Context Factors Facilitating and Hindering Patient Participation in Dialysis Care: A Focus Group Study With Patients and Staff

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ABSTRACT

Background: Safe health care of good quality depends on structured and unceasing efforts to progress, promoting strategies tailored to the context, including elements such as patients’ preferences. Although patient participation is a common concept in health care, there is yet limited understanding of the factors that facilitate and hinder it in a healthcare context.

Aims: This paper identifies what patients and health professionals depict in terms of enablers and barriers for patient participation in dialysis care.

Methods: An explorative qualitative design was applied with seven focus group discussions with patients, staff, and managers across different types of hospitals, with the texts analyzed with content analysis.

Results: The dialysis context represents three key elements—people, resources, and interactions—that can both enable and hinder patient participation. Both barriers and facilitators for patient participation were found to reside at individual, team, and organizational levels, with a greater number of enabling factors implied by both patients and staff.

Linking Evidence to Action: While the dialysis context comprises opportunities for progress in favor of patient participation, a shared understanding of the concept is needed, along with how contextual factors can facilitate conditions for participation by patient preferences. In addition, the most favorable strategy for implementing person-centered care is not yet known, but to facilitate patient participation from a patient perspective, creating opportunities to enable staff and patients to share a common understanding is needed, along with tools to facilitate a dialogue on patient participation.

BACKGROUND

Safe health care of good quality depends on structured and persistent efforts to keep up to date with contemporary evidence (Grol, Wensing, Eccles, & Davis, 2013). The uptake of innovations into practice is enhanced by strategies tailored to the particular context, including elements such as patients’ preferences, leadership, resources, and culture (Damschroder et al., 2009; Harvey & Kitson, 2016).

Over the last few decades, healthcare legislations and policies have come to favor partnerships between healthcare professionals (HCPs) and patients (Coulter, 2007). This is facilitated by promoting methods such as shared decision-making (Légaré et al., 2011; Stacey et al., 2017), patient-centered care (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016), and person-centered care (Ekman et al., 2011; McCormack et al., 2010), illustrated by the concept of patient participation (Thórarinsdóttir & Kristjánsson, 2014).

Although patient participation can be identified as being active in making decisions regarding one’s health care (Castro et al., 2018), several studies emphasize the need for a broader perspective, particularly as patients recognize participation as a wider concept (Kvael, Debesay, Langaas, Bye, & Bergland, 2018; Thompson, 2007). To patients, participation connotes:

- recognition of one’s shared experience of symptoms and treatment;
- the provision of information facilitating comprehension of one’s condition and healthcare interventions; and
• one’s actions in relation to health care, and in order to regain, attain, or retain health (Eldh, Ekman, & Ehnfors, 2010; Luhr, Eldh, Nilsson, & Holmefur, 2018; Luhr, Holmefur, Theander, & Eldh, 2018).

The importance of patient participation is well rehearsed across the Western world (Anell & Glenngard & Merkur, 2012; World Health Organization, 1994). Yet, given the potential scope of the concept, there is a need for a further discussion as to whether, when, and how patient participation is fortified. In particular, for people with a long-term illness, it is important to better understand how repeated and prolonged contact with the healthcare sector can foster conditions beneficial for patient participation. Living with end-stage renal disease (ESRD) requires that the individual engages around the clock, for example, in repeated healthcare interactions and everyday adaptations (Årestedt, Martinsson, Hjelm, Uhlin, & Eldh, 2019). Current data suggest that about 10,000 individuals are treated for ESRD in Sweden, and 4,000 of those are patients in hemo- or peritoneal dialysis (Swedish Renal Registry, 2018). Worldwide, roughly 2.5–3 million people are estimated to be receiving dialysis (Liyanage et al., 2015). Dialysis is performed on a regular basis to decrease the individual’s exposure to uremic toxins (Vanholder, 2018). A common procedure is hemodialysis, performed at least three times a week for approximately 4 hr per treatment. Dialysis is thus a life-saving treatment, yet requires compliance with a therapy that influences one’s entire life, including adhering to restrictions in food and fluid intake, medication, management of health technology devices, and adaption to the bodily and psychological manifestations of renal failure, such as a certain level of fatigue (Bonner, Wellard, & Caltabiano, 2010).

While the last few decades have shown a vast change in terms of what the patient may, and is supposed to, comprehend and execute, little is known as to what facilitates and hinders patient participation in dialysis care. This paper identifies what patients and HCPs depict in terms of their perceptions of enablers and barriers for patient participation in dialysis care.

METHODS
Design
An explorative, qualitative design was used to address the context of dialysis care by means of focus group discussions (FGDs) with patients, HCPs, and managers.

Setting and Sample
This study identified seven dialysis units in an average Swedish healthcare region. All invited units engaged in the study after consent was provided by each unit’s head of department. Once inclusion was confirmed, the manager of each unit was asked to identify potential stakeholder candidates for interviews, including two to three patients (those having had at least five dialysis treatments), two to three HCPs (employed for more than 6 months in dialysis care), and one to two managers of the dialysis unit. These people were invited to partake in FGDs and received written and verbal information that emphasized that participation was voluntary and based on the individual’s own choice. All participants provided written informed consent prior to taking part in the FGD. Altogether, 42 individuals participated in the seven FGDs. Their demographics are shown in Table 1.

Procedure
The FGDs were held in a private room at each clinic on a date and time that was convenient for the participants. During the FGDs, the participants were seated as a group so as to encourage dialogue. Two researchers facilitated the FGDs (ACE & LLÅ), with one acting as a nonparticipating observer and the other directing each FGD by means of an interview guide. This included two main issues: to ask the participants to depict what patient participation means to them (Årestedt et al., 2019) and the conditions for patient participation in health care, particularly dialysis care. During the introduction, the researcher clarified that the aim of the study was not to conduct an assessment of patient participation, but instead, the participants were encouraged to conceptualize patient participation, individually and as a group. Both researchers had extensive experience in qualitative interviewing with individuals and groups, including FGDs. The FGDs lasted between 49 and 71 min (mean 60 min); they were performed March through May 2018 and audio-recorded, with the recordings transcribed verbatim by an authorized secretarial service.

Analysis
For analysis, qualitative content analysis was applied (Elo & Kyngäs, 2008). The transcribed interviews in Word text files were read several times to obtain an overall understanding and to reveal facilitating and impeding aspects for patient participation. This phase of the analysis signified an inductive approach and was performed separately by all researchers and then subsequently discussed jointly. All researchers were experienced in analyzing qualitative

Table 1. Overview of Demographics of the Participants

<table>
<thead>
<tr>
<th>Sex</th>
<th>Age, years (median)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td></td>
</tr>
<tr>
<td>5 women</td>
<td>30–82 (59)</td>
</tr>
<tr>
<td>10 men</td>
<td></td>
</tr>
<tr>
<td>Staff</td>
<td></td>
</tr>
<tr>
<td>18 women</td>
<td>25–58 (41)</td>
</tr>
<tr>
<td>0 men</td>
<td></td>
</tr>
<tr>
<td>Managers</td>
<td></td>
</tr>
<tr>
<td>9 women</td>
<td>38–63 (51)</td>
</tr>
<tr>
<td>0 men</td>
<td></td>
</tr>
</tbody>
</table>
data but with different clinical backgrounds in terms of familiarity with dialysis care, other groups of patients with short- or long-terms conditions, or of investigating contextual factors in health care. This procured a matrix including human and structural factors, respectively, divided into (a) patients and staff, (b) organization and leadership, and (c) tools and devices.

The structured analysis was then performed by means of the matrix, and thus was deductive in its approach; this phase engaged one researcher (LLÅ) analyzing the entire text, including all interviews, with two additional researchers (CM & CH) performing separate structured analyses for a set of two interview transcripts each. Consecutive analysis meetings were held to contemplate the mounting analysis, also including the entire team, to arrive at the most trustworthy understanding.

To complete the analysis, the team collaboratively formed a comprehensive understanding, conceptualizing the categories and whether they represented enablers and barriers, respectively, with regard to patient participation in dialysis care.

RESULTS
Overall understanding of barriers and enablers for patient participation in the dialysis context
The dialysis context comprises various elements that can enable or hinder patient participation. The main elements encompass people, resources, and interactions:

- People correspond to the patients and HCPs, as individuals or as groups and teams.
- Resources comprise the learning and understanding trajectory of the patient affected by ESRD, which is influenced by time, the availability of dialysis and different types of treatment, the dialysis equipment, and the training provided by other individuals and staff, directed by stakeholders or management.
- Interactions indicate the relations formed between people (patients and staff) as well as the exchange of knowledge and experience.

These key context elements affect patient participation, including barriers or enablers, as pictured in Figure 1, with further features described below. An overall theme illustrates that the dialysis context includes the people who are engaged, by means of needing or facilitating dialysis, and the resources available, including the individuals and teams, their knowledge and understanding, as well as the devices and the time required to use them. Concurrently, each of these elements produces, reproduces, and represents a culture that enables or hampers patient participation.

People
People correspond to the patients and HCPs, as individuals or as groups and teams. Patient participation can be hampered by ESRD; the patient’s cognitive function may be diminished by high levels of uremic substance in the blood. Thus, the patient in pre-dialysis or dialysis can have trouble appreciating complex information or tasks, limiting the potential to engage in his or her health care. Further, at the onset of kidney failure, accepting one’s illness and the necessity of dialysis may require one’s full attention; in the acute phase, the patient often has severe symptoms, such as overwhelming fatigue, limiting the patient’s opportunities to engage in activities.

Further, the initial part of the dialysis trajectory can cause concerns for the patient; the dialysis process is complex and includes technical, emotional, physical, and social aspects. Once one has had time to settle into the new life situation that dialysis entails, an increased level of engagement may or may not occur, depending on the individual’s preferences for enacting patient participation. Furthermore, patients’ personal traits and preferences affect in which way and to what extent they will participate.

While encouraging patient participation, HCPs rely on aiding patients to an understanding of their individual situation. If an HCP believes that the engagement of patients is of limited value, the HCP will not engage in guiding the patient to an increased health literacy, which will constrain the patient’s opportunities to participate.

When the HCPs have no or limited trust in a patient’s health literacy, they limit their efforts to promote patient participation in terms of being involved in the performance of the dialysis. If the HCPs view that a patient has no or limited understanding of the illness, the dialysis, or of other aspects of the treatment, they will be reluctant to entrust tasks to the patient—regardless of whether their perception is accurate or not.

The nurses, who are the primary providers of care and support for the patient in dialysis, can hamper patient participation in particular. Where they find it easier to complete a task associated with the dialysis, they may perform it themselves rather than take the time and effort to supervise the patient. A patient becoming more involved and engaging in the performance of the dialysis can also challenge the nurse’s sense of control and expertise; any HCP with a sense of being “the dialysis expert” can hamper the active engagement of a patient, particularly if he or she believes that a staff member’s performance of a task will be swifter or completed with a higher level of accuracy.

Patient: Yes, when I started the dialysis treatment, I didn’t feel well. I was very tired and worried about the situation and then to dress the machine—it is not...
the first thing you think of, it will come in due time.

(Interview 3)

Resources

Resources comprise the learning and understanding trajectory of the patient affected by ESRD, which is influenced by time, the availability of dialysis and different types of treatment, the dialysis equipment, and the training provided by other individuals and staff, directed by stakeholders or management.

Considering oneself the master of the illness in the sense that, as a patient, one has control over the situation facilitates patient participation. A sense of control can include, for example, understanding the relation between one’s symptoms and one’s actions in daily life and the dialysis, which originates from knowledge and understanding. HCPs mainly employ information-sharing as a means to facilitate patient participation. To ensure that all patients receive the same information and are exposed to a set standard for participation, the staffs rely on checklists. These conceptualize patient participation as active engagement in dialysis, although a common understanding of what patient participation can convey and how patient participation is facilitated from a patient perspective is lacking.

To patients, participation is facilitated by opportunities to learn—for example, from fellow patients. Such opportunities can transpire in spontaneous contact prior to, during, or after dialysis sessions but can also be facilitated through training programs organized by the staff.

The kidney program offers such ventures to patients in pre-dialysis, including classes where patients meet on a regular basis with the HCPs on the dialysis team and more experienced patients. Another opportunity to share experiences of the treatment options and procedures are when patients are exposed to fellow patients with different dialysis treatment forms. This is facilitated when various forms of dialysis are offered in parallel at the same unit, and the patients meet, for example, in common areas, such as lounges, and can engage in a dialogue about the available options.

When patients perceive a lack of knowledge, it hinders their participation. Considering that one does not know or cannot capture what the illness or healthcare procedures mean makes it difficult for the patient to grasp what he or she can do, both in terms of everyday life and the dialysis treatment. However, appreciating the HCPs’ expertise can also signify patient participation, such as actively surrendering either the management of the dialysis or any decision regarding the treatment, or both, to the HCPs. Yet, if the patient favors patient participation to equal active involvement in decisions, a passive approach indicates that the patient is not participating on his or her terms.

Time affects patient participation; gradually learning about the illness and getting to know each other is vital for the forming of a joint team, where the HCPs get to know the individual and his or her terms and preferences. A lack of time reduces the opportunities for a mutual dialogue and understanding for both patients and staff. For the HCPs, a lack of time means that conversations and reflections are

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**Figure 1.** Barriers and enablers for patient participation in the dialysis context.
limited, suppressing opportunities to learn about the individual and his or her medical condition, preferences, and ambitions.

The more experience the patient has, the easier it is for the patient to actively be involved in the dialysis. Staff emphasize training as a route to participation and suggest that the patient should be supported to take one step at a time, engaging in treatment while supported by the nurses, for example, by starting their own dialysis machine or preparing for treatment by positioning the insertion set. Nowadays, the apparatus for hemodialysis is fairly easy to operate; the technology reduces the risks of inaccurate trimming, and the computer program indicator alarms are self-instructing. Although the HCPs believe in a slow introduction, and gradual engagement only for patients with a cognitive capacity to perform safe procedures, a mastering of the dialysis is considered a primary form of patient participation. Yet, to patients, managing the equipment primarily means an increase in one’s freedom; they do not have to wait for the staff to set up, perform, or finalize the dialysis session for them. Although one knows its purpose and functionality, the equipment can be intimidating—the management of the apparatus is not vital for one’s sense of participation, but, as a patient, one can choose to participate by, for example, taking one’s measures, calculating the amount of fluids to extract during the dialysis, or managing the insertion or retraction of the cannulas post-dialysis.

Patient: “But I’ve received support from the nurses, and they encouraged me all the way, but also the other patients on the ward, they’ve explained things to me.”

HCP: “Yes, that’s our way of working: The nurses are responsible for the education, but you also get ideas from other patients and those who have been coming here longer and who manage more of their treatment themselves.”

(Interview 4)

Interactions indicate the relations formed between people (patients and staff) as well as the exchange of knowledge and experience. Having a common policy regarding patient participation facilitates its realization in practice; HCPs need to agree on the importance and purpose of providing equal information and opportunities to all patients to facilitate their participation. Consensus also scaffolds consistency. Thus, agreement between the HCPs about what is to be shared and when is vital, promoting trust and mutual commitment and hence enabling patient participation.

Because it necessitates regular and repeated contact over long periods of time, dialysis care might present an opportune condition for patient participation. However, patient participation does not occur naturally; instead, it requires a climate where questions phrased by the patients are genuinely appreciated. Continuity and possibilities for the patient and the HCPs to get to know each other facilitate patient participation by means of building authentic relationships. Because this requires sharing a common language, patients whose first language does not match that of the HCPs have less opportunities to learn and engage.

From a patient perspective, having opportunities to learn about one’s illness is vital—not only to improve understanding but also in taking actions in one’s daily life and in relation to the dialysis. Dialysis implies a collaborative mode; when learning a new technical skill, patients search for assistance from nurses or other patients who they recognize as being more skilled.

Patient participation in dialysis has been increasingly highlighted over the last decade, partially because initiatives in particular dialysis units have been shared in regional or national dialysis networks. As a result, others have learned about and adopted ideas for patient participation. The key to promoting such changes is leadership. Managers’ support in changing practice is vital to determining whether patient participation is adopted. In addition, if few HCPs emphasize patient participation, the conditions facilitating participation will not spread. Rather, the promotion of patient participation requires that either managers or people recognized as opinion leaders support the HCP teams. Training, regular staff meetings, and time for reflection are further activities associated with the HCPs’ adoption of new ideas and identification of routes to attain common goals, such as increased patient involvement.

Manager: We [some of the staff] took a course in motivational interviewing, to get new ideas … but then, all staff must have a common idea, an agreement. From physician to nurses, together with the patient. To think in the same way—and that is where the dialogue starts—it requires a lot from us, the HCPs, to find the tools [for such improvements].

(Interview 6)

DISCUSSION
What is known about what facilitates and hinders patient participation in health care is generally limited (Kvael et al., 2018), but this study identified that the barriers and enablers consist of both human and organizational factors, including the structures and resources of health care in general and the dialysis unit and its equipment in particular. The results indicate that staff and patients depict several enabling factors for patient participation in dialysis care, primarily at the level of healthcare delivery. However, there are barriers to patient participation, some of which are the opposite of enablers and some of which are distinct. Overall, internal and external factors at individual,
team, and context levels constitute hindering and facilitating aspects for patient participation in the dialysis context. Although the dialysis context seems progressive, with several enablers, a further need for facilitating the implementation of patient participation is suggested, along with current initiatives to safeguard person-centered care.

The conditions for patient participation in dialysis care are supposedly productive; patients with ESRD have an illness that requires their engagement around the clock and in the long term (Karolich & Ford, 2010). Thus, elements such as having confidence in oneself and others are common in the dialysis context, with both suggested as being beneficial for patient participation (Havas, Douglas, & Bonner, 2017). Health literacy is related to one’s engagement in health care for patients living with ESRD, suggesting that the promotion of a combined understanding of one’s illness, bodily reactions, and treatment, favored and facilitated by the dialysis staff, is beneficial for patient participation (Wong, Velasquez, Powe, & Tuot, 2018). In addition, self-care support, facilitating an understanding of one’s illness and treatment, is beneficial for patient engagement when living with long-term conditions such as chronic kidney failure (Havas et al., 2017) as well as chronic heart failure and obstructive lung disorder (Lühr, Holmefur, et al., 2018).

The investigation of patient participation as a core healthcare concept has been suggested to be incomplete, with further research needed to clarify its fundamentals by considering the patient voice, legislation, ethics, and semantics (Eldh, 2019). Today, assumptions that patient participation primarily denotes the decision-making process have been rejected for the benefit of a wider conceptualization. Yet, while patients suggest that the full range of attributes apply to what it is to participate in dialysis care, staff propose a hierarchical order as to what the conditions are for patient participation and what constitutes patient participation (Årestedt et al., 2019). As a result, the HCPs may aim for a different level of involvement in dialysis, regardless of the patient’s preferences and engagement by means of, for example, sharing experiences and managing self-care in daily life. Without a shared understanding, opportunities to promote participation by patient preferences may be lost. Tools to facilitate patient participation may be needed to bridge the potential gap between patients’ preferences and staff’s assumptions. By means of mutual communication, co-production may be established, promoting an agreed understanding and thus facilitating patient participation (Siouta, Hedberg, Hedman, & Broström, 2012).

The elements identified as enabling or hindering patient participation in the inductive analysis supporting this paper correspond to structures depicted as influencing evidence-based practice: People, resources, structures, and interactions convey important context domains for the implementation of innovations (Harvey & Kitson, 2016). In this case, staff identified initiatives that facilitate patient participation in their contact with other dialysis units, indicating that patient participation has been promoted primarily by inherent diffusion-and-adoption rather than allocated structures or programs (Rogers, 2003). While this is known to possibly bridge a gap between what is suggested as most beneficial, in terms of evidence-based or perceived value in health care, it is a gradual and weak strategy for securing best practice. Rather, several strategies are noted as being more appropriate to facilitate knowledge translation, such as appointing and training local facilitators (Harvey et al., 2019). Further, while the context, including characteristics of the individuals, will influence the process of improving health care and implementing change (Damschroder et al., 2009; Helfrich et al., 2010), having a better understanding of the contextual elements of dialysis care may aid further studies on facilitating implementation of patient participation, providing opportunities to tailor the strategies and to incorporate both patient and HCP perspectives.

To date, there are few means available to facilitate a mutual dialogue on what constitutes and supports patient participation, both in healthcare in general and in dialysis care in particular. The current and parallel studies indicate that there are both context and conceptual issues that should be considered to advance patient participation. What is needed to bridge barriers and employ enablers to facilitate the implementation of means to support increased patient participation in particular is not yet fully known. Rather, we suggest further implementation studies are warranted.

Because the research team members had various experience of studying concepts, including patient participation, the repeated discussions provided for a critical discourse with regards to the trustworthiness of the analysis (Elo & Kyngäs, 2008). Even if FGDs were appropriate to initially investigate barriers and facilitators, additional studies will be needed to further elucidate if and how context factors influence implementation of innovations and evidence-based practices. Further, although some of the participants of the FGDs knew each other and others did not, we found that all were likely to speak freely, with extensive sharing of experiences from professional and patient perspectives. Yet, FGDs were motivated as for providing opportunities for staff, patients, and managers to share and thus learn of each other’s perspectives on patient participation. Such forums are rare in everyday clinical practice, and the FGDs could thus presumably offer immediate payback. For the study’s purpose, we found participants to build on each other’s accounts and thus to further elaborate on what constitutes barriers and enablers, as intended (Kreuger & Casey, 2015).

CONCLUSIONS

This study shows that the dialysis context contains several factors that could favor patient participation represented in three key elements, including people, resources, and interactions. These have only been employed to facilitate
improvement, and the barriers addressed, to a limited extent. To further execute patient participation in dialysis care, further studies are suggested, particularly projects countering barriers and supporting enabling factors. Such initiatives should include context elements such as people, resources, and interactions, and should aim to promote the necessary conditions for patient participation in the dialysis context.

**LINKING EVIDENCE TO ACTION**

- Dialysis care offers both barriers and enablers for patient participation.
- A further process to facilitate patient participation from the patient perspective is needed, addressing the conditions favorable for or hindering improvements.
- Forums such as focus groups provide opportunities to identify various experiences, given that they engage stakeholders such as managers, patients, and staff.
- Joint dialogues allow staff and patients to share a common understanding of routes for individuals to participate in their health care, in relation to living with ESRD and requiring dialysis.
- Barriers to procure conditions for patient participation, like time and availability of dialysis treatment, need to be addressed.
- Today, there is limited evidence for evidence-based methods and tools for patient participation, calling for further studies.

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