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Shared decision making

Shared decision-making in chronic kidney disease: A retrospection of recently initiated dialysis patients in Germany

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ABSTRACT

Objective: To compare differences in shared decision-making (SDM) and treatment satisfaction (TS) between haemodialysis (HD) and peritoneal dialysis (PD) patients.
Methods: 6–24 months after initiation of dialysis, we surveyed 780 patients from throughout Germany (CORETH-project) regarding SDM, the reason for modality choice and TS. Data were compared between two age-, comorbidity-, education-, and employment status-matched groups ($n = 482$).
Results: PD patients rated all aspects of SDM more positively than did HD patients (total score: $M_{PD} = 84.6$, SD = 24.1 vs. $M_{HD} = 61.9$, SD = 37.3; $p \leq 0.0001$). The highest difference occurred for the item "announcement of a necessary decision" (delta = 1.3 points on a 6-point Likert-scale). PD patients indicated their desire for independence as a motivator for choosing PD (65%), whereas HD patients were subject to medical decisions (23%) or wanted to rely on medical support (20%). We found positive correlations between SDM and TS ($0.16 \leq r \leq 0.48$; $p \leq 0.0001$).
Conclusion: Our findings increase awareness of a participatory nephrological counseling-culture and imply that SDM can pave the way for quality of life and treatment success for dialysis patients.
Practice implications: Practitioners can facilitate SDM by screening patient preferences at an early stage, being aware of biases in consultation, using easy terminology and encouraging passive patients to participate in the choice.

1. Introduction

1.1. The choice of dialysis modality and shared decision-making

Persons suffering from chronic kidney disease (CKD) often have the choice between two significantly different types of dialysis therapy [1]. On the one hand, hemodialysis (HD) is usually performed three times a week in an outpatient unit. Supervised by a medical team, the patient is connected to a blood purification system for four to five hours each session. Consequently, this is a passive treatment. The patient has to follow certain rules regarding diet and the correct medication. On the other hand, there is the option for peritoneal dialysis (PD), which can be performed at home by the patient himself. Through an implanted PD catheter, dialysis fluid is filled into the abdominal cavity, with the peritoneum functioning as a membrane. PD patients treat themselves several times a day by replacing the dialysis fluid. Furthermore, outpatient consultations are necessary only every four to eight weeks, and there are few dietary restrictions. At a minimum, every third CKD patient could opt for both modalities; however, this estimation varies among the nephrology expert community. Decisions in favor of PD only occur in 5% of all cases in Germany, although the two methods are considered to be equivalent in terms of mortality [2,3]. The literature is heterogeneous regarding the "optimal" assignment to one modality, even if some characteristics covariate with the choice [2]. Young and employed patients are, in general, assigned to PD rather than HD. Initiation of HD often occurs as an urgent lifesaving action or as a bridging treatment while waiting for transplantation. Moreover, patients who live closer to the dialysis unit or come from disadvantaged backgrounds are more likely to be treated with HD. The empirical trial to assign patients to one of the two modalities at random failed [4]. In addition, assignment is determined by characteristics of the consulting nephrologist, such as education or attitude toward PD [5].

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Previous findings suggest that approximately one-third of CKD patients feel insufficiently involved in the treatment choice [6,7]. Especially in multi-morbid CKD patients aged 65 years and older, informed decision-making appears to be poorer [8,15]. More vulnerable CKD patients often appear to be excluded from extensive and fair consultation before their choice [16,17], even though they have the same right to obtain unbiased information and to take part in decision-making. However, there are empirical indications that up to 20% of HD patients would have chosen PD if they had received comprehensive consultation before selecting a treatment modality [9]. This number matters in light of the percentage of patients who receive PD treatment in Germany (only 5%; see above). A recent study shows that educating patients with decision aid tools led to a 50/50 distribution of PD and HD choice [34]. Furthermore, the use of decision aids corresponded to a high level of stability regarding the definitive modality, even in unplanned dialysis starters.

Another patient survey in Germany that included various indication groups ($N = 1500–1800$) showed that more than half of the respondents would have preferred a participatory medical decision-making process [9]. This process is called "shared decision-making (SDM)" between doctor and patient. SDM is defined as a decision situation, in which 1) at least two participants are involved, who 2) both share 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 [10,11]. A systematic review summarises the barriers (Fig. 1) of SDM [18]. Situational facilitators are, for example, nurses who function as mediators between physicians and patients. SDM is particularly eased when patients take responsibility for their treatment. In return, physicians create good conditions for SDM when they are able to recognize their patients' needs (empathy). However, patients cope better with treatment failure if they can assign the responsibility to the physician [18]. A body of literature, including a Cochrane review [19–21], focuses on interventions to improve the adoption of SDM by healthcare professionals. Researchers recommend, for example, staff training and teaching communication skills for talking to patients, decision aids, coaching and prompt sheets for patients, the distribution of information material, and rigorous quality measures.

On the one hand, the SDM concept is heterogeneously applied; there are no evidence-based guidelines and no data for CKD patients [12,13,34]. On the other hand, successful SDM can promote treatment satisfaction (TS), adherence and compliance, as well as knowledge about the disease. SDM can reduce symptoms, and hence, even indirect costs [9,14]. Even though SDM has been identified as a key for positive patient-centered outcomes, until now, it was not clear how medical counseling and SDM are perceived from a dialysis patient's perspective, what reasons influence the choice of dialysis modality and how CKD patients evaluate their participation in the process. Additionally, no evidence is available regarding differences in how PD and HD patients rate SDM.

1.2. Summary and research questions

To address those gaps, our study aims to investigate CKD patients' retrospective SDM ratings with respect to the two

Physician
Only limited amount of time for consultation
Explains treatment options in biased manner
Only uses professional terminology
Considers that SDM is not applicable to patient or situation
Overspecialisation
Patient
High morbidity
Cognitive impairment
Advanced age
Lack of articulation skills
Low level of education
Ethnic background, dialect or language other than that of the physician
High obedience to authorities ("not asking questions", "good patient")
Passiveness (rejects responsibility for disease)
Too much trust in physician
Lack of knowledge about treatment options or alternative modalities
Feeling that SDM could delay treatment
Decision situation
Noisy environment
Lack of privacy
Hurriedness
Too many physicians involved in treatment
No familiarity between physician and patient
Patient may not/cannot choose physician
No participative culture in the whole organisation/treatment unit

Fig. 1. Barriers of SDM [20].