

The role of different nephrology experts in informed shared decision-making for renal replacement therapy

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Abstract

Background: Interprofessional teams and peer support are being increasingly considered in informed shared decision-making. In Germany, there appear to be deficits in the implementation of informed shared decision-making in the choice of renal replacement therapy, such as the lack of collaboration in interprofessional teams and the absence of structured peer support programmes for patients with chronic kidney disease.

Objective: To explore nephrologists' and nurses' perspectives regarding their involvement in shared decision-making when choosing renal replacement therapy.

Design: Guideline-based, problem-centred interviews were used.

Participants: A total of 20 nephrologists and 15 nurses were recruited from 21 dialysis units all over Germany.

Approach: Interviews were audio-recorded and transcribed. They were analysed thematically using structuring and summary content analysis, supported by the qualitative data analysis software MAXQDA 12.

Results: The most important findings were the late or missing participation of nurses in the informed shared decision-making process and the unstructured peer support. Along with time and financial factors, these aspects were seen as barriers to shared decision-making with patients who are often overwhelmed by the diagnosis. Furthermore, informed shared decision-making has been insufficiently considered in professional education and training.

Conclusion: Shared decision-making in the choice of renal replacement therapy is particularly challenging due to the patients' high disease burden. The greater incorporation of informed shared decision-making in education and training as well as the consistent involvement of nursing staff and structured peer counselling already in the predialysis phase with adequate reimbursement can address the identified hurdles.

KEYWORDS

informed shared decision-making, interprofessional care, peer counselling, renal replacement therapy

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INTRODUCTION

Patients with advanced chronic kidney disease (CKD) must make complex decisions about possible renal replacement therapies. In Germany, renal replacement therapy (RRT) is mainly performed as centre haemodialysis (HD), with the proportion of home-based peritoneal dialysis (PD) at about 6% (Medical Netcare GmbH, 2018). Both treatment concepts are equivalent in terms of survival time (Vonesh et al., 2006; Yeates et al., 2012), but affect the patients' lives in different ways. The choice of RRT is a typical situation for 'informed shared decision-making' (iSDM). iSDM is defined as a decision situation, in which (1) at least two participants are involved, who (2) both share evidence-based information, and (3) take steps to build a consensus about the preferred treatment, and where (4) an agreement is reached on the treatment with joint responsibility (Charles et al., 1999; Kriston et al., 2010). iSDM has been identified as a key for positive patient-centred outcomes. Successful iSDM can promote treatment satisfaction, adherence and compliance, as well as knowledge about the disease. iSDM can reduce symptoms, and hence, even indirect costs (Braun & Marstedt, 2014; Oshima Lee & Emanuel, 2013). Despite interdisciplinary research for over 30 years, the implementation of iSDM in a clinical practice routine has proven to be difficult and has been successful to varying degrees in the different disciplines. There are positive examples in oncology and cardiology as well as in diabetes mellitus type 2 and unipolar depression. For these diseases, evidence-based decision aids and decision-support interventions have been developed, tested and partially made available via the internet (Härter et al., 2017).

Although guidelines (National Kidney Foundation., 2015) state that patients and relatives should be adequately prepared to make informed decisions, a large proportion of nephrology patients do not feel sufficiently involved in the decision-making process (Robinski et al., 2016a). In a previous project, the patient perspective on iSDM was examined with empirical data in a large sample of German dialysis patients ($N = 780$). The study revealed that a successful shared decision is one of the main factors influencing the long-term treatment satisfaction of dialysis patients (Robinski et al., 2016b).

Ideally, patients have several sources of information available to them to make this choice. The advice of the nephrologists is essential because of their medical competence. Nursing professionals can play an important role in explaining the options in layman's terms and in providing emotional support. Important family members are also often involved because their support is required, and their everyday life may be profoundly influenced by the disease and the RRT. Peers can help with the decision process because of their experience and motivational effect on quality of life with dialysis (Loiselle et al., 2016; Morton et al., 2010; Winterbottom et al., 2012). Peer support has the potential to strengthen patients' self-management skills and activities (Ghahramani, 2015). While nephrologists and nurses can be considered professional experts, peers and family members are experts by virtue of their experience (Cordier, 2014). Structured programmes for the involvement of peers in the decision-making process on the choice of RRT are only available from other countries. Especially in

the United Kingdom and the United States (Trasolini et al., 2020), there are different models of peer-to-peer support, ranging from professionally led group visits and peer coaches through telephone and web-based programs (Bennett et al., 2018). Hughes et al. (2009) described the development and evaluation of an individual face-to-face peer programme in two hospitals in the United Kingdom, in which nurses match patients with peers, organise the process and train peers. In the Netherlands, young people with end stage renal disease (ESRD) can attend a yearly, nationwide 1-week camp, mainly organised by peers (Sattoe et al., 2013).

The authors are not aware of any studies from Germany on the role of nephrology nurses in the iSDM process. In the English-speaking and Asian countries, on the other hand, interprofessional work is already more advanced including iSDM with numerous professional groups (involvement of nursing professionals, psychologists, social workers, and nutritionists) (Chen et al., 2019; Lin et al., 2018). These studies have shown a lower risk of terminal renal failure due to the delayed decline of renal function in patients treated by an interprofessional team. The resulting later start of dialysis has a positive effect on the quality of life and the health-care costs of patients. However, there is little evidence of a positive effect on mortality, treatment quality, or adherence (Reeves et al., 2017). The important role of nurses in the iSDM for the choice of dialysis treatment has been supported by several studies (Bennett & Oppermann, 2006; Davison & Cook, 2015; Loiselle et al., 2016). In special predialysis teams, they take on tasks in the information and decision-making process as well as a trainer role, thus promoting the independence of patients (Davison & Cook, 2015). Interprofessional collaboration is not yet sufficiently developed. One of the reasons for this is traditionally grown hierarchies, especially between the medical and nursing professions (Dangel & Korporal, 2020).

We investigated the perception of different attitudes and actions of nephrology staff and their contributions to shared decision-making as well as their opinion on peer support. The following questions were addressed: To what extent are nurses and peers involved in the decision-making process for RRT, and how is the power of influence distributed among the groups involved in the iSDM process (nephrology staff, peers, and relatives)?

METHODS

Study setting and participants

In an explorative, qualitative study, nephrologists and nurses were interviewed in guideline-based, problem-centred interviews. By including representatives of different professional groups in different areas of care, a wide representation of content was intended. The interview partners were chosen according to the expected increase in knowledge (Glaser et al., 2010) and included in the study. Based on similar studies, a saturation of the increase in knowledge was expected for a sample size of $N = 40$ ($N = 20$ physicians, $N = 20$ nurses).

The study participants were recruited through an existing network from a previous project (Robinski et al., 2014) of $N = 55$ dialysis units

(all levels of outpatient care including private practice, nonprofit dialysis providers, and hospital-associated dialysis centres) in Germany. Additional units for chronic RRT in Germany were asked to participate, which, unlike the existing network, do not offer PD. The nephrologists and nurses were informed about the project via mail and invited to the telephone interview. For better comparability within the sample, we asked for the participation of one doctor and one nurse per centre. Interested participants replied with their informed consent and were asked for consent again at the beginning of the recorded interview. Therefore, all interviews were recorded and subsequently transcribed.

The contents of the interview guideline were selected based on a comprehensive literature search carried out in advance and of the findings of our previous study (Robinski et al. 2016b, 2016a). In total, the guideline contained four areas of interest (Table 1).

Ethical consideration

The study was conducted in accordance with the current law and regulations of Germany and the 1975 Helsinki Declaration (in its current revised version). Participation was voluntary and all participants were provided with an information sheet explaining the purpose of the study and told that they could withdraw at any time without any penalty. All interviewees gave their informed consent. The study is based on a detailed data protection concept which, along with the interview guideline, can be requested from the authors. The ethics committee was presented with the study design and asked to evaluate it. Given the study design, a separate ethical vote was not deemed necessary. Due to this being a one-time study and the anonymisation of the transcript, no personal or sensitive data were stored past the date of the interview.

Data collection

The interviews with participants across Germany were conducted alternately by two research assistants by telephone with an

TABLE 1 Topics of the interview guide

Subject area	Interview contents
Information and decision-making process	<ul style="list-style-type: none"> Information on the procedure Scope Persons involved
Evaluation and implementation of iSDM	<ul style="list-style-type: none"> Knowledge Training Implementation and judgment
Obstacles and possibilities for improvement	<ul style="list-style-type: none"> Factors that prevent the implementation Proposed solutions
General information	<ul style="list-style-type: none"> Professional experience Dialysis facility

Abbreviation: iSDM, informed shared decision-making.

approximate duration of 30 min. Both interviewers followed the same interview guide. All interviews were recorded using a digital recording device and fully transcribed according to transcription rules.

Analysis

All interviews were analysed thematically (Mayring, 2008) using structuring and summary content analysis, supported by the qualitative data analysis software MAXQDA 12. The deductive category formation was based on the interview guidelines. If text passages could not be assigned to a given category, they were inductively coded using summary content analysis. In particular, this concerned the solution approaches. A first category system was created and jointly reviewed by two authors after independent analysis. The coding framework was revised and the remaining interviews were coded. The data saturation was assessed by comparing whether new codes emerged from the last three interviews. The influence on the choice of RRT from the perspective of physicians and nurses was evaluated on a Likert rating scale from 0 'no influence' to 10 'very large influence'.

RESULTS

Sample

Thirty-five interviews ($N = 20$ nephrologists and $N = 15$ nurses) were conducted in a total of 21 dialysis centres (out of 99 units contacted) (Table 2). Both HD and PD are being offered in all participating facilities. Centres offering only HD gave no response. The average duration of professional experience of the nephrologists (18.3 years)

TABLE 2 Sample characteristics

	Total	Nephrologists	Nurses
Number of participants	35	20	15
Gender, female	63%	40%	93%
Work experience in years ^a , M (min-max)	17.9 (4–41)	18.3 (5–41)	17.3 (4–33)
Equivalent training with regard to HD/PD, yes	20%	10%	60%
Type of dialysis facility ^b			
Private practice	19	10	9
Nonprofit dialysis provider	11	7	4
Hospital-associated dialysis units	5	3	2

Abbreviations: HD, haemodialysis; M, mean; min, minimum; max, maximum; PD, peritoneal dialysis.

^aIn nephrology.

^bRelated to the place of work of the interview participants.

and nurses (17.3 years) was similar. Only 10% of the physicians stated that they had received equivalent training in HD and PD compared with 60% of the nurses.

iSDM in everyday practice

The information and decision-making process in RRT is structured differently in the dialysis units regarding the quantity and quality of information and the involvement of nursing staff. The scope of the information and decision-making process or the number of conversations ranges from one information conversation to several consecutive conversations.

Limited consideration of iSDM

The reason for the heterogeneous implementation can be seen in an insufficient focus on iSDM in the scope of education, training, and continuing education. Regardless of their previous professional experience, both physicians and nurses claim that they were not or only insufficiently 'trained in this regard' (187_A), so that, in some cases, they 'have never heard the term iSDM' (159_P). An additional problem is the training focusing on HD and the resulting uncertainties in dealing with PD. A nurse (170_P) describes this as follows:

"[Our doctors] have their dialysis machine, they know exactly, we do five hours, draw three litres of water and he goes home. With the PD it's always a bit like: 'Well, hopefully nothing will happen. And what will it be like? How much water are we going to draw? Hopefully he won't die.' It's always such an unknown, where they're; well, I don't want to say scared, but they're intimidated by it."

Participating doctors stated that the lack of education on PD leads to 'all kinds of fears in the background or even rejection (...). They're not backing it and the patient notices that' (163_A). This can lead to the point where 'PD is not discussed at all' in the information and decision-making process (125_A).

Lack of time and reimbursement

The respondents also attribute unbalanced information discussions and the resulting unequal distribution of HD and PD in Germany to the 'immense time pressure' (941_P), because 'an HD initiation is carried out very quickly by default' (1037_A). The suggested solution is 'a better reimbursement for extensive patient information', to be able to 'talk through everything in more detail [and] repeatedly' (1037_A). According to both professional groups, inadequate staff resources, especially among nurses, make the implementation of training courses or home visits more difficult and mean that patients

must 'learn and carry out the PD procedure relatively quickly' (372_A). Nursing services could provide support, but they do not always have the necessary training and are not sufficiently reimbursed by the health insurance funds. As a result, potential PD patients (e.g., people in need of care) must ultimately be treated in the HD procedure, 'because we have no one to support the patients in the PD procedure' (110_A). More structured and interinstitutional patient education is also not financed, although 'the personnel who can do this are available' (125_A). Further economic considerations are related to the occupancy rate of HD places in the units and the wish 'that PD is also better reimbursed' (404_P).

Timing of information

Individual patient characteristics and attitudes are also identified as obstacles to iSDM and may lead to patients not feeling involved in the decision-making process. The most frequently cited barriers were cognitive performance, multimorbidity, dementia and a very high need for care and assistance. This is mostly due to the disease burden, which leads to a lack of attention to all aspects of one's own disease. Accordingly, the process of information transfer and decision-making in these patients can be accompanied by fear and excessive demands as well as confusion regarding treatment options: 'Sometimes it is simply too much information for the patients. And they can't absorb it properly and then block it out and don't want to and can't hear all of it' (380_P). Additionally, there seems to be repression of the disease in some patients that hinders an engagement with treatment options: 'The patients don't even understand it, because they don't want it at that point' (170_P). A nurse explains the effect of the disease on the decision process as follows: 'Because that is a major change in life for most of them, and that is a big reason why many push, push, push it away' (404_P). The respondents see room for improvement on the part of the nephrology staff primarily in improved communication. Both the nursing staff and the physicians emphasise that greater empathy and care should be brought into the discussions and the individual 'situation [of the patient] has to be considered' (163_A). But there is some proportion of 'patients who actually reject any form of personal responsibility and who are focused on haemodialysis from the outset' (941_A).

Involvement of nursing staff

In one-third of the units, the nephrologists alone are responsible for information and make the 'decision [...] with the patients' (494_A). In two-thirds of the units, both medical and nonmedical staff (e.g., nutritionists, social workers, and psychologists) are involved in the information process. In most cases, the nursing staff are only called in 'when at least the procedure has already been determined [...]' (494_P). The nursing staff criticise this procedure and expresses the wish 'that the nurse takes part in the discussion from the start' (494_P). According to the interviewees, the essential tasks of the

nursing staff during the information and decision-making process consist of conducting patient seminars, organising guided tours on site or meetings with those affected themselves. Nursing professionals are permanent contact individuals and have advisory functions, carrying out practical training and home visits. The nephrology staff have experienced that 'when a physician conducts [the information session], patients often do not [dare] ask questions' (163_A). Several units have already reacted and have adapted the information process so that patient seminars are conducted exclusively by the nephrology nursing staff. Some participants were critical and felt that the involvement of many individuals could hamper the decision-making process: "[This information] from different directions tends to confuse the patients, and in this respect, if more levels, then only with standardisation and prior consultation" (125_A).

Integration of peers

For some units, the inclusion of other affected individuals as peers is a good solution to this problem and is regarded as 'the best thing ever (...)', because patients then '(...) have a lower inhibition threshold to ask what they actually wanted to ask but would not ask otherwise' (110_A). According to an interviewed doctor 'nothing is as credible for an affected patient as talking to another affected person' (1037_A). However, this positive assessment of the peers' impact in the information process is not always put into practice. The centres differ in their approach to the integration of patients with self-affected persons. In 16 of the 21 units, peers are involved in the information process on a regular to selective basis: 'We try to establish contact in individual cases when people are quite uncertain or the available information is apparently not sufficient (...) or they simply say that they would like to have direct one-to-one contact with a patient' (941_A). There is no structured peer support programme in any of the participating units. The units without peer involvement cited a lack of structures, lack of time, or too few PD patients being available as the reasons for this. In part, it was also explained by the attitude of the patients who often do not want to acknowledge the problem and 'postpone the illness or the decision for a long time and do not seek contact with other patients' (404_P). Additionally, respondents reported that some prospective dialysis patients feel 'uncomfortable when they have to talk to other patients' (380_P) who are already on dialysis.

Influence of advisory groups

The assessment of physicians and nurses regarding the influence of nephrologists, nursing staff, peers and relatives on the choice of RRT treatment differed only slightly (Table 3). Both professional groups rated the influence of physicians as the highest. The influence of peers is assessed only marginally lower. The physicians saw the nurses in third place, while nurses ranked themselves last and considered the influence of relatives to be greater than their own.

TABLE 3 Influence of different actors on the choice of renal replacement therapy from the perspectives of nephrologists and nurses

Influence of	Rated by nephrologists	Rated by nurses	<i>p</i> value ^a
	M (range)	M (range)	
Nephrologists	7.8 (5–10)	7.7 (5–10)	0.811
Nurses	5.8 (1–10)	5.5 (3–8)	0.700
Peers	7.2 (3–10)	7.0 (5–10)	0.800
Relatives	5.3 (1–9)	6.6 (3–10)	0.227

Note: The influence was measured as self-assessment on the Likert scale from 0 'no influence' to 10 'very large influence'.

^aThe *t* test was used to determine the differences between the groups.

DISCUSSION

This study shows for the first time the assessment of nursing staff on the implementation of iSDM in the choice of RRT in everyday practice in Germany. The most important results are the demand for early involvement of the nursing staff in the information and decision-making process and the structured involvement of peer support. Both professional groups name identical barriers for implementing iSDM: lack of time, neglect of PD in training, and the associated preference of physicians as well as the excessive demands on patients. The reimbursement of special consultation hours as well as the standardisation of peer support with the funding agencies' aid are seen as primary measures against time and structural problems. The content of nephrology training and continuing education should be adapted in favour of iSDM and peer support. Interprofessional care, as already practiced in other countries (Collister et al., 2019), should be implemented in nephrology care in Germany in the context of the choice of RRT. In particular, the role of nurses should be strengthened.

Whether patients are not included in the iSDM or (un)consciously do not want to be included is controversially discussed. According to Finderup et al. (2019), patients express the feeling that their opinion is unwelcome. The making good decisions in collaboration study showed that there are often misunderstandings among physicians about what patients want (Joseph-Williams et al., 2017). The participants in our study showed that patients are overwhelmed with a lot of information during the late stages of CKD and are not receptive, mainly due to an insufficient processing of the disease. Therefore, it makes sense to distribute the information and decision-making process over several appointments. Especially for older patients, spreading the iSDM over time is helpful before the start of dialysis as they can be particularly affected by comorbidities, physical and cognitive functional limitations and a lack of social support (Winkelmayer & Kurella Tamura, 2012). The distribution of information could be better managed with the earlier involvement of nursing staff or peers. To improve the self-management of the disease, interventions should be developed and offered to patients according to their individual needs during the predialysis phase.

The assessment of the nephrology nurses with regard to their influence on the choice of treatment shows the subordinate role of nursing staff in the German health system. The influence of relatives

is estimated to be higher than that of nurses. In Walker's study (Walker et al., 2017), the influence of nurses (in the predialysis team) on the RRT choice of patients is rated at least as high as that of nephrologists. In New Zealand, as in other countries (e.g., Australia, Canada, Great Britain, and the United States), nurses play a more important role in the decision-making process than in Germany (Collister et al., 2019; Johns et al., 2015; Walker et al., 2017). This seems to be more in line with the wishes of the interviewed nursing professionals, who would like to see an earlier and greater involvement in the process. Nursing professionals are not only the contact persons for questions but also an integral part of the predialysis team taking on tasks in the information and decision-making process from the very beginning. In contrast, participants in our study often report that nurses are only called in after the decision has already been made. Although the positive effect of an interprofessional team in the predialysis phase (e.g., maintaining social participation and functionality and quality of care) has been pointed out several times (Barrett et al., 2011; Bennett & Oppermann, 2006; Davison & Cook, 2015; Loiselle et al., 2016), not all participants in the study see this advantage. Concerns mentioned were the possible overburdening of patients and lack of funding. Against the backdrop of staff shortages, the workload of care workers and adequate reimbursement should also be taken into account. So far, little is known in Germany about experiences with interprofessional predialysis teams in the decision-making process regarding RRT. Further research is needed, including possible effects on the provision of different types of RRT in Germany and health-related targets. One challenge is to rethink and break up established care routines and to question a dominant organisational culture (Bennett & Oppermann, 2006). Reforms of existing profiles and roles of the health-care professions in Germany can be seen, among other things, in the increasingly interprofessional design of university teaching and training (Frenk et al., 2010; MFT Medizinischer Fakultätentag der Bundesrepublik Deutschland e. V., 2015; Robert Bosch Stiftung, 2013; Wissenschaftsrat, 2012).

Similar to the results of Winterbottom et al. (2012), the participants in our study also report that patients are more willing to ask nurses and other patients questions than physicians. Peer support programmes address this problem due to their nonhierarchical and reciprocal patient-to-patient relationship already being successfully used in various clinical settings in other countries (Giese-Davis et al., 2016; Greenwood et al., 2013; Hanly et al., 2020). Regarding the choice of RRT, structured programmes for the involvement of peers are also available from other countries (Bennett et al., 2018; Hughes et al., 2009; Trasolini et al., 2020). In their review of several studies (four United States, two United Kingdom, and one Taiwan), Bennett et al. (2018) found the following advantages of peer counselling in dialysis: improved goal setting, decision-making, and increased self-management. The specific framework/setting for peer involvement seems to be important, however, as some respondents in this study reported inhibitions among patients. One-to-one peer mentoring, spread over several appointments, could reduce the reported patient difficulties in confronting the disease. The authors are not aware of any systematic peer support programmes for

nephrology patients in Germany. The cross-facility creation of such programmes for the selection of RRT could be based on the process of developing training for patients with CKD (Iles-Smith, 2005).

Implications for practice

The focus on iSDM and PD should be increased in education, training, and continuing education to reduce uncertainty and prejudice among nephrology staff. Dialysis facilities should ensure that all patients with CKD are given adequate access to the iSDM support that both nurses and peers can provide. Interprofessional care should also be implemented in nephrology care in Germany in the context of the choice of RRT with scientific support and be adapted as necessary. This also applies to the introduction of structured peer counselling or peer mentoring programmes, especially in the predialysis phase. The adequate support of iSDM by the funding agencies appears indispensable, especially since it can increase the quality of care, patient satisfaction and adherence to therapy and, finally, reduce medical costs.

Further research into the implementation process of iSDM in nephrology care including barriers and facilitators is needed. A survey of patients and peers on implementation possibilities and requirements for a structured peer programme is necessary. In long-term implementation studies, a theory-based programme should be evaluated regarding the effectiveness of this intervention.

Conclusion

As RRT options are limited and induce major life changes, it is important that patients feel included and know the options—even if they then want to relinquish responsibility. However, shared decision-making in the choice of RRT is particularly challenging due to patients' high burden of disease and the related suppression or postponement of the decision and the information involved. This article has identified several areas in which practical implementations of iSDM for the benefit of patients can be successful. While an adequate reimbursement of iSDM is a particular challenge, other approaches with targeted measures are more feasible. In the opinion of both professional groups, more can be done to include the patients in iSDM and respect their decisions. If they are involved in the iSDM process in a timely manner as they would like to be, nurses can use their skills to take on important tasks synergistically, share the burden of medical staff and support patients from the very beginning. Peer counselling or peer mentoring programmes can improve iSDM through individual, flexible adjustments, and encourage patients to participate in the management of their disease.

Limitations

Due to the study design, a representative sample cannot be assumed. It should be noted that despite the invitation of facilities not offering PD, only facilities with both HD and PD responded. Therefore,

a positive bias of the results cannot be ruled out. In addition, most of the interviews revealed very committed professionals, which may further reinforce positive selection.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Anja Stoye performed the interviews, analysed the data, and wrote the manuscript. Julia-Marie Zimmer aided in analysing the data and worked on the manuscript. Wilfried Mau and Matthias Girndt critically revised the paper. All authors discussed the results and commented on the manuscript.

ETHICS APPROVAL

The ethics committee was presented with the study design and asked to evaluate it. Given the study design, a separate ethical vote was not deemed necessary. Due to this being a one-time study and the anonymisation of the transcript, no personal or sensitive data were stored past the date of the interview.

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