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
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.

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 (Grünlöf, 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, Kerpicilik, 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, Kvangstroms, & 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 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>
<thead>
<tr>
<th>Table 1</th>
<th>Interview guide</th>
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<tr>
<td><strong>Questions</strong></td>
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<tr>
<td>How would you describe to live with kidney failure and dialysis treatment?</td>
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<tr>
<td>Explain how you experienced the start-up?</td>
<td></td>
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<tr>
<td>Which information did you receive before you started?</td>
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<tr>
<td>How did you get involved in the choice of treatment?</td>
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<tr>
<td>How are you on a daily basis involved in your treatment?</td>
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<tr>
<td>In what way are you included in decisions that concern yourself/your treatment?</td>
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<tr>
<td>How do you experience to be seen and heard by the staff members?</td>
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<tr>
<td>How do you experience the coordination of your healthcare services to be?</td>
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<tr>
<td>Is there anything else you want to convey?</td>
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</tbody>
</table>
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

<table>
<thead>
<tr>
<th>Trajectory phase</th>
<th>Exemplifying quotes</th>
<th>Categories</th>
<th>Theme</th>
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<tbody>
<tr>
<td>Treatment initiation</td>
<td>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)</td>
<td>Good information Not involved in the choice of treatment modality</td>
<td>Informed, but not involved in treatment choices</td>
</tr>
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</table>
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 to 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; Tusso, 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 interdisciplinarity 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 acknowledges patients’ preferences while maintaining best practices for quality and safety.

7 METHODOLOGICAL CONSIDERATIONS

Purposeful 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.