective compared with meetings that involved the patient, and informed patients about findings and treatment plans through ward rounds. Some nephrologists assessed it inappropriate to bring patients into professionals' meetings, as it would expose them to medical terms they would not understand. To support patient privacy, confidential conversations between the nephrologist and the patient could be arranged on the patient's request.

Discussion

The current study explored the experiences of nephrologists with patient participation for people of working ages in need of long-term dialysis. Following the ESRD trajectory, the nephrologists focused on choice when deciding on dialysis modality and emphasised that patients should make the final decision. We identified two approaches to accomplish this goal. In the first approach, nephrologists expected patients to make their choices based on information provided by healthcare professionals. In the second approach, they recognised patient values and preferences through shared decision-making. Within hospital haemodialysis, nephrologists associated patient participation with self-management, for instance, hands-on self-care activities. They identified tensions occurring from divergent patient–professional values and organisational structures as barriers to patient participation.

Nephrologists attending our study experienced the modality decision as complex but considered it important to let patients make the final choice. In westernised cultures, the ability to exercise choice is valued as an expression of autonomy (Zolkefli, 2017). Choice enables patients to direct their own course in accordance with individual preferences. However, it also leads to patient responsibility for their choices, and awareness of the possibility of making the wrong choice could be experienced as stressful (Zolkefli, 2017). Such positioning could lead to an underestimation of a patient's vulnerability and lowered capacity for decision making when faced with the unfamiliar arena of medicine (Gulbrandsen et al., 2016). This point to the delicate balance between involving patients in medical decisions without leaving them with a feeling of abandonment during the process (Rowland & Politi, 2016).

Providing patients with well-balanced information about treatment options to enable them to choose the most suitable modality is in line with medical guidelines (Chan et al., 2019; Winterbottom et al., 2016). However, people's choices may differ depending on how the information is provided (Abhyankar, Summers, Velikova, & Bekker, 2014; Kirklin, 2007). Although focused on the freedom of choice, nephrologists in our study framed information about treatment options in a way that steered the patients towards a specific dialysis modality. Nephrology guidelines and health policy advocate a PD-first approach to increase home-based uptake (Winterbottom et al., 2016). This could lead nephrologists to downplay disadvantages of this treatment or to favour the advantages of the treatment with which they are most familiar (Morton, Tong, Howard, Snelling, & Webster, 2010; Stiggelbout, Pieterse, & De Haes, 2015). By actively framing information, subjective interpretation is recognised as an integral part of the information (Kirklin, 2007). Uneven knowledge in patient–professional relationships may favour medical preferences to achieve specific goals. Patients may let the professional decide, believing their individual preferences are superfluous compared to medical expertise (Joseph-Williams et al., 2014).

In the current study, nephrologists considered self-care activities equal to patient participation, seeing self-care as a source of patient empowerment. This is in line with a Swedish study (Årestedt, Martinsson, Hjelm, Uhlin, & Eldh, 2019) which found that professionals viewed the performance of dialysis as the ultimate form of patient participation in ESRD care. Patients, however, considered the choice of having the staff run their dialysis, at certain times or continuously, as an act of participation (Årestedt et al., 2019). This is in accordance with a broader understanding of patient participation that includes dialogue, involvement in care, mutual shared knowledge and the management of self-care (Thórarinsdóttir & Kristjánsson, 2013). Patient participation is moreover contextual, allowing patients to move between different levels of participation (Thompson, 2007). The shifting of tasks from professionals to patients may increase patient empowerment. As suggested by some of the nephrologists in our study, task shifts may additionally have economic outcomes as they can compensate for a shortage of healthcare providers (EXPH, 2019).

Nephrologists in our study supported patient participation, which is in accordance with previous findings (Grünloh et al., 2018). They nevertheless sustained traditional patient–professional approaches, for instance, by excluding patients from discussions about treatment plans or self-care tasks. Additionally, they limited patient engagement by expressing that patients should not decide 'too much'. Hence, patient participation may be considered acceptable only if it does not deviate from healthcare professionals' decisions to ensure proper treatment (Aasen & Misund Dahl, 2019). Some nephrologists did not trust their patients' experiential knowledge. Trust is an essential part of the patient–professional relationship, often directed from patients to the provider (Choy & Ismail, 2017). However, trust is reciprocal, which implies that professionals may also trust or mistrust their patients (Cook & Stepanikova, 2008). This reciprocity is evident in how patients being trusted by professionals may honour this trust by following medical advice (Cook & Stepanikova, 2008).

In the present study, we found that when the clinics got busy, biomedical values overrode patient participation. This indicates that patient participation is possible only when nephrologist timeframes allow it, suggesting incomplete implementation. Monitoring hypervolemia or imbalanced electrolytes may be a matter of life and death, and critically ill patients express less need for participation (Thompson, 2007). Time is the most frequently cited barrier to any change in clinical practice, but there is no robust evidence to indicate that more time is required, for instance, in shared decision making than in a more traditional approach (Rowland & Politi, 2016). The process of patient involvement has value by itself no matter whether the patient or clinician makes the final decision (Rowland & Politi, 2016). The focus of healthcare systems on efficiency requirements may nevertheless contradict and challenge the ideals of individually customised care (Holmqvist & James, 2019; Vandenberg et al., 2019).

Evidence-based medicine is currently the dominant paradigm for medical practice, focusing on populations rather than individuals (O'Hare, Rodriguez, & Bowling, 2016). However, as shown in our study, treatment goals on the population level may not align with individual preferences, and tensions may occur (Chan et al., 2019; O'Hare et al., 2016; Tong et al., 2017; Vandenberg et al., 2019). Shared decision-making is a way to support patients' capacity to restore autonomy and regain control of areas of their lives which are important to them (Eldh, Ekman, & Ehnfors, 2006; Gulbrandsen et al., 2016; Håkansson Eklund et al., 2019). However, patients entering the ESRD trajectory may not be aware of their legal right to participate (Joseph-Williams et al., 2014; Schinkel, Schouten, Kerpiclik, Van Den Putte, & Van Weert, 2019). Nephrologists should therefore emphasise and encourage patient participation from their very first pre-dialytic patient meetings, as expressed by some of our study participants.

Nephrologists attending this study recognised several existing factors that hampered patient participation. Diminishing these factors requires a broadened attention on individual and organisational levels as well as collaboration and commitment within the healthcare team. Lack of a common understanding of patient participation may result in practice approaches based on individual conceptualisations. This may in turn lead to a belief by professionals that they are facilitating patient participation even though they are practising within traditional frameworks (Castro et al., 2016; Grünloh et al., 2018). Hence, a common understanding of patient participation within the healthcare team is needed. Heightening individual competence in shared decision-making—as well as team competence—enables patient–professional discussions that go beyond the giving of information and incorporate patients' values and lifestyle preferences in joint treatment plans. On an organisational and political level, moving patient participation from ambition to reality is an ongoing activity. However, modern healthcare is complex and multifaceted, entailing organisational, political and economic features that may be less compatible with the ideals of patient-centred care (Holmqvist & James, 2019; Vandenberg et al., 2019). For nephrologists, the requirement of patient participation adds to several other requirements that are imposed on healthcare professionals (Grönlund et al., 2011). No incentives are included, however, and opting out of it has no consequences for care providers. It may be easier and more effective for professionals to adhere to well-established clinical standards. Ultimately, the responsibility for implementing patient participation lies at political and organisational levels, for instance, through optimising working conditions and educating staff.

Strengths and limitations

The study sample consisted of ten nephrologists of various ages and gender who have their nephrology practice in Central Norway. We closed data collection when both variance and patterns appeared in the data. Although generalisation of the findings was not the intention, the issues presented in our study are legitimate and may be applicable to other contexts of haemodialysis. The first author has previously served several years as a haemodialysis nurse. Her extensive field knowledge was valuable in conducting the study. However, field knowledge comes with potential preconceived notions. Having co-authors from other backgrounds allowed for new interpretations of the findings. We conducted most interviews at the nephrologists' workplaces, which implied disturbances. It is a limitation that all participants came from one health region in Norway.

Conclusion

Our study shows that nephrologists have different approaches to patient participation in different phases of the ESRD trajectory. Addressing individual understanding as well as organisational structures are important factors to increase patient participation in ESRD care. Shared decision making, in which patient values are balanced against biomedical treatment targets, allows for mutual agreement between patients and healthcare professionals concerning medical plans and minimises the potential for patient–professional tensions.

Abbreviations

N/A

Declaration

- **Ethics approval and consent to participate**

The study was approved by the Norwegian Centre for Research Data (case number 702797). We obtained written informed consent from all participants.

- **Consent for publication**

N/A

- **Availability of Data and Materials**

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

- **Competing interests**

The authors declare no competing interest.

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- **Authors' contribution**

TAH, TH and MK drafted the study. TAH conducted and coded all interviews and was in charge of writing the article. BJL, MS, MK and TH commented on manuscript drafts, contributed in the process of analysing and interpreting data, and in approving the final version of the manuscript.

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